

August 2018

Self-management Experiences of Community-Dwelling Adults with Chronic Obstructive Pulmonary Disease

Wendy Bauer

University of Wisconsin-Milwaukee

Follow this and additional works at: <https://dc.uwm.edu/etd>



Part of the [Nursing Commons](#)

Recommended Citation

Bauer, Wendy, "Self-management Experiences of Community-Dwelling Adults with Chronic Obstructive Pulmonary Disease" (2018). *Theses and Dissertations*. 1747.
<https://dc.uwm.edu/etd/1747>

This Dissertation is brought to you for free and open access by UWM Digital Commons. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of UWM Digital Commons. For more information, please contact open-access@uwm.edu.

SELF-MANAGEMENT EXPERIENCES OF COMMUNITY-DWELLING ADULTS WITH
CHRONIC OBSTRUCTIVE PULMONARY DISEASE

by

Wendy S. Bauer

A Dissertation Submitted in
Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy
in Nursing

at

The University of Wisconsin-Milwaukee

August 2018

ABSTRACT

SELF-MANAGEMENT EXPERIENCES OF COMMUNITY-DWELLING ADULTS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

by

Wendy S. Bauer

The University of Wisconsin-Milwaukee, 2018
Under the supervision of Professor Rachel F. Schiffman, PhD, RN, FAAN

Chronic Obstructive Pulmonary Disease (COPD) is an incurable lung illness causing significant individual and public health burden. Individuals with COPD often experience high symptom burden, unpredictable exacerbations, numerous comorbid conditions, and frequent health care utilization. Self-management can improve health outcomes and reduce health care costs; however, many individuals with COPD struggle with effective self-management. Improving the self-management of individuals with COPD and the delivery of self-management support from health care providers is crucial to reducing the individual and societal costs of the illness.

The purpose of this study was to explore the self-management experiences of community-dwelling adults living with COPD with an emphasis on understanding the daily challenges they face, their response to these challenges, and their experiences when seeking health care. This qualitative study informed by the Individual and Family Self-Management Theory (IFSMT) used one-time, in-depth interviews to explore the experiences of 28 men and women living with COPD.

Thematic analysis resulted in the identification of eight themes: 1) accepting the disease; 2) maintaining function; 3) paying for it; 4) dealing with triggers; 5) getting through

exacerbations; 6) getting information; 7) feeling rushed and; 8) not feeling heard. Three additional sub-themes related to maintaining function were also identified: 1) staying active; 2) preventing infections; and 3) medicating or not. Results of the analysis were mapped to the IFSMT.

The results of this study offer new insights regarding the contextual and process factors impacting self-management behaviors. Specifically, the impact of financial resources on medication management behaviors and the self-regulatory processes related to disease acceptance, environmental triggers, and patient-reported cough syncope were described. Descriptions of self-management support were also identified from participants' accounts of their COPD-related health care encounters. These findings have implications for informing evidence-based recommendations and improving the quality of care for people living with COPD. Future research is indicated to further explore the impact of these context and process variables on self-management behaviors and to test the findings of this study as mapped to the IFSMT to expand theoretical and conceptual understanding.

© Copyright by Wendy Bauer, 2018
All Rights Reserved

TABLE OF CONTENTS

Abstract ii
List of Figures vii
List of Tables viii
Acknowledgments..... ix

CHAPTER

I. Introduction 1
Statement of the Problem 4
Purpose of the Study and Research Questions 9
Significance to Nursing 10
Theoretical Guide 11
Assumptions 12
Definition of Terms 13
Chapter Summary 14

II. Literature Review
Background 15
Chronic Illness 15
Patient-Centered Care 18
Models, Theories, and Frameworks..... 19
Health Behavior Theories 19
Chronic Care Model 20
Chronic Illness Trajectory Framework 21
Self-Management 22
Summary of Models and Theories 23
Review of the Literature 24
Findings of Literature Review 24
Literature Summary 29
Major Strengths 29
Major Weaknesses 30
Summary 31

III. Methods
Research Design 33
Sample Selection and Recruitment 33
Sample 35
Data Collection Procedure 37
Human Subjects Protection 37
Data Management and Analysis 38
Ensuring Scientific Rigor 40
Limitation of Proposed Research 41
Strength of Proposed Research 41
Summary 41

IV. Results	
Results	42
Participant COPD Characteristics	42
Within Case Data Analysis	43
Across Case Data Analysis	63
Research Question 1: Daily Challenges and Response to Daily Challenges	64
Accepting the Disease	64
Maintaining Function	66
Staying Active	68
Preventing Infection	70
Medicating or Not	71
Paying for It	73
Dealing with Triggers	77
Getting Through Exacerbations	79
Research Question 2: Health Care Experiences	83
Getting Information	84
Feeling Rushed	87
Not Feeling Heard	89
Summary	90
V. Discussion	
Major Findings	91
Research Question 1: Daily Challenges and Response to Daily Challenges	92
Research Question 2: Health Care Experiences	96
Application of the Study Findings to the IFSMT	97
Limitations	99
Implications for Future Research	100
Implications for Practice	102
Implications for Nursing Education	104
Implications for Policy	104
Conclusion	106
References	108
Appendix A: UWM IRB New Study Approval	129
Appendix B: UWM IRB Modification/Amendment Approval	130
Appendix C: Study Recruitment Flyer	131
Appendix D: Study Handout Flyer	132
Appendix E: Agnesian Health Care IRB Approval	133
Appendix F: Consent to Participate in Research Form	134
Appendix G: Participant Socio-demographic Information Form	136
Appendix H: Interview Guide	140
Appendix I: Resources for Participants in Case of Emotional Distress Handout	143
Appendix J: Curriculum Vitae	144

LIST OF FIGURES

Figure 1. Model of Individual and Family Self-Management Theory	12
Figure 2. Individual and Family Self-Management Theory Applied to Chronic Obstructive Pulmonary Disease	99

LIST OF TABLES

Table 1. Demographic Characteristics of Participants	36
Table 2. COPD-Related Characteristics of Participants	42
Table 3. Individual Characteristics of Participants	44
Table 4. Summary of Themes and Sub-Themes from Interviews with Community-Dwelling Adults with COPD	64

ACKNOWLEDGEMENTS

I am thankful for the participants who generously shared their stories with me for this study. This work would not have been possible without their participation. I am deeply grateful to Dr. Rachel Schiffman, for her mentorship and guidance over the years and her dedication and patience in helping me complete this dissertation. I am thankful to my committee, Dr. Jeanne Erickson, Dr. Dimitri Topitzes, and Dr. Julie Ellis for their thoughtful readings and feedback of this work. I also acknowledge the late Dr. Aaron Buseh for his guidance in developing this study; Dr. Patricia Stevens for getting me started and patiently sharing her qualitative expertise; Dr. Kathleen Sawin, for her kindness that kept me going in the early days and beyond; the whole Center grant team for providing encouragement and sharing their knowledge with me; Dr. Leona Dempsey for encouraging me to take this journey; Stephanie Yenter, RN for her enthusiastic support of this study; and for my classmates for sharing this doctoral journey with me.

This work is dedicated to my family. To my dad, whose brave journey with respiratory disease inspired this study. I am grateful for his genuineness, teaching me the value of hard work, education, and humility. To my mom, who instilled in me the importance of self-reliance. I thank her for unconditional love and unwavering support at every step in my life and for her expert care of my babies while I took this journey. To my husband, for his love and support, even when I don't deserve it. I am so lucky to share my life with you. We made it. And to my children Eden, Ivy, and Jonah. You are my heart and soul. Everything is for you. I am so blessed to be your mama.

Chapter I

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a progressive, incurable lung illness causing significant individual and public health burden. COPD is the third leading cause of death in the United States (U. S.) (National Center for Health Statistics, 2016) and the world (World Health Organization [WHO], 2018). In the U. S., COPD alone accounts for \$32 billion in adjusted annual medical costs (Ford et al., 2015). Individuals living with COPD often experience high symptom burden, unpredictable exacerbations, numerous comorbid conditions, and frequent health care utilization (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2018). Effective self-management can reduce symptoms, decrease health care costs, and improve health-related quality of life (HRQoL) for those living with the disease (Cannon et al., 2016; GOLD, 2018; Zwerink et al., 2014). Improving the self-management of individuals with COPD and the delivery of effective self-management support from health care providers is crucial to reducing the individual and societal costs of the illness.

Managing the day to day challenges of living with COPD can be complex. Individuals with COPD need to engage in a range of behaviors in order to effectively self-manage their disease. These behaviors include obtaining knowledge about their condition, implementing treatment recommendations, monitoring and managing symptoms, problem solving and responding to change, and managing the impact of the disease on daily life (Disler, Gallagher, & Davidson, 2012). The progressive course of COPD is punctuated by acute exacerbations that alter the course of the disease, accelerate worsening of lung function, and increase symptom burden (Suissa, Dell'aniello, & Ernst, 2012). The fluctuating episodic decline and overall complexity of the disease trajectory influences health care encounters and can negatively impact

behaviors, including informed decision-making about treatment and self-management (Curtis, 2008; Goodridge, 2006).

Many individuals with COPD struggle with effective self-management (GOLD, 2018) and often lack a basic understanding of their illness and its treatment (Bourbeau & Bartlett, 2008; Hoogendoorn, Feenstra, Hoogenveen, & Rutten-van Mólken, 2010; Kale et al., 2015). Self-management emphasizes the patient's central role in managing their health and the need for collaborative relationships between health care providers and patients. Self-management support from health care providers is vital to improving patient use of recommended therapies but individuals with COPD may experience poor self-management support (GOLD, 2018; Halding, Heggdal, & Wahl, 2011). The reluctance of some health care providers to clearly discuss COPD with their patients leaves some with the illness unable to even name their disease (Ansari, Hosseinzadeh, Dennis, & Zwar, 2014; Nelson & Hamilton, 2007). Such limited understanding of COPD and its usual progression may impact self-management behaviors, including engagement in treatment recommendations (Ray et al., 2013).

The use of prescribed medications for those with COPD has been cited as low as 10 percent (Bryant et al., 2013) and as many as 39 percent of adults diagnosed with COPD continue to smoke tobacco (Centers for Disease Control and Prevention [CDC], 2012). The goals of effective COPD management are to prevent disease progression, complications, and exacerbations; improve exercise tolerance and health status; relieve symptoms and reduce mortality (WHO, 2018). Smoking cessation, vaccinations, pharmacologic therapy, pulmonary rehabilitation, oxygen therapy and ventilatory support are strategies used to maintain function and prevent exacerbations in COPD (GOLD, 2018). Bronchodilator medications are central to managing the daily symptoms of COPD and are also used in conjunction with other medications,

such as glucocorticosteroids, during acute exacerbations of the disease (GOLD, 2018; WHO, 2018). Ineffective inhaler dosing technique, underuse of medications during periods of stability, and overutilization of medications during exacerbations are among the factors influencing sub-optimal medication management by those living with COPD (Bryant et al., 2013). Poor medication management and failure to quit smoking increases the COPD symptom burden and causes a faster decline in lung and airway function (Blackstock, ZuWallack, Nici, & Lareau, 2016).

Self-management interventions aim to motivate, engage, and support patients to develop skills to improve disease management. Interactions between health care providers and patients are central to self-management interventions aimed at changing health behavior and improving the motivation, confidence, and competence of those living with COPD (Effing et al., 2016). Patient education and action plans are often central to self-management interventions and are included as a part of pulmonary rehabilitation and telehealth programs (Murphy et al., 2017). Effective self-management interventions have been shown to reduce hospitalizations and improve health-related quality of life (Jonkman et al., 2016), particularly those interventions that include negotiated action plans for worsening symptoms (GOLD, 2018).

However, the content of self-management interventions for those living with COPD have been heterogeneous and understanding of the sub-groups of individuals who would benefit the most are limited (Jonkman et al, 2016). Future studies are needed to identify the most effective components of self-management interventions. In order to inform future interventions, more research exploring the process of and barriers to self-management in COPD is needed from the perspective of those living with the disease (Jordan et al., 2015; Rees & Williams, 2009).

The purpose of this dissertation was to explore the self-management and health care experiences of individuals living with COPD from their own perspective. This chapter presents the statement of the problem, the significance and prevalence of the problem, and the purpose of this study. The Individual and Family Self-Management Theory (IFSMT) (Ryan & Sawin, 2009) that was used as a general guide for this study, a definition of terms, and assumptions are also presented.

Statement of the Problem

More than 3 million people die worldwide from COPD each year (GOLD, 2018). COPD is a disease that is increasing in prevalence with subsequent increases in morbidity, and mortality. Eleven million people are reported to have COPD in the U.S. although the true prevalence of the disease is likely higher due to being under-diagnosed and under-treated (American Lung Association, 2017). The disease is diagnosed based on patient report of symptoms and fixed airflow obstruction as evidence by spirometry. As the symptoms of COPD may not be recognized until the disease is more advanced and spirometry is infrequently performed, the disease is under-diagnosed (Tashkin & Murray, 2009).

COPD severity is defined by the forced expired volume in one second (FEV₁) achieved during spirometry and then categorized according to GOLD criteria as mild (Stage I - 80% of normal lung function), moderate (Stage II – 50-79% of normal lung function), severe (Stage III – 30-49% of normal lung function), and very severe (Stage IV – less than 30% of normal lung function) (Benzo, Abasxal-Bolado, & Dulohery, 2016; GOLD, 2018). Spirometry is the gold standard of detecting the presence of airway obstruction and can assist in differentiating COPD from other lung conditions (GOLD, 2018).

COPD is most commonly associated with either one or both of the conditions emphysema and chronic bronchitis. Previous definitions emphasized the terms ‘emphysema’ and ‘chronic bronchitis’ as separate diseases existing under the umbrella of COPD (GOLD, 2018). Chronic bronchitis is clinically defined as a productive cough occurring on most days of the week for at least three months total duration in two successive years and with evidence of airflow obstruction as measured by spirometry. Emphysema is the destruction of lung tissue that increases the risk of airway collapse, the enlargement of airspaces, and the development of blebs or bullae. Emphysema can be pathologically or radiologically defined. Many individuals with COPD have features of both chronic bronchitis and emphysema (Wise, 2017; GOLD, 2018).

COPD is characterized by airflow obstruction and an abnormal inflammatory response in the lungs that results in a progressive deterioration of lung function. The inflammation present in COPD is the result of an immune response to long term exposure to noxious particles and gases, particularly from tobacco cigarette smoke. This abnormal response results in mucous hypersecretion, tissue destruction, and the disruption of repair and defense mechanisms. Such pathological changes result in an increased resistance to airflow in the small airways, air trapping, and progressive airflow obstruction. The airway obstruction progressively traps air during expiration and results in hyperinflation at rest and during activity, leading to breathlessness and limited exercise capacity (MacNee, 2006). In addition to airflow limitation and respiratory insufficiency, the complications of COPD include pulmonary hypertension, respiratory infection, and weight loss. Acute COPD exacerbations can occur sporadically, resulting in an increase of the severity of symptoms and may become more frequent as the disease progresses (Wise, 2017).

Smoking is the primary cause for the development of COPD. Up to 75 percent of those with COPD are current or former tobacco smokers. Other risk factors include exposure to secondhand smoke, occupational dusts and chemicals, indoor air pollution from open fires, and high levels of urban air pollution. Rarely, COPD is the result of a genetic disorder called alpha-1-antitrypsin (AAT) deficiency (GOLD, 2018). American women are twice as likely as males to be diagnosed with COPD and its prevalence in the United States is highest in Midwestern and Southeastern states (American Lung Association, 2017; CDC, 2012).

COPD leads to significant societal costs. In the United States, the disease is associated with estimated annual direct and indirect costs of nearly \$50 billion. Over time, people with COPD experience an insidious decrease in the ability to breathe, reducing overall activity and quality of life. As lung capacity declines and the disease progresses, dyspnea worsens and difficulty performing activities of daily living increases. As the severity of COPD increases, the cost of care directly increases, particularly for hospitalization, ambulatory oxygen costs, and the under-represented cost of care provided by family members in the home (GOLD, 2018).

COPD exacerbations are a significant burden on the health care system (GOLD, 2018). In developed countries, COPD exacerbations are the principal reason for unscheduled health care visits (Perera, Armstrong, Sherrill, & Skrepnek, 2012) and COPD alone accounts for the greatest proportion of health care utilization in the United States (Murphy et al., 2017). Nearly one out of five patients 40 years of age or older in U.S. hospitals has a diagnosis of COPD. Overall, COPD accounts for 15.4 million physician visits, 1.5 million emergency department (ED) visits, and 636,000 hospitalizations each year and these costs are expected to rise as the prevalence of COPD increases (Dalal, Shah, D'Souza, & Rane, 2011; Ford et al., 2015; & Mannino et al., 2015). Just over 20 percent of people living with COPD will require admission to an intensive

care unit (ICU) during the course of their disease (Valley, Sjoding, Ryan, Iwashyna, & Cooke, 2017). Many individuals living with COPD experience extensive use of acute care services centered on prolonging life in the terminal phase of the disease and receive less cost effective palliative care services (Faes, De Frene, Cohen, & Annemans, 2016).

Chronic and progressive dyspnea is the most characteristic symptom of COPD and is frequently accompanied by fatigue, wheezing, cough, and sputum production (GOLD, 2018; Park & Larson, 2013). Individuals with COPD also experience symptoms such as anxiety, depression, and pain that may decrease adherence to treatment recommendations and HRQoL (Bentsen, Miaskowski, & Rustøen, 2014). The systemic nature of COPD and its chronic inflammatory state increases the development of comorbidities in those with the condition (Cavaillès et al., 2013; Smith & Wrobel, 2014) and subsequently, the cost and complexity of disease management.

Multimorbidity, the presence of two or more chronic conditions, frequently affects people with COPD and the disease is present in the majority of older adults who suffer from multiple chronic conditions (Ansari et al., 2014; Westney et al., 2017). Individuals living with COPD are often also diagnosed with diseases such as congestive heart failure (CHF), ischemic heart disease, cardiac arrhythmias, peripheral vascular disease, hypertension, osteoporosis, anxiety, depression, lung cancer, diabetes, and gastroesophageal reflux (GERD) (GOLD, 2018). Those who live with multiple chronic conditions including COPD may struggle with the concurrent use of multiple medications and give COPD lower prioritization than other diseases, impacting COPD self-management capacity and the utilization of health care services (GOLD, 2018; Perera et al., 2012). In addition, symptoms common in comorbid conditions that are similar to those

experienced with COPD, such as breathlessness (CHF and lung cancer) or reduced physical activity and fatigue (depression) may be overlooked (GOLD, 2018).

Effective self-management allows individuals with COPD to control their symptoms, slow disease progression, and improve their quality of life (Disler et al., 2012). Self-management and its support is a complex interaction among patients, families, health care providers, and the health care system in which the patient is an active and equal participant (Hillebregt, Vlonk, Bruijnzeels, van Schayck, & Chavannes, 2016; Lorig & Holman, 2003). Health care providers play an important role in helping patients to understand their disease, the potential benefits of treatment, and the development of self-management skills (Bourbeau & Bartlett, 2008). Collaborative partnerships between health care providers and patients centered on self-management can assist in establishing effective behavior change based on informed decision-making and shared goals (Bourbeau & Bartlett, 2008; Kaptein, Fischer, & Scharloo, 2014; Thorne, Harris, Mahoney, Con, & McGuinness, 2004).

It is known that individuals living with COPD engage in a number of self-regulatory behaviors when self-managing their disease including symptom monitoring, decision-making, and planning (Chen, Liu, Shyu, & Yeh, 2016; Warwick, Gallagher, Chenoweth, & Stein-Parbury, 2010). People living with COPD develop knowledge and beliefs about their disease over time (Ehrlich, St. John, & Kendall, 2010) and seek balance between self-management tasks and everyday life (Disler et al., 2012). However, the process of and factors influencing self-management in COPD are not well-defined compared to other chronic conditions (Disler et al., 2012; Chen et al., 2016).

Existing research centered on assessing the impact of self-management interventions on health outcomes in COPD are diverse in content and duration limiting the development of

targeted interventions capable of making an impact on effective and sustained self-management behaviors (Jordan et al., 2015; Zwerink et al., 2014). In particular, more research is needed to understand the impact of the health care provider interaction and the influence of socio-economic factors on the self-management of individuals with COPD (Disler et al., 2012).

Purpose of the Study and Research Questions

Research focused on the experience of living with and managing COPD lags behind that focused on other chronic diseases even though the societal impact of COPD is great (Kaptein et al., 2014; Disler et al., 2012). It is recommended that health care providers support patients with COPD to self-manage their disease and to place emphasis on patient-centered outcomes but there is insufficient evidence about how to best do so (Jordan et al., 2015; Celli et al., 2015).

Continued insight into the chronic illness experience from those living day to day with such diseases is needed as health care transitions toward more patient-centered, self-management approaches. Limited research exists that is focused on the patient perspectives of self-management and self-management support received, particularly for those living with COPD and in the context of their broader illness experience (Jonsdottir, 2013). Eliciting individual stories of the daily challenges of living and managing chronic illness allows insight into the development of disease knowledge and understanding (Sandelowski, 1994; Hall & Powell, 2011; Kleinman, Eisenberg, & Good, 1978). A qualitative approach can assist in our understanding of the facilitators and barriers to effective COPD self-management and in the development of interventions aimed at addressing patient-valued outcomes (Panos et al., 2013).

The purpose of this dissertation was to explore the self-management experiences of community-dwelling adults living with COPD using in-depth interviews. Specifically, the following was explored from the participants' perspective:

- 1) What are the daily challenges community-dwelling adults face in living with COPD and what are their responses to these challenges?
- 2) What are the health care experiences of community-dwelling adults living with COPD?

Significance to Nursing

Results of this study may contribute to the science of nursing by providing insight into the self-management and health care experiences of individuals living with COPD as told from their own perspective. Self-management is one of the four key themes identified by the National Institute of Nursing Research (NINR) as part of the organization's strategic plan and is a major part of the national nursing research agenda (NINR, 2016). The NINR describes the science of self-management as the examination of the strategies that help individuals with chronic conditions and their caregivers better understand and manage illness, improve health behaviors, and improve quality of life. According to the NINR, self-management research encompasses the strategies that allow individuals to work together with their health care providers to adapt treatments to individual circumstances by accounting for the contextual factors that can influence health and quality of life (NINR, 2016). The experiential accounts shared by the participants in this study may be used to inform future investigations centered on improving self-management behaviors and approaches to health care delivery for individuals with COPD and deepen our understanding of the contextual factors impacting outcomes for this population.

In addition, the results of this study can be used to strengthen evidence-based clinical nursing practices. Nurses, the largest group of health care providers in the U.S., provide care to individuals with chronic conditions such as COPD across the care continuum. Registered and advanced practice nurses are optimally positioned to play a major role in providing self-management support to patients and families across the care continuum. Self-management

support is an important part of patient-centered care (Agency for Healthcare Research and Quality, 2018), a concept synonymous with the nursing profession's rich history of providing holistic and individualized patient care (Lusk, 2013). The results of this study may be used to strengthen quality improvement projects aimed at improving self-management support and the delivery of care for individuals living with COPD. Contributions from leaders in nursing science and practice centered on self-management hold promise to impact chronic illness health care policy and deepen our theoretical and conceptual understanding of this phenomenon.

Theoretical Guide

The Individual and Family Self-Management Theory (IFSMT) (Ryan & Sawin, 2009) is a descriptive, middle-range theory that draws upon decades of health promotion, health behavior, and self-management research (Ryan & Sawin, 2009). The IFSMT addresses both the individual and family experience of chronic illness and proposes that self-management is a complex, phenomenon consisting of the dimensions of context, process, and proximal and distal outcomes. The IFSMT was used in the current study to assist in understanding the context, processes, and outcomes of self-management as described in participants' stories of their experiences of living with and managing COPD. The theory assisted in organizing the literature review and the codes derived from data analysis and interpreting the identified themes.

According to Ryan and Sawin (2009), self-management is a multidimensional, complex phenomenon in which behaviors are used by individuals, dyads, and families across all developmental stages to manage chronic conditions as well as engage in health promotion. The process of self-management includes the facilitation of knowledge and beliefs, the enhancement of self-regulation skills and abilities, and social facilitation. As depicted in Figure 1, self-management includes condition-specific risk and protective factors, components of the physical

and social environment, and unique characteristics of individuals and families. Knowledge and beliefs, self-regulation skills and abilities, and social facilitation are elements of the process of self-management which impact behavior-specific self-efficacy, decision-making, and collaboration. The context dimension consists of risk and protective factors including condition-specific factors, physical and social environments, and individual and family characteristics. Individual and family-centered interventions impact self-management within the context or process dimensions. According to this perspective of self-management, individuals are more likely to engage in recommended health behaviors if they have information about and embrace health beliefs consistent with behaviors (Ryan & Sawin, 2009).

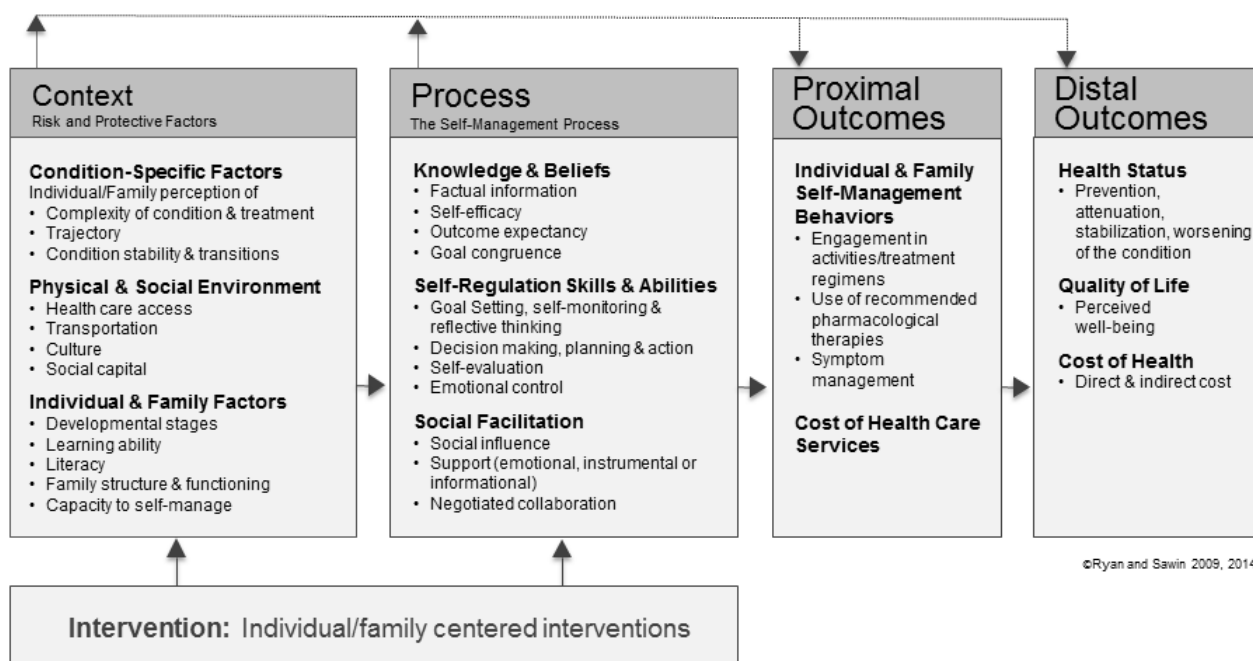


Figure 1. Model of Individual and Family Self-Management Theory

Assumptions

The following assumptions are proposed for this study:

- 1) The illness experience is unique to the individual yet possesses shared commonalities across participants.

- 2) Individuals living with COPD who participate in this study will be willing to speak openly and honestly about their experiences, perceptions, and behaviors.
- 3) Transcribed interviews are accurate accounts of participants' statements.
- 4) Transcribed interviews can be analyzed to understand how people experience illness in the context of their lives.
- 5) Interviews occurring at a fixed, specific time in the often long, progressive, and unpredictable illness trajectory of COPD will provide insight into the broader COPD illness experience.

Definition of Terms

Disease: Disease is an alteration in biological structure or functioning (Kleinman, 1988).

Health care provider: Physicians, registered nurses, allied health professionals.

Illness: Illness is the human experience of symptoms, suffering, and disability and refers to how a disease is perceived, lived with, and responded to by individuals, their families, and their healthcare providers (Kleinman, 1988; Larsen, 2013a).

Illness experience: The illness experience includes categorizing and explaining, in common-sense ways accessible to lay persons, the forms of distress caused by pathophysiological processes (Kleinman, 1988).

Self-management: Self-management is a process by which individuals and families use knowledge and beliefs, self-regulation skills and abilities, and social facilitation to achieve health-related outcomes. Self-management takes place in the context of risk and protective factors specific to the condition, physical and social environment, and individual and family (Ryan & Sawin, 2009, 2014; UWM Self-Management Science Center Working Group, 2011).

Self-management support: Self-management support is the “systematic provision of education and supportive interventions by health care staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support” (Institute of Medicine, p. 52, 2003). It involves patient-centered attributes, health care provider attributes, and health care organizational attributes (Kawi, 2012).

Chapter Summary

In this chapter, an introduction of the research problem and the significance of this study focused on the self-management experiences of community-dwelling adults living with COPD was provided. In Chapter II, an overview of seminal chronic illness works and an in-depth review of existing research focused on COPD self-management will be presented. In Chapter III, a discussion of the research design and the methods and procedures used in data analysis and synthesis are presented. In Chapter IV, the findings of the study are provided. Lastly, in Chapter V, a discussion of the findings of the study, limitations, and implications for practice, policy, education, and future research are presented.

