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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

THE LIVED EXPERIENCE OF DISCHARGED AND READMITTED AFRICAN
AMERICANS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE TO A
SAFETY-NET HOSPITAL

by

Kiiyonna L. Jones

A dissertation presented to the

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UNIVERSITY OF SAN DIEGO

In partial fulfillment of the

requirements for the degree

DOCTOR OF PHILOSOPHY IN NURSING

April 2019

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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

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DISSERTATION: The Lived Experienced of Discharged and
Readmitted African Americans with Chronic
Obstructive Pulmonary Disease to a Safety-Net
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Abstract

Background: Chronic Obstructive Pulmonary Disease (COPD) is a debilitating respiratory disease that negatively affects the quality of life of those affected and has been a major contributor to the continuous rise in healthcare cost in the United States (Guarascio, Ray, Finch, & Self, 2013; National Heart Lung and Blood Institute, 2009; Shavelle, Paculdo, Kush, Mannino, & Straus, 2009; Scott, Smith, Sullivan, & Mahajan, 2001). In 2014, Centers for Medicare & Medicaid Services (CMS) identified COPD as an applicable condition to the Hospital Readmissions Reduction Program, which penalizes healthcare organizations having readmissions higher than the national average. In doing so, these healthcare organizations are subjected to a reduction in reimbursement amounts based on excessive readmission ratios within 30 days of a hospital discharge. COPD is the second leading cause of hospital readmissions and was estimated to cost the U. S. healthcare system approximately \$50 billion in direct and indirect cost in 2012, with a projected cost of \$101 billion by 2020. Simply penalizing hospitals for increased readmission rates, rather than understanding extrinsic and intrinsic influencing factors from the patient's perspective, could not only lead to increased disparities among certain populations, primarily minority populations, but could also have an indirect effect on the quality of care provided by hospitals and likely have little to no effect on readmission rates.

Objective: The purpose of this study is to explore the lived experience of African American (AA) COPD patients readmitted to a community hospital, within 30-days of a previous discharge.

Research question: What is the human experience of patients discharged from the hospital and then subsequently readmitted within 30 days?

Conceptual Model: Transitional Care Model

Research Aims: To explore the lived experience of AA COPD patients discharged from the hospital and readmitted 30-days post discharge. To explore recently discharged AA patient's management of COPD in their homes and within the community.

Methods: The purpose of this study is to explore the lived experiences of readmitted AA patients with COPD. An interpretive phenomenology research approach will be adopted to collect data through semi-structured interviews. Also termed, Hermeneutics, this type of phenomenology seeks to interpret the meaning embedded in the lived experiences of the participants (Cohen, Kahn, & Steeves, 2000; Spiegelberg, 1976). The researcher in this study understands that human experiences, subjective collected data, are interrelated within social, political, and cultural contexts and therefore, the relation of the phenomenological inquiry is related to the world in which the individual exists (Heidegger, 1962). Data will be collected, analyzed, and written using the scientific methodology of hermeneutic phenomenology.

Discussion: Thirty-day readmission rates in patients with COPD are costly to the US healthcare system; however, no studies have explored the experience of the patients who are readmitted and their perceptions of why they are being readmitted (Baker, Zou, & Su, 2013). Moreover, no studies have focused on the complexities of readmitted patients within a social construct, considering disadvantages experienced by low income African American patients who reside in communities with limited medical care accessibility.

Dedication

This dissertation is dedicated to my grandmother, Martha Louise Scott, who was instrumental in my success during the start of my academic journey. Although you are no longer physically present, I feel your presence often and know that you are smiling down on me at this very moment as I write this dedication. You were my biggest supporter, and once I showed you how serious I was about education, you were front row for every graduation, academic ceremony, and every other accomplishment along the way. I will miss you at this graduation but find resolve in knowing none of this could have been possible without your foundational love, support, and care. Getting through this program required strength, determination, grit, and faith, all which you instilled in me. I know this is just the beginning, and every step of the way I will take you with me in my heart and soul. Grandma, this is the first PhD in our family and without your undying support, this would not have been possible. You have planted seeds and now the harvest will bloom for generations to come. I hope I have made you proud. This one is for you, Grandma!

Love Forever and Always,

Your Granddaughter Dr. Kiiyonna L. Jones

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weekly just to take Keyon to school on the days I had class. Daddy, you are the reason I studied COPD because I wanted to understand your experience with this chronic disease. I love you always daddy. To my committee members, Drs. Georges, Connelly, and Ekwegh, thank you for your support during this journey and for providing a balance of the love, support, and matter-of-factness needed during this journey. Last but definitely not least, Sharon Ezell aka, Momma, words cannot express how much I appreciate your support, encouragement, and love for me. From the sacrifices you made for me as a child, to the sacrifices you continue to make for me as an adult, I will forever be grateful. Thank you for talking to me weekly for 3 years during the 3-hour trip to Los Angeles from San Diego with no complaints. Thank you for our 5am morning calls when I was driving to San Diego from Los Angeles. Mom, you have been there through the highs and lows of this program and I thank you for always believing in me and seeing in me what I sometimes could not see in myself. Your undying love has made me stronger and better through this process.

To the African American community, I will not fail you. I know my purpose is to improve health, access, and to be a voice for our community and my life's work will be to fulfill this purpose.

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CHAPTER 1

The Problem

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a debilitating respiratory disease that negatively affects the quality of life of those affected and has been a major contributor to the continuous rise in healthcare cost in the United States (Guarascio, Ray, Finch, & Self, 2013; National Heart Lung and Blood Institute, 2009; Shavelle, Paculdo, Kush, Mannino, & Strauss, 2009; Scott, Smith, Sullivan, & Mahajan, 2001). It is estimated that in the United States, a staggering 15 million people are living with COPD and as stark as this may be, it is likely an underestimate as many individuals with low pulmonary function disease are often misdiagnosed or undiagnosed (Centers for Disease Control and Prevention, 2011; Mannino, Gagnon, Petty, & Lydick, 2000; Soriano, Zeilinski, & Price, 2009). The third leading cause of death in the United States, COPD is also the number one cause of hospital readmissions and is estimated to cost the U. S. healthcare system approximately \$50 billion in direct and indirect cost with a projected cost to be as high as \$101 billion by 2020 (Baker, Zou, & Su, 2013; Centers for Disease Control and Prevention [CDC], 2015; Ford et al., 2015; Jencks, Williams, & Coleman, 2009). The Centers for Medicare and Medicaid Services (CMS) (2019) added COPD as a measure in the core set of adult health care quality measures for Medicare and Medicaid. As a result, national data regarding Medicare and Medicaid patients with COPD is now collected and analyzed in order to develop a national system to measure quality, identify successful evidence-based practices based on objective outcomes, and to

collect data to develop a better understanding of the quality of care these patients receive while in health care facilities.

In addition, in FY2015, COPD was added to the Hospital Readmissions and Reduction Program (HRRP) as a condition that requires CMS to reduce reimbursement to hospitals participating in the inpatient prospective payment system (IPPS) that have 30-day readmission rates above the national average (CMS, 2016). This readmission penalty can range from 1-3% based on the established formula utilized by CMS. Although it is evident that COPD is a condition with high readmission rates that are costly to the U. S. healthcare system, simply penalizing hospitals for increased readmission rates rather than understanding extrinsic and intrinsic influencing factors from the patient's perspective could not only lead to increased disparities among certain populations, primarily minority groups, but also have an indirect effect on the quality of care provided by hospitals (Feemster, & Au, 2014).

More specifically, hospitals that provide care for large indigent, racial minority, low income, uninsured, and vulnerable populations, termed safety-net hospitals, are more likely to be penalized compared to other hospitals (Berenson & Shih, 2012; Gilman et al., 2014; Joynt & Jha, 2013). These additional penalties could lead to safety-net hospitals being unable to sustain financially, discouraged from providing care to these vulnerable populations, and/or unable to provide quality care and leading to decreased access to the populations who have the most complex healthcare needs.

Study Purpose

The purpose of this study is to explore the lived experience of African American COPD patients readmitted, within 30 days of discharge, to a safety-net community

hospital in Southern California. This community hospital serves a predominately minority population, 96% Hispanic and African American, who are members of the most underserved and financially disadvantaged populations and who have the most complex healthcare needs in Los Angeles County. Located in Service Planning Area 6 (SPA6), this community has the highest percentage of adults who have no health insurance, residents who have the least access to primary care providers, adults who report the most difficulty accessing medical care, and highest rates of homelessness (Department of Public Health County of Los Angeles, 2014). Learning more about the lived experiences of readmitted African American COPD patients can provide information that can assist with filling in the gaps in literature pertaining to the external social factors that may increase readmission rates, particularly in safety-net hospitals.

This study will be guided by the hermeneutic phenomenological approach as the researcher interviews men and women with COPD who have been readmitted to this community hospital within 30 days of a previous discharge. The findings of this study will be helpful for policy makers, healthcare stakeholders, and community members by providing insight of the transitional care needs of African American COPD patients in low income and Health Professional Shortage Areas (HPSAs). This study will contribute to the support of innovative strategies to improve post discharge support for minority populations, and ultimately decrease hospital readmission rates for this fragile group.

Specific Aims

The following specific aims are proposed:

Aim 1: To explore the feelings of African American patients who are readmitted to the hospital after recently being discharged.

Aim 2: To explore recently discharged African American patients' adjustment to life after their initial discharge from the hospital.

Aim 3: To explore the perceived feelings of barriers to disease management of readmitted African American patients with COPD in their homes and within the community.

Aim 4: To identify perceived needs and barriers to managing COPD within the community.

Overview of the Literature

Previous studies have yielded unclear results regarding specifically which transitional care interventions, if any, are most impactful in decreasing short term, 30-day, hospital readmission rates, particularly among patients with chronic illnesses (Boutwell, Johnson, & Watkins, 2016; Brand, et al., 2004; Jackson, Trygstad, DeWalt, & DuBard, 2013). Verhaegh et al. (2013) have shown that high intensity interventions, including nurse care coordination, primary care provider and hospital collaborative communication, and home visits by a nurse, when used conjointly, can be effective in decreasing 30-day readmission rates. Moreover, these high intensity interventions have also shown an absolute risk reduction of 5% in short term readmissions (*OR*: 0.59; 95% *CI*: 0.38, 0.92) (Verhaegh et al., 2013).

Effective management of COPD after hospital discharge is of utmost importance, particularly when considering the potential cost-savings for the U. S. healthcare system. Emphasis has been placed on the need to reduce healthcare cost and hospital readmission rates utilizing transitional care; however, no studies have been able to identify specifically which intervention, when considering transitional care, has the most impact

on decreasing readmission rates nor have any focused on one of the most vulnerable underserved groups, the African American population in medically underserved areas (Englander, Michaels, Chan, & Kansagara, 2014). Homelessness has been identified as a risk for hospital readmission and, with Los Angeles County having the highest homeless rates in the entire state of California, it is of utmost importance to explore the impact of homelessness when seeking to reduce hospital readmission rates among this population (Kushel, 2018; Los Angeles Homeless Service Authority, 2017; Shalen, Patts, Weinberg, & Philippides, 2016). While sufficient data have shown that patients with COPD have one of the highest hospital readmission rates, the specific benefit of transitional care in decreasing hospital readmission rates for chronic diseases, such as COPD, remain unclear (Kangovi & Grande, 2014). This is likely due to the lack of understanding of the experiences recently discharged patients may have in the home and community of which they reside and the unmet needs and/or barriers that may limit their ability to manage COPD while in the community.

Previous qualitative studies have explored coping capabilities of individuals affected with COPD, the effect COPD has on social relationships, and the effect of telemonitoring on quality of life for COPD patients (Barken, Thygesen, & Soderhamn, 2016; Chang, Dai, Chien, & Chan, 2016). Moreover, from the perspective of readmissions and COPD, a qualitative study from Tang and Lee (2016) explored the lived experiences of readmitted older Chinese adults; however, no studies have explored the lived experiences of readmitted African American patients with COPD who reside in low income communities with limited access to medical care.

Sensitized Model

Transitional Care Model (TCM) is the sensitized model that will be used to guide and explore the multifaceted considerations of the lived experience of the recently discharged and subsequently readmitted African American patient with COPD (Naylor et al., 2015). This transitional care model is implemented after high-risk patients with chronic conditions are identified while admitted in the hospital setting. Conceptually, the transitional care nurse is at the center of the model with the patient and both are surrounded by these core elements: managing symptoms, educating, collaborating, assuring continuity, coordinating care, maintaining relationships, screenings, and engaging elder/caregiver (Figure 1). According to the TCM, continuity of care is the missing piece that leads to increased readmissions of chronically ill patients in the U. S. healthcare system (Naylor & Sochalski, 2010). The essential components of the TCM have been shown to prevent unplanned readmissions (Naylor et al., 2015). However, demographical considerations as they relate to ethnicity/race, social, and income level are not included in this model and, therefore, may not prevent 30-day readmissions in individuals who have lower income status, who are racial/ethnic minorities, or who live in communities that are disproportionately affected by medical care disparities, such as healthcare access and primary care provider shortages.

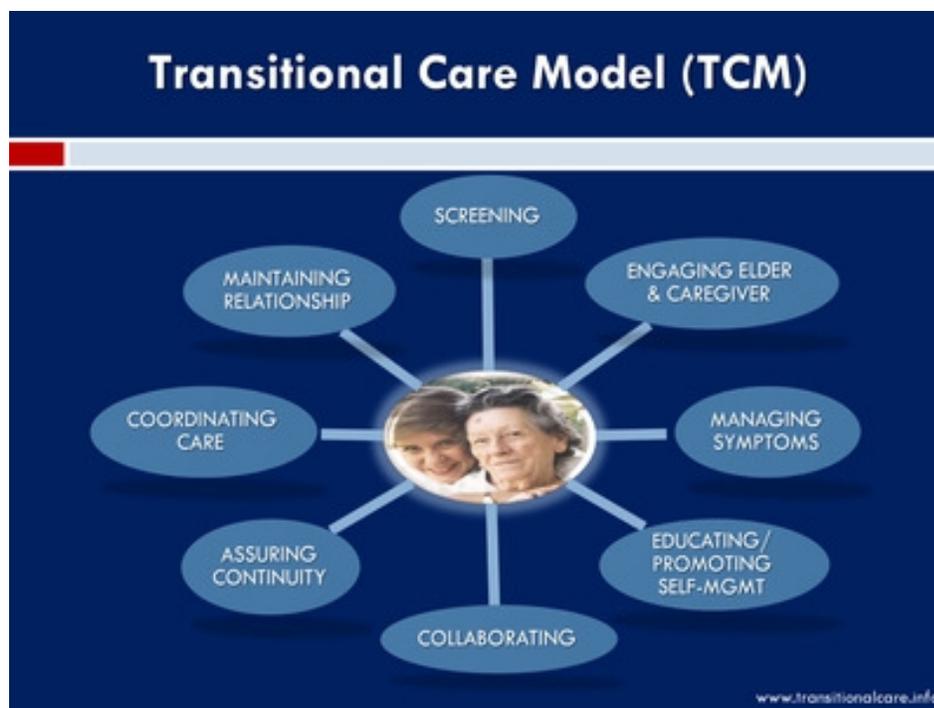


Figure 1. Transitional Care Model (TCM)

Methods

Study Design

The purpose of this study is to explore the lived experiences of readmitted African American patients with COPD. An interpretive phenomenology research approach will be adopted to collect data through semi-structured interviews. Also termed hermeneutics, this type of phenomenology seeks to interpret the meaning embedded in the lived experiences of the participants (Cohen et al., 2000; Spiegelberg, 1976). The researcher in this study understands that human experiences and subjectively collected data, are interrelated within social, political, and cultural contexts and therefore, the relation of the phenomenological inquiry is related to the world in which the individual exists

(Heidegger, 1962). Data will be collected, analyzed, and written using the scientific methodology of hermeneutic phenomenology.

Participant Characteristics

The study population will be participants who were flagged as being readmitted within 30 days of discharge and having a primary or secondary diagnosis of COPD.