Chapter II

Literature Review

In this chapter, existing published literature focused on self-management and related concepts are presented. Prior to presenting this literature review, it is essential to discuss seminal chronic illness perspectives and theoretical approaches that have guided current thinking in self-management science and chronic illness health care delivery. In the beginning of this chapter, an overview of the chronic illness literature that grew to inform current self-management perspectives and the related adoption of more patient-centered approaches to health care is discussed. This is followed by a review of the current literature focused on self-management experiences in COPD. The goal of this focused literature review was to describe what is known about the self-management experiences of individuals living with COPD. Search strategies used to identify relevant studies are detailed.

Background

Chronic illness

Chronic illnesses such as COPD are among the greatest healthcare problems in the United States. Many conditions that were once fatal have now become chronic due in part to significant increases in the detection, prevention, and treatment of disease. The illness experience of individuals living with chronic disease and their associated narratives have grown to become a significant source of research across multiple disciplines over the past forty years (Kleinman, 1988; Morse, 2012; Thorne & Paterson, 2000). As a part of these explorations, important distinctions have been made regarding the terms *disease* and *illness* (Kleinman, 1988). Disease has been described as “the pathophysiology of the condition, such as an alteration in structure and function” whereas illness is the “human experience of symptoms and suffering, and refers to

how the disease is perceived, lived with, and responded to by individuals, their families, and their health care providers” (Larsen, 2013a, p. 4). Such distinctions have been important in influencing the call for incorporating more patient-centered rather than disease-focused approaches into health care. However, deepening our understanding and defining the experience of chronicity outside the biomedical domain remains complex.

The science of self-management has become central to understanding more about how individuals with chronic conditions understand and manage their health. The term has been widely used across the chronic illness literature. Among the first uses of the term self-management was based on self-efficacy and Bandura’s Social Cognitive Theory and is credited nearly a half a century ago to Thomas Creer in his work on the rehabilitation of chronically ill children (Bandura, 1977; Creer, 2008; Lorig & Holman, 2003; Novak, Costantini, Schneider, & Beanlands, 2013). The concept of self-management was further developed by Corbin and Strauss (1988, 1991) who identified medical, behavioral, role, and emotional management as tasks central to the process of chronic illness self-management. Lorig and Holman (2003) expanded upon this work in the identification of problem solving, decision-making, resource utilization, patient-healthcare provider partnerships, and taking action as five core self-management skills. Self-management is now recognized as an essential component of effective health care delivery models for the treatment of individuals with chronic illness.

The past generation of research focused on the illness experience and related behaviors has provided great insight into how the body, the self, and society interact (Rier, 2010). The early work of sociologists, such as that of Parson’s (1951) focused on the sick role and of Suchman’s (1965) on illness careers, was followed by the pioneering work of Anselm Strauss and Barney Glaser (Glaser & Strauss, 1968; Strauss & Glaser, 1975) who explored the

experience of illness from the perspective of the patient (Rier, 2010). These studies initiated a shift toward exploration of the patient's subjectivity and the meanings individuals attribute to their experience of illness through the use of metaphors, cognitive representations, and images (Pierret, 2003) and expanded our understanding of illness behavior (Larsen, 2013b).

The work of sociologist Bury (1982) made an important contribution to the chronic illness literature by recognizing the biographical disruption that occurs in chronic illness. Focusing on the meaning of an illness, the setting in which it occurs, and the resources available to the individual, Bury (1982, 1991) suggested that meaning and context in chronic illness are not easily separated. Acknowledging that individuals draw upon ideas and forms of lay knowledge often difficult to disentangle from medical expertise, Bury (1982, 2001) recognized the increased loosening of the authority of the narratives of science and medicine in our understanding of the response to chronic illness.

Over time, the chronic illness experience has been explored with a variety of methods, in the context of numerous chronic diseases with differing stages and populations of interest, and in relation to a range of illness behaviors. Focus on the subjective illness experience and related perceptions of health has contributed to consideration of how individuals self-manage their disease and of how health care is delivered. The provision of patient- or person-centered approaches to health care in which health care providers' acceptance of the illness experience and the acknowledgement of patient expertise on their own lives are increasingly viewed as legitimate aspects of the clinical encounter (Hudon et al., 2012). The move toward less disease-centered care in the context of the expansion of information about illness available to lay persons has impacted the chronic illness experience within and outside of the health care domain. Understanding the illness experience from the patient's perspective is now recognized as a core

part of improving health care delivery and health outcomes (Hudon et al., 2012; Stewart et al., 2003).

Patient-Centered Care

Patient-centered care is central to the provision of effective self-management support (AHRQ, 2018) and has become the term used to describe approaches to care focused on the individual, not the disease. Patient-centered approaches to therapy emerged in humanistic psychology in the 1950s (Rogers, 1952) and were soon after promoted in the medical field by psychoanalysts Enid and Michael Balint in their work on patient-centered doctor-patient relationships in the late 1950s and 1960s (Balint, 1957, 1969; Hudon et al., 2012). The specific concept of patient-centered care emerged in the nursing literature in the 1960's, although elements of patient-centered approaches appeared in nursing much earlier (Mitchell, 2008).

Florence Nightingale discussed patient preferences for care in her seminal work *Notes on Nursing*, first published in 1860 (Mitchell, 2008) and Virginia Henderson, another early nursing leader, is credited with introducing patient-centered, rather than disease-focused approaches to the nursing curriculum as early as the 1930's (McEwen & Wills, 2007). Sister John Gabriel's book, *Through the Patient's Eyes – Hospitals, Doctors, and Nurses*, published in 1935, preceded publication of the seminal book, *Through the Patient's Eyes – Understanding and Promoting Patient-Centered Care* (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993) by nearly sixty years (Mitchell, 2008). In addition, early nursing theorists focused on patient needs, (Abdellah, Beland, Martin, & Matheney, 1960; Meleis, 2012) and the individualization of care (King, 1968; Orlando, 1961; Paterson & Zderad, 1976; Peplau, 1952, 1991; Wiedenbach, 1964; Travelbee, 1966) can be credited with developing understanding of patient-centered approaches (McEwen & Wills, 2007; Mitchell, 2008). The parallel efforts focused on patient-centered care

that have developed in the fields of medicine and nursing have furthered our understanding of the conceptualization, development, implementation, and evaluation of this approach to health care delivery (Mitchell, 2008).

Work on patient-centered care and related concepts, such as person-centered care and patient engagement have proliferated across the health disciplines and specialties (Kitson, Marshall, Bassett, & Zeitz, 2013; Mitchell, 2008). In the United States and many other countries in the world, patient-centered care is now widely promoted as a model capable of improving health outcomes and transforming health care systems (Pelzang, 2010; Kitson et al., 2013). Patient-centered care is an approach to health care grounded in mutually beneficial partnerships in which individuals have the information and support they need to make decisions and self-manage (Mauer, Dardess, Carman, Frazier, & Smeeding 2012).

Models and Theories

Health Behavior Theories

Health behavior theories have been used to deepen our understanding of the individual experience of chronic illness management through exploration of individuals' use of recommended treatments and engagement in health promotion activities. These models have origins in theories of stimulus response and focus on the key concepts of cognition, motivation, behavior, and environment. The cognitive processing of information is central to such models that focus on the individual perception and interpretation of experience and its direct effect on behavior (Pender, Murdaugh, & Parsons, 2006).

The Health Belief Model (HBM) was initially proposed in the 1960's by social psychologists as a framework for exploring why some people take action to avoid illness, whereas others fail to engage in prevention (Pender et al., 2006). The major preposition of the

model is that the likelihood of an individual to engage in recommended health behaviors is based on perceived illness severity, individual estimation that a specific action will reduce the threat, and perceived barriers to following recommendations. The HBM remains widely used to assist in explaining the relationship of attitudes and behaviors to the use of recommended treatments (Berg, Evangelista, Carruthers, & Dunbar-Jacob, 2009); however, it is limited in addressing the modifying individual internal and contextual factors impacting health behavior (Pender et al., 2006).

Social cognitive theory has also been widely used to describe human behavior and to design individual change interventions (Pender et al., 2006). Social cognitive theory combines environment, cognition, and emotion to understand health behavior change (Bandura, 1977). The theory places emphasis on self-direction, self-regulation, and self-efficacy and the ability of individuals to self-monitor and self-regulate health behavior. In social cognitive theory, individuals develop beliefs through observation and self-reflection. Explorations of self-efficacy and self-regulation and the relationship to health behaviors as guided by social cognitive theory have led to the development to self-management interventions and deepened our understanding of the complexity of the motivations underlying behavior change (Pender et al., 2006; Berg et al., 2009). Social cognitive theory and its related constructs remain widely used in health research. However, this perspective may be limited in assisting in understanding of the complexities of the individual characteristics and processes impacting the chronic illness experience and related health outcomes.

Chronic Care Model

The Chronic Care Model (CCM) (Wagner, 1998) was designed to support individuals with chronic illness to self-manage their health using appropriate community and healthcare-

based resources (Larsen & Lubkin, 2009). Today, the CCM has been adopted by health care organizations and has served as a guide for a number of national quality improvement initiatives (Coleman, Austin, Brach, & Wagner, 2009). At the center of the model is the idea that the optimization of outcomes for patients with chronic illness requires engaged, competent individuals receiving the most effective care and treatment as part of productive interactions between patients and health care providers (Wagner et al., 2005). It is described in the CCM that the health care system needs to have developed self-management support to promote productive interactions between prepared, proactive practice teams and informed, activated patients.

Active patient participation in care and an increase in patient self-management competence and confidence are described as organizational priorities in the CCM (Wagner et al., 2005). Although self-management is a central concept in the CCM, as it is a disease management model, the CCM does not offer a theoretical or conceptual framework for deepening our understanding of how individuals live with and manage disease in the context of their lives in order to develop effective interventions (Larsen & Lubkin, 2009).

Chronic Illness Trajectory Framework

The Chronic Illness Trajectory Framework was developed as a conceptual base and nursing model for practice, teaching, and research related to the care of individuals and families faced with chronic illness (Corbin & Strauss, 1991). The framework was built upon Strauss and colleagues' work in understanding the experience and care needs of dying patients. The major, unifying concept of the framework is trajectory, which is defined as an illness course over time and as impacted by the actions of individuals, families, and healthcare professionals (Corbin, 1998; Larsen & Lubkin, 2009). Biography, defined as the life course and the many aspects of the self, is a central concept of the model. Biographical and everyday life impact is

used to describe the ways that aspects of the self can be altered by illness, illness beliefs, illness management, or other life experience which can result in a changed trajectory. In addition, the concept of reciprocal impact is identified in the framework as one addressing the complexity of chronic illness management and the potential compounding of problems that may occur as a result of the interactions of illness, biography, and everyday activities (Corbin & Strauss, 1991). Although the framework is helpful in describing the phases of and general impacts on a chronic illness trajectory, it and other models focused on the chronic illness experience are limited in conceptualizing in more detail the processes and outcomes associated with the individual and family experience and perception of chronic illness and often complex day-to-day management.

Self-Management

More recently, theories, frameworks, and programs have been developed that are centered specifically on chronic illness self-management. Of considerable note is the work on chronic illness self-management of Lorig and colleagues. In 2003, Lorig and Holman built upon the previous work of Corbin and Strauss and others and more clearly defined and operationalized the concept of self-management and described core self-management skills. Lorig and Holman (2003) described these skills as problem solving, decision-making, resource utilization, forming of a patient/health care provider partnership, and taking action. Lorig has credited Bandura's work on self-efficacy as the theoretical perspective of most influence to her work on self-management (Ryan & Sawin, 2009). The Chronic Disease Self-Management Program (CDSMP), an evidence-based self-management program originally developed at Stanford University by Lorig and colleagues, has repeatedly been associated with improved outcomes (Brady et al., 2011; Ory et al., 2013)

In 2006, Grey, Knafl, and McCorkle first presented their framework focused on the self- and family management of chronic conditions. This framework made explicit the importance of incorporating the family into chronic condition management. The authors aimed to identify themes common among chronic conditions and relevant to both the individuals and families living with such illnesses (Grey, Knafl, Ryan, & Sawin, 2010). A revised Self-and Family Management Framework was published in 2015 by Grey, Schulman-Green, Knafl, & Reynolds which clarified elements of the model, namely the facilitators and barriers, processes, and proximal and distal outcomes of self-and family management of conditions.

In 2009, Ryan and Sawin (2009) published the IFSMT, a descriptive mid-range theory that focuses on the self-management of individuals, dyads within the family, or the family unit as a whole. The theory expanded prior work on self-management and built upon the Integrated Theory of Health Behavior Change (ITHBC) (Ryan, 2009) and the Ecological Model of Secondary Conditions and Adaptation (Sawin, Brei, Buran, & Fastenau, 2002; Sawin, Cox, & Metzger, 2003). The IFSMT is useful for understanding the context, processes, and outcomes associated with self-management not only for behavior change but also for health promotion (Ryan & Sawin, 2009).

Summary of Models and Theories

This review of major conceptual, theoretical, and care perspectives important to the study of the chronic illness experience offered insight into the foundation of self-management science. These perspectives have evolved over time, impacting clinical care and establishing the importance of the individual experience of illness. Familiarity with concepts key to the study of behavior in chronic illness was critical prior to undertaking a review of the current literature related to COPD self-management.

Review of the Literature

In order to more deeply understand the existing research on the self-management and health care experiences of individuals living with COPD, a review of the literature was performed. The focus on this review was to identify existing research related to the self-management experiences of COPD as described by those living with the disease. Electronic databases, including CINAHL Plus with Full Text, ERIC, MEDLINE, and the Cochrane Library were searched. A review of the gray literature was also performed via Google search. Key words used in the searches were chronic obstructive pulmonary disease with self-management; self-management support; illness experience; qualitative; or intervention, all in quotation marks. Articles in academic journal published between 2006 – 2017 and written or translated into the English language were reviewed for duplicates and inclusion. Articles were excluded if the focus was on the individual experience of a specific intervention.

Findings of Literature Review

The context of managing the unpredictable trajectory of COPD and the challenges present in symptom recognition and disease management are complex. In an integrative review focused on the factors influencing self-management in COPD, Disler and colleagues (2012) noted the physical, psychological, social, existential, and health care system related factors impacting self-management of the disease. The presence of physical and psychological symptoms such as shortness of breath, cough, fatigue, anxiety, and depression and the potential for and/or actual associated functional and psychological impairments are common to the COPD illness experience, particularly in advanced disease (Ansari et al., 2014; Disler et al., 2014; Ek & Ternstedt, 2008; Fraser, Kee, & Minick (2006); Jeon et al., 2010; Landers, Wiseman, Pitama, &

Beckert, 2015; Sossai, Gray, & Tanner, 2011; Stridsman, Lindberg, & Skar, 2014) and may inhibit the capacity to self-manage (Disler et al., 2012).

The impact of symptoms on physical activity are significant for those with advanced COPD who experience difficulty in performing activities of daily living (Disler et al., 2014). Decreased mobility can lead to restrictions on the work and/or social capacity of those living with the illness (Jeon et al., 2010). Such restrictions can limit social opportunities and physical involvement in activities, such as engaging with active grandchildren or in intimate relationships with significant others and may lead to a sense of or actual isolation (Cooney et al., 2013). In a study by Ek and Ternstedt (2008), participants with advanced COPD described how their lack of physical strength and use of assistive devices and oxygen therapy led them to forgo activities and avoid social situations. In another study, participants with advanced COPD who lived alone described feeling the need to restrict contact with other people to avoid a potential lung infection, particularly during the winter months, very isolating (Ek, Sahlberg-Blom, Andershed, & Ternstedt, 2011). Sossai and colleagues (2011) reported that even people with less severe COPD may stop socializing all together due to feelings of embarrassment and fear resulting from their COPD symptoms and treatments. The increasing isolation experienced by those living with advanced COPD has been identified as a milestone of disease progression (Landers et al., 2015) and underscores part of the contextual complexity of the condition.

Access to health care resources and low socio-economic status was also identified as a contextual issue impacting individuals with COPD (Ansari et al., 2014; Disler et al., 2012). Access to resources such as transport to healthcare facilities and pharmacies impact patients' ability to self-manage. Limited access to transport, whether caused by financial hardship or physical limitations, decreases individuals' access to health care centers, including pulmonary

rehabilitation (Disler et al., 2012). Identifying the determinants that influence an individual's ability to self-manage their disease can help in the development of effective interventions.

In a study by Chen and colleagues (2008), participants with COPD identified self-management behaviors as those that prevented an exacerbation and helped them maintain stability in their lives. These behaviors centered around symptom management, activity and exercise implementation, environmental control, emotional adaptation, and maintaining a healthy lifestyle. The participants' descriptions of their behaviors were included as part of an integrative review derived from the results of 44 papers published between 2000-2010 focused on the factors influencing self-management in COPD (Disler et al., 2012). The behaviors described as important to COPD self-management as a part of the integrative review were: 1) Obtaining knowledge about COPD to engage in active and informed decision-making; 2) Adopting positive health-seeking behaviors; 3) Implementing treatment recommendations; 4) Monitoring and managing symptom fluctuation; 5) Problem solving and responding to change; and 6) Managing the impact of disease on daily life (Disler et al., 2012). Gaining control over the physical and emotional losses in the context of an unpredictable disease course by knowing when to ask for help and continuing to perform tasks when one was able assisted participants to maximize their full psychological and physical potential and maintain control in life (Lowey, Norton, Quinn, & Quill, 2013).

The capacity to engage in the process of self-management and perform self-management behaviors was dependent upon a range of internal and external factors. The increasing demands of COPD in participants lives can made it difficult to find a balance (Jeon et al., 2010). The influence of dyspnea and the desire to balance COPD in the context of daily life are key elements that influence self-management for individuals living with the disease (Disler et al. 2012). The

ability to transcend meaninglessness by adapting and planning for participation led participants to continue to find purpose and enjoyment in life in the face of disability (Cooney et al., 2013). This situation was described as a trade-off between dependence on assistive devices for independence in daily activities and the need to create a new normality by adapting to the illness and its symptoms (Lowey et al., 2013).

Jeon and colleagues (2010) discussed that balancing life and COPD was influenced by a number of factors amendable to change, including the type and level of health care encounters and knowledge and understanding of the condition and its management. Possessing adequate knowledge and understanding of the condition was highlighted as important to enhancing the coping strategies of those with COPD and the self-management necessary to manage symptoms (Jeon et al., 2010; Cooney et al., 2013). However, the burden of self-blame and stigmatization of living with a smoking-related disease led some individuals with COPD to not only feel socially isolated, but to also feel devalued by health care professionals (Halding et al., 2011). Self-judgmental attitudes were found to hinder acceptance of diagnosis, limited attempts to stop smoking, and restricted the seeking of information (Lindgren et al., 2014)

Participants described the important role health care providers played in providing instructions on how to self-manage their disease and of family members to help support them (Chen, Chen, Lee, Cho, & Wang, 2008; Chen et al., 2016). Generally, health care professionals were viewed as genuinely caring and supporting of COPD patients (Disler et al., 2014). However, individuals living with COPD have also expressed issues with their interactions with health care providers, perceiving their own beliefs and concerns were ignored by health care providers who did not have an understanding of their circumstances or an appreciation of their expectations. They described a reluctance of health care providers to provide information

regarding COPD diagnosis, pathology, treatment, and prognosis (Ansari et al., 2014; McDonald et al., 2013).

Individuals living with multiple comorbidities were particularly frustrated by encounters with health care providers who were perceived as single disease focused and health care teams who provided conflicting opinions and recommendations. Ansari and colleagues (2014) identified limited communication between participants with multimorbidity and their health care providers regarding COPD when compared to their other diseases, with COPD given low prioritization. Only 6 out of the 17 participants in the study knew what their lung condition was called (Ansari et al., 2014). The experience of managing numerous medications and maintaining different health care appointments was difficult for these participants living with multiple chronic health conditions including COPD (Ansari et al., 2014).

High-quality communication between patients and their health care providers is an expectation of self-management programs for patients with COPD, however there is limited evidence regarding which health outcomes may be facilitated by improved communication (Slatore et al, 2010). Opportunities remain to incorporate patient-centered principles into the care of those living with COPD. Few studies exist in the literature assessing the impact of patient-centered communication as part of self-management interventions; however, the limited available evidence provides some evidence of a potential impact on outcomes such as quality of care and confidence in dealing with breathing problems (Slatore et al., 2010).

Recent systematic reviews have aimed to assess the impact of self-management interventions on outcomes, such as HRQoL and health care utilization (Cannon et al., 2016; Jonkman et al., 2016; Jordan et al., 2015; Zwerink et al., 2014). Self-management interventions have demonstrated mixed improvements in HRQoL as measured by the St. George Respiratory

Questionnaire (SGRQ), reductions in respiratory-related and all cause hospital admissions, and improvements in dyspnea as measured by the modified Medical Research Council (mMRC) Dyspnea Scale. The self-management interventions that have been tested and assessed are those that have included an iterative process between individuals with COPD and their health care providers that ideally includes the formulation of goals and delivery of health care provider feedback. Existing interventions have included information on smoking cessation, self-recognition and/or self-treatment of exacerbations, exercise or physical activity, and/or advice about diet, medications, or coping with breathlessness (Zwerink et al., 2014). Inclusion of an action plan, defined as a guideline for participants describing when and how to change course in medication or other treatment in the case of worsening symptoms (Zwerink et al., 2014), has demonstrated a positive effect on activity and symptom scores in some reviews (Cannon et al., 2016). However, recommendations regarding the most effective form and content of self-management interventions for those with COPD are difficult to discern because of the heterogeneity among tested components.

Literature Summary

Major Strengths

A major strength of the literature included in this review regarding the self-management experience in COPD is the existence of articles discussing studies completed in countries around the world. This provides a breadth to the literature that suggests that the commonalities identified across studies are not culture bound. The articles identified for this review were published from more than ten countries (Australia, Belgium, China, Ireland, Netherlands, New Zealand, Norway, Sweden, Taiwan, United Kingdom, United States) and also included a systematic and integrative reviews. This broad interest is encouraging when considering the

rising global rates of COPD and provides insight that may be helpful when comparing and contrasting results within diverse U. S. participants.

The literature identified in this review also solidifies the central role of self-management in the COPD experience. This was particularly evident in the description of the experience of individuals with advance disease identified in studies of this review (Ek & Ternstedt, 2008; Ek et al., 2011; Fraser et al., 2006; Landers et al., 2015; Lowey et al., 2013; Stridsman et al., 2014), which included a qualitative metasynthesis focused on this population (Disler et al., 2014). It is also encouraging to find studies investigating this issue from a perspective that embraces the patient-centered and collaborative direction modern health care is headed while continuing to build upon the substantial work that has been done in the overall exploration of chronic illness and related concepts such as self-efficacy.

Major Weaknesses

A weakness of the studies identified for this review was the small sample sizes and the homogeneity of the recruitment sites. The majority of studies identified for this review were qualitative and had small sample sizes recruited from health care organization. This makes sense in that this review sought to understand the experience of individuals, however the recruitment of individuals from single health care organizations limits our understanding of the broader COPD experience and may restrict understanding of the phenomenon to that particular system or health care provider.

When aiming to deepen understanding of the self-management experience of Americans living with COPD, the literature identified for this review was limited (Benzo et al., 2016; Fraser et al., 2006; Lowey et al., 2013). Although it is a strength that the topic is broadly studied in diverse countries, the small number of studies identified from the U. S. may limit our

understanding of the experience of how Americans live with and manage COPD and how that is like or dissimilar to those living with the disease in other parts of the world.

The availability of resources was also identified in the review as a key influence on the individual ability to self-manage COPD yet one that had received less attention than other variables of interest (Disler et al., 2012). A limited amount of demographic information was collected about the participants of the studies, restricting understanding of the contextual factors impacting the self-management of individuals living with the disease.

An additional weakness identified in the studies included in this review is a lack of conceptual clarity and theoretical guidance. The studies identified in this review used differing and inconsistent definitions of the self-management concept and none were guided by a self-management theory. Conceptual clarification through the use of standardized terminology and the use of established self-management theories will assist in the advancement of the science of self-management (Grady & Gough, 2014).

Summary

In this chapter, a review of the literature related to the self-management experiences of individuals with COPD was discussed. This review has provided insight into the state of the existing research related to this topic. More research is needed that directly addresses the barriers to COPD self-management and what those living with the disease do in response. In addition, more work is needed to understand how the health care encounter and access to resources impacts this process for participants in varying stages of the disease and who receive health care in differing organizations. Larger sample sizes could be sought from outside of health care organizations for future qualitative investigations to address this issue. Improvements in the recruitment of larger sample sizes from more heterogeneous settings may

deepen our understanding of the contextual factors impacting the self-management of individuals with COPD and inform future interventions. To assist in addressing this gap in the literature, the following chapter describes the research design for the current study focused on exploring the self-management experiences of community-dwelling adults living with COPD.

Chapter III

Methods

The purpose of this chapter is to describe the methods used for the study. The chapter is arranged in the following order: Research design, sample selection and recruitment, sample, data collection procedure, data management and analyses, ensuring scientific rigor, limitation of proposed research, strength of proposed research, and summary.

Research Design

The purpose of this dissertation was to explore the self-management experiences of individuals living with COPD from their own perspective. This study utilized a qualitative in-depth interview design in which participants were recruited to provide narratives of their experiences of living with COPD. Qualitative in-depth interviews assist in deepening understanding of social phenomenon and related context through identification of what exists in the social world and how it is manifested as described by study participants in their own terms. The use of qualitative methods can strengthen our understanding of the social and psychological processes underlying behavior within social contexts (Snape & Spencer, 2003). In health research, qualitative inquiry can provide insights into illness experiences, the identification of health care needs, and the processes of seeking health care (Morse, 2012).

Sample Selection and Recruitment

A non-probability, purposive, convenience approach was used to select the sample for this study (Ritchie & Lewis, 2003). As a demographically diverse sample was desired, participants were recruited from locations throughout Southeastern and East Central regions of Wisconsin. Inclusion criteria for participation in the study were: 1) 18 years of age or older; 2) conversant in English; and 3) self-report of health care provider diagnosed COPD, chronic

bronchitis, and/or emphysema. Exclusion criteria included: 1) under 18 years of age; 2) non-English speaking; and 3) observance of significant cognitive impairment and the inability to consent for one's self.

The sample size used in qualitative research is often smaller than those found in quantitative research studies. The aim of qualitative research is often to provide an in-depth understanding of a phenomenon rather than making generalizations to a larger population (Dworkin, 2012). Morse (2000, 2015) suggests several considerations when considering sample size including the scope of the study, the nature of the topic, the quality of the data, and the study design. The quality of the data and the number of interviews per participant will determine the amount of usable data obtained; the greater the amount of useable data obtained from each person, the fewer the number of participants needed to obtain richness of data. Thorne (2008) describes that saturation of data does not eliminate the possibility that more information could be obtained from additional participants, but rather that exposure to the existing data has led to a saturation of themes in accordance with the aims of the study (Thorne, 2008). For the current study, sample selection focused on the ability of participants to provide meaningful information to answer the research questions (Thorne, 2008), the use of a one-time, in-depth interview and the desire for heterogeneity of participants (Morse 2000, 2015; Thorne, 2008).

Following University of Wisconsin-Milwaukee Institutional Review Board (IRB) approval (Appendix A) and with minor modification to the initial approval (Appendix B), participants were recruited through flyers created by the student Primary Investigator (PI) (Appendix C) and posted in common areas at multiple health care centers, grocery stores, senior centers, and hair salons and distributed (Appendix D) within pulmonary disease support groups.

Flyers were also distributed within one pulmonary care clinic within a specific hospital system following that system's Institutional Review Board approval (Appendix E).

Flyers provided phone contact information for the student PI for those interested in learning more about the study. Individuals who were interested contacted the student PI and were screened over the telephone for eligibility to participate in the study. Following determination of eligibility, a discussion of the purpose of the study and inclusion criteria took place during first phone call contact. For those who remained interested in participation following this discussion, a mutual time and place was set to meet for one face-to-face, in-depth interview scheduled to last between 60-90 minutes with participants at their convenience. Participants were encouraged choose a private location where they would feel comfortable to talk freely about their health condition. Twenty-six participants chose to have the interviews conducted in their own homes and two participants chose to have the interviews conducted in a private meeting room of a hospital reserved for this purpose. Informed, signed consent to participate in the study and to audio-recorded was obtained and documented on the day of the interview (Appendix F).

Sample

Between July 2016 and April 2017, 30 people contact the student PI with an interest in participating in the study. One participant was deemed to not be eligible for participation in the study due to evidence of cognitive impairment including not being able to provide a consistent age or current date and not being able to understand the purpose of the study. Another participant declined to participate after being told about the study. In total, 28 community-dwelling adults who self-reported a diagnosis with COPD (chronic bronchitis and/or emphysema) participated in this in-depth interview study. The sample consisted of 12 (43%)

men and 16 (57%) women. The mean age of all participants was 68.7 years (range 48-82); the mean age of the 16 female participants was 69.1 years (range 51-82) and the mean age of the 12 male participants was 68.0 years (range 48-79). The individuals who participated in this study lived in geographically diverse communities. Nine (32%) of the participants reported living in a metro area with a population of 1,000,000 or more while the other 19 (58%) participants lived in or near less densely populated smaller cities. All of the participants of this study reported having health insurance. Twenty-seven (96%) participants reported this as Medicare with or without supplemental insurance or Medicaid; one participant reported coverage through a state-funded insurance program and was in the process of obtaining Medicaid coverage. Twenty (71%) participants stated they were retired, 7 (25%) participants reported disability status, and one participant reported unemployment. Four out of the five participants who lived in poverty self-identified as Black/African American. These same participants also accounted for four out of the five participants who were less than 60 years of age. Table 1 presents demographic characteristics of the sample.