Inclusion criteria: African American English-speaking participants who were discharged and subsequently readmitted within 30 days from November 2017 to January 2018 with a primary or secondary diagnosis of COPD, a discharge to home or recuperative care from their first admission and an anticipated discharge disposition to home or recuperative care for their subsequent readmission. **Exclusion criteria:** Cases will be excluded if they are 18 years or younger, were admitted before November 2017 or after January 2018, non-English speaking, non-African American ethnic identity, readmitted more than twice since their primary admission, admitted after 30 days of their initial hospital discharge, or expected discharge disposition anywhere other than home, e.g. skilled nursing facility, rehabilitation facility, long-term acute care, etc.

Human Subject Issues: The data collected will be collected prospectively by interviewing patients with a primary and secondary diagnosis of COPD who are readmitted to the hospital. IRB approval will be obtained from the University of San Diego. (See Appendix A.)

Sampling Procedures

With approval from the Chief Executive Officer at the community hospital, all cases readmitted within 30 days with a primary and secondary diagnosis of COPD will be flagged. Registered nurses on the Medical Surgical and Telemetry units will be provided information regarding the study and contact information for the researcher to notify her in the event they identify a patient who meets inclusion criteria. Potential participants will be asked by the nurse if they are willing to participate in the study and handed an informational pamphlet regarding the study and the small gift being offered for their participation. If the participants meet the inclusion criteria and agree to speak with the researcher, a signed consent will be obtained by the researcher. (See Appendix B). If the potential participant cannot read and/or write, the consent will be read and thoroughly explained to the participant by the researcher. Once consent is obtained and the participant is informed of the confidentiality and anonymity of the study, the interview will begin. The expectation is that all interviews will take place at the patient's bedside.

Setting/Location

The setting for the research will be at the community hospital in Los Angeles, California.

Data

Data Acquisition

The researcher will obtain demographical data from the participant in the form of a questionnaire. (See Appendix C). The data exploring the experiences of the phenomena, the feeling of being readmitted, will be collected via semi-structured interview questions, which will be guided by hermeneutic phenomenological

methodology. (See Appendix D). The interviews will be recorded and transcribed verbatim to construct texts for analysis (Cohen et al., 2000). In order to enhance the quality of the data, field notes will also be used to capture nonverbal, meaningful data such as dress, body language, and environmental details, to assist the researcher with interpretation of the experience during data recollection.

Data Analysis Plan

The goal of the interviews will be met once a saturation of themes and/or categories are obtained; it is predicted this will occur between 12 and 15 participant interviews. The process of phenomenological analysis exists in two metaphorical spheres: field text and narrative text (Cohen et al., 2000). The former of the two, field text, is constructed through the process of collecting data whereas the latter, narrative text, is the conveyance of the collected data, based on the researcher's interpretation and understanding, to other readers (Cohen et al. 2000). The ultimate goal will be to capture and communicate the meaningful experience of the phenomena from the participant's perspective via the hermeneutic circle (Cohen et al., 2000; Spiegelberg, 1976). The hermeneutic circle metaphor considers the individual texts in relation to the larger text and allows for the researcher to gain a deeper level of understanding through a reflexive awareness of the continuous analysis of this back-and-forth integrative process.

Limitations

Although the study will attempt to consider most variables, there will be limitations. Cases with multiple chronic conditions will not be considered. This could lead to cases with COPD being excluded and therefore, not included in the study. Patients with primary care providers (PCPs) are more likely to seek care after discharge

from the hospital and as a result, are less likely to be readmitted to the hospital and not included in the study. Although the researcher will attempt to prevent biases, qualitative interpretation of the data is subject to the interpretation of the researcher and can be unknowingly influenced by the researcher's life experiences.

Discussion

This will be a hermeneutic phenomenological study which will focus on the lived experience of African American patients with COPD who are readmitted to a community hospital within 30 days post-hospital discharge. Concrete scientific inquiry has confirmed that 30-day readmission rates in patients with COPD are costly to the U. S. healthcare system; however, no studies have explored the experience of African American patients who are readmitted and their perceptions of why they are being readmitted or their experiences to actual and perceived barriers to disease management within their community (Baker et al., 2013). Furthermore, no studies, to the knowledge of the author, have focused on the complexities of readmitted patients within a social construct such as consideration of the impact that social determinants of health may have on readmission rates in predominately minority communities with limited access to healthcare and lower socioeconomic status. To decrease the cost of 30-day readmissions in African American COPD patients, it is of utmost importance to identify transitional care interventions that can prevent readmissions and are inclusive of, and consider, social determinants of health within the community in which these populations reside to decrease readmission rates, particularly for this vulnerable population. The transitional care model has identified elements shown to decrease readmission rates among elderly patients with chronic conditions; however, this model does not include social disparities

that exist in communities with predominately minority populations and the influence these factors may have on readmission rates. This study will explore the human experience of being discharged from a hospital and ultimately readmitted and will explore the realities from the world in which they live.

Study Timeline: It is anticipated that the request for IRB approval will initiate in October 2017 with approval anticipated in November 2017. Research will begin in November 2017 and continue until March 2018.

CHAPTER 2

Literature Review

Global Overview of COPD

Chronic Obstructive Pulmonary Disease (COPD) is a group of progressive chronic respiratory conditions primarily encompassing two chronic lung diseases: emphysema and bronchitis, which in tandem cause limitations in lung airflow and breathing-related complications (World Health Organization, 2019). The Global Initiative for Chronic Obstructive Lung Disease (GOLD) and the American Thoracic Society (ATS)/European Respiratory Society (ERS) define COPD as a chronic condition that is not fully reversible or curable and is associated with abnormal response to noxious stimuli by the lungs, leading to acute exacerbations and breathlessness among those who are affected (Barnes & Kleinert, 2004; Celli & MacNee, 2004; Pauwels, Buist, Calverley, Jenkins, & Hurd, 2001). In 2002, it was estimated globally that COPD affected 210 million people; 62 million people suffered from moderate to severe COPD, and 60% to 86% remained undiagnosed (Decramer & Sibille, 2011; Hvidsten, Storesund, Wentzel-Larsen, Gulsvik, & Lehmann, 2010; Miravittles et al., 2009; World Health Organization, 2004).

Since 2002, the World Health Organization (WHO) has not provided additional data on the global prevalence of COPD; however, as of 2015, COPD was identified as the fourth leading cause of death and is predicted to become the third leading cause of death globally by 2030 if interventions targeting high-risk populations are not implemented (Lopez et al., 2006; Mathers, 2005). In 2010, according to the Global Burden Disease

Study, COPD was responsible for 5% of global disability-adjusted life-years (DALYS) and 5% of all deaths worldwide (Lozano et al., 2012; Murray et al., 2012).

COPD in the United States

In the United States, COPD has been identified as the third leading cause of death in 2015 and the fourth leading cause of death in 2016 with residents in rural areas experiencing higher prevalence, hospitalizations, and COPD-related deaths compared to metropolitan areas (Croft et al., 2018). In a National Center for Health Statistics data brief, Ni and Xu (2016) found the age-adjusted death rates for those affected with COPD in the United States declined for White men and women and Black men age 25 and over from 2000 to 2014; however, for Black women, the age-adjusted death rate increased by 4.2%. Although additional research has also shown there has been an overall decline in mortality rates of those affected with COPD, these studies did not stratify the age-adjusted death rates for poor, vulnerable, or medically underserved communities with predominately minority populations (Ford, 2015).

Even with this notable decline in mortality rates among Whites and male Blacks, in 2010 COPD attributed to 700,000 hospitalizations, 10.3 million outpatient visits, and 1.5 million ED visits with the total medical costs, including direct and indirect, estimated between \$50 and \$101 billion dollars (Ford et al., 2013; Ford et al., 2015; Baker et al., 2013). Of the direct costs, it is estimated most were associated with highly utilized healthcare services related to exacerbations, or flare ups, of COPD leading to in-patient hospital stays, increased hospital readmissions, physician visits, and other uses of the U. S. healthcare system (Ford et al., 2015; Mapel, Douglas, Lydick, & Marton, 2010). These excessive demands on the U. S. healthcare system by individuals with COPD

poses a significant economic burden on society and requires an in-depth scientific inquiry to develop an understanding of effective management of this chronic condition from the perspective of those affected by COPD.