Table 1

Demographic Characteristics of Participants

Characteristics	<i>n</i> = 28 (100%)
Race/ Ethnicity	
Black/African American, non-Hispanic	5 (18%)
White, non-Hispanic	22 (79%)
More than one race	1 (3%)
Living Arrangement	
With spouse	15 (54%)
Alone	9 (32%)
Other	4 (14%)
Income*	
At or below poverty level	5 (18%)
Low-income	10 (36%)
Above low-income	13 (46%)
Education (highest completed)	
Less than high school diploma/GED	2 (7%)
High school diploma/GED	21 (75%)
Earned college degree	5 (18%)

* Per U. S. Department of Health & Human Services Poverty Threshold Guidelines

Data Collection Procedure

Following informed consent, the semi-structured interview began by reiterating the purpose of the project and providing assurance of confidentiality. Participants were first asked to answer questions related to socio-demographic information and self-report clinical information using a structured format (Appendix G). These questions serve to describe the sample and provided a context from which to begin in-depth interviews. Questions were read to and with participants to facilitate understanding. Twenty-two participants were alone during the interview, five participants preferred to have spouses present during the interview, and one participant chose to have the interview conducted in a shared space in the home where others were present; comfort with this situation was repeatedly reassured by the student PI.

A semi-structured interview guide was used to collect stories from participants (Appendix H). The interview guide was developed from questions created to answer the aims of the study and from those of Jeon and colleagues (2010) focused on the chronic illness experience. Questions were chosen, modified, and created to explore the illness experience of individuals with COPD, specifically their interactions with health care providers and experiences with self-management. Interviews were transcribed verbatim using a professional transcription service.

Human Subjects Protection

IRB approvals from the University of Wisconsin-Milwaukee (Appendix A, B) and Agnesian Health Care (Appendix E) were obtained prior to beginning the study. During the process of informed consent, participants were provided with information about the purpose of the study, the use of data, what participation required of them, and were told that they could choose to withdraw from the study or stop the interview at any time without any consequences.

If at any time participants appeared or expressed fatigue during the course of the interview process, rescheduling of the interview was offered (Ritchie & Lewis, 2003); however, no participants expressed this need. In the case of emotional distress requiring follow-up, participants would have been encouraged to contact their primary or other appropriate health care provider with contact information made available in a hand out (Appendix I); however, this did not occur. In gratitude, retail store gift cards in the amount of \$25 were provided to consented participants whether or not they completed the interview as a token of appreciation.

To maintain confidentiality, personal identifiers were removed from transcribed interviews. Data were protected through the use of a password-protected computer and password-protected files. All informed consent documents were secured in a lock box in the student PI's home and only accessible by the student PI. Information collected from participants are reported in aggregate and are not linked directly back to them.

Data Management and Analyses

Frequencies were calculated for socio-demographic data and self-report clinical information. A non-linear, thematic analysis approach (Braun & Clarke, 2006) related to the reviewed literature and the purpose and aims of the study was used to analyze the interview data. Thematic analysis is a method for identifying, analyzing, and reporting themes within data allowing for the rich description of data sets. In this analytic approach, themes capture something important about the data in relation to the research questions and represent some level of patterned response or meaning within the data (Braun & Clarke, 2006). In accordance with this approach, six phases of analysis were performed: 1) familiarizing oneself with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report.

In phase one, familiarizing oneself with the data, each transcript was read repeatedly in order to begin the search for patterns and meaning. Notes were made during this stage about ideas to consider for coding during subsequent analysis. Any initial impressions and reflections on potential analytic perspectives captured in field notes during interviews were considered and reflected upon in this and future stages of analysis (Braun & Clarke, 2006).

In phase two, initial codes were produced from the data. Codes are the most basic segment of the data and identify a feature of the data of interest to the analysis. Coding was manually performed and during this process the data were organized into meaningful groups. This process was repeated using NVivo for Mac version 11.4.2. The entire data set was worked through systematically, with full and equal attention given to each data item. The transcript of each participant was the unit of analysis for this within-case analysis (Buseh & Stevens, 2006). Color-coded charts and memos were created in NVivo to assist with identifying codes and matching them with demonstrative data extracts while maintaining the extract's origins to assist in contextual understanding (Braun & Clarke, 2006).

Phase three, searching for themes, involved sorting the different codes into potential themes and collating all the relevant coded data extracts within the identified themes. A visual thematic map was created to assist in this process of sorting codes into themes. The relationship between codes, between themes, and between different levels of themes was considered (Braun & Clarke, 2006).

In phase four, reviewing themes, themes were reviewed and refined at the level of the coded data extracts and in relation to the entire data set. This process of reviewing and refining continued until refinements no longer added anything substantial to the analysis. In phase five, defining and naming themes, the essence of the theme was identified. A detailed analysis was

conducted and written for each theme identifying the story that each theme tells and how it fits into the broader overall story in relation to the research questions. In the final phase, a within and across theme analysis that included data extracts capturing the essence of the analysis without unnecessary complexity was completed. The aim was to tell a story about the data that goes beyond description and instead makes an argument in relation to the proposed research question and aims (Braun & Clarke, 2006).

Ensuring Scientific Rigor

The criteria of representative credibility, analytic logic, interpretive authority, moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness, and probable truth were used to address scientific adequacy and credibility. Maximal variation in the breadth and/or depth of sampling assisted in representational credibility. Analytic logic is addressed by explicit documentation of the decision-making process used during the course of the study. Making explicit intent about revealing knowledge and insight gained from the study assists to address interpretive authority. Moral defensibility is addressed by linking findings to potential benefits. Disciplinary relevance and pragmatic obligation is addressed by assessing the relevance of the proposed study and any related findings to the nursing discipline and clinical practice. Research credibility is addressed by maintaining contextual awareness during the study and the reporting of findings. Lastly, the probable truth of the findings is addressed by recognizing a departure from a seeking of absolute truths (Thorne, 2008).

To further assist with scientific rigor, the first six interviews were reviewed with the dissertation Committee Chair following professional transcription to discuss preliminary findings and to address any potential issues or concerns. Following completion of data collection and

preliminary analysis, all transcripts and identified codes and themes were read closely by the Committee Chair and discussed.

Limitation of Proposed Research

A main limitation of all qualitative research is the difficulty in generalizing findings to wider populations due to the collection of data from a small number of participants. In addition, the quality of the research may be more dependent on the individual skills of the researcher and more easily influenced by personal biases (Munhill & Chenail, 2008).

Strength of Proposed Research

Research conducted using qualitative methods such as in-depth interviews is useful for exploring phenomena that have not yet been described and for generating insights for consideration for future studies. The value placed on subjective and experiential knowledge in qualitative research assists in deepening understanding of the illness experience from the perspective of those living with chronic illnesses such as COPD. In addition, qualitative findings have the potential to contribute to the incorporation of patient-centered perspectives into clinical practice and guidelines (Thorne, 2008).

Summary

This chapter summarized the methods used for the study including description of the research design, recruitment and data collection strategies, sample, data management and analyses, and limitations and strengths of the proposed research. In accordance with the stated research aims, findings from this study are presented in Chapter IV.

Chapter IV

Results

In this chapter, the findings of the current study are presented. The COPD-related characteristics of the participants are followed by a presentation of the within-case results and a thematic cross-case analysis centered on the research questions.

Participant COPD Characteristics

Eight (29%) of the 28 participants were able to state a specific stage of their disease while the remainder of participants (71%) were unaware of the stage of their disease and were also unaware that it could be staged at all. Participants reported living with and managing an average of four other chronic conditions (range 0-15) with similarities within and across income status. Female participants reported living with a mean of 5 other chronic conditions compared to 3 for male participants. The most frequently reported conditions for female participants were: arthritis (44%), osteoporosis or issues of the back (degenerative disc disease, herniated disc, sciatica) (25%), and hypertension or incontinence (19%). The most frequently reported conditions for male participants were: diabetes mellitus type II (42%), hypertension (33%), and arthritis or high cholesterol (25%). Table 2 provides additional COPD-related characteristics.

Table 2
COPD-Related Characteristics

Characteristics	<i>n</i> = 28 (100%)
Time since COPD diagnosis	
Within last year	2 (7%)
1 - 3 years	6 (21%)
4 – 6 years	5 (18%)
7 or more years	15 (54%)
Tobacco Smoking history	
Never	4 (14%)
Quit < 5 years ago	4 (14%)
Quit 6-20 years ago	8 (32%)
Quit > 20 years ago	7 (29%)
Current (daily/occasionally)	5 (18%)
Current (Vaping)	1 (3%)
Number of co-morbidities (self-report), mean (SD, range)	4 (3.3; 0-15)

Within Case Data Analysis

Participants provided unique stories of living day to day with COPD and their experiences when seeking health care for their disease. Table 3 presents individual demographic characteristics of the participants. This is followed by a brief narrative description of each participant centered on providing their perspectives on their diagnosis, cause of their illness, understanding of their illness, symptoms, treatment, and motivation for managing their illness.

Participant 1 (68-year-old white female, diagnosed less than 1 year ago), lived in a second story rented apartment in a small town that she had recently moved to with her adopted teenage daughter. She had lived most of her adult life as a single mom who had raised her own children and multiple grandchildren. She identified her disease as “early stage COPD”. She described her understanding of the disease as a process of the air going into to her lungs and “getting stuck”. She believed that her symptoms were due to allergies from moving near a large marsh and mold in the air conditioning unit and windows of her apartment. She doubted she truly had COPD but if she did, she ascribed it to the nearly two decades she had worked in a bindery. She reported shortness of breath with activity. She stated mold, household cleansers, and allergies were symptom triggers. She used inhalers for treatment but did not use some as prescribed due to her feeling the inhalers caused her weakened and hoarse voice. She also expressed that she didn’t believe inhalers made much of a difference in her symptoms. She expressed frustration with her doctor for continuing to prescribe her inhalers and with health care providers in general for not explaining things to her and for not listening to her more. She reported being motivated to manage her disease in order to “get rid of it”.

Table 3
Individual Characteristics of Participants

Participant	Age	Gender	Race/ Ethnicity	Partner Status	Employment status	Former occupation(s)	Annual Income Status*	Education	Time since COPD diagnosis	Number of other health conditions	Smoking status	Attended Pulmonary Rehab
1	68	Female	White	Divorced	Retired	Child care, Welding, Bindery	Above low income	Some college	<1 year	1	Never	No
2	52	Female	Black	Divorced	Disabled	Home health caregiver	Low income	Diploma	1-3 years	5	Current	Yes
3	61	Male	White	Married	Disabled	Printing, Corrections, Retail, Truck Driver	Above low income	Diploma	>10 years	0	Quit 25 years ago	No
4	61	Male	White	Married	Retired	Small Business Owner	Above low income	Some college	>10 years	1	Quit 17 years ago	No
5	73	Male	White	Married	Retired	Leather tannery	Above low income	Diploma	4-6 years	10	Quit 32 years ago	No
6	76	Male	White	Widowed	Retired	Sales, Welding	Above low income	Diploma	>10 years	1	Quit >40 years ago	Yes
7	73	Female	White	Married	Retired	Retail, Manufacturing	Above low income	Diploma	1-3 years	3	Quit >40 years ago	No
8	48	Male	Black	Single	Unemployed	Cook, janitor, auto mechanic	Poverty	GED	4-6 years	6	Quit 2 years ago	Yes
9	75	Female	White	Divorced	Retired	Administrative Assistant	Low income	Diploma	>10 years	3	Quit 16 years ago	Yes
10	52	Male	Black	Single	Disabled	Handyman	Poverty	Less than Diploma/ GED	4-6 years	5	Current	No
11	76	Female	White	Widowed	Retired	Chef/Small Business Owner	Low income	Diploma	1 year	15	Quit 10 years ago	Yes
12	82	Female	White	Married	Retired	Brokerage sales assistant	Above low income	Less than diploma/GED	1-3 years	3	Quit 27 years ago	Yes
13	78	Male	White	Married	Retired	Engineer/ Professor	Above low income	College Degree	4-6 years	1	Quit 13 years ago	Yes
14	77	Female	White	Married	Retired	Kitchen Aide	Above low income	Diploma	>10 years	4	Quit 18 years ago	Yes

Table 3
Individual Characteristics of Participants

Participant	Age	Gender	Race/ Ethnicity	Partner Status	Employment status	Former occupation(s)	Annual Income Status*	Education	Time since COPD diagnosis	Number of other health conditions	Smoking status	Attended Pulmonary Rehab
15	76	Male	White	Married	Retired	Inside journeyman/ wireman	Above low income	Some college	4-6 years	6	Quit 40 years ago	No
16	73	Female	White	Married	Retired	Human resources assistant	Above low income	Diploma	1-3 years	4	Quit >50 years ago	No
17	79	Male	White	Married	Retired	Counselor	Low income	College degree	7-10 years	8	Quit 15 years ago	No
18	73	Female	White	Married	Retired	Housekeeper, Waitress	Low income	Diploma	7-10 years	3	Quit 23 years ago	Yes
19	76	Male	White	Married	Retired	Telephone Company	Low income	Some college	> 10 years	1	Quit 2 months ago	No
20	65	Male	White	Married	Retired	Welder, EMT	Low income	Some college	7-10 years	2	Quit 20 years ago	No
21	72	Female	White	Single	Retired	Social Worker	Above low income	Graduate degree	7-10 years	4	Quit 15 years ago	Yes
22	76	Female	White	Divorced	Retired	Physical Therapist/ Lecturer	Poverty	Graduate degree	7-10 years	5	Never	No
23	58	Male	Black	Separated	Disabled	Electrician/ Consultant	Poverty	Diploma	>10 years	2	Quit 1 year ago	Yes
24	73	Female	White	Widowed	Retired	Retail, Small Business Owner	Low income	Diploma	< 1 year	5	Never	No
25	51	Female	White	Single	Disabled	Nurse's Aide	Low income	Some college	>10 years	9	Current	No
26	60	Female	White	Separated	Disabled	GED program teacher	Low income	Diploma	1-3 years	6	Current	No
27	63	Female	White	Single	Disabled	Special Education Aide	Poverty	Some college	>10 years	6	Never	No
28	62	Female	Black	Single	Retired	Middle School Teacher, X-ray technician	Above low income	Graduate degree	7-10 years	4	Quit 5 years ago	No

* Per U. S. Department of Health & Human Services Poverty Threshold Guidelines (2017)

Participant 2 (52-year-old female, diagnosed 1-3 years ago), lived in a two-story rented apartment in a large city with an adult son and teenage granddaughter. She identified her disease as “COPD” but was not aware that it could be defined in stages. She had a complex medical history that included a congenital heart condition, heart failure, pacemaker, multiple knee surgeries and a replacement, and manic depression. Although considered disabled due to her multiple health conditions, she described being of help to all of her children and grandchildren daily and expressed pleasure at spending time with them. She reported current tobacco smoking with attempts to cut down and believed smoking and lack of exercise were the cause of her COPD. She described her understanding of the disease in terms of the symptoms she experienced and described it as feeling “heavy” and like “someone is squeezing”. She reported shortness of breath with activity, dizziness, fatigue, anxiety, and experienced exacerbations that left her too weak to get up to go the bathroom. Her symptoms were triggered by the cold air in winter and hot weather in the summer. She used inhalers and a continuous positive airway pressure (CPAP) machine but only when she felt she needed to. She had also tolerated prednisone for her COPD in the past. She reported feeling positive about her health care experiences and emphasized that she thought it was important for health care providers and patients to get to know each other. She also felt it was important for patients to speak up and let health care providers know their perspectives if they want to be heard. She reported that she enjoyed being involved in the lives of her 13 grandchildren.

Participant 3 (61-year-old male, diagnosed more than 10 years ago), lived in a lower rented duplex in a large town with his wife. He described spending most of his time doing chores and taking care of his multiple pet cats and dogs. He identified his disease as emphysema and as “end-stage”. He believed his disease was caused by tobacco smoking and his past work in the

printing industry. He understood COPD was progressive and described the disease process as the “upper and lower lungs no longer working together very well” and of “air being trapped” the “air sacs” of the lungs. He reported shortness of breath with exertion, excess mucous production, panic, weakness during exacerbations that left him feeling unable to move, and at times feeling depressed about his illness. He used oxygen intermittently and inhalers for treatment, but neither as prescribed. He also reported every other day dosing of Prednisone. He did not use his inhalers as prescribed due to cost. He reported overall positive experiences with his health care providers, although he felt his pulmonologist was often too serious and a bit difficult to talk to. He was appreciative of the help his health care providers had been in providing free samples of inhalers he could not afford and for helping get him an oxygen concentrator during an insurance coverage gap while waiting for his government status disability payments to begin. He expressed deep frustration with pharmaceutical companies and the cost of medications. He stated he was motivated to manage his illness as his wife and multiple pets depended on him.

Participant 4 (61-year-old male, diagnosed more than 10 years ago), lived with his wife between a single-family house, an owned apartment, and a vacation condominium. He described spending most of his free time helping out in the pizza business he had owned for most of his life or relaxing in the winter months in a vacation condominium in the South. He described his disease as “very severe” COPD. He believed smoking was the cause of his illness. He had asthma prior to being diagnosed with COPD. He understood COPD was comprised of chronic bronchitis and emphysema. He stated the diseases were different in that “if you have chronic bronchitis, only one lung is diseased” as opposed to having “both lungs diseased” in emphysema. He reported fatigue, shortness of breath, feeling depressed about his illness, weakness, and

reduced quality of life. He used inhalers and a nebulizer as prescribed but didn't feel these medications worked as well as they used to when he had first started taking them. He was also regularly prescribed prednisone, which he tolerated. He expressed frustration with how much his medications cost. Overall, he stated his health care experiences were positive although he did feel his primary doctor had more time to spend with him than his pulmonologist, who he was too busy and a bit difficult to talk to. He stated he was motivated to manage his illness to continue to be able to take trips to Florida with his wife during the winter

Participant 5 (73-year-old male, diagnosed 4-6 years ago), lived with his wife in a single-family house they owned in a large town. He described his disease as COPD and believed it was caused by smoking and his work for decades in a leather tannery. He had a complex medical history, including numerous issues with his heart, kidney, diabetes, and anemia. He reported that he really didn't understand how his illness worked or why some people smoke for fifty years and have no problem but that he only smoked for ten years and got COPD. He did, however, understand that the damage done to his lungs was largely irreversible and that the disease is progressive. He stated that his heart issues, in particular, made it difficult for him to distinguish the cause of his symptoms. He reported fatigue, shortness of breath with activity, weakness, dizziness, hoarseness, and feeling depressed at times about his illness. He stated his symptoms got worse in humid weather. He used inhalers and a nebulizer as prescribed but struggled with the cost of his COPD medications in the context of his other medication expenses. He reported positive experiences with his health care providers although he related that "all they can do when you got COPD is give you different medications." He was motivated to manage his illness to continue to take trips with his wife and live to see his grandchildren get married and have their own children.

Participant 6 (76-year-old male, diagnosed more than 10 years ago), lived alone in the single-family house he owned that was located on a few acres of land outside of a small town. He was diagnosed with asthma and emphysema “around the same time”. He believed he “inherited a good percentage of this” but also thought that smoking, welding, and other chemical exposures throughout his life did not help. He described emphysema as restricting airflow and then “you don’t get enough oxygen in your system”. He described that “COPD is a combination. Emphysema, asthma, and all the other stuff that goes with it”. He underwent lung reduction surgery about three years prior to the time of the interview. Before surgery, he experienced shortness of breath, weakness, and fatigue. Since surgery, he reported only weakness. He used inhalers and a nebulizer but less than was prescribed because he did not feel it was needed. He reported having overall positive experiences with his health care providers although he stated it was difficult to get an appointment with his pulmonologist as well as his general practitioner. He emphasized that he isn’t afraid to speak up if he doesn’t agree with them. He was not motivated to manage his illness for any particular reason but rather because “I just get up and do it.”

Participant 7 (76-year-old female, diagnosed 1-3 years ago), lived with her husband in their own house within a small retirement community on the outskirts of a large town. She was diagnosed with asthma and COPD and stated she did not have any idea what caused either condition and stated, “I can’t tell you about it...I only know about the breathing and that’s it.”. She used inhalers as prescribed although she had to be switched to a different kind due to cost. She believed if she stopped using the inhalers she wouldn’t feel any differently than when she used them. She also wore oxygen at night. She reported shortness of breath with activity and a raspy voice. She stated that she “loved all of her doctors” however she also had complaints of her

pulmonologist acting very rushed during visits and not spending time talking to her. She was motivated to manage her illness to fend off having to wear oxygen 24 hours a day.

Participant 8 (48-year-old male, diagnosed 4-6 years ago), lived with his girlfriend in a rented apartment in a large city. He was diagnosed with COPD and sarcoidosis. He had a complex medical history including pulmonary hypertension, sleep apnea, and steroid-induced diabetes, among others. He understood the progressive nature of COPD as “you can’t get rid of it once it’s there. You can only treat it to try to keep it from developing even more”. He stated his disease was probably caused by smoking. He reported shortness of breath, weakness, fatigue, coughing, depression, and passing out. He used inhalers, nebulizers, prednisone, and oxygen as prescribed but that had only started in the last few months following an extended hospitalization that included prolonged intubation. Activities such as bending over, hot showers, smoke, pollen, perfumes, cleaning products, rain, and cold and hot weather, worsened his symptoms. He felt cared for and informed during his health care experiences however stated that wasn’t always the case as he used to not trust his doctors. His girlfriend helped him with chores and his sister helped to take him to his medical appointments and to get his medications. He was motivated to manage his illness to stay out of the hospital, keep his disease “right where it’s at”, and “to live as long as possible.”

Participant 9 (75-year-old female, diagnosed more than 10 years ago), lived alone in a rented senior apartment in a large city. She was diagnosed with COPD and she believed it was caused by smoking. She did not understand if she could stop her disease from progressing or if it would get worse, stating that no one had ever talked to her about that. She did not understand why there wasn’t more being done for people with COPD. She stated she had mostly difficult health care experiences, including being told by a doctor, “Well, it’s all your fault because you

smoked.” She also expressed frustration communicating with doctors in general, and with pulmonologists in particular, and with breathing tests and pulmonary rehabilitation. She was frustrated by the limited options of oxygen delivery systems available for her. She was also very frustrated with pharmaceutical and insurance companies, particularly with upcoming changes to her insurance that would increase her office visit and medication costs. She described shortness of breath with activity, coughing, hyperventilating, gagging, and excess phlegm as her symptoms. Hairspray, mold, and cleansers were triggers. She used inhalers for treatment but felt like they didn’t work the way that they used to. She remained motivated to manage her disease in order to continue to see her grandchildren grow.

Participant 10 (52-year-old male, diagnosed 4-6 years ago), lived with his fiancé, in a rented apartment in a large city. He called his lung disease COPD and believed it was caused by smoking tobacco, marijuana, and crack cocaine. He had a complex medical history, including kidney failure, type II diabetes, heart murmur, congestive heart failure, hypertension, increased cholesterol, and past substance abuse to crack cocaine. The symptoms of heart failure made it particularly difficult for him to manage his COPD. He described what was going on in his lungs with COPD as “...after a certain length of time, everything starts closing up and it’s sticking to itself”. He described his symptoms as shortness of breath, weakness, and anxiety. He identified heat, perfumes, and the smell of cooking foods, such as fish, as triggers for his symptoms. He was motivated to see his grandchildren grow.

Participant 11 (76-year-old female, diagnosed 1 year ago), lived alone in a senior condominium community in a small town. After living with asthma for nearly twenty years, she stated her pulmonologist had recently “changed it to COPD”. She had a complex medical history that included multiple hip and back issues. She used inhalers, a nebulizer, and prednisone

as prescribed. She also used oxygen 24 hours per day, but she didn't like to use it at the 6 liters per minute (LPM) during activity that she had been prescribed stating that, "There might come a time where I'm going to have to stay at six, but if I can get by with two or four, I'd like to keep it that way." Her doctor was working with her at the time of the interview to attempt to wean back her prednisone dosage but she stated that whenever they do that, "I get in trouble". She reported shortness of breath with activity and at rest, "gurgling" in her chest, coughing, hoarseness and loss of voice, and feeling depressed at times about her limitations. Tobacco smoke, hot weather, and extended talking were triggers. One of her biggest complaints about her health care experiences was waiting to get an appointment, particularly when she was having an exacerbation. Most recently, she was very pleased to have her primary doctor agree to have her call one of the office nurses directly when she was feeling the need to be seen. She was supported by four adult daughters who took turns checking in on her and taking her to her medical appointments. She was motivated to continue to manage her illness to stay alive long enough to see her 13-year old grandson graduate from high school.

Participant 12 (82-year-old female, diagnosed 1-3 years ago), lived with her husband in their single-family house located on ten acres of land near a small town. She identified her disease as "emphysema asthma", although she said it took some time for doctors "to get to the bottom" of her symptoms and provide her that diagnosis. She did not realize that COPD was progressive or that it could be staged, even though she was rather knowledgeable about the societal impact of lung diseases in general and of COPD in particular. She stated she had chronic bronchitis since childhood and had been diagnosed with allergies and acid reflux prior to being diagnosed with emphysema and asthma. She had other significant health conditions including congestive heart failure, kidney failure, and a history of obesity. She stated she had received

much more education from her health care providers about her other conditions than she did about COPD.

She reported a “garbled” voice, wheezing, anxiety, and coughing. Fireplace ashes, smoke, fragrances, septic smells, perfumes, and fragrances from items such as candles and air fresheners were triggers. She used inhalers and a nebulizer as prescribed and had tolerated prednisone in the past. She reported positive experiences with her health care providers but stated it was “hard to get an appointment” with her pulmonologist and that they, and primary doctors, were just too busy to provide the kind of education she received from the nurses at pulmonary rehabilitation. She also expressed concern that health care payment structures encouraged doctors to look for easy answers when diagnosing patients and discouraged them from caring for more complicated patients. She was very grateful for her participation in pulmonary rehabilitation as she credited it with helping her to lose nearly fifty pounds and helped her to face the impact of food addiction, weight, and lack of activity on her health. She stated she stayed physically and mentally active by volunteering for numerous organizations and attending phase three pulmonary rehabilitation. She was deeply motivated to maintain her health, stating through tears, “I don’t want to go back to that 300-pound person who just sat. I want to be who I am...I just refuse to go back to that.”

Participant 13 (78-year-old male, diagnosed 4-6 years ago), lived with his wife between two owned houses, one in the North and one in the South of the United States, where they spent the winters. He identified his disease as stage four “COPD and emphysema” but did not understand COPD as an umbrella term that emphysema. He understood the progressive nature of the disease but stated he chose, “not to concentrate on that day to day.” He believed smoking caused his disease. He experienced shortness of breath with activity, weakness, and fatigue. He

used oxygen 24 hours/day, inhalers, nebulizers, and Prednisone as prescribed. He struggled with his temperament on Prednisone and was working with his doctor try to cut down his dosage. He was overall pleased with his health care experiences but noted differences in the delivery of care between the hospital systems he accessed in different regions of the country and expressed frustration with payment structures, insurance companies, and pharmacies at large. He also expressed that it would have been helpful if someone would have provided more information about COPD when he was diagnosed but he felt time constraints during health care encounters limited such conversations. He emphasized the advantages he felt he had financially and educationally in seeking the care he felt he should receive and the importance of people speaking up and asking questions. He was motivated to keep managing his disease so he could continue to spend winters in the South and because he stated, “I am just not ready to quit yet.”

Participant 14 (77-year-old female, diagnosed more than 10 years ago), lived with her husband in their own house on a few acres of land near a small town. She identified her disease as COPD and believed smoking caused it. She understood the condition as treatable, not curable, and that “people progress at different rates”. She understood the disease process as, “it isn’t the fact that you can’t breathe oxygen in. It’s the fact that you can’t get it out, the old stuff.” She experienced shortness of breath with activity and weakness. She used inhalers and intermittent oxygen for treatment, although not as prescribed stating, “I don’t like to take medicine unless I have to.” She had used Prednisone in the past. She struggled with multiple acute side effects while taking the drug and had steroid-induced diabetes she continued to manage. She struggled with the cost of health care, particularly with the cost of her inhalers and with the need to have an office visit for what she considered routine flare-up issues. She discussed a positive relationship with her primary care provider with whom she felt very comfortable talking to. She liked to keep

her mind active by quilting and doing word searches and enjoyed spending time with her pet dogs and a “favorite” granddaughter.

Participant 15 (76-year-old male, diagnosed 4-6 years ago), lived with his wife in their own house in a large town. He identified his illness as emphysema and believed it was caused by smoking and filthy working conditions he experienced early in his career as an inside journeyman. He stated he didn’t understand “emphysema more than any other type of lung disease” and that he had no idea about what to expect from the disease in the short or long-term. He experienced shortness of breath with activity, coughing, dizziness, and fatigue. He identified warm weather as a trigger. He used inhalers for treatment but not as prescribed due, in part to feeling like it wasn’t needed. He also limited his inhaler use because of the concern of putting more medication in his body as he had known someone who had died as the result of an adverse reaction to inhaled treatment. He expressed frustration overall with his health care experiences emphasizing how rushed he feels doctors are during office visits. He also related an experience of feeling as though he contracted a respiratory infection from a nurse who was caring for him during a hospitalization for his heart. He was motivated to keep managing his illness “to stay out of the hospital and not have to go to the doctor’s office”.