Economic Impact and US Policy

Acute COPD exacerbations (AECOPD) account for more than half of the \$50 to \$101 billion spent on this chronic condition, leading to unscheduled hospital visits and increased healthcare utilization among this group (Celli & MacNee, 2004; Toy, Gallagher, Stanley, Swensen, & Duh, 2010). More specifically, direct medical costs of those affected with COPD were estimated to be \$2,507 per patient with 54% of those dollars being spent on inpatient hospitalizations (Miller et al., 2005). For AECOPD patients, primary hospitalizations have a one in five chance of leading to rehospitalizations within 30 days of hospital discharge, which also has a significant impact on the economic burden of COPD (Jencks et al., 2009).

Due to the continued rise in healthcare costs related to COPD and the major source of those costs being associated with readmissions, the Centers for Medicare and Medicaid Services (CMS), under the direction of the Secretary of the Department of Health and Human Services, established the Hospital Readmissions Reduction Program (HRRP) to incentivize reduction in excessive hospital readmissions and improve patient care, which would lead to a reduction in COPD-associated healthcare utilization and expenditures (CMS, 2015). In 2014, CMS, using excess readmission ratios (ERR) to measure performance, expanded applicable conditions to include COPD. This expansion affects reimbursements paid to hospitals by 1% to 3%, based on their COPD readmission ratios through CMS's Inpatient Prospective Payment System (IPPS). In theory, HRRP

should encourage hospitals to become creative in reducing rehospitalizations of patients with chronic conditions, such as COPD, which should also improve patient care. However, research is unclear on whether these penalties could unexpectedly have a negative impact on the most vulnerable populations and the safety-net hospitals that serve them (Gilman et al., 2014; Jencks et al., 2009; Shah, Churpek, Perraiillon, & Konetzka, 2015).

Safety-Net Hospitals

The Institute of Medicine, renamed National Academy of Medicine, defines safety-net hospitals and providers as “providers that organize and deliver a significant level of both healthcare and other health-related services to the uninsured, Medicaid-insured, and other vulnerable populations, [and providers] who by mandate or mission offer access to care regardless of a patient’s ability to pay and whose patient population includes a substantial share of uninsured, Medicaid, and other vulnerable patients” (Institute of Medicine, 2000). Joynt, Orav, and Jha (2011) sampled 3,282 hospitals using publicly available data from HRRP and linked the data to the American Hospital Association’s annual survey to identify which hospitals would more likely be penalized for readmissions under the HRRP. In this study, 2,189 (66.7%) hospitals received penalties because of HRRP. Of the 66.7%, 40% of large hospitals (≥ 400 beds) and 28% of small hospitals were highly penalized. Safety-net hospitals were more likely to be highly penalized, 44% and 33% respectively, compared to their non-safety-net hospital counterparts. Moreover, the authors of this study found the adjusted odds of being highly penalized were the greatest among safety-net hospitals. Considering that majority of patients who receive care at safety-net hospitals are uninsured, receive Medicaid, are

socioeconomically disadvantaged, and are likely vulnerable, a penalty of 1% could lead to negative outcomes not only for the hospital, but also for the patients who need the services the most.

Gilman et al. (2014) sampled 242 hospitals to ascertain whether safety-net hospitals were more likely to incur penalties compared to non-safety-net hospitals for patients hospitalized with chronic conditions. The researchers used the Medicare Impact file for 2013, a CMS list of hospitals who received payment in March 2013, Hospital Compare data for 2011, the California Office of Statewide Health Planning and Development, and data from the Dartmouth Institute on regional hospital referrals for their study. For the purposes of this study, we focus on the results of the readmissions penalty under the HRRP. Based upon chi-square tests, statistically significant differences in the proportions of rewards and penalties under the HRRP between safety-net and non-safety-net hospitals were found. The Hospital Compare file was used to determine the 30-day risk-adjusted hospital readmission rates for chronic conditions being studied and the t-test was the statistical analysis used to detect statistically significance differences between the two groups.

Safety-net hospitals were more likely than non-safety-net hospitals to be penalized under HRRP and experience a reduction in their reimbursements (Gilman et al., 2014). It is of importance to note this study was conducted prior to the addition of COPD to HRRP and did not include COPD as one of the chronic conditions. However, considering 20% of COPD patients are rehospitalized within 30 days, the addition of COPD to HRRP would further support the results of this study and increase the

likelihood that safety-net hospitals would continue to be disproportionately penalized considering the population they serve.

COPD Readmission Risk

Socioeconomic status (SES), an indicator of vulnerability in the United States, is strongly patterned by race and influenced by social and political factors (Williams, Priest, & Anderson, 2016). Persons in the lower echelon of this status are typically stigmatized and have poorer health outcomes, lower income, and higher rates of premature death than their societal counterparts (Williams, 2012). African Americans are the predominate racial group with lower socioeconomic status, as compared to other groups, and have been found to have lower educational attainment, poorer health, and lower overall economic status compared to their White counterparts (Williams et al., 2016). Compared to their White, Asian, and Hispanic counterparts, African Americans have the least wealth and are the most socioeconomically disadvantaged (U. S. Census Bureau, 2010; U. S. Census Bureau, 2014; Williams et al., 2016). Socioeconomic status has been reported to be a significant risk factor for hospital readmissions (Barnett, Hsu, & McWilliams, 2015; Calvillo-King et al., 2013; Coffey et al., 2012; Dailey, Cizik, Kasten, Chapman, & Lee, 2013).

The Healthcare Cost and Utilization Project (HCUP), sponsored by The Agency for Healthcare Research and Quality (AHRQ), examined 15 states with 190,000 index admissions with COPD as the principal diagnosis and found African American patients with COPD had higher readmission rates compared to their White, Hispanic, and Asian counterparts (Elixhauser, Au, & Podulka, 2011). Other studies argue risks may not be the only reason for hospital readmissions and generic transitions of care programs may be

effective in reducing overall readmission rates but are ineffective in reducing readmission rates in specific illnesses such as COPD (Ohar, 2015). Therefore, in order to reduce readmissions, Ohar (2015) found that healthcare organizations should also be evaluating the effectiveness of their transitional programs through stratification of the diseases and not combining them into one category.

One study showed COPD patients with comorbidities were at increased risk for readmissions. In this retrospective study using data from the Truven Health MarketScan Commercial Claims and Encounters database, Baker et al. (2013) analyzed 6,095 patients aged 40-65 years with a primary diagnosis of COPD. Univariate descriptive and regression methods were used to measure all readmissions from patients with a previous primary admission diagnosis of COPD. This study found that out of the 6,095 COPD patients who met their inclusion criteria, 503, or 8%, were readmitted with 60.7% of those readmitted for COPD. Although results of this study support the significant increased risks of patients with comorbidities being more likely to be readmitted within 30 days than those without comorbidities, the patients in this study had employer-sponsored insurance. Having employer sponsored insurance indicates the patients were employed, which could indicate a higher socioeconomic status and could have resulted in lower rates of readmission in this study than a study with a sample population more generalizable to the United States. Furthermore, this study does not include race, income level, or current smoking status, which have all been shown as indicators of poorer health and increased readmission rates (Barnett et al., 2015; Elixhauser et al., 2011).

A Deeper Inquiry

Based on the literature, reducing readmissions among patients affected with COPD could lead to a reduction in the economic strain placed on the U. S. healthcare system; however, it is important to look beyond the risks and develop an understanding of those who are affected, which could also lead to a reduction in readmission rates. In a qualitative study, Chang et al. (2016) explored the lived experience of 14 participants with COPD following a hospitalization of acute exacerbation or pneumonia. The participants were recruited from a hospital located in Taiwan, had an average age of 77 years (63-86 years), and the mean duration of COPD was 5.8 years. Through semi-structured interviews a qualitative approach was used for data collection. The interviews were analyzed using the phenomenological methodology to extract the meaning of the lived experience for the participant. It was found people with COPD experienced a feeling of confinement, were in constant fear of exacerbations (especially in the winter months), and at times felt burdensome to their families (Chang et al., 2016). What was also found is participants were willing to quit smoking; only 1 in 14 of the participants still smoked (11 participants were former smokers) at the time of the interviews and the participants were overall positively coping with their disease.

In a study exploring prodromal symptoms of COPD patients prior to an exacerbation, Chin (2017) found that all 14 participants experienced prodromal symptoms prior to their acute episode of exacerbation. The participants were primarily White (11 out of 14), 49-87 years old (average age 66.2), with four hospitalizations per year (mean = 4.1). A qualitative descriptive design grounded in a naturalistic paradigm was used to explore, from the patient's perspective, the symptoms of recognizing COPD

exacerbations, the prodromal symptoms the patients experienced, and the reasons for delaying medical treatment. It was discovered the common prodromal symptoms among the participants were worsening dyspnea, cold symptoms, cough, and sore throat (Chin, 2017). The themes identified during this prodromal phase were an initial recognition of a change in baseline symptoms (Titled: Something's Coming) and a preparation phase in which the participant accepted and acknowledged the change (Titled: Here We Go Again). The other themes captured during this phase were the participants' deciding to either seek medical attention (Titled: Seeking Urgent Treatment) or attempt to self-manage their symptoms through lifestyle modification and medication management in hopes the exacerbation would be avoided (Titled: Riding it Out). Participants accepted, at some point in the prodromal phase, they no longer had control of their disease and outside help was necessary (Titled: Not in Charge Anymore) with an inevitable fear of dying (Titled: My Last Day) described by 64% of the participants. This study supports the idea there is a need to understand the persons affected with COPD and the general health beliefs held by that group. Moreover, it demonstrates that educating patients on identification of pre-exacerbated symptoms and on actions that should be taken during the prodromal phase may lead to patients seeking treatment earlier, which could, in turn, lead to a reduction in hospital admissions and readmissions. Although this study has profound potential implications from an educational aspect for COPD patients, it is not generalizable to minority, socioeconomically disadvantaged, or vulnerable populations.

In a phenomenological study, Barken et al. (2016) found the use of telemedicine in informants' homes lead to increased knowledge of COPD and improved quality of life, which lead to overall better management of COPD. Communication and monitoring of

the informants occurred via digital dialog between a nurse with expertise in COPD and the informant for one to three months. Ten informants were interviewed and asked two open-ended questions to facilitate the informants' narrative of their experience with the use of the devices. Identification of the potential benefit telemedicine has on the quality of life in individuals with COPD is paramount as it could lead to a reduction in readmissions, improve access to healthcare professionals, and lead to less utilization of healthcare services. This could potentially reduce U. S. spending on chronic diseases, such as COPD, due to better management of the disease. Although promising, this study does not provide demographic data of the informants. Moreover, considering those who live in medically underserved areas, or disadvantaged and vulnerable populations, it is unclear whether these populations will have the resources to utilize the telemedicine devices as many may have unstable homes and/or may be homeless.

In an editorial, Kushel (2018) examined the unique considerations that should be addressed in hospital readmission rates in homeless populations. The veteran homeless population was the focus in this study; therefore, the considerations identified may not be applicable to all homeless populations. One obvious consideration identified when trying to improve the health of this population was homeless people are without homes and as such experience a scarcity of daily resources that non-homeless people do not face. Food insecurity, limited access to clean water, clean toileting facilities, exposure to the elements due to unsheltered environments, and lost or stolen medical equipment and supplies are a few of the challenges that lead to less utilization of preventative services and increased likelihood of acute care utilization and hospital readmissions (Kushel, 2018).

Maslow's Hierarchy of Needs (1943) states essential basic and immediate human needs must be met before less urgent, secondary, nonemergent needs can be addressed by an individual. This suggests homeless people will be less likely to use preventative or primary medical care and only use healthcare services when it is necessary for survival and is prioritized along with food shelter and water. Homelessness has been identified as an independent risk factor for hospital readmissions in other chronic conditions such as heart failure (HF) (Shalen et al., 2016). In this study, the researchers examined 271 HF cases who were admitted to a safety-net hospital in Boston, Massachusetts and who were also participants in the homeless program in the area. Researchers used 745 non-homeless controlled cases to compare to the homeless HF cases. The study results showed that people affected by homelessness were significantly more likely to be readmitted within 30 days from their index admission (adjusted *OR*, 2.9; 95% confidence interval [CI], 1.5-5.6; $p=0.001$).

Transitional Care Model

The Transitional Care Model (TCM), a care management model led by an Advanced Practice Nurse (APN), is a team-based approach for improving outcomes of older adults who are transitioning from acute care to home (Naylor et al., 2015). The TCM has 10 core components, shown in Table 1, that are designed to overcome scientifically based identified challenges faced by elderly adults when being discharged from the hospital to home and lead to increased rehospitalizations and poorer outcomes. The bond between the core components and the patient is the APN who initiates contact with the patient at the time of the hospitalization and continues the delivery and coordination of care after discharge in the patient's home.

Acute care transitions from hospital to home in the current U. S. healthcare system can be difficult for elderly adults with multiple chronic medical conditions; management of chronic diseases is complex (Naylor, 2000). Moreover, for this vulnerable population, navigating through the healthcare system, while simultaneously trying to manage their diseases and recovering from a previous hospital admission, can be difficult for this fragile group. In a follow-up study, Naylor et al. (2018) sampled 582 transitional care clinicians and community-based healthcare organizations and found 342 (59%) of the respondents reported implementation of all or part of the TCM. Most of the respondents reported adaptations of the model with a mean of 4.4 adaptations to the 10 core components. Table 1 shows the core components along with the definition of the component, and the criteria to assess if the respondent used the component. This study speaks to the use of evidence-based practice among healthcare organizations as the TCM was developed based on strong scientific evidence of the need for comprehensive discharge planning for chronically ill elderly who are at increased risk for rehospitalization.

The support for TCM has been directly related to the verified outcomes these interventions have had in the healthcare community (Hirschman, Shad, McCauley, Pauly, Naylor, 2015). Unfortunately, there is no known study that has been as comprehensive as the TCM that improves outcomes for individuals who are socially, economically, and medically disadvantaged. The TCM relies on the premise the patient has a home and a phone where the APN can contact the patient and visit the patient. If the patient is homeless and/or does not have a telephone to communicate with the APN, none of the components of the TCM can be implemented. The effectiveness of the TCM should not

be determined simply by those who are helped by this model but also by those who are not helped. The TCM model should be able to be adapted based on those who are most in need, which not only includes the elderly as a vulnerable group, but also the medically underserved and those who are disenfranchised.

The Lived Experience of Readmitted COPD Patients

In the literature, Tang and Lee (2016), in a phenomenological study, explored the lived experience of readmitted Chinese adults living in China. Twenty-two Chinese adults aged 62 and older, who were readmitted to the hospital within 28 days, participated in unstructured interviews. In this study, most of those interviewed made every attempt to avoid going to the emergency room prior to their hospitalization. Moreover, the participants expressed their need to relieve the breathlessness they were experiencing as well as the possible burden placed on their families (Tang & Lee, 2016). The setting of this study was in China with only Chinese participants. Understandably, there are limitations regarding this population relating to culture, the healthcare system, and laws governing the Chinese population and will not be generalizable to the U. S. population or minority groups. What is likely to be similar are the lived experience of their participants when they suffer from AECOPD and the feeling of being rehospitalized in such a short time. To the researcher's knowledge, there have been no phenomenological studies that have explored the lived experienced of readmitted African Americans with COPD. Additionally, there has been no study that has explored the lived experience of readmitted African Americans with COPD who reside in a medically underserved area with high rates of homelessness in one of the most socially and economically disadvantaged areas of Los Angeles County.