Participant 16 (73-year-old female, diagnosed 1-3 years ago), lived with her husband in their own house in a large town. She identified her disease as COPD but stated she had “chronic bronchitis for years” prior to her COPD diagnosis. She didn’t know what had led to her having the disease and did not understand how the disease worked. She wished she had more information to know what to do about it. She experienced shortness of breath with activity, coughing, wheezing, fatigue, and panic during coughing fits. Her symptoms were triggered in part by hot weather. She felt like she needed to see a specialist for her lung disease as she had

been diagnosed by her general medicine physician. She hoped that a specialist would provide her more information on her condition. She was motivated to continue to manage her illness in order to, “keep breathing... and to be able to do the things that you have to do without it causing too much of a problem...I just want to be able to enjoy my time left on this earth.”

Participant 17 (79-year-old male, diagnosed 7-10 years ago), lived with his wife in an assisted living apartment facility. He identified his disease as COPD and believed smoking was the cause of his illness. He described his understanding of his illness as, “when you inhale...it’s got to go through the bronchials and its got to go through the lungs and get cleaned out and go to the rest of the body”. He was unaware of the stage of his disease. He had a number of other chronic conditions but struggled most with neuralgia that was the result of a shingles vaccination. He reported shortness of breath when walking up steps. His shortness in breath could also triggered by chemicals, fragrant sprays, and smoke. He used inhalers for treatment as prescribed stating it was important to “stay with the medical program that’s set up for you.” He liked to stay active by taking walks. He reported that his health care experiences for his lungs were favorable due to his trust in his general practitioner who understood his lung disease in the context of his other conditions. However, he reported a number of negative health care experiences related to his neuralgia. He was motivated to keep managing his illness because “it’s just the way I am...that’s just me. If I feel myself getting down, I put a stop to it just like that.”. He also stated he was motivated to keep managing in order to have more time to spend with his wife and five great grandchildren.

Participant 18 (73-year-old female, diagnosed 7-10 years ago), lived with her husband in their own house in a large town. She identified her disease as both emphysema and COPD and believed smoking was the cause of her illness. Prior to her illness she was a very active woman

who exercised regularly. She stated she had been told her COPD was severe but that this was not expressed in terms of “stages”. She had a history of a complicated episode of community-acquired MRSA that resulted in an extended hospitalization and a partial lung removal. She reported shortness of breath with activity, cough, and weakness. She used inhalers for treatment as prescribed and had tolerated Prednisone in the past. She reported overall positive experiences with her health care providers but stated that her current pulmonologist was too busy. She stated she was motivated to keep managing her illness because she didn’t “want to end up sitting in a chair doing nothing.”

Participant 19 (76-year-old male, diagnosed more than 10 years ago), lived with his wife in their own house in a large town. He identified his diseases as emphysema and asthma, adding that the doctor refers to it as COPD. He did not have any idea about the stage of his disease and although he stated he had an understanding of his illness, he did not provide any details about this. He reported shortness of breath with activity and weakness. He used multiple inhalers for treatment but did not always use them as prescribed due to the cost. He reported that he didn’t have many issues with his health care providers except for receiving conflicting information at times and feeling they were often rushing and are “pretty pushy on getting you in and out”.

Participant 20 (65-year-old male, diagnosed 7-10 years ago), lived with his wife and teenage granddaughter in an owned mobile home in a court in the countryside near a large town. He identified his diseases as COPD, both emphysema and chronic bronchitis. He shared that he had been told by his doctor that both diseases were at the “serious” stage. He reported that he had chronic bronchitis “all his life” sharing that every year as a kid he had a flare. He felt he knew a lot about his illnesses and topics related to health care in general as he had been an emergency medical technician for nine years in the 1970s. He shared that “the disease stopped because I’ve

quit smoking, of course. The emphysema part of it that is. The bronchitis will never go away.”. He believed chronic bronchitis to be a virus. He reported shortness of breath with activity, excessive cough and mucus, and passing out. He used multiple inhalers, although not as prescribed due to the cost. He also used nebulizers and had been prescribed and tolerated Prednisone in the past. He reported really liking his current primary care physician that helped care for his lung disease and described him as “the kind of guy that’ll sit there and chat with you.” He stated he was motivated to keep managing his illness for his grandchildren, calling them “my life”.

Participant 21 (72-year-old female, diagnosed 7-10 years ago), lived in a rented independent apartment in an assisted living apartment community in a large city. She identified her lung disease as COPD and stated it was termed “severe”. She believed it was probably caused by tobacco smoking and wondered if marijuana smoking didn’t have something to do with the development of the disease as well. She stated she didn’t know what to expect about the progression of the disease but wondered if maybe if that was okay, that perhaps that was best. She reported shortness of breath with activity, fatigue, and weakness. She also reported that she experienced for a time difficulty falling sleep because she was afraid she would stop breathing. She used inhalers, nebulizers, and oxygen at night during sleep as prescribed. She also reported tolerating prednisone use in the past. She reported having good and bad experiences with health care providers and stated that it was important to find those who are willing to work with her. She also stated that it was important to ask them questions. She was motivated to continue managing her disease to have what she described as “some semblance of normalcy” and to help care for her sister who had mental and physical health needs. She also stated that she was “still

learning things” and that “life is good...if I was in pain, or absolutely couldn’t breathe...that would be a different story, but I feel pretty okay”.

Participant 22 (76-year-old female, diagnosed 7-10 years ago), lived in an apartment in a building that her family owned in a large city. She identified her disease as COPD and stated that at the last time she had been to the doctor, she was told the stage was “mild”. She believed her disease was caused from long-term exposure to the burning of toxic sawdust from a furniture factory near where she had lived and taught while living and teaching in rural South America. She reported that she did not fully understand her disease. She understood that lung tissue was damaged and that there was reduced gas exchange but she did not understand why lungs can improve when someone stops smoking but not for COPD? She reported shortness of breath with activity, wheezing, and post-nasal drip. She was prescribed inhalers but only used them when she really felt she needed it as she reported feeling “jittery” with use. She had also tolerated the use of Prednisone in the past but said she had to be careful with that as it will also make her feel the same way as the inhalers. She was also cautious with how many antibiotics she took. She overall felt positive about her health care experiences feeling that staff have been helpful and competent. She was motivated to keep managing her illness because she stated, “That’s my nature...I love life. I love what I’m able to do.”

Participant 23 (58-year-old male, diagnosed more than 10 years ago), lived in an informal group home assisted living house in a large city. He identified his disease as COPD and stated it was “final stage”. He believed it was caused by smoking and from exposure to dust, chemicals, and asbestos during his time working as an electrician. He understood his illness as the alveoli in his lungs “expanding and they’re not contracting and carbon dioxide is staying in my lungs.” He expressed understanding of the progressive nature of the disease as he stated the

disease “only goes one way, down.” He reported shortness of breath at rest and activity, hyperventilating, and anxiety. He used oxygen 24 hours a day, inhalers, and nebulizers as prescribed. He reported having that his current experiences with his health care providers were good and he felt “keep it real”. He did report, however, that in the past he had experienced a situation where a doctor he had only wanted to give him a pill. He stated he preferred to see his primary physician due to the cost of seeing specialists. He was also frustrated with pharmacies as he felt they were overcharging him. He reported that some of his symptoms were triggered by cold and hot weather, However, he expressed deep frustration about being denied being put on the transplant list due to his current living situation and support. He stated he was motivated to keep managing his illness because he had affairs he still needed to put in order and he wanted to spend some time with his grandson.

Participant 24 (73-year-old female, diagnosed <1 year ago), lived alone in her own house in a large town. She identified her illness as “moderate” COPD. She speculated that her disease might have been caused by second hand smoke exposure during childhood and young adulthood and/or frequent bouts of bronchitis she had throughout her life. She stated she didn’t really understand what was going on inside her lungs except for that she was “not getting rid of oxygen”. She reported shortness of breath with activity, coughing, and excessive phlegm production. She stated that numerous triggers made her cough and feel short of breath including perfumes, detergents, fragrant flowers, and hot and cold weather. She was frustrated that she felt that her primary care provider and pulmonary specialist did not seem to take her complaints about symptom triggers seriously. She also expressed frustration with the amount of information health care providers had told her about her disease but also felt that she should ask more questions during her encounters. She was prescribed inhalers but did not use them as directed

because of the cost and also because she doubted that it made any difference. She had tolerated use of Prednisone in the past. She stated that she was motivated to keep managing her illness for her family, particularly to see her younger grandchildren grow up.

Participant 25 (51-year-old female, diagnosed more than 10 years ago), lived alone with her cat and dog in a rented duplex in the countryside near a small town. She identified her disease as a mixture of “moderate to mild” COPD and asthma but also felt she may have received a misdiagnosis because she had been diagnosed more than ten years ago but felt that the disease hadn’t progressed much. She figured if it was a progressive disease she should have had her illness get worse in that time period. If she did have COPD and asthma, she believed the cause was smoking tobacco (a habit she started at age seven) but she also thought she might have inherited it. She reported shortness of breath with activity and coughing. She used inhalers but not as prescribed. She had tolerated Prednisone in the past without issue. She was frustrated with health care providers because she felt that the diagnoses listed on her medical record were not accurate and that she felt she was being pegged as “drug-seeking” due to her Medicaid status and her past substance abuse and chronic pain history. She also felt that her doctors were not willing to work with her and take her seriously. She stated she was motivated to keep managing her illness because she had a lot of people who cared about her and that she also cared about herself enough to keep managing.

Participant 26 (60-year-old female, diagnosed 1-3 years ago), lived with her daughter and school-age granddaughter in a rented upper duplex. She had a complex medical history including a recent stroke that had impacted her speech and ambulation but from which she had rehabilitated. She was recently approved for long-term disability from the Social Security Administration. She identified her disease as “chronic bronchitis which may turn into COPD”

and believed it was caused by tobacco smoking. She was not aware of the stage of her disease nor that COPD even could be staged. She had a limited understanding of her disease, describing it in terms of her symptoms, but did understand the disease could not be cured and was progressive. She reported shortness of breath with activity and cough. She used inhalers for treatment as prescribed. She stated she had positive experiences during hospitalizations for COPD as well as other conditions but was less pleased with the care she received as an outpatient. She reported difficulty keeping a health care provider at her clinic due to turnover. This resulted in new providers not knowing or trusting her assessment of her symptoms. She stated her current doctor at the clinic always seemed rushed and didn't offer time for her to ask any questions. She was motivated to keep managing her disease because she still felt "young at heart".

Participant 27 (63-year-old female, diagnosed more than 10 years ago), lived alone in a rented apartment in a large city. She identified her lung disease as chronic bronchitis. She wasn't sure what may have caused her disease but believed it may have been exposure to second hand smoke as a child. She had a complex medical history that included multiple sclerosis, active Crohn's Disease, and orthostatic hypotension associated with autonomic dysreflexia. She reported shortness of breath with activity, cough, dizziness, and weakness. She was wary of using medications for her illness. She stated tobacco smoke, mold, and hot weather were triggers of her symptoms. She expressed frustration with the cost of seeing specialists for her lung disease, particularly in the context of her other illnesses. She was motivated to keep managing her illness to spend more time with her grandchildren.

Participant 28 (62-year-old female, diagnosed 7-10 years ago), lived alone in a senior apartment community. She identified her lung disease as COPD. She also had been diagnosed with asthma, arthritis, and fibromyalgia. She believed her disease was caused by smoking and

perhaps exposure to chemicals from the time she spent working as an x-ray technician when she was younger. She was not aware of the stage of her disease or that it could be staged. She understood the COPD disease process as one in which ‘it’s almost like pneumonia, like its’ (lungs) are filling up with fluids’. She also described this process of her lungs filling up with fluid as her primary symptom. She stated that dust and pollen were a trigger for her symptoms. She used inhalers as prescribed, a nebulizer, vitamins and other supplements to treat her symptoms. She reported a close relationship and positive experience with an independent pulmonologist she saw in the past but stated she had not experienced anything even close to that more recently. She was motivated to keep managing her illness to ‘stay out of the oxygen stage’ and to be ‘in the presence (of God)’ because her religion inspired her to do things ‘with and for other people’.

Across Case Data Analysis

Although each participant presented his or her own individual story related to the experience of living with COPD, commonalities were identified across the participants’ stories. The overall challenge of living with COPD was described by participants as a process of learning to live day-to-day with symptoms of increasing severity in the short- and long-term and their associated treatment. Participants shared similar stories of the progressive symptoms they experienced living with COPD and of those they endured during exacerbations. The analysis performed across all 28 cases resulted in the identification of themes and sub-themes, presented in Table 4. This table is followed by a discussion that includes exemplar quotes organized under broad headings related to the research aims of the study.

Table 4

Summary of themes and sub-themes from interviews with community-dwelling adults with COPD

Themes and Sub-themes	Definition
Accepting the disease	Acknowledgement of the existence of lung condition, the cause, sequelae, and the need to act
Maintaining function	Strategies used to maintain health and functioning
Staying active	Formal and informal exercise, doing chores
Preventing infections	Strategies to avoid infections
Medicating or not	Using or not using medications
Paying for it	Issues with paying for medications and other treatments
Dealing with triggers	Products and situations that trigger symptoms and response
Getting through exacerbations	Exacerbations and strategies used in response; weakness and fatigue, extended bouts of coughing, and passing out
Getting information	Receiving information about COPD from health care providers
Feeling rushed	Experiences of time during health care provider visit
Not feeling heard	Feelings of health care providers not listening to the patient

Research Question 1: Daily Challenges and Response to Daily Challenges

Accepting the Disease

Even in the face of physical and financial challenges, the men and women of this study described strategies they used to manage COPD and expressed a largely positive outlook of living with the disease, offering examples of the ways in which they had learned to accept and manage their disease. Participants told stories of moving from ignoring the reality of their day-to-day symptoms to accepting the existence of the disease in their bodies, particularly after experiencing exacerbation episodes and/or recurrent symptoms.

All of the participants acknowledged the existence of a lung disease. Two participants questioned whether or not they really had COPD but neither of these individuals denied having some type of lung disease. Many believed the cause of their disease was multi-faceted with nine (32%) individuals reporting significant work-related exposures they believed in part contributed to their illness.

Some participants expressed feeling depressed and frustrated when they first learned they had COPD. Many of the participants shared that learning to live with COPD was a process that had developed over time. For those with a smoking history, learning to accept the disease was a part of also accepting, at least in part, the impact of tobacco smoking on their health. One participant described his experience about coming to terms with his disease, one that was shared by others. He described:

“Before (being diagnosed with COPD) I had a normal quality of life. I could pretty much do anything I wanted. Then I got this stuff and at first, it was bitterness, like ‘Why did I do this to myself?’ Then as it went along, I went into a depression. Not really depression, but depressed...Kind of a combination of being depressed because of what you’ve done to yourself and feeling sorry for myself. That’s a stage I could still go through to this day. But, now I try not to get depressed about it anymore...I have a wife that depends on me. I have pets that depend on me. I enjoy life. That’s what keeps me going.”

- Participant 3, Male, age 61 years.

In addition, men and women with advanced disease shared that accepting the physically smaller world of COPD was key to maintaining a positive outlook. Symptoms at times left participants feeling too weak to participate in activities and, for some, the need for supplemental oxygen made travel more complicated and cumbersome. This was particularly difficult for younger participants with advanced disease who desired to share in many of the physical and social activities common for their age. For some younger participants, the experience of a severe exacerbation led to acceptance of the disease. A younger participant with advanced disease described how he only accepted the disease when he understood the potential lethality associated with an uncontrolled exacerbation:

“I got to respect the illness. More than anything else, I got to respect it because it will kill you for real. I know that because I’ve been to the crossroads a couple of times. I just learned I got to respect.”

Participant 10, male, age 52 years.

Participants of all ages described the need to accept and face the physical limitations the disease caused. Living with COPD made many participants more aware of the aging process and led them to reframe their outlook on life. One woman described:

“I’ve always been a busy bee, darting here and there. I’ve had to bring it down a notch with COPD. I’m aware that I’m a lot slower now than I used to be and that’s just the way it is. I try to lean into that a little bit more. I have a friend, who said something like, “Lean into death’. I like that concept. You have to kind of lean into the fact that you’re slowing down. You know? I still can do a lot...I drive, I run around with the dog, and I go here and there. But that’s going to get slower and slower. I need to make friends with that. I am a little bit more selective about what I do. I used to not be all that selective. Now I am. If I’m going here, then I’m not going there. You have to choose.”

- Participant 21, female, age 72 years.

Maintaining Function

Many older participants told stories of how symptoms affected their ability to perform chores and for some with advanced disease, complete activities of daily living. Shortness of breath was one symptom that all participants described as experiencing every day. Descriptions of shortness of breath, cough, weakness, fatigue, excessive sputum, anxiety, and depressed mood were universal amongst the participants of this study, particularly those who had more advanced disease. For those with less severe COPD, some symptoms, such as weakness and fatigue, were associated with exacerbations, whereas, for those with more advanced disease, such symptoms were a part of daily life. One participant with advanced disease described this experience. He shared:

“How does it feel? Take a deep breath, hold it, and walk...don’t let that breath out. Walk a couple hundred feet and don’t let that breath out...That’s what it feels like. Your air is being taken in but you can’t get it all out. It just keeps getting trapped and you can’t get it out of your body.”

- Participant 3, Male, 61 years old.”

Such shortness of breath with activity was universally described by participants as one that greatly impacted their lives. One participant with advanced disease aptly described the range of these challenges with:

“There are so many things you can’t do. It’s hard trying to get your housed cleaned. It’s hard trying to make your bed. It’s even an effort sometimes when you take a shower, especially when you get out and try and get dressed. Day to day living has changed so much.”

- Participant 11, female, 76 years old

Another older participant elaborated on how COPD symptoms made showering difficult for her:

“It’s very hard to take a shower. I’m getting to the point that I even hate to go in there and take a shower anymore. It’s a major job, you know what I mean? It kills you to get into it. Especially when I have to crawl over the tub...It’s hard to even sit there and scrub myself because it’s just exhausting. To wash my hair, oh my God, that’s even worse. All I can do is just really fast soak my hair.”

- Participant 9, Female, 75 years old

Participants also shared how time-consuming living with their disease had become in that it took more time for them to perform tasks that they previously hadn’t thought about much. In addition to her challenge with showering, Participant 9 also described how time-consuming chores had become for her. She stated:

“I can’t really clean house anymore. I just can’t. I’ll still try. I’ll go to try and clean out a drawer. It’s a struggle. It’s hard. I have to sit down and rest in between. It may take me all day just to straighten up and dust the apartment because I have to sit down in between.”

Another older participant with advanced COPD described a similar difficulty with performing errands, one shared by others in the study. He described:

“If I have to go to the side of the parking lot, walking over there, it’s going to be slow and it’s going to be a chore, and it’s going to take some effort on my part to get it accomplished. There’s no question that for me to go to a grocery store is a major chore.”

- Participant 13, 78 years old.

While accepting the limitations COPD can cause, nearly all of the participants also described the importance of maintaining function to help decrease the rate or extent to which

COPD could progress and to improve their quality of life. Participants told stories of maintaining functioning by staying active, using or not using medications, and taking steps to prevent infection.

Staying active. Staying active was described as an important, but often complex, part of maintaining function by the men and women in this study. Participants shared that past experiences with exercise, pulmonary rehabilitation, and/or exacerbations, as well as a concern about future oxygen use, helped them stay active and assisted in maintaining their current level of functioning. For some, staying active meant participating in exercise and for others it meant performing chores. Whether participants were working to maintain the ability to walk across a room or go for a run, many of their motivations and strategies were the same.

The potential for oxygen therapy motivated many of the study participants who were not already using oxygen to stay active, in part, to avoid or put off starting to use it. These participants were concerned about being restricted by oxygen use and also that the introduction of oxygen therapy meant a serious progression of COPD that led them that much closer to dying. One woman discussed how being in pulmonary rehabilitation with others who used oxygen motivated her to stay active. She shared:

“In pulmonary rehab I learned I could exercise to a certain extent...There were people in there that were older than I and people that were on oxygen. That was my main goal. To not have to go on oxygen. I had already quit smoking, so that wasn't an issue...I'm older now and I can't do as much now as when I was first diagnosed. But I definitely still feel that by staying as active as I can keeps my lungs stronger than if I wasn't. They're going to go downhill but I'm taking these precautions to kind of level it.”

- Participant 18, female, age 73 years.

For those already using oxygen therapy, the motivation to stay active remained important. One participant with advanced disease and limited activity tolerance who used oxygen summarized the importance he placed on staying active and some of the strategies he

used to deal with his symptoms during activity. This was echoed by others in the study. He shared:

“You have to learn to manage it. I do not sit back and do nothing. I realize how hard it can be to walk ten, even fifteen feet. I have no problem bending over a table and standing like that to get my breath. It helps. I eat smaller meals and do not gorge because when you gorge your diaphragm pushes up on your lungs. It’s not good... You don’t have to exercise, you can also just move around. Some people don’t even want to leave the house. I won’t be that way”

- Participant 3, male, age 61 years.

Other study participants described the important role walking played in their lives. Some had been walking for years prior to their COPD diagnosis and others started going for walks after receiving their diagnosis. One participant succinctly described how walking helped her manage her disease:

“I think the thing that helps me the most, especially when it’s nice out, is walking. I feel more invigorated when I walk. I feel more energetic when I walk. I think my lungs do better when I walk... Staying active, to me, is what helps me manage my COPD”.

- Participant 24, female, age 73 years.

A number of participants described living with allergies and/or asthma throughout their lives and later on being diagnosed with COPD. Some of these participants shared how this had, in part, limited their physical activity over the years. One woman described the important role walking played in her life since her participation in pulmonary rehabilitation a few years prior to the time of the interview. She shared how she overcame internal barriers to being active:

“My doctor suggested I go to pulmonary rehab. And that’s where my life changed. I weighed about 293 pounds. I was very sedentary. I just wanted to sit, I didn’t want to move my lungs. My body still doesn’t want to move, but I do. I lost 42 pounds and increased my steps... It wasn’t until about three years ago that I was actually diagnosed with COPD. If I hadn’t been, I would still be 300 pounds sitting home watching soap operas. Really and truly resting my lungs. My lungs don’t want to move. I found that I have to push myself. I live on ten acres out in the country and I take the dog for a walk three or four times a day just to get outside in the air... My COPD challenges me to do the things I want to do. I don’t want to use COPD as an excuse... I think that’s the thing that’s made me far more active than I’ve ever been.”

- Participant 12, female, 82 years old

A few participants who had led active adult lives shared how their past experiences with exercise impacted their perspective and choices regarding exercising with COPD. One woman who had regularly engaged in vigorous exercise throughout adulthood, including running a half-marathon at age 61, described how COPD impacted her level of activity:

“I used to think nothing of going up five flights of stairs. Where I lived before I had five flights of stairs and I’d say to myself, ‘I will not use the elevator. I’m using those stairs.’ I didn’t have any problem with that. But winded is so different from shortness of breath, isn’t it? Now I force myself up those stairs. I make sure I go up the stairs but I get short, I wheeze... I love running and I just can’t do it the same. I used to run every morning. Now I can’t do it so easily. I don’t nearly have that kind of endurance. I keep thinking that maybe I can improve my capacity if I push it. I kind of know what my limits are though now and, well, it is less. With muscle, I know I just have to go through pain to make it stronger but muscle is so much different than lung. I still really want to get exercise. I feel it’s very important for me. It’s important for my sense of well-being. I have started using the inhaler when I exercise and that seems to help.”

- Participant 22, female, age 76 years.

Preventing infection. Participants also described the many ways they tried to keep away infections in order to reduce exacerbations and subsequently maintain function. For most, it meant washing and/or sanitizing hands frequently, getting an influenza and/or pneumonia vaccination, and avoiding crowds or wearing a mask during peak flu season and/or when in contact with people with a known infection. Some participants who reported a strong relationship with a health care provider also described that their process to prevent infection included keeping health care providers informed of their symptoms and at times, taking antibiotics prophylactically or using an antiviral such as Oseltamivir. One participant described a recent experience she had in which she was concerned about a change in her symptoms. She described:

“The doctor says, “Be very careful.”. So I am. I get my flu shot, get my pneumonia vaccination. If I have anything close to an exposure to the flu, I should call. And that happened last year. I was with my daughter and her three little darlings. They’re lovely. But they’re also lovely, resilient Petri dishes for bacteria and viruses, aren’t they? I can’t

stay away from them though. He said, "Just call me if you think you've been exposed to the flu". And of course, I had been exposed to the flu with a fever as the family definitely had it. Well, I think I didn't get it because I did call and go and take the antiviral."

- Participant 22, female, age 76 years.

Participants expressed taking some or all of these steps in order to keep away an infection. It was viewed as an integral part of their experience of living with COPD which helped them to stay well.

Medicating or not. Other participants also described that taking medications was an important part of being able to exercise in order to maintain function. This was particularly true for those with more advanced disease who had experienced severe exacerbations after not taking medications as prescribed. Overall, eleven (23%) participants of this study reported taking the medications prescribed for COPD by their health care provider, believing they made some kind of difference in their health. As one participant with advanced disease stated who had recently experienced a severe exacerbation:

"The inhalers...the albuterol, the nebulizer, all of those, they help me best they can, you know? I could be a lot worse right now and I've been a lot worse than right now. So, by me using my medications, I guess I'm at this right here, where I'm now. I can walk through the room and walk back here and then walk outside and back in. Without taking my medication, that would be a hard task for me."

- Participant 8, Male, age 48 years.

Participant 8 went on to describe the process of how he came to feel that taking his medications as prescribed were important after a severe exacerbation:

"Before I started being serious with it...I didn't really trust the doctors, what they were talking about. I figured, 'This ain't helping me. I'll just do the things I've been doing'. But then, I started taking the medication, doing what they saying, and the next thing I know, things just stayed better...One time I went to the hospital. I couldn't hardly breathe. I went into a coma for about 17 days. After I came up out of the coma, I was weak and I couldn't stand up. That was the first time I'd been in something like that. I mean, I could hardly lift my arms up. I had lost about 30 pounds. That was it. I started taking my medications on time. As prescribed. Doing these little exercises. I went to therapy where they gave me little exercise pointers to do. She said 'walk as much as possible'. At first, I felt down and fatigued. I would just sit down all day in front of the

TV. But then I started getting up, doing things. Like I'd do just some cleaning off the stove. It wasn't much, but it was something to keep it moving...Then I'm walking with the walker all around the house. They telling me, 'lift your legs up, why you sitting down there, lift your arms up. Use some exercises'. It helped me build up a little more muscle."

Conversely, other participants made modifications to their prescribed pharmaceutical treatment regimen. For these individuals, not taking medication at all or less than prescribed was viewed as an important part of staying healthy. These participants did not find value in taking medication from which they did not perceive a direct benefit. Frustration was also expressed about a lack of not understanding how prescribers determined, if at all, medications were making any difference. For some, medications caused uncomfortable side effects they had difficulty living with and/or managing. Others believed the medications would harm them more than their COPD did and/or felt that the risk of harm from use was greater than any positive effect they experienced from their prescribed medication regimen. As one participant shared:

"I've taken all of this medication and what in the world good is it doing? Because I don't think I'm coughing any less than before I started taking this stuff. In fact, sometimes I think I'm coughing more now since I've been taking it. I look back and I think, "I don't know if I'm any better off at all for getting and taking all of this stuff because I don't think anything's changed with taking the medication."

- Participant 24, female, age 73 years.

Another participant not only felt that her COPD medications didn't work to reduce her symptoms, she also expressed how she found the overall COPD treatment regimen challenging to follow and thought it caused unpleasant side effects. She discussed how she believed her inhaler use made her voice weakened and hoarse. This issue was also shared by other study participants. She described:

"I was put on Advair and I totally couldn't talk. Then I was switched to Symbicort and the same thing happened. Now, I take the Incruse once a day and the Albuterol was added back. I take it as needed. So far, I really hate to use it. I just don't think it's good for me. I don't like putting foreign junk in my body. The Advair don't work, the Symbicort don't work, and the Incruse doesn't seem to be doing a whole hell of a lot. And then there's albuterol that I'm only supposed to use every four hours and then be careful I'm

not using it close to the Incruse or Advair. It was like four hours before or after. Who can keep track of all of that? If it's not working, why am I taking it? All of the side effects say if you have a heart problem, you shouldn't be taking it. I do have a heart problem, so that's not good either."

- Participant 1, female, age 68 years.

Inhalers were not the only cause of medication concerns for participants. Some of the men and women of this study also described the challenges they faced with taking Prednisone. Although a number of participants shared that they tolerated taking the drug during exacerbations and then being able to decrease its dosage without issue, others described challenges they faced with taking the drug. Some participants described difficulty with weaning off of the drug while others described how terribly they reacted to it. One participant shared her reaction to the medication:

"Prednisone is terrible and I hate it. I will always deny it when they try to make me take it. It does such terrible things. Break you out, swell you up. You're always hungry and you're puffed up. It just does so many things that make me feel so terrible inside. So terrible. When they just want to give me Prednisone, I refuse to take it."

- Participant 28, female, age 63 years.

Another participant described how she experienced the drug:

"He put me on 40 mg of Prednisone per day. That was a nightmare. I hallucinated. I can remember the time it was probably at it's worse because I was going to have Easter dinner here... My daughter ended up cooking because I was like in a... I don't know. It was like I was in a dark area... I tried to get up. I was bumping into everything. I didn't know if I was in a room or if I was on a cliff. That was pretty intense...After that weekend my granddaughter told me, 'Grandma, you've got to do something. You look like hell. You're really bad. You have to.' I called the doctor and I said, 'You got to do something with this Prednisone or something. I can't deal with it.' It was kind of scary"

- Participant 14, female, age 77 years.