Table 1

Transitional Care Model Components

TCM Component	Definition	Uses ALL of the following criteria to measure component
Delivering Services from Hospital to Home	TC program begins during a hospital admission, with visits occurring in the hospital and at home following hospital discharge.	Conducts one or more in-person visits in hospitals AND patients' homes following hospital discharge.
Screening At Risk Older Adults	TC service a standardized protocol to target hospitalized older adults who are at risk for poor outcomes.	Older adults with one or more of the following characteristics are targeted for TC services: hospitalized within the past 30 days or multiple times within past six months, physical function, cognitive function, emotional function Screening occurs during early phase of hospitalization.
Relying on APNs	APNs assume primary responsibility for TC services focused on management of patients throughout episodes of acute illness.	Organization consistently uses a protocol to identify older adults who may benefit from receiving TC services. APNs both deliver and coordinate hospital and home care services.
Promoting Continuity	TC services are designed to prevent breakdowns in care from hospital to home by having same clinician involved across these sites who uses evidence-based strategies to communicate patients' priority needs, goals and plans of care	The same clinician coordinates TC plan of care across hospital and post- home sites of care. Information tools are used to communicate patients' needs, goals and plans of care within and across care sites. Information regarding patients' needs, goals and plans of care is transferred to all health team members
Coordinating Care	Promotes communication and connections between health care and community-based practitioners.	Care is coordinated among clinicians and sites. Follow-up referrals for health and/or community-based services are provided. Patients are monitored to assure follow-up health and community-based services are received. Routinely assesses that all recommended TC services have been received by patient

Collaborating with Patients, Caregivers & Team	Promotes consensus on plan of care between older adults, family caregivers, and members of the care team.	Collaborates with care team occurs within site; Collaborates with care team occurs across sites;
Maintaining Relationships with Patients & Caregivers	Establishes and maintains a trusting relationship with the patient and family caregivers involved in the patients' care.	Assures direct communication occurs between hospital and primary care clinicians. Makes one or more visits or calls to at least two locations: hospital, next site of care (e.g., skilled nursing facility, nursing home), home. Employs at least five strategies or tools routinely to establish and maintain trusting relationships with patients and their caregivers: patient engagement, family engagement, patient activation, communication techniques, shared decision making, patient goal setting, family caregiver goal setting, motivational interviewing, team meetings.
Engaging Patients & Caregivers	Engages older adults in design and implementation of the plan of care aligned with their preferences, values and goals.	Documents patients' and caregivers' goals; Engages patients and family caregivers in decision making; Regularly engages patients and family caregivers in meetings with clinicians related to TC planning.
Managing Symptoms and Other Risks	Identifies and addresses patients' priority risk factors and symptoms.	Assesses each patient's or caregiver's TC needs; Develops a comprehensive TC care plan; Uses medication management; Uses symptom management.
Educating/Promoting Self-Management	Prepares older adults and family caregivers to identify and respond quickly to worsening symptoms.	Promotes patients and caregivers capacity for self-care/self- management. Provides patients and caregivers with emergency plans.

CHAPTER 3

Research Design and Methods

The purpose of this study was to explore the lived experiences of readmitted African American patients with COPD. An interpretive phenomenology research approach was adopted to collect data through semi-structured interviews. Also termed, hermeneutic phenomenological research, this type of phenomenological research seeks to interpret the meaning embedded in the lived experiences of the participants using philosophical underpinnings of hermeneutics (Cohen et al., 2000; Spiegelberg, 1976). The researcher in this study understands human experiences and subjectively collected data are interrelated within social, political, and cultural contexts and therefore, the phenomenological inquiry is related to the world in which the individual exists (Heidegger, 1962). Data were collected, analyzed, and written using the scientific methodology of hermeneutic phenomenology.

Research and literature addressing effective interventions to prevent hospital readmissions remain elusive among patients with chronic conditions such as COPD. Since the CMS established the HRRP, more published articles have sought to identify specific interventions to prevent rehospitalizations among certain populations. Despite the growing body of literature, there is still a lack of understanding from the patient's perspective of why certain conditions have higher rates of readmissions than others. In this study, the lived experiences of readmitted African American patients with COPD were explored. To reveal, from the position of the patient, the feeling of being readmitted and an interpretation of why the participant believed they were being readmitted, the researcher selected a phenomenological approach.

The use of qualitative methods to study the experiences of the participants within the hospital, as well as in the community, provides additional data to create successful readmission reduction programs in underserved areas. One hermeneutic phenomenological study explored the lived experience of being readmitted with COPD among an elderly Chinese group living in China and was able to provide insight into the feelings associated with COPD patients being readmitted after a previous hospitalization (Tang & Lee, 2016). This current study sought to explore these feelings among African Americans with COPD in the U. S. healthcare system. The inductive method of qualitative research improves understanding and is effective for exploring little known phenomena (Cohen et al., 2000; Spiegelberg, 1976). To the researcher's knowledge, no study has explored the lived experience of readmitted African Americans with COPD using a phenomenological approach. Phenomenological research was used to understand this experience as it was understood by those who were experiencing it.

An Interpretive Phenomenological research approach was adopted to collect data through participant interviews. Prior to, during, and after the interviews, the researcher understood each participant's experience was subjective and interrelated within the contextual experiences of the participant to relate the experience to the life of the individual (Heidegger, 1962). Data were collected, analyzed, and written using the scientific methodology of hermeneutic phenomenology. The phenomenon of inquiry was the lived experience of being readmitted with COPD among African American patients. Using phenomenology provides a means for understanding the patient's feelings after the initial discharge until the subsequent readmission. An interpretation of the lives of the participants and the meaning of what they experience is the role of the hermeneutic

phenomenologist (Cohen et al., 2000). This study interpreted meaningful data from each individual patient experience on the feeling of being readmitted.

Transitional Care Model

The Transitional Care Model (TCM) is a conceptual framework that uses a care management-based model to decrease readmissions among a chronically ill elderly population (Naylor, 2010; Naylor et al., 2015). This model was used as a guide as it comprehensively studied evidence-based interventions to prevent rehospitalizations among the chronically ill and has been utilized, all or in part, by healthcare organizations to effectively decrease readmission rates. Arguably the most comprehensive and supported model in preventing rehospitalizations, this model does not include social, cultural, or economic factors, which increase readmission rates in underserved communities. The researcher examined the essential components of the TCM compared to the participant interviews to assess if this model, or a variation of this model, could have positive implications for safety-net hospitals, which provide care to medically underserved communities.

Patient Sampling

With approval from leadership at the community hospital, cases readmitted within 30 days and a primary and/or secondary diagnosis of COPD were identified by the researcher. **Inclusion criteria:** African American English-speaking participants, discharged and subsequently readmitted within 30 days from November 2017 to January 2018, a primary or secondary diagnosis of COPD, a discharge to home or recuperative care from their first admission, and an anticipated discharge disposition to home or recuperative care for their subsequent readmission. **Exclusion criteria:** Cases were

excluded if participants were under 18 years old, non-English speaking, non-African American ethnic identity, readmitted more than twice since their primary admission, admitted after 30 days of their initial hospital discharge, or with an expected discharge disposition anywhere other than home or recuperative care, e.g. skilled nursing facility, rehabilitation facility, long-term acute care, etc.

Registered nurses on the Medical Surgical and Telemetry units provided patients, who met inclusion criteria, with information regarding the study, e.g. brochures. Potential participants were asked by the floor nurse if they were willing to participate in the study and were handed an informational pamphlet regarding the study along with contact information for the researcher. The participants who met the inclusion criteria and agreed to speak with the researcher signed a consent retained by the researcher. (See Appendix B). Two participants were unable to read the consent, therefore, the researcher read and explained the consent thoroughly to the participants. Consent was obtained and the participants were informed of the confidentiality and anonymity of the study. Each interview took place at the patient's bedside. There were no specific days selected for the interviews as they were based on the researcher's availability. Participants received a small gift of \$25 for their participation.

Patients who were readmitted to the hospital where the study was conducted with a primary or secondary diagnosis of COPD during both admissions were considered. A small sample size is common in phenomenological research; the goal for this study was between 8 to 10 participants (Cohen et al., 2000).

Data Acquisition

According to Cohen et al. (2000), “A basic premise of hermeneutic phenomenological method is a driving force of human consciousness is to make sense of the experience.” (pp. 59). Other qualitative researchers suggest the narratives of the participants are autobiographical and meaningful and, therefore, the inquiry should be aimed at understanding the meaning of the human experience (Denzin, 1989). For this study, the researcher’s goal was to gather deep information and perceptions through qualitative inquiry utilizing multiple interviews. With foresight of social, economic, and cultural considerations, the participants were interviewed and the researcher was careful to create a calm, nonjudgmental environment that established trust and openness between the researcher and the participants, often speaking in culturally appropriate language to facilitate an environment of comfortability. This process was likely elicit a more interactive session and yield rich, descriptive responses. During transcription, the researcher phonetically transcribed the words exactly as stated by the participant to accurately capture feelings and the emotions and clarified the meanings of the words in parenthesis for the reader.

The researcher obtained demographical data from each participant in the form of a questionnaire. (See Appendix C). The questionnaire asked basic questions regarding educational attainment, marital status, age, living conditions, ethnicity, medical insurance status, and gender. The data exploring the phenomena, readmission, was collected via semi-structured interview questions, which was guided by hermeneutic phenomenological methodology. (See Appendix D). The interviews were recorded and transcribed verbatim to construct texts for analysis (Cohen et al., 2000). To enhance the

quality of the data, field notes were used to capture nonverbal, meaningful data such as dress, body language, environmental details, and the feelings of the researcher during the interview to assist the researcher with interpretation of the experience during data recollection.

Each interview was unique to the participant. The questions were informal and were used as guides based on the flow of the conversation with the participants. All questions were covered during each interview but in no specific order. Open-ended questions such as, “Tell me how you felt when the healthcare team, doctor or nurse, informed you that you were going to be readmitted?”, “Tell me how you feel about the support you receive to manage your disease in your home and in this community?”, and “When you were discharged from the hospital the first time, tell me how you felt being at home with COPD?”, were asked to provoke recall and recollection from the participant. (See Appendix D). The purpose of the interview questions was to explore the feeling of being readmitted and to understand, from the patient’s perspective, what was needed in the community to help them better manage COPD. The semi-structured interviews lasted up to than 25 minutes.

Data Analysis Plan

The goal of the interviews were met once saturation of themes and/or categories were obtained. Ten participants, five men and five women, were interviewed. The process of phenomenological analysis exists in two metaphorical spheres: field text and narrative text (Cohen et al., 2000). The former of the two, field text, was constructed through the process of collecting data; in contrast, narrative text, was the conveyance of the collected data based on the researcher’s interpretation and understanding to other

readers (Cohen et al., 2000). The ultimate goal was to capture and communicate the meaningful experience of the phenomena from the participant's perspective via the hermeneutic circle (Cohen et al., 2000; Spiegelberg, 1976). The hermeneutic circle metaphor considers the individual texts in relation to the larger text and allows for the researcher to gain a deeper level of understanding through a reflexive awareness of the continuous analysis of this back-and-forth integrative process. The researcher was aware her own biases could affect the outcome of the interpreted data, therefore, a log was kept identifying potential biases before and after each interview. Since the researcher's father has end-stage COPD and is a member of the community within which the study took place, the researcher made note of participants who she may have favored due to resemblance of her father or similar characteristics, which could affect the interpretation of the data. Also termed bracketing, the researcher intentionally examined personal commitments to become self-aware and reduce the likelihood of prejudices during data collection and analysis (Cohen et al., 2000).

Upon completion of the interviews, the researcher interpreted the data, which began during field note collection, by listening to recorded interviews and developing a list of significant statements and themes while immersing in the data as if she were experiencing the interview again. During the analysis, parts of the text were understood while simultaneously considering the whole text—a reiterative process. The hermeneutic circle leads to a deeper analysis of the data and a better understanding of the whole through examination of its parts. Being a member of the community, the researcher understood the social biases that could affect her interpretation of the data but found the participants' perception differed than the researcher's expectation. The researcher

attributes this to her being estranged from the community for over 20 years, yielding an unexpected disconnect with the current social and economic downshift.

The texts from the interviews were examined line by line (Cohen et al., 2000). Once clear themes were recurrent and meanings interpreted, the themes were then clustered and used to create categories related to the studied phenomena. The themes were then compared to the research questions in search of any parallel meanings and unrelated identified data was removed by the researcher. The overall understanding of the text led to tentative names of each theme. Upon labeling themes, subthemes, if any, were also identified and named.

Writing and rewriting is a core component of the interpretive phenomenological approach (van Manen, 1994). Once themes and subthemes were named, the researcher began to describe, in narrative text and from a larger context, the essence of the experience of being readmitted as seen through the eyes of the participants.

Ethical Considerations

Ethical issues are inherent when conducting qualitative research in a natural setting. Patients who are admitted to the hospital are vulnerable physically, mentally, and emotionally. At the point of exploration of the phenomena, ethical considerations began and were considered throughout the study. From a hermeneutic phenomenological perspective, researchers are likely to form close relationships with the participants, which could lead to potential ethical issues if not addressed early in the study. The researcher, being aware of historical traumas that have occurred to African Americans in the United States during research experiments, was careful to maintain the confidentiality, integrity, and safety of all study participants. Moreover, the researcher understood from a societal

perspective that the participants in the study were likely to have experienced some form of discrimination whether based on race, gender, or socioeconomic status. The surrounding community, being a medically underserved area with the highest rates of homelessness and food insecurity, was also taken into consideration throughout the study.

In contemporary hermeneutics, Charles Taylor (1985) argues human agents understand, and *mis*understand, themselves, which inescapably affects their interpretation of data. He suggested that identified conditions of worth and value are conveyed by one's social context and filtered through one's self-understanding. The essence of naturalistic studies does not truly occur when a human agent is studying a phenomenon even under "natural" conditions. The researcher understood her moral and ethical beliefs, shifted the ontological perspective of studying the phenomena in a natural setting, and likely had an effect on the overall data interpretation. These considerations were unpacked before, during, and after analysis of the data, which minimized the potential biases of the researcher.

Trustworthiness

Reducing bias in qualitative research should be in the thoughts of the researcher during every step of the study. Other researchers use terms such as reliability, validity, rigor, goodness, quality, or bias control. Cohen et al. (2000) referred to this integrity maintaining approach as reducing bias. Qualitative methods, such as the hermeneutic phenomenological approach, does not assume the interpretation of the data is based on facts, rather, it is in part based on the interpretation of the perspective and historical context of the researcher (Cohen et al., 2000). Other researchers argue phenomenological research should be evaluated based on adequacy that readers must see the validity based

on the descriptions, and the participants must agree with the accuracy of interpretation by the researcher (Dahl & Boss, 2005; McLain & Weigert, 1979; Schultz, 1962). The narrative text produced by the researcher will be based on the researcher's own perspective; however, the reader of the text will bring their lived experiences and biases during the act of reading. This is not to say accuracy cannot and should not be attained, only that complete accuracy is somewhat lucid and somewhat tentative.

The goal of the researcher of this study was to accurately relay the feelings of the participant's experience of being readmitted. In order to achieve this goal, the researcher intentionally reviewed the field notes, visualized the interview as the recorded audio played, and reported the experience as it occurred while in the field rather than how the researcher would have preferred. Keeping a journal of the emotions during the interview as well as an easily accessible notepad to jot down notes as the researcher spontaneously reflected on the experiences, decreased the likelihood of contamination of personal preconceptions and unspoken assumptions. Lastly, an unbiased person, other than the researcher or committee members, reviewed the study and provided critical feedback for confirmation of a relatively free-from-biased study.

Summary

The research focused on the lived experience of African Americans with COPD readmitted to the hospital within 30 days. Literature examining readmissions among the chronically ill remain unclear on effective interventions to reduce rehospitalizations and there is even less available data on reducing readmissions among African Americans. Exploring a phenomenon that has not been studied led to a qualitative inquiry into the subject matter. The research questions focused on the following:

1. The feeling of being readmitted
2. Possible contributing factors (according to the participant) inside and outside of the hospital
3. Examination of social and community support
4. Self-management of the illness from the participants' perspective.