For others, trying to get off the drug was difficult, leaving them to deal with some of its effects more long-term. One participant who had been taking Prednisone for a number of years shared:

"The interesting part of the meds has been my Prednisone. My temperament is not at all what it used to be. I'm a lot less patient and I lose control rather quickly. But we're working hard on it, working hard on getting the Prednisone down...The Prednisone is kind of rough. If there's a medication that's driving us, it's the Prednisone. It's the feel-

good drug in that it keeps the airways open and so on and so forth but basically, I'm a druggie and I'm hooked and I don't know that I'll ever get off of it."

- Participant 13, male, age 78 years.

These descriptions of how individuals chose to use or not use medications to maintain function in the context of their illness provide insight into the complexity involved in medication behaviors in COPD.

Paying For It

In addition to the symptoms and related limitations participants faced each day, the men and women of this study also discussed how COPD and its treatment had a significant financial impact on their lives. The cost of medications, specialty visits, and the loss of the ability to work led many of the participants to make difficult decisions about treatment, particularly inhalers and nebulizers. Affording the cost of care was particularly difficult for participants with multiple chronic conditions and for younger participants with severe disease, some of whom already lived in poverty and who also did not yet qualify for aged-based programs, including social security retirement benefits. It was also true for many retired participants who described making difficult decisions about how much of their fixed incomes could be spent on treating COPD. Even participants with higher incomes expressed frustration with the cost of treating the disease. Participants repeatedly discussed how the cost of medications, health care visits, and formalized exercise programs impacted how they could choose to treat their illness. This was particularly true for those participants with multiple chronic conditions who had other health care related costs they had to consider.

All of the participants in the study acknowledged the actual or potential financial impact of living with and managing COPD. One upper income participant who lived with his wife aptly described how the availability of resources positively impacted his treatment options:

“We’re fortunate that we’re in a position to do whatever we want to do, such as in terms of buying helpful aids like that (generator and Inogen portable oxygen concentrator). Because I don’t have to depend on insurance to buy it and so on. That helps. It’s not a big deal for us because we are able to go ahead and equip ourselves.”

- Participant 13, male, age 78 years.

Other lower income participants had to make difficult choices. Many participants chose to not take a medication as prescribed or for some, to not take it at all because of the cost. As one participant described:

“I have the problem that I can’t afford the medicine. By the middle of the year I’m going to meet my donut hole (Medicare Part D coverage gap), especially if I take both of my medications. I’m going to have to decide to not take one. And it’s going to be Breo because it’s more expensive. I’m going to have to make that big decision. Otherwise I pay \$400.00 a month for those medications.”

- Participant 24, female, age 73 years.

Another participant shared:

“I’m supposed to use Advair twice a day but I only use it once because it’s too damn expensive. I have that donut hole that I fall into and then all of a sudden it’s going to cost me \$600 or something. So, I only use it once a day.”

- Participant 19, Male, age 76 years.

Reducing the frequency of the use of medications or choosing not to take them at all were the most common strategies described by participants in this study. Even participants who relied on inhaler samples from a health care provider made similar decisions, as the samples did not provide enough medication to use as prescribed. As one participant shared:

“The Symbicort is very easy to get through the samples from the doctors... I take the Advair in the morning, Symbicort at night. I don’t take them together. One in the morning, one in the evening. I can make things last this way. That helps.”

- Participant 3, Male, age 61 years.

Other participants relied upon patient assistance programs to help them to afford medications. However, although it reduced the cost of medications, it wasn’t quite enough and it was complicated. One woman shared:

“The medications impact the budget. It used to be I didn’t have to think about things budget wise. Donating here, tipping there, or birthdays. Now I have to think. The medications have made me think. I don’t cut back on them. I deal with them. I buy them. It’s a lot to keep track of though. A lot. Then when you’re trying to get patient assistance, well, you’ve got applications, you’ve got phone calls, you’ve got questionnaires. You have to order what you can and then you have the price changes. It’s really hard keeping that all tracked. I take about 12 meds including the inhalers and the nebulizer. What do you have to order and when? Who pays for what? How’s your budget going to handle \$300 off the top for the next few months? It’s a lot.”

- Participant 21, Female, age 72 years.

One participant who lived in a senior apartment building described another strategy that allowed her to take her medication as prescribed. She shared:

“When Advair came, I used that. It worked and I rarely had to use my rescue inhaler. Do one in the morning and do one in the night. But, then my insurance changed. So now I buy those off the street. Just like drugs, I get it off the street. They’re people that have insurance that cover it and they don’t even use them when they get them. So, they can get the prescription and then I’ll give them twenty bucks for one. It would cost me \$300. And they get them for free! So that’s what I have been doing. That’s how I’ve been keeping myself healthy so to speak. I have been buying it for about five years off the street. Ever since I’ve been living here, pretty much. It’s a big difference. That will last me for two months. I haven’t any shame. I tell the doctor too because they know it costs a lot. Many people end up meeting their donut hole.”

- Participant 28, Female, age 62 years.

Some participants expressed difficulty affording the expense of seeing their pulmonologist as they had to pay more to see a specialist. Using specialty care was a particularly difficult financial strain for those participants who had multiple chronic conditions and saw a number of different specialists in addition to a primary care provider and for those living on small, fixed incomes. One participant who lived alone on a fixed income not only managed COPD but also multiple sclerosis and Crohn’s Disease. She shared the challenges she faced with specialty care:

“My doctor wants to see me every three to four months just to keep in touch about everything. He wants me to go see a different pulmonary specialist. It’s like they want you to see a specialist for everything. I haven’t made an appointment. I told him, ‘With my insurance at Medicare for every specialist I go to, I have to pay a \$45 co-pay.’ He’s a

general or internal medicine doctor and I only pay \$15 to see him. He's trying to talk me into going to these other specialty clinics but it's like, you know, I don't have the money for that."

She also discussed her difficulties with transportation to see specialists with:

"I do not drive. I have a friend who takes me for all of my doctor appointments. It used to be that the bus stop on the corner used to go out to the hospital. Which was nice, because then I could just walk to the corner and take the bus all the way out there and back. But, since the bus has changed within the last couple of years, I don't even know what I'd have to take to get out there. So I just feel lucky to have this friend who takes me."

- Participant 27, female, age 63 years.

Other participants also thought that participation in a formal, monitored exercise program or attending a gym was beneficial but identified barriers to doing so, particularly related to the cost of transportation and/or phase three pulmonary rehabilitation. The cost of transportation was of particular issue for those living in more rural areas who couldn't afford the expense of gas as well for urban dwellers who relied upon public transportation. Participant 23, a 58-year-old man with advanced disease who had recently attended pulmonary rehabilitation had made a commitment to exercise by walking on a treadmill at a local community center. However, he had limited transportation options to get there. His main source of transportation was his motorized scooter, which he used, even in the middle of winter, while wearing his oxygen and a face mask, to go to the center. He acknowledged that it was at times scary to be exposed to the elements, particularly if it was well below freezing.

Another participant with advanced disease, who wore oxygen and lived in a small town senior condominium community described the financial barrier to exercise she experienced and her response to this challenge. She shared:

"I would love to join rehab. They have that you can come in on Mondays, Wednesdays, and Fridays in the afternoon and one of the girls are there and you could use the equipment. But it's \$60 for 12 sessions. I can't afford that so I can't do that. Then my daughter and her family, they have a treadmill but it is downstairs and I can't go up and

down the steps. I'd really like one of my own. I've asked around if anyone wasn't using theirs if I could borrow it but so far, no luck. At least here we have a clubhouse and we do things almost every day. We have a calendar that we keep. We had a walking club but when the hot weather came that kind of fell apart. Now I walk in the afternoon or I walk at night. I like to go walk at night. I always have. I know my daughters don't like it but there's lights on every place around here."

- Participant 11, female, age 76 years.

Dealing with Triggers

Twenty-one participants (75%) of this study shared at least one trigger they described as causing shortness of breath and/or coughing. Some participants shared at length about what they perceived as the environmental triggers of their symptoms, describing how exposures to smoke, mold, fragrances, chemicals, cooking fumes, and weather would instigate coughing and shortness of breath. This was true for those at all stages of the disease. Participants told stories of how terribly such triggers made them feel and the social impact it had on them. They reported not knowing what else they could do about such triggers besides changing habits, confronting people about their use of scents, and/or avoiding or removing oneself from the situation. One participant shared how environmental triggers could impact his symptoms:

"Sometimes, maybe it's the pollen in the air or something, maybe it's the dust in the air, or something like that, or some smoke in the air. I just can't breathe in stuff like smoke, pollen, and perfumes. It messes with my lungs...I also used to like my showers real hot and steamy. I can't breathe in them now. I feel like I'm suffocating in the shower...I can't barbecue no more, the smoke from the grill...Anything that you can pretty much inhale or smell, I don't want to be around it."

- Participant 8, male, age 48 years.

This participant went on to share the following story related to his triggers and his response to them:

"Like when we was at the park...Somebody's grill was smoking so bad because they didn't know how to barbecue...put too much lighter fluid on it and it didn't get a chance to soak into the coals and they just threw a match on it. That smokes. Smoked up our whole little area, so I had to move away from that. I mean it might not have been that bad, but for me, I couldn't be around it like that. So I had to get up and get out that little area...Also, I was in the car with my son one day and he had a lot of cologne on. I was like, 'Man, that cologne is just bothering me.' I said, 'You going to have to go in and take

that shirt off or something because you just sprayed too much cologne on that shirt. I can't be driving with you with that cologne on like that.' I can't function with those smells. Bleach, cleaning stuff, you know, I can't be around that type of smell. It just takes my breath away."

Another participant shared how she was impacted by environmental triggers and how, in particular, it made her feel out in public:

"When it first started, when I came around anything that had a lot of scent to it, meaning flowers, perfumes, detergents, anything like that, it would produce a lot of coughing. And some of that kind of stuff means you can't be around people, because they all had scent on them. It was kind of difficult, it still is, to control it. I hate it because it makes me feel incompetent at times being out in public and trying to control it...When you're at a funeral, you don't want to be sitting there coughing and all of that kind of stuff. It bothers me that I can't control it, that I have no method of controlling it...There's a lot of places where I watch where I go, from a floral shop to a church, where there's a lot of people with perfume on. In the funeral home, I sit in back so that if I start having a coughing attack, I can leave suddenly, because the coughing can be persistent and long, and I don't want to disturb people. So, yeah, there's places...even in a place where you're watching your grandchildren at a play or a show, I think, 'I hope I don't cough, I hope it doesn't start.' There's many places I think about before I go."

- Participant 24, female, age 73 years.

Other participants shared their experiences with exposure to what they perceived as mold:

"At church, they have Adoration in this one room. I've tried on several occasions to go in there. Within a couple of minutes, I will start coughing and coughing. So, I don't go anymore, because I end up actually having to leave because I just keep coughing. Cough drops won't help or anything. I'll go out into the hallway and I'll go sit in a chair and keep coughing and coughing until it finally passes. I don't know if it's mold or something. Because there is carpeting which has gotten wet in there. I've gone several times, but each time...So, now I don't go at all because I don't want to bring it on."

- Participant 27, female, age 63 years.

This participant also shared her reaction to chemicals, one echoed by others in the study:

"If I go into a bleach smell, it brings it on right away. I can feel it in my throat. It's like I can't breathe. And then I'll start the coughing. Bleach is definitely something that does it. I would say that's a big one, bleach. Also is when someone sprays Lysol and stuff. That stuff will bring it on me. It will be like it's in my throat or something."

Many of the participants with a history of asthma and/or allergies were less surprised by these triggers. For those without any previous experience of having issues with environmental

exposures, it was surprising. Participant 10 shared:

“That’s another thing about me. Scents. Certain scents I know take my breath away. Exhaust. Cheap perfume. Smell of fried fish takes my breath. Takes my breath, yes. When somebody cooking fish, and I love fish, but I can’t breathe. I have to stand outside. I can eat it, though. It’s fine once it’s cooked. But I just get away from it when it’s cooking.”

- Participant 10, male, 52 years old.

Getting Through Exacerbations

All of the participants of this study shared stories of their experience of living with an COPD exacerbation. Exacerbations and flare-ups were often described as key events that could result in a decline of physical status that was not regained or pushed participants to understand their disease in a different way. Participants described a range of exacerbation experiences, including stories of weakness and fatigue, extended bouts of coughing, and passing out. At the core of each story was a description of an increase of symptoms and a decreased ability to function. Weakness exacerbation stories were common among the participants of the story. As described by one participant:

“During the winter, when there’s respiratory infections going around it’ll knock me down to where I can’t even walk. My wife has to push me in a wheelchair and I can be weak like that for four or five days. I get so weak I can barely move at times. It’s terrible. You feel like a newborn. You can’t move.”

- Participant 3, Male, age 61 years.

Participants also described how their coughing got worse during exacerbations. One woman shared:

“Within the last two years, I get these really bad coughs where I can’t catch my breath. I call them coughing spells and I’m getting those more often. I’ll take cough drops but sometimes the cough drops won’t help and I just keep coughing and coughing. That’s happening more often. My time of coughing is lasting sometimes for over a month...I don’t usually go to the doctor for it. I try to drink a lot of fluids and stuff like that. I have told my doctor that the coughing spells are starting to get more and more. Now we are just going to watch it”

- Participant 27, female, age 63 years.

In addition, some participants described coughing fits that made them feel as if they would stop breathing or pass out. Some individuals described episodes that did lead to an actual

loss of consciousness. This left participants to feel not only the physical effects of extended coughing but also, for some, led them to anxiety and/or panic. This also impacted those around them. One man with advanced COPD shared:

“An exacerbation...well, it’s probably more scary for my wife and the people around me. I know I’m going to catch up sooner or later. Meanwhile you just kind of hang in there, knowing you’re having an exacerbation and it’s going to take time. I can tell rather easily when it starts to fade or return to semi-normal. Sometimes it’s just pretty damn tough, not so much on myself, although that’s hard too. You know when you’re sucking air. I don’t get scared. I don’t get worried. I haven’t passed out, fallen down, or anything like that. But it’s probably more disconcerting in terms of the people that are around me. Now, my wife knows how to handle it and she’s all over it. When she does, she tries to just kind of calm me and do that kind of thing. But it’s scary for people who don’t know what it is. When I feel it coming on, I try to get a little more air flowing and try to get relaxed. Some of it has to do with the tension associated with it. I’ve never gotten panicked, so to speak, but I also know that at some point in an exacerbation, the body may take over control as to what it wants to do and what it doesn’t want to do. Once you realize that, then you become a little bit more cautious about putting yourself in situations where you might be in trouble.”

- Participant 13, male, age 78 years.

A number of other participants discussed the difficulty they had in controlling anxiety and panic during an exacerbation and how this was shared by their partners. One man, who lived with other multiple chronic conditions including congestive heart failure and kidney failure, described an exacerbation experience:

“I tell my fiancée, ‘Just dial 911.’ Just dial 911 and we’ll be alright but whatever you do, don’t get all, ‘You alright? You need anything? What can I do?’ You can’t do nothing. Just call 911 and let me sit here and calm down or try to calm down. Don’t say nothing. She can’t do that. She panics. Then when they (the paramedics) get here, she get on their nerves too. All I’m thinking is, ‘Let’s go, let’s go, let’s go to the hospital.’...It’s nice to have somebody in your corner because it is a very scary experience. Real scary and then being mad on top of that with somebody you care for and you know they are trying to help is hard. It’s hard because I all I want to do is breathe right then. And you can’t. That’s just scary as hell. I watch movies now with a different respect for people that get hung or drowned or something. That’s cruel and unusual punishment. I’d rather just get shot. Because at least you ain’t trying to breathe..”

- Participant 10, male, age 52 years.

For others, living alone during an exacerbation presented the problem of having no one around to call for help. One woman who lived alone described a coughing fit she experienced during an exacerbation:

“There was just one time where I couldn’t stop coughing for, I would say, almost five minutes. It was terrible. My face was just fire red and I just couldn’t stop coughing. I was fearful then because I thought about how I couldn’t even call somebody to say, ‘Hey, I can’t stop coughing.’”

- Participant 24, female, age 73 years.

Another woman who lived alone described an experience she had with a past exacerbation:

“About a month ago I was taken to the hospital by ambulance. I had woke up in the morning and I don’t know, I was out of it. I went back to sleep. When I have this, it’s all sleep. I just sleep, sleep, sleep. Then all of a sudden I started coughing. One of the neighbors was walking by and she heard it. She tried to get in but the door was locked. I just coughing and coughing and coughing. She has my daughter’s name, so she called my daughter. When my daughter got here she said, ‘All I did was take one look at you and know that it was out of control.’ She called 911.”

- Participant 11, female, 76 years old

Some of the participants with extended coughing fits expressed fear about the potential to pass out. One participant shared:

“I get two or three bad events every year from the fall through the early spring. And I will cough sometimes so hard that I thought I was going to black out. Things actually went black and then I would come back. I mentioned it to the doctor but he said, ‘You won’t pass out from that.’ I though well, that’s pretty darn close!”

- Participant 15, male, age 76 years.

Three participants reported extended bouts of coughing that led to loss of consciousness

This left participants particularly vulnerable. As one participant described:

“One day, I was standing in a motel and I just started coughing. I couldn’t stop coughing. Next thing you know, I woke up and my head was in between the dresser and the bed. Blood was all in my eyes, blood on my head. I busted my head on the dresser. That was the first time I passed out. Since then, I passed out maybe 10, 11 times. Grown coughing fits. Now I learned how, if I feel a cough coming, I sit down so I won’t pass out standing up.”

- Participant 8, male, age 48 years.

These exacerbation experiences also led participants to take steps to try to ensure they would not find themselves caught during an exacerbation without a rescue inhaler. One participant shared how one exacerbation experience he had led to him working to make sure he would always have it close in the future. He shared:

“...We were supposed to go to church that night and I said, ‘I don’t think I’m going to church. I just don’t feel very well.’ And I went and laid down. So, I laid down and the power went out. I just couldn’t breathe. I was really having problems breathing. I said, ‘We’re going to have to go to the hospital.’ But the power had went out and I’m looking for my inhaler. Everything’s dark, I couldn’t even find my inhaler. When I get all excited like that it makes it all the worse as far as the breathing is concerned.”

- Participant 4, male, age 75 years.

Other participants shared how they tried to prepare for a potential exacerbation. One man shared:

“The only things that make it more difficult is if I’m trying to go out of town. I have a friend and he works on airplanes a lot. All of a sudden, he’ll yell, ‘Hey, we got to go to Minnesota.’ Then we’ll jump in the car and go to Minnesota. Now, if I happen to be stupid enough to forget my inhaler, that’s a problem. In those case, I always got extra stuff in my little travel bag...In my car, I’ve got some stuff planted in my care that I can always go to.”

- Participant 6, male, 76 years old.

Another man shared how not having his short-acting inhaler on hand when he would most need it was one of his biggest fears. He relied on public transportation and he discussed his concern about not being prepared for an exacerbation in that setting. He replied the following in response to what he feared most about living with COPD:

“Dying in my sleep. Or on a bus. Going somewhere and then all of a sudden, don’t nobody know what going because I take this (inhaler) with me everywhere I go. But, sometimes it don’t work.”

- Participant 10, male, 52 years old.

Exacerbations often led to participants having a different outlook on their disease. Some only really accepted the COPD diagnosis after experiencing multiple exacerbations. As one participant stated:

“I had to come to the conclusion where I say, ‘Okay’. I’ve had a couple of episodes. Now this is my life. I can let it control me or I can deal with it and try to do something to trigger less episodes or less trips to the doctor.”

- Participant 2, Female, age 52 years.

Research Question 2: Health Care Experiences

The participants of this study shared their experiences and perspectives of interacting with their health care providers and, for some, of the health care system at large. Participants overall shared positive feelings about their health care providers however they struggled with what they described as the challenges present in today’s health care system. Feeling rushed at appointments, not getting enough information, and limited opportunities to ask questions left some participants feeling frustration overall with their health care experiences and options. Participants also expressed great frustration with pharmaceutical companies often blaming them for the high cost of medications. Although participants had complaints about specific health care providers, they were at large more inclined to associate provider-level issues with it being a “bad fit”, instead placing responsibility for the care received with the “system” at large. Participants openly shared their concerns about their health care interactions, often sharing ideas for improvement. In accordance with research aim 2, the following themes summarize the health care experiences as described by the participants of this study.

Getting Information

Although most of the participants had positive things to report about individual health care providers, there were still issues present in their health care experiences and they shared ways they felt health care could be improved. Participants of this study, overall, had a very mixed understanding of the terms associated with the disease and its trajectory. Confusion about the term COPD and how it was related to emphysema, chronic bronchitis, and asthma was evident, even among participants who expressed they had a good understanding of their illness,

had advanced formal education, and/or among those with advanced disease. Most participants were not aware that COPD could be staged, however almost all understood it broadly as a disease that could progress, even if it wasn't quite clear how that may impact their experience or what details may be associated. One participant discussed her thoughts about the progression of COPD:

"I don't know what to quite expect. I just want to know more like, 'What is the progression of this disease? Do you eventually go on oxygen with a tank? Do you just increase your oxygen levels? I just don't know what to expect. Maybe that's good. I don't know. I suppose I'd feel okay asking my doctor at some point. But, usually now, we just talk about what is. Maybe that's the way life is? You just talk about what is because nobody quite knows what to expect. But, I'm not exactly sure of progression of the disease. I've often thought it'd be nice to be in some kind of little support group because then you could get some information...I'd probably like to know more because I think I could learn and maybe share something I know."

- Participant 21, female, aged 72 years.

Most of the participants stated their primary health care providers and pulmonologist were not doing enough to help them to understand their disease. Even those who had few complaints about their health care experiences felt that these providers in particular could have at some point or another throughout the course of their illness done a better job explaining COPD or its treatment. Explanations at the time of diagnosis, about the progression of the disease, and medications were identified as being particularly important to many participants. Regarding information at the time of diagnosis, one participant shared:

"I think there could have been at least the inquiry, 'Do you need information?' Nobody ever said to me that. Nobody ever said to me, 'Do you know what COPD is?' Nobody ever said, 'COPD stands for.' Nobody said, 'Here, read this,' or, 'go to the library and check out this book.' It would have been helpful if I had been given a little bit more information early on about COPD."

- Participant 13, Male, aged 78 years

For some, the sharing of information at diagnosis was emotional and they expressed frustration at the lack of support that was offered:

“I think when the doctor first said in the clinic, this is your diagnosis, that was kind of a heavy blow. I’m not usually tearful or self-indulgent in that way but that was heavy. Had I thought that would come up, I would have had my family with me. That would have been comforting. Maybe doctors need to think about that, I mean they deal with it every day: ‘Oh, yeah, you’ve got COPD’. But for me a diagnostic label is a heavy moment...to a doctor this is another patient in and out. I’m not saying he’s cold-hearted at all. I just think maybe doctors need to be careful of the moment when they give a diagnosis to somebody sitting there...This may be the first time this person has ever had a label put on them and maybe it’s going to be a heavy moment. Maybe they should just consider, what resources do we have in the clinic? Maybe even a nurse or if there was another person there...just another person to listen along with me would have been helpful.”

- Participant 22, female, aged 76 years

Another participant also expressed frustration with the communication from her health care provider at the time of diagnosis and beyond. She shared:

“They haven’t actually told me hardly anything. And that’s very frustrating. I go there and they just tell me, ‘Well, you have moderate COPD. Take the Breo, take the Spiriva, and live with it’. That’s what I get out of it, that what I get out of going to, well, especially my lung doctor. I like him very much, but I don’t know if it’s because he deals with so many people with COPD, that this is just something normal to him but it’s not normal to me. It is not normal to me. It’s upsetting to me to have this. I don’t like being sick. I don’t like having chronic disease of any kind and so it’s very frustrating. I think that they could take just a little bit more time, to say, you know, explain, like, what does moderate mean? To me, I don’t know, I don’t know what moderate means. It doesn’t mean anything except that it’s not mild and it’s not severe. But what does that mean in the healthcare profession, I don’t know. I don’t know where that’s taking me to the next step or where it’s even at this step. How long do you stay moderate?”

- Participant 24, female, aged 73 years

Although a number of participants stated they had at some point received information in the form of a pamphlet, some had not, particularly those who had never been hospitalized for COPD. One participant shared:

“It would have been nice if someone gave me a brochure or something. I didn’t get anything. Nothing. She didn’t take me up to the wall and say, ‘Here’s your lungs, this is what’s happening to you.’ No, none of that.”

- Participant 1, female, aged 68 years

Conversely, there were participants who felt they received the information they needed in their health care interactions. Many people felt this way about pulmonary rehabilitation and

credited this experience with providing them with most of the information they knew about COPD. A number of participants shared the importance of being proactive about getting information during the health care encounter. One woman shared:

“I’ve learned to ask questions and try to work with the medical people. But if they’re not telling me things or working with me, it’s very important to change, so I did. Now I have a pulmonologist who I really respect and appreciate.”

- Participant 21, female, aged 72 years

Another participant with advanced disease shared his positive feelings about the information he received during his health care encounters:

“My doctors, they act like they care. They show me that they care about me, they tell me the right things to do, and everything like that. They take care of me, they make me feel better. They give me the right medications... They used the plastic lung and showed me everything. Pointed at things that’s going on in the lungs and the heart and everything like that, like how the blood goes from the heart to the lungs.”

- Participant 8, male, age 48 years

Some participants also expressed what they felt was the need to advocate for one self.

One woman described her perspective on how she got the information she needed from her health care providers:

“They are very helpful. They are very understanding. They want to know. They want to listen. Because they thing is, that when I come and talk to my doctors about it, I make sure they listen. I explain to them in-depth. You have to get to know them. They have to feel you out or whatever. I think, ‘This is my health. You’re here to serve me. It’s not what I can do for you, it’s what you can do for me.’ I feel as though if I’m not satisfied, I’m quick to say, ‘Listen, no disrespect to you, it’s your profession but me and you ain’t working. We ain’t vibing. You need to hear me.’. How can they help me if I don’t tell them?”

- Participant 2, female, aged 52 years.

Navigating providers was viewed as frustrating by participants and presented more challenges to getting the information needed for managing COPD. Having to switch primary care providers and going between specialists was challenging. However, again, participants more often viewed this as a system flaw, not an individual one and emphasized the need to

advocate for oneself. As one participant who navigated health care systems in two different states shared:

“I think the health care system, where the boots are on the ground, is good. The gals and guys that are doing three twelves, which turn into fourteens or sixteens, there’s not a damn thing wrong with those folks. They’re under tremendous pressure, they got their own problems at home, the kiddies and everything else...The healthcare system will lose through the cracks, anybody that isn’t financially, or from an educational standpoint, or even from a strength of character standpoint, strong enough. Because if don’t advocate for yourself, and if you don’t ask the right questions, or push in the right direction, it can trample you. Or it can ignore you. The same old crap happens that the people that need it the worst, which are the ones that are at the lower social economic scales with the education and everything else, probably get the poorest care.”

- Participant 13, male, aged 78 years

Feeling Rushed

Participants expressed frustration with the amount of time they were allotted during visits with their health care providers. They shared how difficult this made it to ask questions or get more information as well as to really get to know their health care provider. Participants were particularly frustrated with the time spent with specialists of whom they spoke as rushed. One participant shared his experience with:

“It’s not like it was years ago where it’s sit down and talk. Like you knew them and stuff...they always go two, three rooms with people waiting.”

- Participant 19, male, age 76 years

Another man shared:

“It’s down to the point where I’ve been told more than once that they have 21 minutes to spend with me”.

- Participant 13, male, aged 78 years

Some participants felt this was particularly difficult when it came to talking about medications.

One participant described:

“I think most doctors can only remember so many meds at one time. They’re overloaded. I don’t know how they do it. From what I’ve got to know and all they go through and then it’s pushed, pushed, pushed by the clinics to hurry up and get patients of there. Like you’re running cattle.”

- Participant 15, male, aged 76 years

Another woman shared the experience of her yearly office visit with her pulmonologist:

“He doesn’t spend time sitting and talking to you. He runs out the door because he’s so busy. He doesn’t say much otherwise I would certainly have liked him to tell me about it (medication) but you don’t think he’s going to stay in my room five minutes, do you? One time he was running out and I put my leg up and said, ‘Wait a minute, I have a question for you.’ He’ll run out right after he’s done with you because he’s so busy.”

- Participant 7, female, aged 73 years.

In spite of these challenges, participants overall expressed feeling respected by their health care providers. Even though some had difficulty with paying for specialty care, a number of participants who had been with their pulmonologists for a number of years, deeply respected this relationship and were grateful for it, even if this was the one provider participants spoke the most frequently about feeling rushed during appointments. Only one participant expressed feeling stigmatized and dismissed by a health care provider whom she thought judged her and provided her poor, rushed care because of COPD being a disease that is largely caused by tobacco smoking. She shared:

“I was having a hard time breathing. I did end up having pneumonia. They put me in the hospital. That’s when they came in and told me I had COPD. They gave me this respiratory doctor. He was just terrible. He practically laughed in my face, ‘Well, it’s all your fault because you smoked.’ ...I was so frustrated to the point of anxiety.”

- Participant 9, female, age 75 years.

This perspective was not typical. Most participants shared that health care providers tried to connect with them and were supportive even if they were making bad decisions. One participant, who struggled with drug addiction, shared how he appreciated a firm, supportive, non-judgmental approach from his health care provider:

“I smoked weed more than I did cigarettes and between the weed, the cigarettes, and the crack, I was drinking. I was killing myself and I knew it. I knew it but after I stopped doing those things, that’s when all these other sicknesses, that whole list of sickness popped up. You got this, you got that. I’m like, “Well, I should have kept smoking dope.” The doctor told me, ‘Don’t you say shit like that in my office no more.’ That’s how he

said it to me! I was like, 'Wow, okay, you alright. You ain't got to worry about that no more.'

- Participant 10, male, aged 52 years.

Not Feeling Heard

Most participants felt they could talk to their health care providers but some expressed concerns about being heard in regard to their symptoms. They expressed how they did not feel heard by health care providers during health care encounters. This was described as particularly frustrating for one woman with multiple chronic conditions when it came to discussing her symptoms. She shared:

"Sometimes I think the doctor doesn't always listen because I have concerns with getting dizzy and breathing. I think he focuses more on something else like my MS. That's what I feel sometimes that sometimes the doctors don't always listen to what I'm saying because they're trying to focus on this or on that. Like when I go to my MS doctor and I'll tell him something and he'll say, 'Oh, well that's probably not MS, that's probably this.' Or if I go to the Crohn's disease doctors, 'Well, I don't think that's this, it's probably MS.' I get frustrated a lot."

- Participant 27, female, aged 63 years.

Another participant shared how she didn't feel heard by her health care providers when she tried to discuss triggers that made her cough. She stated:

"Both my primary doctor and my lung doctor kind of foo-foo the idea that I get this reaction from scents, from the smell of perfume and the other stuff. They don't seem to correlate that with my coughing and I think that's a big deal. I think it's what really sets it off...I get no kind of answer, it's just like, 'Well, you have COPD.'"

Summary

The findings of this study were presented in this chapter. The community-dwelling adults with self-report of COPD (emphysema/chronic bronchitis) who participated in this study shared stories of the daily challenges they faced in living with COPD and their response to these challenges. They described resilience and determination in overcoming barriers to performing self-management behaviors and in dealing with the impact of the disease and its treatment.

Participants shared stories of living with and managing the symptoms of COPD. They described acceptance of the disease, how they worked to maintain function by staying active, making choices about medications, dealt with the triggers of their disease, and made it through exacerbations. They also shared their perspectives on their interaction with their health care provider, many sharing how they overall like their individual provider but struggled with getting information, feeling rushed during appointments, and with being heard during their interactions. describe reasoning behind following or not following health care provider recommendations related to taking medications as prescribed. The next chapter will present a discussion of the findings of the current study based on the literature and research questions. The implications of this study for nursing practice, education, policy, and future research and theory are presented.

Chapter V

Discussion

This chapter presents the findings of the current study based on the literature and research questions. Discussion, major findings, application of the IFSMT to the study findings, and the implications of this study for nursing practice, education, policy, future research and theory are presented.

Major Findings

The results of this study support previous work focused on the experience of individuals living with COPD. Many of the symptoms described by the participants of this study are key indicators for considering a COPD diagnosis including chronic cough, dyspnea, and chronic sputum production and are a part of standardized assessments of the disease (GOLD, 2018). In addition, findings of this thematic analysis support the results of other qualitative studies that described the sustained COPD symptom experience of fatigue, anxiety, breathlessness, and frailty (Disler et al., 2012). The results of this study add to the existing literature presented in chapter II and to that published since the commencement of this study.

The results of this study support the limited existing work that is centered on the individual report of self-management processes and behaviors in COPD (Chen et al., 2016; Disler et al., 2012; Genoe & Zimmer, 2018). Similar to other qualitative studies, examples of how individuals with COPD respond to and work to manage the impact on COPD on their lives such as by doing activities to support staying active and preventing infections were described (Bourbeau, 2009; Chen et al., 2016; Disler et al., 2012). Participants of this study also shared stories that add perspectives on the self-management experience of living with COPD that are

scarcely found in the existing literature. The following will describe these findings in accordance with the research questions of this study.

Research Question 1: Daily Challenges and Response to Daily Challenges

Although it is well-recognized that the costs associated with living with COPD make it difficult for patients and their families to afford necessary living expenses while also paying for the health care expenses associated with COPD (Essue, Kelly, Roberts, Leeder, & Jan, 2011), there is limited research directly assessing how the availability of resources influences patients' ability to self-manage their condition in the community (Disler et al., 2012; Huetsch, Uman, Udriș, & Au, 2012). Qualitative findings from the participants of this current study provided first-hand insight into the processes of decision-making and reasoning behind their choices to take or not take medication as prescribed, much of which depended upon their ability to afford prescribed treatments. This supports findings from a recent study in Denmark in which researchers identified that lower socioeconomic status was associated with poorer adherence and non-use of inhaled medications in COPD (Tøttenborg et al., 2016). In this study, less economic resources not only impacted medication behaviors but also limited participation in pulmonary rehabilitation. The results of the current study also support existing research in which an association has been identified between reduced attendance to pulmonary rehabilitation and socioeconomic disadvantage (Oates et al., 2017).

The stories the participants of this study shared add an American perspective to the literature, specific to the unique health care insurance payment structure in place in the United States. Participants shared their concerns about the cost of medications and the insurance limitations they experienced and the associated impact on the ability to pay for medications. The approach one participant shared of buying inhalers from other residents in her senior apartment

complex has not been identified in the existing literature and offers new insight of the actions individuals living with COPD might take in order to treat their illness in the face of economic hardship. In addition, the stories participants shared highlight the important role that finances play in the choice to reduce the frequency of medication use, particularly in the context of multimorbidity. These results add to the growing body of literature on the impact of multiple chronic conditions (Ansari et al., 2014).

Research elicited from the perspective of the patient and focused on trigger factors of symptoms in COPD is scarce. Little is known about the trigger factors of COPD, particularly the role played in the control of COPD symptoms and exacerbations (See, Phua, & Lim, 2016). There are few empirical studies that have explored the risks of acute environmental exposures on COPD exacerbations (Sama, Kriebel, Gore, DeVries, & Rosiello, 2017). Despite the well-known importance of preventing COPD exacerbations, existing studies on the preventable causes of exacerbation have been limited, focused primarily on respiratory infections and second-hand tobacco smoke and less so on urban air pollution and temperature (Sama et al., 2017). Sama and colleagues (2017) reported that environmental chemical exposures, car and truck exhaust, and use of scented laundry products were associated with an increased risk of COPD exacerbation. However, little else is known about the impact of other potentially preventable triggers in COPD.

The results of this study provide new insight into the experience of triggers as told by the participants of this study. Twenty-one participants (75%) described the symptoms they experienced, such as shortness of breath or coughing, when exposed to triggers such as smoke, mold, fragrances, chemicals, steam from bathing, cooking fumes, and weather and the actions they took in response. These actions included avoidance and asking others to accommodate requests for a reduction or removal of identified triggers. They also provided stories of the social

impact taking action to prevent or reduce exposure to triggers had on them, including feelings of isolation and embarrassment. Those who self-reported a previous history of allergies and those with more advanced disease were more skilled in trigger identification than other study participants. Some expressed frustration with health care providers for not taking their experience with trigger factors seriously, a finding not identified elsewhere in the existing literature. The mechanisms by which exogenous and endogenous trigger factors exacerbate COPD are largely unknown (See et al., 2016). The findings of this study provide the basis for more inquiry into the role of trigger factors in the experience of COPD, its management, and related health care utilization.

The results of this study also provide insight into the role of occupational exposures on the development of COPD. Occupational exposures to workplace dust and fumes are known to cause nearly 20 percent of cases of COPD and up to 20 percent of the symptoms and functional impairment in COPD (GOLD, 2018) yet little is known about the experiences and behaviors related to these exposures. The participants of this study provided examples of how they believed work in a range of occupations impacted their development of COPD while also not dismissing the role of tobacco smoking in disease development. Some of the participants stated that health care providers had discussed occupational exposures with them, while most had not. These findings support the need for more research to explore the impact of occupational and environmental exposures on the prevalence of COPD as well as the importance of considering and discussing such exposures during clinical encounters.

The first-hand accounts provided by the participants of this study of their self-described acceptance of the disease and the related impact on self-management behaviors offer new insights into the process of acceptance in COPD self-management. Accepting the disease was

related to an increased willingness to consider treatment recommendations and perform self-management behaviors as described by the participants in this study. Acceptance in chronic illness has been: 1) defined as a potentially adaptive way of coping with chronic illness and a key to goal attainment (Van Damme, De Waegeneer, & Debruyne, 2016); 2) as a starting point for living successfully with chronic illness; 3) a necessary pre-cursor to self-management (Ambrosio et al., 2015) and; 4) a well-recognized end-point in the grieving process (Kubler-Ross, 1969). However, the role of acceptance in the process of living with and self-managing COPD is not well understood or documented in the literature. The results of this study provide a first-hand account of the role disease acceptance played in self-managing COPD for the participants of this study, particularly as related to medication management.

Although loss of consciousness following cough is recognized in relation to COPD in the existing literature, relatively little is known about the experience and frequency of this phenomenon (Dicpinigaitis, Lim, & Farmakidis, 2014). Cough was a symptom that was identified by many participants, regardless of severity of disease and/or use of recommended treatments or smoking status. Coughing was described as socially isolating by some participants and often unrelated to shortness of breath. For some, it was also related to syncope. These three participants (11%) described how coughing fits led to loss of consciousness that also resulted in injury, such as lacerations to the head. They also described actions, such as sitting down at the start of coughing fits, to prevent the potential injury that could occur with syncope. Syncope is, in general, associated with an increased fall risk, however the prevalence of cough syncope and its effect on fall risk or fear of falling in COPD or its potential impact on self-management behaviors, such as engaging in physical activity, is unknown (Roig, Eng, Road, & Reid, 2009). No qualitative studies were identified that discussed this experience from the patient perspective.

More research is indicated to deepen our understanding of the cough syncope phenomenon in COPD and its impact on the illness experience and our understanding of the behaviors individuals take to prevent injury.

Research Question 2: Health Care Experiences

The second research question of this study was aimed to explore the health care experiences of community dwelling adults living with COPD. Although participants of this study overall expressed that they liked their health care provider(s), they also expressed numerous frustrations with their health care encounters as identified in the sub-themes of “getting information”, “feeling rushed”, and “not feeling heard”. These findings support that of existing studies in which participants have similarly expressed frustration with their health care encounters, particularly in relation to information provision, feeling recognized and heard by health care providers (Disler et al., 2012; Jeon et al., 2010; McDonald et al., 2013), and in the collaborative management of multimorbidity in the context of COPD (Ansari et al., 2014). The need for more effective self-management support from health care providers was evident in the patient’s stories.

The lack of stigma participants of this study expressed in relation to their health care encounters is notable. Existing studies have reported that individuals with COPD felt stigmatized during health care encounters due to the perception of COPD as a smoking-related disease, which led to self-blame and guilt (Halding et al., 2011; Berger, Kapella, & Larson, 2011; Rose, Paul, Boyes, Kelly, & Roach, 2017). However, only one participant of this study expressed this concern related to health care providers with only one other participant expressing it in relation to people other than health care providers. Most participants who had a current or past history of smoking shared that they understood their disease was likely smoking related and

did not feel judged or stigmatized from health care providers about this issue. Rather, some participants shared that health care providers had provided them information about the additional occupation-associated exposures that may have promoted the development of their disease.

Application of the Study Findings to the IFSMT

The IFSMT was used in the current study to assist in understanding the context, processes, and outcomes of self-management as described in participants' stories of their experiences of living with and managing COPD. The theory assisted in organizing the codes derived from data analysis and interpreting the identified themes. The results of the analysis have been mapped to the IFSMT in accordance with the results of the thematic analysis to deepen conceptual and theoretical understanding.

The context dimension of the IFSMT addresses the risk and protective factors that influenced the self-management behaviors of individuals with COPD who participated in this study. The complexity of an unpredictable illness trajectory with acute exacerbations, the stage of disease, and the number and extent of comorbid conditions have the potential to impact the process and/or outcomes related to COPD self-management. In addition, as discussed by the participants of this study, the ability to pay for the treatments related to COPD and the availability of transportation to access health care services in the context of their overall socioeconomic status impacted their decision-making processes and engagement in self-management behaviors.

The themes of getting information and accepting the disease are identified as knowledge and beliefs within the IFSMT process dimension. According to the IFSMT, knowledge and beliefs have the potential to impact behavior-specific self-efficacy, outcome expectancy, and goal congruence (Ryan & Sawin, 2009). Participants in this study discussed how their

knowledge of medications and the COPD disease trajectory impacted their decision-making and self-regulation in line with this construct. In addition, participants discussed at some length the process of self-regulation, as identified in the themes ‘getting through exacerbations’ and ‘dealing with triggers’. These participants described the self-monitoring of symptoms, self-evaluation, decision-making, and planning for and engaging in specific behaviors as part of their process of dealing with triggers and getting through exacerbations (Ryan & Sawin, 2009). The emotional and informational support received or not received by participants of this study and as identified as part of the analysis within the themes of ‘feeling rushed’ and ‘not feeling heard’ potentially highlights the extent of negotiated collaboration present for those living with COPD and their health care providers.

The themes of ‘maintaining function’ along with the sub-themes of ‘staying active’, ‘preventing infections’, and ‘medicating or not’ along with the avoidance of triggers and navigating the health care system have been identified as proximal outcomes in accordance with the IFSMT. Engaging in physical activity, being vaccinated, and taking or not taking medications as prescribed are examples of the behaviors discussed by the participants of this study as representative of these action-oriented themes. Participants also described how, after the recognition of triggers, they engaged in actions to avoid or reduce their exposures and those they took to keep themselves safe. In addition, navigating the health care system was identified as part of the actions taken by the participants as part of the COPD illness experience.

The mapping of these results provides encouragement for future delineation and application. Of particular interest is deepening understanding of the interventions that could be implemented to improve the self-regulation skills and abilities of individuals living with COPD, subsequently improving self-management behaviors and distal outcomes such as health-related

quality of life while accounting for the contextual factors affecting this population. Such work has the potential to not only improve the care and health outcomes of those living with COPD, but will also deepen understanding of the IFSMT and add to the broader self-management science literature. Figure 2 illustrates the mapping of the thematic analysis to the IFSMT.

Individual & Family Self-Management Theory Applied to Chronic Obstructive Pulmonary Disease

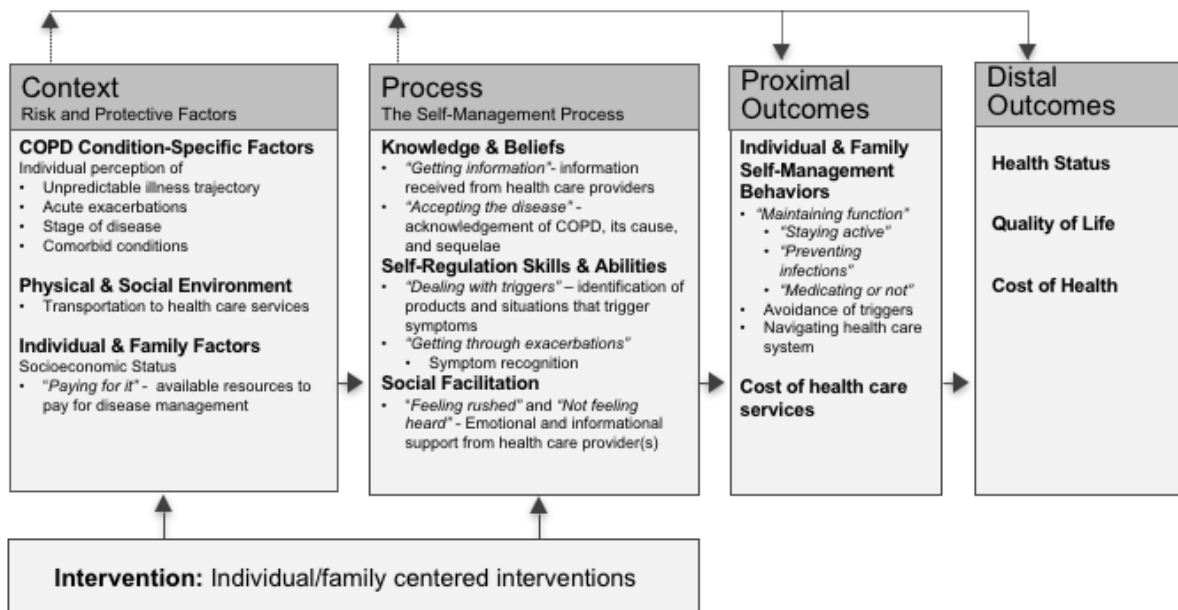


Figure 3. Model of Individual and Family Self-Management Theory Applied to Chronic Obstructive Pulmonary Disease. Adapted from *Individual and Family Self-Management Theory*, by P. A. Ryan and K. J. Sawin. Copyright 2009, 2014 by Ryan and Sawin. Adapted with permission.

Limitations

The limitations of this study must be acknowledged. While the qualitative methods used assisted in examining in-depth the participants' self-management experiences in COPD, the findings are limited in that they cannot be generalized to a larger population or taken to represent the experiences of all individuals living with COPD. The findings of this study also represent

only the perspective of individuals living in one region in Wisconsin, USA all of whom reported having health insurance. In addition, this study was focused on the self-management and health care experience related concerns of individuals living with COPD and does not address other issues of importance in the care and management of this disease, particularly those centered on health care providers and their care of this patient population. Lastly, the participants of this study self-reported their disease and medical records were not reviewed to provide an additional source to identify data points such as specific diagnosis, stage of disease, time since diagnosis, and comorbid conditions.

Implications for Future Research

The current study aimed to gain an in-depth understanding of the self-management experiences of individuals living with COPD. Although the results of this study contribute to the broader literature as previously discussed, more research is needed to deepen understanding in this area. As indicated from the results of this thematic analysis, more research, both qualitative and quantitative, is needed in a number of areas important to COPD self-management.

The results of this study highlight the need for more research focused on the impact of environmental triggers in COPD. Participants of this study described numerous disease-related trigger factors and related symptoms and behaviors. More studies are needed to describe trigger factors as well as to correlate identified trigger factors to symptoms, exacerbations, self-management behaviors, and health care utilization. First, more qualitative work centered on gathering descriptions of trigger factors in COPD and any action individuals living with the disease take in response are needed. Next, quantitative studies are needed to describe the prevalence and range of trigger factors reported in a sample of individuals living with COPD and to identify the correlation of such factors to variables such as frequency and severity of

exacerbations, health care utilization, and HRQoL. Such studies have the potential to assist in the development of intervention studies centered on identifying the impact of incorporating trigger factors into self-management support, particularly as included in action planning. In addition, future studies focused on trigger factors may also contribute to identifying correlations with COPD phenotypes and related biomarkers.

The findings of this study also highlight the need to conduct more research on the impact of limited resources on COPD self-management. Health disparities are more commonly seen in respiratory diseases when compared to other chronic illnesses, due in part to occupational exposures, environmental risk factors, and health behaviors related to lifestyle (Pleasant, Riley, & Mannino, 2016). The minority participants of this study had, by self-report, the most advanced disease at a younger age and were more disadvantaged when compared to other participants, an issue that warrants consideration when conducting future studies. Participants across this sample discussed, in particular, how limited resources impacted their decision-making and engagement in medication management behaviors, however the negative impact on lower socioeconomic status was greater. They provided stories of the methods they used to obtain expensive medications, including one woman who reported buying inhalers “off the street”, a practice that has not been identified elsewhere in the existing COPD-related literature and should be explored in future studies in order to deepen understanding of and identify the prevalence of this practice. Participants across the sample also described numerous occupational and environmental exposures. The results of this study can be used to inform future research centered on the impact of health disparities and occupational exposures on COPD self-management, particularly in understudied, minority populations.

The role of acceptance in the process of self-management and engagement in self-management behaviors should also be further explored based on the results of this study. Participants of this study repeatedly described the important role disease acceptance played in how they lived with their disease and made decisions about its management. Future research is needed to incorporate measures of acceptance with self-management behaviors. Findings from such studies would be beneficial in the development of interventions centered on improving non-acceptance and subsequently, health outcomes in COPD.

In addition, further quantitative research should be completed to test the findings of this study as mapped to the IFSMT to expand theoretical and conceptual understanding in the science of self-management. Continued research in this area may assist in directing effective evidence-based recommendations for self-management and its support in COPD, ultimately improving health outcomes and lowering the cost of care for those living with the disease. The initial mapping of the results of this study provide the first steps toward the development of an intervention focused on improving outcomes for those living with COPD.

Implications for Practice

The participants of this study provided insight into their experiences and perspectives of health care encounters when seeking care for COPD. They provided numerous examples of their perspectives of receiving informational support and communication focused on the diagnosis and management of their disease. Participant recommendations were offered regarding communication at the time of diagnosis as well as regarding fact-based information about the disease label, physiology, and its treatment. Views on the time spent and the approach of health care providers during their health care encounters with participants provide additional opportunities for exploring the development of evidence-based strategies to improve the care of

individuals living with COPD, including strengthening the self-management support role of health care providers.

The results of this study provide numerous opportunities for improving the health care experience of individuals with COPD. As the largest group of health care providers in the U.S., nurses have the opportunity provide self-management support to individuals with COPD across the health care continuum. Staff nurses and advanced practice nurses interact with COPD patients in numerous health care settings including during hospitalization, at primary and specialty care visits, during pulmonary rehabilitation, and telemedicine. These results may be used to strengthen and develop evidence-based and quality improvement projects centered on self-management support for individuals living with COPD across care settings. The results of this study can also be used to strengthen evidence-based clinical nursing practice, such as improving the role nurses in acute care may play in providing self-management support to patients and families during hospitalization for exacerbations.

The participants of this study shared dissatisfaction with how busy their specialty care providers seemed and with the limited opportunities to discuss issues with them. Advanced practice nurses may help to fill this gap in care by supporting busy specialty pulmonary practices and improving the application of the holistic principles of nursing practice in the care of individuals with COPD. Registered nurses may also help to fill this gap by providing telehealth services to support individuals in need of guidance during acute onset of exacerbation symptoms and/or for those following a negotiated action plan. In addition, insights have been gained from this study regarding the importance of providing disease-related information in a manner sensitive to the potential impact of diagnostic labels and prognoses on those living with COPD and in recognition of the contextual factors that could impact self-management behaviors.

Improving the ability of nurses to provide effective self-management support may improve outcomes for those with COPD as well as reduce health care costs by reducing unnecessary health care utilization.

Implications for Nursing Education

The results of this study provide opportunities to teach nursing students about the care of a chronically ill patient population. Case studies and vignettes based off the results of this study could provide the opportunity to teach nursing students about how to engage patients and families in action planning in the event of an acute exacerbation. The results of this study also provide the opportunity to discuss with students the impact of lower socioeconomic status on health behavior and outcomes, particularly in the context of multiple chronic conditions. Simulation scenarios could be presented to guide student nurses as part of a multidisciplinary team in the care of a patient presenting with COPD with multimorbidity. The COPD experience discussed by the participants of this study also offers insight into the role of inhalation therapies and provides student nurses with the opportunity to learn skills related to teaching patients and families how to properly manage inhaler use.

Implications for Policy

Recognition of the barriers to effective self-management in this population and factors impacting the development of symptoms provides a place to begin discussing how to better design health care services to serve not just acutely ill persons, but chronically ill persons as well. Currently, the Centers for Medicare and Medicaid Services (CMS) includes COPD as part of the Hospital Readmissions Reduction Program (HRRP), a program designed with the intent to link payment to the quality of hospital care (CMS, 2018). This program provides hospitals with financial incentives to reduce hospital readmission within 30 days of discharge for select

diagnoses, including COPD, by improving communication, care coordination, and post-discharge planning. However, risk stratification models used by CMS do not include race or socioeconomic status as adjustment variables potentially penalizing those facilities providing care to disadvantaged patients. In addition, the policy offers minimal evidence or guidance to hospitals on how to reduce such admissions (Shah, Press, Huisingh-Scheetz, & White, 2016) although recently, action plans and self-management have been emphasized as potential strategies (Jalota & Jain, 2016).

Such policies, although intended to improve the quality of care as well as individual and aggregate health outcomes may actually increase poor outcomes for patients with COPD. This approach may de-incentivize health care providers to admit patients presenting to the hospital with an acute exacerbation who are truly in need of emergent care, as documented for patients with congestive heart failure (CHF) (Shah et al., 2016). In addition, such policies rely on index condition identification at admission, a determination that is often difficult in the presence of multiple chronic conditions. The unpredictable disease trajectory inherent to the COPD experience necessitates careful consideration of policies that may impede service provision.

The results of this study provide first-hand narrative accounts of the impact of socioeconomic factors on self-management behaviors and provide additional evidence to support the inclusion of such variables in health care policies. It may be premature to put policies in place before solid evidence exists to guide recommendations for strategies available to achieve desired outcomes. Although progress has been made, as has been discussed, the heterogeneity of self-management intervention research has limited cohesive recommendations. Future interventions studies are needed to have a better understanding of the factors impacting admissions for acute exacerbations; however, the results of this study do offer insight into how

communication and self-management support may be improved for patients with COPD during hospitalization.

This study also provided additional evidence, not related to hospitalization, of the challenges present in the health care system that may impede individual ability to self-manage chronic illness. Participants of this study provided descriptions of how payment and reimbursement structures, pharmaceutical costs, and the structure of health care visits impacted their experience of living with and managing COPD. Changing policy to allow for longer health care provider visits and offering extra time for health care providers to explain conditions and their treatment may positively impact outcomes.

In addition, this study has implications for continued exploration of the potential for changing public policy regarding allowable occupational and other public exposures to respiratory irritants. Tobacco smoking policies have reduced the exposure of this irritant in the public realm. The participants of this study described how exposure to other respiratory irritants impacted the development of COPD and acted as symptom triggers. More research and increased research funding is needed to explore the role of these potentially preventable triggers on the development of COPD and its symptoms. Deepening our understanding of ways to prevent the development of COPD and reducing its sequelae is imperative to decreasing the societal cost of the disease.

Conclusion

The purpose of this study was to explore the self-management and health care experiences of community-dwelling adults living with COPD. A discussion of the findings of this study and of the relationship to the broader literature were presented in this chapter. Implications of these findings to research and clinical practice were discussed and

recommendations for future research and practice were provided. The results of this study offer insight into the barriers and facilitators of self-management and its support and provide additional avenues for future research.

References

- Abdellah, F. G., Beland, I. L., Martin, A., & Matheney, R. V. (1960). *Patient-centered approaches to nursing*. Macmillan Co: New York.
- Agency for Healthcare Research and Quality (2018). *Self-Management Support*. Retrieved from <http://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/index.html>
- Ambrosio, L., Senosiain García, J. M., Riverol Fernández, M., Anaut Bravo, S., Díaz De Cerio Ayesa, S., Ursúa Sesma, M. E., & ... Portillo, M. C. (2015). Living with chronic illness in adults: A concept analysis. *Journal of Clinical Nursing*, 24(17/18), 2357-2367.
doi:10.1111/jocn.12827
- American Lung Association (2017). *Trends in COPD (Chronic Bronchitis and Emphysema): Morbidity and mortality*. Retrieved from <http://www.lung.org/lung-disease/copd/resources/facts-figures/COPD-Fact-Sheet.html>
- Ansari, S., Hosseinzadeh, H., Dennis, S., & Zwar, N. (2014). Patients' perspectives on the impact of a new COPD diagnosis in the face of multimorbidity: A qualitative study. *NPJ Primary Care Respiratory Medicine*, 2414036. doi:10.1038/npjpcrm.2014.36
- Balint, E. (1969). The possibilities of patient-centered medicine. *The Journal of The Royal College of General Practitioners*, 17(82), 269-276.
- Balint, M. (1957). *The doctor, his patient and the illness*. London: Pitman Medical.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84,191–215.
- Bentsen, S. B., Miaskowski, C., & Rustøen, T. (2014). Demographic and clinical characteristics associated with quality of life in patients with chronic obstructive pulmonary

- disease. *Quality of Life Research*, 23(3), 991-998. doi:10.1007/s11136-013-0515-5
- Benzo, R. P., Abascal-Bolado, B., & Dulohery, M. M. (2016). Self-management and quality of life in chronic obstructive pulmonary disease (COPD): The mediating effects of positive affect. *Patient Education and Counseling*, 99(4), 617-623. doi:10.1016/j.pec.2015.10.031
- Berg, J., Evangelista, L. S., Carruthers, D., & Dunbar-Jacob, J. M. (2009). Adherence. In P. Larsen & I. Lubkin (Eds.), *Chronic illness: Impact and intervention* (pp. 161-187). Sudbury, MA: Jones and Bartlett Publishers.
- Berger, B. E., Kapella, M. C., & Larson, J. L. (2011). The experience of stigma in chronic obstructive pulmonary disease. *Western Journal of Nursing Research*, 33(7), 916-932. doi:10.1177/0193945910384602.
- Blackstock, F. C., ZuWallack, R., Nici, L., & Lareau, S. C. (2016). Why don't our patients with Chronic Obstructive Pulmonary Disease Listen to Us? The Enigma of Nonadherence. *Annals of The American Thoracic Society*, 13(3), 317-323. doi:10.1513/AnnalsATS.201509-600PS
- Bourbeau, J. (2008). Clinical decision processes and patient engagement in self-management. *Disease Management & Health Outcomes*, 16(5), 327-333.
- Bourbeau, J. (2009). Activities of Life: The COPD Patient. *COPD: Journal of Chronic Obstructive Pulmonary Disease*, 6(3), 192-200. doi:10.1080/15412550902902638
- Bourbeau, J., & Bartlett, S. J. (2008). Patient adherence in COPD. *Thorax*, 63(9), 831-838. doi:10.1136/thx.2007.086041
- Brady, T. J., Murphy, L., Beauchesne, L., Bhalakia, A., Chervin, D., Daniels, B.,...O'Colmain, B. (2011). Sorting through the evidence for the Arthritis Self-Management Program and the Chronic Disease Self-Management Program: Executive summary of ASMP/CDSMP

- meta-analyses. Retrieved from <https://www.cdc.gov/arthritis/docs/ASMP-executive-summary.pdf>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi:10.1191/1478088706qp063oa
- Bryant, J., McDonald, V. M., Boyes, A., Sanson-Fisher, R., Paul, C., & Melville, J. (2013). Improving medication adherence in chronic obstructive pulmonary disease: A systematic review. *Respiratory Research*, 14109. doi:10.1186/1465-9921-14-109
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167-182. doi:10.1111/1467-9566.ep11339939
- Bury, M. (1991). The sociology of chronic illness: A review of research and prospects. *Sociology of Health & Illness*, 13(4), 451-468. doi:10.1111/1467-9566.ep12449468
- Bury, M. (2001). Illness narratives: Fact or fiction?. *Sociology of Health & Illness*, 23(3), 263-285.
- Buseh, A. G., & Stevens, P. E. (2006). Constrained but not determined by stigma: Resistance by African American women living with HIV. *Women & Health*, 44(3), 1-18. doi:10.1300/J013v44n03-01
- Cannon, D., Buys, N., Sriram, K. B., Sharma, S., Morris, N., & Sun, J. (2016). The effects of chronic obstructive pulmonary disease self-management interventions on improvement of quality of life in COPD patients: A meta-analysis. *Respiratory Medicine*, 12181-90. doi:10.1016/j.rmed.2016.11.005
- Cavallès, A., Brinchault-Rabin, G., Dixmier, A., Goupil, F., Gut-Gobert, C., Marchand-Adam, S., & ... Diot, P. (2013). Comorbidities of COPD. *European Respiratory Review: An*

Official Journal of The European Respiratory Society, 22(130), 454-475.

doi:10.1183/09059180.00008612

Celli, B. R., Decramer, M., Wedzicha, J. A., Wilson, K. C., Agusti, A., Criner,

G. J....ZuWallack, R. L. (2015). An official American Thoracic Society/European

Respiratory Society statement: Research questions in COPD. *European Respiratory*

Journal, 45(4), 879-905. doi: 10.1183/09031936.00009015

Centers for Disease Control and Prevention (2012). Chronic Obstructive Pulmonary Disease

among adults - United States, 2011. *MMWR*, 61(46):938-943

Centers for Medicare and Medicaid Services (2018). *Readmissions reduction program (HRRP)*.

Retrieved from: [https://www.cms.gov/medicare/medicare-fee-for-service-](https://www.cms.gov/medicare/medicare-fee-for-service-payment/acuteinpatientpps/readmissions-reduction-program.html)

[payment/acuteinpatientpps/readmissions-reduction-program.html](https://www.cms.gov/medicare/medicare-fee-for-service-payment/acuteinpatientpps/readmissions-reduction-program.html)

Chen, K., Chen, M., Lee, S., Cho, H., & Weng, L. (2008). Self-management behaviours for

patients with chronic obstructive pulmonary disease: A qualitative study. *Journal of*

Advanced Nursing, 64(6), 595-604 10p. doi:10.1111/j.1365-2648.2008.04821.x

Chen, K., Liu, C., Shyu, Y. L., & Yeh, S. L. (2016). Living with chronic obstructive pulmonary

disease: The process of self-managing chronic obstructive pulmonary disease. *Journal of*

Nursing Research (Lippincott Williams & Wilkins), 24(3), 262-271.

doi:10.1097/jnr.0000000000000152

Coleman, K., Austin, B. T., Brach, C., & Wagner, E. H. (2009). Evidence on the Chronic Care

Model in the new millennium. *Health Affairs (Project Hope)*, 28(1), 75-85.

doi:10.1377/hlthaff.28.1.75

Cooney, A., Mee, L., Casey, D., Murphy, K., Kirwan, C., Burke, E., & ... Murphy, J. (2013).

- Life with chronic obstructive pulmonary disease: Striving for 'controlled co-existence'.
Journal of Clinical Nursing, 22(7/8), 986-995. doi:10.1111/j.1365-2702.2012.04285.x
- Corbin, J. (1998). The Corbin and Strauss Chronic Illness Trajectory Model: An update.
Scholarly Inquiry for Nursing Practice, 12(1), 33-41.
- Corbin, J., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*.
San Francisco: Jossey-Bass.
- Corbin, J., & Strauss, A. (1991). A nursing model for chronic illness management based
upon the trajectory framework. *Scholarly Inquiry for Nursing Practice*, 5(3), 155-174.
- Creer, T. L. (2008). Behavioral and cognitive processes in the self-management of asthma.
Journal Of Asthma, 45(2), 81-94. doi:10.1080/02770900701247236
- Curtis, J. R. (2008). Palliative and end-of-life care for patients with severe COPD. *The European
Respiratory Journal*, 32(3), 796-803.
- Dalal, A. A., Shah, M., D'Souza, A. O., & Rane, P. (2011). Costs of COPD exacerbations in the
emergency department and inpatient setting. *Respiratory Medicine*, 105(3), 454-460.
doi:10.1016/j.rmed.2010.09.003
- Dicpinigaitis, P. V., Lim, L., & Farmakidis, C. (2014). Cough syncope. *Respiratory
Medicine*, 108(2), 244-251. doi:10.1016/j.rmed.2013.10.020
- Disler, R. T., Gallagher, R. D., & Davidson, P. M. (2012). Factors influencing self-management
in chronic obstructive pulmonary disease: an integrative review. *International Journal of
Nursing Studies*, 49(2), 230-242. doi:10.1016/j.ijnurstu.2011.11.005
- Disler, R. T., Green, A., Luckett, T., Newton, P. J., Inglis, S., Currow, D. C., & Davidson, P. M.
(2014). Experience of advanced chronic obstructive pulmonary disease: Metasynthesis of

- qualitative research. *Journal of Pain and Symptom Management*, 48(6), 1182-1199.
doi:10.1016/j.jpainsymman.2014.03.009
- Dworkin, S. L. (2012). Sample size policy for qualitative studies using in-depth interviews. *Archives of Sexual Behavior*, 41(6), 1319-1320. doi:10.1007/s10508-012-0016-6.
- Effing, T. W., Vercoulen, J. H., Bourbeau, J., Trappenburg, J., Lenferink, A., Cafarella, P., & ... van der Palen, J. (2016). Definition of a COPD self-management intervention: International Expert Group consensus. *The European Respiratory Journal*, 48(1), 46-54. doi:10.1183/13993003.00025-2016
- Ehrlich, C., St John, W., & Kendall, E. (2010). 'Listening to my body' to 'Look after my body': A theory of information use for self-management of chronic obstructive pulmonary disease. *Journal of Nursing & Healthcare of Chronic Illnesses*, 2(4), 262-270. doi:10.1111/j.1752-9824.2010.01067.x
- Ek, K., Sahlberg-Blom, E., Andershed, B., & Ternstedt, B. (2011). Struggling to retain living space: Patients' stories about living with advanced chronic obstructive pulmonary disease. *Journal of Advanced Nursing*, 67(7), 1480-1490 11p. doi:10.1111/j.1365-2648.2010.05604.x
- Ek, K., & Ternstedt, B. (2008). Living with chronic obstructive pulmonary disease at the end of life: A phenomenological study. *Journal of Advanced Nursing*, 62(4), 470-478 9p. doi:10.1111/j.1365-2648.2008.04611.x
- Essue, B., Kelly, P., Roberts, M., Leeder, S., & Jan, S. (2011). We can't afford my chronic

- illness! The out-of-pocket burden associated with managing chronic obstructive pulmonary disease in western Sydney, Australia. *Journal of Health Services Research & Policy*, 16(4), 226-231. doi:10.1258/jhsrp.2011.010159
- Faes, K., De Frène, V., Cohen, J., & Annemans, L. (2016). Resource use and health care costs of COPD patients at the end of life: A systematic review. *Journal of Pain and Symptom Management*, 52(4), 588-599. doi:10.1016/j.jpainsymman.2016.04.007
- Ford, E. S., Murphy, L. B., Khavjou, O., Giles, W. H., Holt, J. B., & Croft, J. B. (2015). Total and state-specific medical and absenteeism costs of COPD among adults aged ≥ 18 years in the United States for 2010 and projections through 2020. *Chest*, 147(1), 31-45. doi:10.1378/chest.14-0972
- Fraser, D., Kee, C., & Minick, P. (2006). Living with chronic obstructive pulmonary disease: Insiders' perspectives. *Journal of Advanced Nursing*, 55(5), 550-558. doi:10.1111/j.1365-2648.2006.03946.x
- Genoe, M. R., & Zimmer, C. (2018). "At first I couldn't catch my breath": Process and strategies for managing chronic obstructive pulmonary disease. *International Journal of Aging & Human Development*, 86(2), 191-214. doi:10.1177/0091415017697727
- Gerteis, M., Edgman-Levitan, S., Daley, J. and Delbanco, T.L. (1993) *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*. Jossey-Bass: San Francisco
- Glaser, B., & Strauss, A. (1968). *Time for dying*. Chicago: Aldine.
- Global Initiative for Chronic Obstructive Lung Disease [GOLD] (2018). Global strategy for the diagnosis, management, and prevention of COPD. Retrieved from <http://www.goldcopd.org/>

- Goodridge, D. (2006). People with chronic obstructive pulmonary disease at the end of life: A review of the literature. *International Journal of Palliative Nursing*, 12(8), 390-396.
- Grady, P. A., & Gough, L. L. (2014). Self-management: A comprehensive approach to management of chronic conditions. *American Journal of Public Health*, 104(8), e25-e31. doi:10.2105/AJPH.2014.302041
- Grey, M., Knafl, K., & McCorkle, R. (2006). A framework for the study of self- and family management of chronic conditions. *Nursing Outlook*, 54(5), 278-286.
- Grey, M., Knafl, K., Ryan, P., & Sawin, K. J. (2010). Differing perspectives on conceptual approaches to self-management. *Nursing Outlook*, 58(2), 111–112. <http://doi.org/10.1016/j.outlook.2009.11.002>
- Grey, M., Schulman-Green, D., Knafl, K., & Reynolds, N. R. (2015). A revised Self- and Family Management Framework. *Nursing Outlook*, 63(2), 162-170. doi:10.1016/j.outlook.2014.10.003
- Halding, A., Heggdal, K., & Wahl, A. (2011). Experiences of self-blame and stigmatisation for self-infliction among individuals living with COPD. *Scandinavian Journal of Caring Sciences*, 25(1), 100-107. doi:10.1111/j.1471-6712.2010.00796.x
- Hall, J. M., & Powell, J. (2011). Understanding the person through narrative. *Nursing Research & Practice*, 1-10. doi:10.1155/2011/293837
- Hillebregt, C. F., Vlonk, A. J., Bruijnzeels, M. A., van Schayck, O. C., & Chavannes, N. H. (2016). Barriers and facilitators influencing self-management among COPD patients: A mixed methods exploration in primary and affiliated specialist care. *International Journal of Chronic Obstructive Pulmonary Disease*, 12123-133. doi:10.2147/COPD.S103998

- Hoogendoorn, M., Feenstra, T., Hoogenveen, R., & Rutten-van Mölken, M. (2010). Long-term effectiveness and cost-effectiveness of smoking cessation interventions in patients with COPD. *Thorax*, *65*(8), 711-718. doi:10.1136/thx.2009.131631
- Hudon, C., Fortin, M., Haggerty, J., Loignon, C., Lambert, M., & Poitras, M. (2012). Patient-centered care in chronic disease management: A thematic analysis of the literature in family medicine. *Patient Education and Counseling*, *88*(2), 170-176. doi:10.1016/j.pec.2012.01.009
- Huetsch, J., Uman, J., Udris, E., & Au, D. (2012). Predictors of adherence to inhaled medications among veterans with COPD. *JGIM: Journal of General Internal Medicine*, *27*(11), 1506-1512. doi:10.1007/s11606-012-2130-5
- Institute of Medicine (2003). Priority areas for national action: Transforming health care quality. Washington, D.C. Retrieved from <http://www.nap.edu/catalog/10593/priority-areas-for-national-action-transforming-health-care-quality>.
- Jalota, L., & Jain, V. V. (2016). Action plans for COPD: Strategies to manage exacerbations and improve outcomes. *International Journal of Chronic Obstructive Pulmonary Disease*, *11*, 1179–1188. <http://doi.org/10.2147/COPD.S76970>
- Jeon, Y., Jowsey, T., Yen, L., Glasgow, N., Essue, B., Kljakovic, M., & ... Aspin, C. (2010). Achieving a balanced life in the face of chronic illness. *Australian Journal of Primary Health*, *16*(1), 66-74 9p.
- Jonkman, N. H., Westland, H., Groenwold, R. H. H., Ågren, S., Atienza, F., Blue, L., ... Hoes, A. W. (2016). Do self-management interventions work in patients with heart failure? An individual patient data meta-analysis. *Circulation*, *133*(12), 1189–1198. <http://doi.org/10.1161/CIRCULATIONAHA.115.018006>

- Jonsdottir, H. (2013). Self-management programmes for people living with chronic obstructive pulmonary disease: A call for a reconceptualisation. *Journal of Clinical Nursing*, 22(5/6), 621-637 17p. doi:10.1111/jocn.12100
- Jordan, R. E., Majothi, S., Heneghan, N. R., Blissett, D. B., Riley, R. D., Sitch, A. J., & ... Jolly, K. (2015). Supported self-management for patients with moderate to severe chronic obstructive pulmonary disease (COPD): An evidence synthesis and economic analysis. *Health Technology Assessment (Winchester, England)*, 19(36), 1-516. doi:10.3310/hta19360
- Kale, M. S., Federman, A. D., Krauskopf, K., Wolf, M., O'Connor, R., Martynenko, M., & ... Wisnivesky, J. P. (2015). The association of health literacy with illness and medication beliefs among patients with Chronic Obstructive Pulmonary Disease. *Plos ONE*, 10(4), 1-10. doi:10.1371/journal.pone.0123937
- Kaptein, A. A., Fischer, M. J., & Scharloo, M. (2014). Self-management in patients with COPD: Theoretical context, content, outcomes, and integration into clinical care. *International Journal Of Chronic Obstructive Pulmonary Disease*, 9907-917. doi:10.2147/COPD.S49622
- Kawi, J. (2012). Self-management support in chronic illness care: A concept analysis. *Research & Theory for Nursing Practice*, 26(2), 108-125 18p. doi:10.1891/1541-6577.26.2.108
- King, I. M. (1968). A conceptual frame of reference for nursing. *Nursing research*, 17(1), 27-31.
- Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-

- centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*, 69(1), 4-15. doi:10.1111/j.1365-2648.2012.06064.x
- Kleinman, A. (1988). *The illness narratives*. USA: Basic Books.
- Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, Illness, and Care. *Annals of Internal Medicine*, 88(2), 251-258.
- Kubler-Ross, E. (1969). *On death and dying*. Springer: New York.
- Landers, A., Wiseman, R., Pitama, S., & Beckert, L. (2015). Patient perceptions of severe COPD and transitions towards death: A qualitative study identifying milestones and developing key opportunities. *NPJ Primary Care Respiratory Medicine*, 2515043. doi:10.1038/npjpcrm.2015.43
- Larsen, P. D. (2013a). Chronicity. In I. M. Lubkin & P. D. Larsen (Eds.), *Chronic illness: Impact and intervention* (pp. 3-22). Burlington, MA: Jones & Bartlett Learning.
- Larsen, P. D. (2013b). The illness experience. In I. M. Lubkin & P. D. Larsen (Eds.), *Chronic illness: Impact and intervention* (pp. 3-22). Burlington, MA: Jones & Bartlett Learning.
- Larsen, P. D., & Lubkin, I. M. (2009). *Chronic Illness: Impact and intervention* (7th ed). Sudbury, MA: Jones and Bartlett Publishers.
- Lenferink, A., Brusse-Keizer, M., van der Valk, P. D., Frith, P. A., Zwerink, M., Monnikhof, E. M., & ... Effing, T. W. (2017). Self-management interventions including action plans for exacerbations versus usual care in patients with chronic obstructive pulmonary disease. *The Cochrane Database of Systematic Reviews*, 8CD011682. doi:10.1002/14651858.CD011682.pub2
- Lindgren, S., Storli, S. L., & Wiklund-Gustin, L. (2014). Living in negotiation: Patients'

- experiences of being in the diagnostic process of COPD. *International Journal of Chronic Obstructive Pulmonary Disease*, 9441-451. doi:10.2147/COPD.S60182
- Lorig, K. R., & Holman, H. R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26(1), 1.
- Lowey, S. E., Norton, S. A., Quinn, J. R., & Quill, T. E. (2013). Living with advanced heart failure or COPD: Experiences and goals of individuals nearing the end of life. *Research In Nursing & Health*, 36(4), 349-358. doi:10.1002/nur.21546
- Lusk, J. M., & Fater, K. (2013). A concept analysis of patient-centered care. *Nursing Forum*, 48(2), 89-98. doi:10.1111/nuf.12019
- MacNee, W. (2006). ABC of chronic obstructive pulmonary disease: pathology, pathogenesis, and pathophysiology...second in a series of 12 articles. *BMJ: British Medical Journal (International Edition)*, 332(7551), 1202-1204.
- Mannino, D. M., Higuchi, K., Yu, T., Zhou, H., Li, Y., Tian, H., & Suh, K. (2015). Economic burden of COPD in the presence of comorbidities. *Chest*, 148(1), 138-150. doi:10.1378/chest.14-2434
- Mauer, M., Dardess, P., Carman, K. L., Frazier, K., & Smeeding, L. (2012). *Guide to patient and family engagement: Environmental scan report* (Prepared by American Institutes for Research under contract HHS 290-200-6000019). AHRQ Publication No. 12-0042-EF. Rockville, MD: Agency for Healthcare Research and Quality.
- McDonald, V. M., Higgins, I., & Gibson, P. G. (2013). Insight into older peoples' healthcare experiences with managing COPD, Asthma, and Asthma-COPD Overlap. *Journal of Asthma*, 50(5), 497-504. doi:10.3109/02770903.2013.790415
- McEwen, M., & Wills, E. M. (2007). *Theoretical basis for nursing* (2nd ed). Philadelphia,

- PA: Lippincott Williams & Wilkins.
- Meleis, A. I. (2012). *Theoretical nursing: Development & progress* (5th ed.).
- Mitchell, P. (2008). Patient-centered care- A new focus on a time-honored concept. *Nursing Outlook*, 56(5), 197-198. doi:10.1016/j.outlook.2008.08.001
- Morse, J. (2000). Determining sample size. *Qualitative Health Research*, 10(1), 3-5.
- Morse, J. (2012). *Qualitative health research: Creating a new discipline*. Walnut Creek, CA: Left Coast Press.
- Morse, J. M. (2015). Analytic strategies and sample size. *Qualitative Health Research*, 25(10), 1317-1318. doi:10.1177/1049732315602867
- Munhill, P. L., & Chenail, R. (2008). *Qualitative research: Proposals and reports* (3rd Ed.). Sudbury, MA: Jones and Bartlett Publishers.
- Murphy, T. E., McAvay, G. J., Allore, H. G., Stamm, J. A., & Simonelli, P. F. (2017). Contributions of COPD, asthma, and ten comorbid conditions to health care utilization and patient-centered outcomes among US adults with obstructive airway disease. *International Journal of Chronic Obstructive Pulmonary Disease*, 122515-2522. doi:10.2147/COPD.S139948
- National Center for Health Statistics (2016). Health, United States 2015 with special feature on racial and ethnic health disparities. Hyattsville, MD: Department Health and Human Services.
- National Institute of Nursing Research (2016). The NINR Strategic Plan: Advancing science, improving lives – A Vision for Nursing Science. Retrieved from <https://www.ninr.nih.gov/aboutninr/ninr-mission-and-strategic-plan>

- Nelson, M., & Hamilton, H. E. (2007). Improving in-office discussion of chronic obstructive pulmonary disease: Results and recommendations from an in-office linguistic study in chronic obstructive pulmonary disease. *The American Journal of Medicine, 120* (8Suppl1), S28-S32.
- Novak, M., Costantini, L., Schneider, S., & Beanlands, H. (2013). Approaches to self-management in chronic illness. *Seminars in Dialysis, 26*(2), 188-194.
doi:10.1111/sdi.12080
- Oates, G. R., Hamby, B. W., Stepanikova, I., Knight, S. J., Bhatt, S. P., Hitchcock, J., ... Dransfield, M. (2017). Social determinants of adherence to pulmonary rehabilitation for Chronic Obstructive Pulmonary Disease. *COPD, 14*(6), 610–617.
<http://doi.org/10.1080/15412555.2017.1379070>
- Orlando, I. (1961). *The dynamic nurse-patient relationship*. New York: G. P. Putnam's Sons.
- Ory, M. G., Ahn, S., Jiang, L., Lorig, K., Ritter, P., Laurent, D. D., & ... Smith, M. L. (2013). National study of chronic disease self-management: Six-month outcome findings. *Journal of Aging and Health, 25*(7), 1258-1274.
doi:10.1177/0898264313502531
- Panos, R. J., Krywkowski-Mohn, S. M., Sherman, S. N., & Lach, L. A. (2013). Patient reported determinants of health: A qualitative analysis of veterans with Chronic Obstructive Pulmonary Disease. *COPD: Journal of Chronic Obstructive Pulmonary Disease, 10*(3), 333-347. doi:10.3109/15412555.2012.752805
- Park, S. K., & Larson, J. L. (2014). Symptom cluster, healthcare use and mortality in patients

- with severe chronic obstructive pulmonary disease. *Journal of Clinical Nursing*, 23(17/18), 2658-2671. doi:10.1111/jocn.12526
- Parson, T. (1951). Illness and the role of the physician: A sociological perspective. *American Journal of Orthopsychiatry*, 21, 452-460. doi:10.1111/j.1939-0025.tb00003.x
- Paterson, J. G., & Zderad, L. T. (1976). *Humanistic nursing*. New York: John Wiley & Sons.
- Pearson, M. L., Mattke, S., Shaw, R., Ridgely, M. S., & Wiseman, S. H. (2007). Patient self-management support programs: An evaluation. Final contract report (prepared by RAND Health under Contract No. 282-00-0005). Rockville, MD: Agency for Healthcare Research and Quality (AHRQ publication NO. 08-0011).
- Pelzang, R. (2010). Time to learn: understanding patient-centred care. *British Journal of Nursing (Mark Allen Publishing)*, 19(14), 912-91
- Pender, N. J., Murdaugh, C. L., & Parsons, M. A. (2006). *Health promotion in nursing practice* (5th ed.). Upper Saddle River, NJ: Pearson Prentice Hall.
- Peplau, H. (1952). *Interpersonal relations in nursing*. New York: G.P. Putnam's Sons.
- Peplau, H. (1991). *Interpersonal relations in nursing: A conceptual frame of reference for psychodynamic nursing*. New York: Springer Publishing Company.
- Perera, P. N., Armstrong, E. P., Sherrill, D. L., & Skrepnek, G. H. (2012). Acute Exacerbations of COPD in the United States: Inpatient Burden and Predictors of Costs and Mortality. *COPD: Journal Of Chronic Obstructive Pulmonary Disease*, 9(3), 131-141. doi:10.3109/15412555.2011.650239
- Pleasants, R. A., Riley, I. L., & Mannino, D. M. (2016). Defining and targeting health disparities in chronic obstructive pulmonary disease. *International Journal of Chronic Obstructive*

Pulmonary Disease, 11, 2475–2496. <http://doi.org/10.2147/COPD.S79077>

- Ray, S. M., Helmer, R. S., Stevens, A. B., Franks, A. S., & Wallace, L. S. (2013). Clinical utility of the chronic obstructive pulmonary disease knowledge questionnaire. *Family Medicine*, 45(3), 197-200.
- Rees, S., & Williams, A. (2009). Promoting and supporting self-management for adults living in the community with physical chronic illness: A systematic review of the effectiveness and meaningfulness of the patient-practitioner encounter. *JBIC Library of Systematic Reviews*, 7(13), 492-582.
- Rice, K., Bourbeau, J., MacDonald, R., & Wilt, T. J. (2014). Collaborative self-management and behavioral change. *Clinics In Chest Medicine*, 35(2), 337-351.
doi:10.1016/j.ccm.2014.02.004
- Rier, D. A. (2010). The patient's experience of illness. In C. E. Bird, P. Conrad, A. M. Fremont, & S. Timmermas (Eds.), *Handbook of medical sociology* (6th ed) (pp. 163-178). Nashville, TN: Vanderbilt University Press.
- Ritchie, J., & Lewis, J. (2003). *Qualitative research practice: A guide for social science students and researchers*. Thousand Oaks, CA: SAGE Publications.
- Roig, M., Eng, J. J., Road, J. D., & Reid, W. D. (2009). Falls in patients with chronic obstructive pulmonary disease: A call for further research. *Respiratory Medicine*, 103(9), 1257-1269.
doi:10.1016/j.rmed.2009.03.022
- Rogers, C. R. (1952). 'Client-centered' psychotherapy. *Scientific American*, 187(5), 66-74. doi:10.1038/scientificamerican1152-66.
- Rose, S., Paul, C., Boyes, A., Kelly, B., & Roach, D. (2017). Stigma-related experiences in non-

- communicable respiratory diseases: A systematic review. *Chronic Respiratory Disease*, 14(3), 199–216. <http://doi.org/10.1177/1479972316680847>
- Ryan, P. (2009). The Integrated Theory of Health Behavior Change: Background and intervention development. *Clinical Nurse Specialist*, 23(3), 161-170.
- Ryan, P. & Sawin, K. J. (2009). The Individual and Family Self-Management Theory: Background and perspectives on context process and outcomes. *Nursing Outlook*, 57, 217-225.
- Ryan, P. A., & Sawin, K. J. (2014). Individual and Family Self-Management Theory [Revised Figure]. Retrieved from <http://www.uwm.edu/nursing/about/centers-institutes/self-management/theory/>
- Sama, S. R., Kriebel, D., Gore, R. J., DeVries, R., & Rosiello, R. (2017). Environmental triggers of COPD symptoms: A case cross-over study. *BMJ Open Respiratory Research*, 4(1), e000179. doi:10.1136/bmjresp-2017-000179
- Sandelowski, M. (1994). We are the stories we tell: Narrative knowing in nursing practice. *Journal Of Holistic Nursing: Official Journal of The American Holistic Nurses' Association*, 12(1), 23-33.
- Sawin, K., Brei, T., Buran, C., & Fastenau, P. (2002). Factors associated with quality of life in adolescents with spina bifida. *Journal of Holistic Nursing*, 20(3), 279-304.
- Sawin, K. J., Cox, A. W., & Metzger, W. S. (2003). Transitions to adulthood. In J. Jackson & J. Vessey, J. Editor (Eds), *Primary care of children with chronic conditions* (pp. 60-73). Elsevier Health Sciences Company: St. Louis.
- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., ... Whittemore,

- R. (2012). Processes of Self-Management in Chronic Illness. *Journal of Nursing Scholarship: An Official Publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau*, 44(2), 136–144. <http://doi.org/10.1111/j.1547-5069.2012.01444.x>
- See, K. C., Phua, J., & Lim, T. K. (2016). Trigger factors in asthma and chronic obstructive pulmonary disease: A single-centre cross-sectional survey. *Singapore Medical Journal*, 57(10), 561–565. <http://doi.org/10.11622/smedj.2015178>
- Shah, T., Press, V. G., Huisingh-Scheetz, M., & White, S. R. (2016). COPD Readmissions: Addressing COPD in the era of value-based health care. *Chest*, 150(4), 916–926. <http://doi.org/10.1016/j.chest.2016.05.002>
- Slatore, C. G., Cecere, L. M., Reinke, L. F., Ganzini, L., Udris, E. M., Moss, B. R., & ... Au, D. H. (2010). Patient-clinician communication: associations with important health outcomes among veterans with COPD. *Chest*, 138(3), 628-634. doi:10.1378/chest.09-2328
- Smith, M. C., & Wrobel, J. P. (2014). Epidemiology and clinical impact of major comorbidities in patients with COPD. *International Journal of Chronic Obstructive Pulmonary Disease*, 9871-888. doi:10.2147/COPD.S49621
- Snape, D., & Spencer, L. (2003). The foundations of qualitative research. In J. Ritchie & J. Lewis (Eds.), *Qualitative Research Methods* (pp. 1 -23). Thousand Oaks, CA: SAGE Publications.
- Sossai, K., Gray, M., & Tanner, B. (2011). Living with chronic obstructive pulmonary disease: Experiences in northern regional Australia. *International Journal Of Therapy & Rehabilitation*, 18(11), 631-642 12p.

- Stewart, M., Brown, J. B., Weston, W. W., McWhinney, I. R., McWilliam, C. L., & Freeman, T. R. (2003). *Patient-centered medicine: Transforming the clinical method* (2nd ed.). Oxon, United Kingdom: Radcliffe Medical Press Ltd.
- Strauss, A., & Glaser, B. (1975). *Chronic illness and the quality of life* (1st ed.). St. Louis: Mosby
- Stridsman, C., Lindberg, A., & Skär, L. (2014). Fatigue in chronic obstructive pulmonary disease: A qualitative study of people's experiences. *Scandinavian Journal Of Caring Sciences*, 28(1), 130-138. doi:10.1111/scs.12033
- Suchman, E. A. (1965). Stages of illness and medical care. *Journal of Health and Social Behavior*, 6(3), 114-128. doi:10.2307/2948694
- Suissa, S., Dell'aniello, S., & Ernst, P. (2012). Long-term natural history of chronic obstructive pulmonary disease: Severe exacerbations and mortality. *Thorax*, 67(11), 957-963. doi:10.1136/thoraxjnl-2011-201518
- Tashkin, D. P. & Murray, R. P. (2009). Smoking cessation in chronic obstructive pulmonary disease. *Respiratory Medicine*, 103(7), 963-974. doi:10.1016/j.rmed.2009.02.013
- Thorne, S. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press
- Thorne, S. E., Harris, S. R., Mahoney, K., Con, A., & McGuinness, L. (2004). The context of health care communication in chronic illness. *Patient Education and Counseling*, 54(3), 299-306. doi:10.1016/j.pec.2003.11.009
- Thorne, S., & Paterson, B. (2000). Two decades of insider research: what we know and don't know about chronic illness experience. *Annual Review of Nursing Research*, 183-25
- Tøttenborg, S. S., Lange, P., Johnsen, S. P., Nielsen, H., Ingebrigtsen, T. S., & Thomsen, R. W.

- (2016). Socioeconomic inequalities in adherence to inhaled maintenance medications and clinical prognosis of COPD. *Respiratory Medicine*, 119160-167.
doi:10.1016/j.rmed.2016.09.007
- Travelbee, J. (1966). *Interpersonal aspects of nursing*. Philadelphia: F. A. Davis.
- U. S. Department of Health and Human Services (2017). *U. S. federal poverty guidelines used to determine financial eligibility for certain federal programs*. Retrieved from <https://aspe.hhs.gov/poverty-guidelines>.
- UWM Self-Management Science Center Working Group. (2011). Individual and Family Self-Management Theory: Definition of self-management. Retrieved from <http://uwm.edu/nursing/research/self-management/>
- Valley, T. S., Sjoding, M. W., Ryan, A. M., Iwashyna, T. J., & Cooke, C. R. (2017). Intensive care unit admission and survival among older patients with chronic obstructive pulmonary disease, heart failure, or myocardial infarction. *Annals of The American Thoracic Society*, 14(6), 943-951. doi:10.1513/AnnalsATS.201611-847OC
- Van Damme, S., De Waegeneer, A., & Debruyne, J. (2016). Do flexible goal adjustment and acceptance help preserve quality of life in patients with multiple sclerosis?. *International Journal Of Behavioral Medicine*, 23(3), 333-339. doi:10.1007/s12529-015-9519-6
- Wagner, E. H. (1998). Chronic disease management: What will it take to improve care for chronic illness?. *Effective Clinical Practice: ECP*, 1(1), 2-4.
- Wagner, E. H., Bennett, S. M., Austin, B. T., Greene, S. M., Schaefer, J. K., & Vonkorff, M. (2005). Finding common ground: Patient-centeredness and evidence-based chronic illness care. *Journal of Alternative & Complementary Medicine*, 11s-7-s-15.
doi:10.1089/acm.2005.11.s-7

- Warwick, M., Gallagher, R., Chenoweth, L., & Stein-Parbury, J. (2010). Self-management and symptom monitoring among older adults with chronic obstructive pulmonary disease. *Journal of Advanced Nursing*, 66(4), 784-793. doi:10.1111/j.1365-2648.2009.05238.x
- Westney, G., Foreman, M. G., Junjun, X., King, M. H., Flenaugh, E., Rust, G., & ... Henriques King, M. (2017). Impact of comorbidities among Medicaid enrollees with chronic obstructive pulmonary disease, United States, 2009. *Preventing Chronic Disease*, 141-11. doi:10.5888/pcd14.160333
- Wiedenbach, E. (1964). *Clinical nursing: A helping art*. New York: Springer-Verlag.
- Wise, R. A. (2017). *Chronic Obstructive Pulmonary Disease (COPD)*. Merck Manual Professional Version. Retrieved from <https://www.merckmanuals.com/professional/pulmonary-disorders/chronic-obstructive-pulmonary-disease-and-related-disorders/chronic-obstructive-pulmonary-disease-copd>
- World Health Organization (2018). *Global status report on noncommunicable diseases*. Retrieved from <http://www.who.int/chp/en/>
- Zwerink, M., Brusse-Keizer, M., van der Valk, P. M., Zielhuis, G. A., Monninkhof, E. M., van der Palen, J., & ... Effing, T. (2014). Self-management for patients with chronic obstructive pulmonary disease. *The Cochrane Database of Systematic Reviews*, (3), CD002990. doi:10.1002/14651858.CD002990.pub3

Appendix A



Department of University Safety & Assurances

New Study - Notice of IRB Exempt Status

Date: May 26, 2016

To: Aaron Busch, PhD, MPH, MSN

Dept: College of Nursing

CC: Wendy Bauer, BSN, RN

IRB#: 16.362

Title: Chronic Obstructive Pulmonary Disease: Illness Experience and Self-Management Strategies Among a Sample of Community-Dwelling Adults

Melody Harries
IRB Administrator
Institutional Review Board
Engelmann 270
P. O. Box 413
Milwaukee, WI 53201-0413
(414) 229-3182 phone
(414) 229-6729 fax

<http://www.irb.uwm.edu>
harries@uwm.edu

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been granted Exempt Status under **Category 2** as governed by 45 CFR 46.101(b).

This protocol has been approved as exempt for three years and IRB approval will expire on **May 25, 2019**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, please respond to the IRB's status request that will be sent by email approximately two weeks before the expiration date. If the study is closed or completed before the IRB expiration date, you may notify the IRB by sending an email to irbinfo@uwm.edu with the study number and the status, so we can keep our study records accurate.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. The principal investigator is responsible for adhering to the policies and guidelines set forth by the UWM IRB, maintaining proper documentation of study records and promptly reporting to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is also your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., [FERPA](#), [Radiation Safety](#), [UWM Data Security](#), [UW System policy on Prizes, Awards and Gifts](#), state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation, and best wishes for a successful project.

Respectfully,

A handwritten signature in cursive script that reads "Melody Harries".

Melody Harries
IRB Administrator

Appendix B



Melody Harries
IRB Administrator
Institutional Review Board
Engelmann 270
P. O. Box 413
Milwaukee, WI 53201-0413
(414) 229-3182 phone
(414) 229-6729 fax

<http://www.irb.uwm.edu>
harries@uwm.edu

Modification/Amendment Notice of IRB Exempt Status

Date: July 11, 2016

To: Aaron Buseh, PhD
Dept: Nursing

CC: Wendy Bauer

IRB#: 16.362

Title: Chronic Obstructive Pulmonary Disease: Illness Experience and Self-Management Strategies Among a Sample of Community-Dwelling Adults

After review of your proposed changes to the research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol still meets the criteria for Exempt Status under **Category 2** as governed by 45 CFR 46.101 subpart b, and your protocol has received modification/amendment approval for:

- Minor changes to recruitment
- Adding two questions to interview
- Removing “encrypted” from data security measures

This protocol has been approved as exempt for three years and IRB approval will expire on **May 25, 2019**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, please respond to the IRB's status request that will be sent by email approximately two weeks before the expiration date. If the study is closed or completed before the IRB expiration date, you may notify the IRB by sending an email to irbinfo@uwm.edu with the study number and the status, so we can keep our study records accurate.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. The principal investigator is responsible for adhering to the policies and guidelines set forth by the UWM IRB, maintaining proper documentation of study records and promptly reporting to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is also your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., [FERPA](#), [Radiation Safety](#), [UWM Data Security](#), [UW System policy on Prizes, Awards and Gifts](#), state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project.

Respectfully,

Melody Harries
IRB Administrator

Appendix C

Do you have a lung disease called COPD?

We would like to learn about your experience of living with Chronic Obstructive Pulmonary Disease (COPD) for a nursing research study

We are interested to hear about:

- How much you know about your lung disease
- Your attitudes of living with your lung disease
- Daily challenges you have of living with your disease
- Your encounters and experiences with the health care system
- Strategies you may use to manage your disease

We want to speak with people 18 years of age or older who have been told by a health care provider they have COPD (chronic bronchitis and/or emphysema)

As a study participant, you will complete a short socio-demographic information form about yourself and participate in a 60 to 90 minute interview. Interviews will be audio-recorded and take place at a mutually agreeable time and place

In appreciation of your time and sharing your experience, you will receive a \$25 retail store gift card

Interested in participating?

**Please contact Wendy Bauer, BSN, RN at 414-559-2889 or wshbauer@uwm.edu
All correspondence will be kept confidential.**

Wendy Bauer is a PhD candidate at the University of Wisconsin Milwaukee, supervised by Aaron G. Buseh, PhD, MPH, MSN. This study has been reviewed and approved by the University of Wisconsin Milwaukee Institutional Review Board

COPD study
Wendy Bauer, BSN, RN
wshbauer@gmail.com
414-559-2889

COPD study
Wendy Bauer, BSN, RN
wshbauer@gmail.com
414-559-2889

COPD study
Wendy Bauer, BSN, RN
wshbauer@gmail.com
414-559-2889

COPD study
Wendy Bauer, BSN, RN
wshbauer@gmail.com
414-559-2889

COPD study
Wendy Bauer, BSN, RN
wshbauer@gmail.com
414-559-2889

COPD study
Wendy Bauer, BSN, RN
wshbauer@gmail.com
414-559-2889

COPD study
Wendy Bauer, BSN, RN
wshbauer@gmail.com
414-559-2889

COPD study
Wendy Bauer, BSN, RN
wshbauer@gmail.com
414-559-2889

COPD study
Wendy Bauer, BSN, RN
wshbauer@gmail.com
414-559-2889

COPD study
Wendy Bauer, BSN, RN
wshbauer@gmail.com
414-559-2889

Appendix D



Do you have a Lung Disease called (COPD)?

**We would like to learn about your experience of living with
Chronic Obstructive Pulmonary Disease (COPD)
for a nursing research study**

We are interested to hear about:

- How much you know about your lung disease
- Your attitudes of living with your lung disease
- Daily challenges you have living with the disease
- Your encounters and experiences with the health care system
- Strategies you may use to manage your disease

**We want to speak with people 18 years of age or older who have
been told by a health care provider they have COPD
(chronic bronchitis and/or emphysema)**

As a study participant, you will complete a short socio-demographic information form about yourself and participate in a 60 to 90 minute interview. Interviews will be audio-recorded and take place at a mutually agreeable time and place

**In appreciation of your time and sharing of your experience, you
will receive a \$25 retail store gift card**

Interested in participating?

**Please contact Wendy Bauer, BSN, RN
at 414-559-2889 or wshbauer@uwm.edu
All correspondence will be kept confidential.**

Wendy Bauer is a PhD candidate at the University of Wisconsin Milwaukee, supervised by Aaron G. Buseh, PhD, MPH, MSN. This study has been reviewed and approved by the University of Wisconsin Milwaukee Institutional Review Board

Appendix E



430 E. Division Street, Fond du Lac, WI 54935
Tel: (920) 929-2300 | Fax: (920) 926-4306 | agnesian.com

June 16, 2016

Ms. Wendy Bauer
31 N Royal Ave
Fond du Lac, WI 54935

Dear Ms. Bauer:

I am writing to formally inform you that the Institutional Review Board (IRB) of St. Agnes Hospital has approved your study "Chronic Obstructive Pulmonary Disease: Illness Experience and Self-Management Strategies Among a Sample of Community – Dwelling Adults."

The IRB has approved your study at the June 15, 2016 IRB meeting. The IRB has requested and you had agreed to provide the IRB with a report of your study when it is completed.

Please contact me if you have any questions.

Sincerely,

A handwritten signature in black ink that reads "James P. Muga".

James P. Muga
IRB Chairperson

Appendix F

University of Wisconsin – Milwaukee Consent to Participate in Interview Research

Study Title: Chronic Obstructive Pulmonary Disease: Illness Experience and Self-Management Strategies Among a Sample of Community-Dwelling Adults

Person Responsible for Research:

Aaron G. Buseh, PhD, Professor and Major Professor

Wendy S. Bauer, BSN, RN, Doctoral Student

Study Description: The purpose of this research study is to explore the experiences of living with Chronic Obstructive Pulmonary Disease (COPD) among a sample of community-dwelling adults who self-report being diagnosed and living with the disease. This is a lung disease that affects many people in their adult years. Approximately 25-50 subjects will participate in this study. If you agree to participate, you will be asked to participate in an interview. You will also complete a brief socio-demographic information sheet that will ask you some questions related to your age, education, gender, etc. This information is intended to be used only in describing the data as a group and will not be linked back to you. For the in-depth interview, you will be asked questions about your knowledge (how much you know about your lung condition), your attitude towards living with the disease as well as the daily challenges you usually experience in living with COPD. We are also interested in learning about your experiences with the healthcare system and strategies you may use to self-manage the disease. This will take approximately 60 to 90 minutes of your time. The interview will take place at a mutually agreed upon place and time. Interviews will be audio recorded.

Risks / Benefits: Risks that you may experience from participating are considered minimal. Some people may feel a bit sad recalling some experiences from the past and reflecting back on their health. This information does not increase your risks of participating in the study. Rather, this process provides participants an opportunity for telling their stories of living with a chronic disease. There are no costs for participating. There are no benefits to you other than that the information you provide us will assist to further research.

In gratitude of your participation, a \$25 retail store gift card will be given to you. All individuals who participate in the study will receive the gift card regardless of whether they complete the entire interview.

Confidentiality: During and after the interview your name will not be used. Your responses will be treated as confidential and all names and or identifying information about anyone else will be removed during the transcription process so that the transcript of our conversation is de-identified. All study results will be reported without identifying information so that no one viewing the results will ever be able to match you with your responses. Direct quotes may be used in publications or presentations. Data from this study will be saved on non-networked, password-protected laptop computer for a period of 5 years. Only the student PI (Wendy Bauer) and her professor (Dr. Aaron Buseh) will have access to your information. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records. Audio recordings will be destroyed at end of student PI dissertation study is analyzed and presented no later than 06//30/17.

Voluntary Participation: Your participation in this study is voluntary. You may choose not to take part in this study, or if you decide to take part, you can change your mind later and withdraw from the study.

You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with the University of Wisconsin Milwaukee.

Who do I contact for questions about the study: For more information about the study or study procedures, contact Wendy Bauer at wshbauer@uwm.edu and/or 414-559-2889.

Who do I contact for questions about my rights or complaints towards my treatment as a research subject? Contact the UWM IRB at 414-229-3173 or irbinfo@uwm.edu.

Research Subject's Consent to Participate in Research:

To voluntarily agree to take part in this study, you must be 18 years of age or older. By signing the consent form, you are giving your consent to voluntarily participate in this research project.

Printed Name of Subject/Legally Authorized Representative

Signature of Subject/Legally Authorized Representative

Date

Appendix G

Socio-Demographic Information

To have a better understanding of you and your condition, please answer the following questions.

These questions are only intended for use in describing all participants as a group.

1. What is your age in years? _____

2. What is your race/ethnicity?

White/Caucasian

Hispanic/Latino

Black/African American

Native American or Alaska Native

Asian American/Pacific Islander

Other _____

3. What is your current relationship status?

Married/Partnered Single Separated/Divorced Widow/Widower

4. What is your living arrangement?

a. Who do you live with? _____

b. Zip code of residence _____

5. How would you describe your current housing status?

Own home Rented apartment/house Live with family/friends Homeless Transitional

6. What is your employment status?

Employed Full-time Employed Part-time Unemployed Retired

7. What is your current/former occupation?

8. What was your total household income from all sources last year?

Less than \$5,000 \$5,000 - \$9,999 \$10,000 - \$19,000 \$20,000 - \$29,999

\$30,000 - \$39,999 \$40,000 - \$49,000 \$50,000-59,999 \$60,000-69,999

\$70,000 or more

9. What is your highest level of education completed?

Less than high school High School Diploma/ GED Some College

College graduate Graduate degree

10. Do you have health insurance? Yes No

11. Are you considered disabled? Yes No

Self-Report Clinical Information

1. What is the length of time since you were diagnosed with COPD (emphysema/chronic bronchitis)?

< 1 year 1-3 years 4-6 years 7-10 years >10 years

2. Diseases such as yours are often categorized in stages. Are you aware of the stage of your disease? Yes No

If yes, which stage has your doctor told you?

Stage I (mild COPD) _____ Stage II (moderate COPD) _____

Stage III (severe COPD) _____ Stage IV (very severe COPD) _____

3. Do you have any other health conditions you have been diagnosed with? If yes, please describe.

4. When was the last time you visited a health care provider, such as a doctor or nurse practitioner?

Weekly Bi-monthly Monthly Quarterly Every 6 months
Yearly Less than once a year Other _____

5. Have you ever been hospitalized for your lung disease?

Yes No

If yes:

How many times? _____

How long ago were you last hospitalized for COPD?

6. Tobacco smoking history:

Have you smoked tobacco before? Yes No

Do you currently smoke? Yes No, quit

If yes, how long have you been smoking? _____

If quit, how long ago did you smoke? _____

Have you ever tried to quit? Yes No

If yes, how long ago? _____

To better understand how we may talk with people such as yourself in the future, please describe
how you learned about this study _____

Appendix H

Interview Guide

Thank you for agreeing to take part in this study. This interview is intended to ask you questions about your experiences of living with COPD. The interview is also intended to ask you questions about your encounters with the healthcare system. This is an opportunity for you to tell me about your experiences of living with this condition. This interview will be recorded. Your responses are completely voluntary and at any time you may choose to not answer a question or end the interview.

Knowledge

Could you describe when you first became aware of your illness?

- Could you describe how you got this disease? What are some things you think that led to you developing this disease?
- Please describe how and when your lung disease was diagnosed?
- How would you describe how your lung disease works?

Tell me about how you have come to understand your illness? I am really interested learning more about how much you know about this lung disease.

- Who or what has assisted you?
- What resources have you sought?

Daily challenges

Describe for me, what life was like before you became diagnosed with the lung disease or before you fell sick?

Tell me what it is like now living with your lung condition on a day to day basis.

- Tell me about any symptoms you may have and how have you come to know that these symptoms are going to cause problems for you?
- In living with this lung disease, what are some things that you think about constantly or that trouble you/concerns you most about living with this disease?
- What do you fear most about COPD?

Encounters with the health care system

Tell me about your experience with seeking health care. I am interested in learning about your experiences of what happens when you seek healthcare, whether with your primary care provider or the specialists.

- What kind of experiences have you had with your physician or health care provider?
- Describe for me what things you like about the current healthcare system when you seek healthcare?
- Describe for me what things you don't like about the healthcare system when you seek healthcare?

Self-management strategies

Although your lung disease is being managed by the doctors, people living with this disease also must be able to know what to do and what not to do (i.e., self-managed their disease). So, tell me about what things you do to self-manage your lung disease day-to-day?

- Describe who and/or what has helped most to manage your illness and how?
- Thinking about the management of your disease, what kinds of things sometimes may get in the way of you controlling your illness?
- What things motivate you to focus on managing your disease?
- What things discourage you from managing your illness?

Additional Prompting Questions

- Can you tell me exactly what happened or walk me through the incident?
- Why do you think that happened?
- How did that affect you?
- How did you cope?
- What do you think you would prevent a similar event from happening again?

Conclusion

- Is there anything you would like to add that we didn't discuss here today related to experiences of living with this lung disease or your encounter with the healthcare system?

Thank you! This is the end of the interview.

Appendix I

Resources for Participants in Case of Emotional Distress

In case of emotional upset, it is always a good idea to seek help from your primary care provider. However, you could also call the following organizations which offer crisis mental health services.

County	Organization	Contact
Brown	The Crisis Center of Family Services Brown County – Green Bay	920-436-8888
Calumet	Calumet County Department of Health and Human Services	920-849-9317 (Chilton) 920-832-4646 (Appleton)
Dodge	Dodge County Clinical and Family Services	920-386-4094 (business hours) 1-888-552-6642 (after hours)
Fond du Lac	Fond du Lac Mental Health Clinic	920-929-3535
Milwaukee	Milwaukee County Crisis Services	414-257-7222, 1-800-273-TALK
Outagamie	Outagamie County Division of Mental Health Crisis Intervention Unit	920-832-4646, 1-800-719-4418
Ozaukee	Ozaukee County Crisis Management Services – COPE Hotline	262-377-2673 Ask for the crisis on-call worker for Ozaukee County
Sheboygan	Sheboygan County Mental Health Crisis Line	920-459-3151
Washington	Washington County Crisis Intervention Team	262-365-6565
Waukesha	Waukesha County Health & Human Services	262-548-7666 After hours: 211 or 414-455-1736
Winnebago	Winnebago County Human Services	920-233-7707 or 920-722-7707

Appendix J

CURRICULUM VITAE

WENDY S. BAUER

Place of Birth – Fond du Lac, Wisconsin, USA

EDUCATION

Doctor of Philosophy in Nursing (anticipated) August 2018
University of Wisconsin - Milwaukee
Milwaukee, Wisconsin
Dissertation: *“Self-Management Experiences of Community-Dwelling Adults with Chronic Obstructive Pulmonary Disease”*
Chair: Rachel F. Schiffman, PhD, RN, FAAN

Bachelor of Science in Nursing, magna cum laude May 2008
University of Wisconsin - Milwaukee
Milwaukee, Wisconsin

LICENSURE & CERTIFICATIONS

Registered Nurse licensure 2008 - present
State of Wisconsin

Basic Life Support Provider Certification 2006 - present
American Heart Association

Advanced Cardiac Life Support Provider Certification 2010 - 2014
American Heart Association

TEACHING EXPERIENCE

Teaching Assistant August 2011 - May 2012
University of Wisconsin - Milwaukee (UWM)
Milwaukee, Wisconsin
50% appointment

Clinical Instructor

Wisconsin Heart Hospital, Acuity Adaptable Inpatient Unit, Milwaukee, WI
Cedar Community, Long Term and Sub-Acute Care Units, West Bend, WI

- Instructed undergraduate nursing students in adult patient clinical rotations
- Directed and evaluated student nursing care plans
- Assisted in clinical skill evaluation using low-fidelity simulation scenarios

Faculty Support

Nursing Leadership Course, Undergraduate Senior Level

- Provided support in the evaluation of assignments
- Monitored and assessed student activity on online discussion boards

RESEARCH EXPERIENCE

Research Assistant

February 2015 - present

Self-Management Science Center (SMSC)
UWM College of Nursing
Milwaukee, WI
33% appointment

Support the Administrative Core of the SMSC, an Exploratory Center in Self-Management funded by the National Institute of Nursing Research (Grant P20NR015339); 5-year \$1.49M (Principal Investigator [PI]: Rachel F. Schiffman, PhD, RN, FAAN)

- Work closely with PI and Executive Committee to implement the specific aims of the SMSC
- Support SMSC evaluation plan and selected pilot projects
- Assist in drafting annual progress reports related to SMSC activities, dissemination, and planning for annual External Advisory Council meeting
- Maintain digital document management applications

Research Scientist

October 2014 - September 2017

Research Intern

May 2013 - October 2014

Aurora Health Care
Center for Nursing Practice and Research (CNRP)
Milwaukee, WI

Variable appointment (range 8 – 40 hours per week)

- Assisted with the development of content for embedding evidence-based nursing practices into the nursing work flow through institutional policy and the electronic health record
- Collaborated with CNRP colleagues to align the goals and activities of the CNRP with the strategic plan of the organization
- Supported the study *The Impact of Electronic Knowledge-Based Nursing Content and Decision-Support on Nursing-Sensitive Patient Outcomes* (Award #W81XWH-13-1-0034, EDMS 5648) funded by the Department of Defense Telemedicine and Advanced Technology Research Center; 3-year \$1.5M (Principal Investigator: Mary L. Hook, PhD, RN-BC)
 - Performed scientific literature searches
 - Assisted in the development of data collection protocols and tools
 - Conducted interviews with research participants in the clinical setting
 - Prepared quantitative data for analysis
 - Contributed to the preparation of materials appropriate for co-authored publications and presentations

Doctoral Student

September 2012 - December 2014

UWM College of Nursing Research Practicum
Milwaukee, WI

Faculty Advisor: Patricia Stevens, PhD, RN, FAAN

Hours dedicated: 6 – 10 hours per week

Performed secondary analysis of 55 qualitative in-depth interviews gathered as part of the National Institute on Child Health and Development (R01-HD055868) funded study *Pathways Linking Poverty, Food Insecurity, and HIV in Rural Malawi*.

CLINICAL EXPERIENCE

Staff Nurse

December 2011 - February 2013

Agnesian Health Care

Cardiopulmonary Services Department

Fond du Lac, WI

Hours worked: Per diem (8 - 24 hours per week)

- Provided bedside cardiac education to patients with select diagnoses and those undergoing cardiac interventions and surgeries.
- Cared for patients undergoing exercise and medication-induced cardiac stress testing and for those participating in cardiac rehabilitation.

Staff Nurse

June 2010 - July 2011

Aurora St. Luke's Medical Center

Cardiothoracic Surgical Unit

Milwaukee, WI

Hours worked: Weekend program (24 hours per week)

Provided nursing care to patients requiring cardiac and thoracic surgical interventions.

Staff Nurse

January 2010 - June 2010

Agnesian Health Care

Intensive Care Unit

Fond du Lac, WI

Hours worked: Per diem (8 – 24 hours per week)

Provided intensive nursing care to the general post-operative, medically intensive, and terminally ill patient populations.

Staff Nurse

April 2009 - June 2010

Agnesian Health Care

Medical Surgical Unit

Fond du Lac, WI

Hours worked: Weekend program (24 hours per week)

- Provided nursing care to surgical patients in the pre- and post-operative period with an emphasis in gastrointestinal, urology, and orthopedic procedures.
- Cared for medical patients requiring end of life care services.

Staff Nurse

May 2008 - February 2009

Columbia St. Mary's Hospital
Cardiac Specialty Unit
Milwaukee, WI
Hours worked: 36 hours per week

Provided nursing care to cardiovascular and peripheral diagnostic and intervention patients and stable cardiac surgical patients.

Nurse Technician

May 2007 - May 2008

Columbia St. Mary's Hospital
Regional Burn Intensive Care Unit
Milwaukee, WI
Hours worked: 24 hours per week

Provided nursing care to burn patients in the critical care setting under the supervision of a registered nurse.

PUBLICATIONS

Mkandwire, L., **Bauer, W. S.**, Stevens, P. E., Galvao, L. W., Grande, K., Yerges, A. L., Emer, L. R., Mwenyekonde, T., & Weinhardt, L. Rural Malawian women's resistance to systematic oppression, violence, and abuse by their husbands. *Journal of Interpersonal Violence*. Advance online publication. doi.org/10.1177/0886260516682518

Yerges, A. L., Stevens, P. E., Mkandawire-Valhmu, L., **Bauer, W. S.**, Mwenyekonde, T., Weinhardt, L. S., & Galvao, L. (2016). Women's narratives of living in polygamous marriages: Rural Malawian experience distilled and preserved in poetic construction. *Health Care for Women International*. Epub ahead of print. doi. 10.1080/07399332.2017.1326494

PRESENTATIONS

Hook, M. L., & **Bauer, W. S.** (2017, April). *Using a mixed-methods design to investigate adherence to evidence-based nursing practices in acute care*. Poster presentation at the Kappa Pi Nursing Research Evening, Bellin College, Green Bay, WI.

Hook, M. L., & **Bauer, W. S.**, (2017, April). *The impact of a technology-based innovation to support evidence-based patient education by nurses in acute care*. Podium presentation at the 41st annual Midwest Nursing Research Society (MNRS) conference, Minneapolis, MN.

Hook, M. L., & Bauer, W. S. (2016, December). *Using a mixed-methods design to investigate adherence to evidence-based nursing practices in acute care*. Poster presented at the 9th annual conference of the Science of Dissemination and Implementation. Co-hosted by the National Institutes of Health and AcademyHealth, Washington, DC.

Bauer, W. S., & Hook, M. L. (2014, May). *Evaluating the impact of evidence-based patient education on patient knowledge and behavior in acute care: Conceptualization and tool development*. Building Bridges to Research Based Nursing Practice, Milwaukee, WI.

PROFESSIONAL SERVICE

Doctoral Student Representative UWM College of Nursing Research Committee	2014 - 2016
Treasurer UWM Doctoral Student Nursing Organization	2012 - 2013
Student Representative UWM College of Nursing Black and Gold Committee	2007 - 2008

RECOGNITION

Advanced Opportunity Program Fellowship Recipient UWM and the State of Wisconsin	2012 - 2015
Nancy A. Wright Memorial Fellowship Recipient UWM College of Nursing	2011 - 2012

PROFESSIONAL MEMBERSHIPS

Council for the Advancement of Nursing Science	2017 - present
Sigma Theta Tau International (STTI) - Eta Nu Chapter	2012 - present
Midwest Nursing Research Society (MNRS)	2012 - present
UWM Doctoral Student Nursing Organization	2011 - 2015
American Nurses Association (ANA)	2008 - present
Wisconsin Nurse Association (WNA)	2008 - present
National Student Nurses Association (NSNA)	2006 - 2008