The researcher extracted common themes from rich descriptions of the phenomena experienced by the participant. The themes were clustered to reveal the meanings of the phenomena from the perspective of the participants. The researcher's purpose was to gain insight and understanding of the needs of the chronically ill within a community with limited resources and who suffer from medical and social disadvantages. Confidentiality and trustworthiness were of the utmost importance for the researcher considering the fragile disposition of the African American community in relation to scientific inquiry.

CHAPTER 4

Presentation of the Findings

The purpose of this phenomenological study was to gain an understanding of the lived experience of readmitted African American patients with Chronic Obstructive Pulmonary Disease (COPD). This chapter presents the findings that emerged from in-depth interviews with 10 participants who were readmitted within 30 days to a safety-net hospital in a large urban community. In order to decrease 30-day readmission rates in a vulnerable and medically underserved community, it is imperative to explore and understand the lived experience of the patient being readmitted. As of this date, no studies have explored this phenomenon in COPD patients within the African American community who reside in socially disadvantaged and medically underserved communities.

Audiotaped recordings of the conversations between the Principle Investigator (PI), also referred to as the researcher or interviewer throughout this study, and the participants were analyzed from the hermeneutical lens of phenomenological research methods (Cohen et al., 2000). This approach was selected because no identified foundational research has explored the feelings of readmitted African American patients with COPD. Hermeneutical phenomenology focuses on the interpretation of the experience as described by the participant to the investigator; the investigator attempts to understand and make meaning of the experience relayed by the participant ultimately resulting in an interpretation of the meaning of the experience within cultural and social contexts. In this chapter, selected examples of participant interviews, including some of

the questions asked by the researcher, will provide insight and a better understanding of the identified themes.

Research Questions

This study was guided by the overarching research question: What is the human experience of African Americans patients with COPD who are readmitted within 30 days to a safety-net hospital? Specifically, an inquiry was conducted to explore the feelings of being readmitted and barriers to COPD management outside of the hospital. The following research questions were used as a guide designed to provide a better understanding of the lived experience of readmitted African American patients with COPD:

- 1) Tell me how you felt when you realized you needed to come back to the Emergency Department?
- 2) Tell me how you felt when the healthcare team, doctor or nurse, informed you that you were going to be readmitted?
- 3) When you were discharged from the hospital the first time, tell me how you felt being at home with COPD?
- 4) How do you manage your disease outside of the hospital?
- 5) Do you have any assistance from family and/or have anyone to call to ask questions about your illness?
- 6) Tell me how you feel about the support you receive to manage your disease in your home and in this community.

Procedures

Patients were initially approached by their primary nurse who provided the patient with a flier advertising the study and then asked if they were willing to participate in the study. If the patient agreed to participate, the PI would then speak with the patient, provide more detailed information, obtain informed consent, and begin the recorded interview. Participation was voluntary with a financial token, a \$25 Visa gift card, given to the patients who agreed to participate in the study.

Demographical data were obtained via a questionnaire to capture social considerations; for instance, caregiver support, homelessness, educational level, and age. A summary of participant demographics is presented in Table 2. An unexpectedly alarming finding was the identified increased homelessness, or alternative living conditions, as well as the lack of educational attainment among the participants.

Participants

Data were provided from 10 self-identified African American inpatients receiving healthcare services in a large urban community hospital located in Southern California. Interviews were conducted at the participants' bedside between November 2017 and March 2018. Participants were evenly distributed by gender; five males and five females. Participants were 50-63 years old, identified as African American, readmitted to the hospital within 30 days of a prior hospitalization, and had a primary or secondary diagnosis of COPD during their initial and subsequent hospitalization. Four of the participants were single, three divorced, two were married, and one participant was married but estranged from their spouse.

Anonymity and confidentiality were of the utmost importance. The participants were informed of the steps the researcher and the dissertation committee put in place to protect their privacy when this study is disseminated. The participants' names were protected by the use of reference to them as participant one, two, three, etc. In addition, all files and any other documents related to the study were stored in a locked cabinet with no one having access to the data except the PI. Any specific details that might inadvertently identify the participant such as street addresses, names of family members, etc., were modified or removed.

Table 2.

Participant Demographic Summary

Participant Number	Gender	Age	Marital Status	Housing Status	Highest Education Completed	Medical Insurance (Yes/No)
Participant # 1	Female	55	Single	Rent room	Less than High School	Yes
Participant # 2	Female	62	Single	Live with family members	Associate's Degree	Yes
Participant # 3	Male	54	Divorced	Board and Care	Less than High School	No
Participant # 4	Female	55	Married (estranged)	Live with family members	Less than middle/junior high school	No
Participant # 5	Male	61	Married	Rent home	High School Diploma/GED plus 2 years Community College	No
Participant # 6	Male	61	Married	Rent home	High School Diploma/GED	Yes
Participant # 7	Male	62	Single	Rent a room	High School Diploma/GED	Yes
Participant # 8	Female	50	Divorced	Homeless	Less than High School	Yes

Participant # 9	Male	63	Never Married/ Single	Rent home	High School Diploma/GED	Yes
Participant # 10	Female	63	Divorced	Live with Friend	11 th Grade	Yes

Categorical saturation was clearly visible after the first seven interviews. Three additional interviews further supported and reinforced the identified themes. The objective of the analysis was to capture the lived experience of COPD patients who had a 30-day readmission based on hermeneutical analysis of the interviews and an interpretation of these experiences for the reader. Each interview was transcribed verbatim to construct texts for analysis. These texts were characterized and analyzed between two different metaphors based on the hermeneutic phenomenological analysis. One metaphor, known as field text, is constructed through activities of data collection and the second metaphor, termed narrative text, conveys the PI's understanding and interpretation of the data to the readers (Cohen et al., 2000). This reiterative process leads to an in-depth analysis of the text and stands alone as the findings of this hermeneutical study.

Findings

The lived experience of African Americans readmitted to a safety-net hospital is based on the hermeneutical analysis of the interpretation of the participant's narratives. Four themes emerged during the analysis of the interview text. The hermeneutic circle attempts to analyze portions of the text in relation to the text as a whole. It is a reiterative process that helps the PI understand and interpret the meaning each individual text has on the entire text but also the meaning the entire text has on the individual text. The following themes were interpreted using this metaphor: 1.) The COPD Effect, 2.)

Weakness in Disease, 3.) Unknown Power in Knowing, 4.) Limitations in Activities of Daily Living. In this chapter, these themes will be discussed in-depth from the interpreted perspective of the interviewer, with excerpts of texts transcribed verbatim, to validate the interpretation. Since the excerpts were transcribed verbatim, some of the ethnic language used will have synonymous words in parenthesis for clarification. The themes and subthemes are represented in Table 3.

Table 3

Themes and Subthemes

Categorical Saturation	Related Themes
The COPD Effect	Feelings of relief Air is here Fear of death
Weakness in Disease	
The Unknown Power in Knowing (Health Literacy)	Poor Health Literacy Self-efficacy Patient Activation
Limitations in Activities of Daily Living	

The COPD Effect

COPD causes extreme shortness of breath and anxiety, difficulty taking a deep breath, and frequent coughing and wheezing among those who are affected (CDC, 2018). When patients experience acute COPD exacerbation, it is usually associated with a sense of impending doom and patients are unable to breathe resulting in increased anxiety (Brooke, 2013; Breland et al., 2015). As a result, patients feel a sense of relief when they are informed they will be readmitted to the hospital because they know they will be able

to receive relief in their struggle to breathe and there is recall of that relief from their previous admission. This relief extends beyond being physically relieved because they are able to breathe, but also the participants experienced relief attributed to the feeling of another chance at life. There were three sub-themes that emerged in relation to this category: 1.) Feelings of Relief; 2.) Air is Here; and 3.) Fear of Death.

Feelings of relief. The participants were asked how they felt about being readmitted to the hospital after being discharged within the last 30 days. Prior to the interviews, the PI anticipated the participants would have feelings of frustration and resentment as a result of having to spend yet another day in the hospital and being unable to be home or with their families engaging in their normal daily activities. However, as she interviewed the participants, she found that each one expressed a sense of relief and resolve in being readmitted. The initial relief was related to the ability to physically breathe and the potential to no longer be short of breath, be restricted and limited in their mobility, or be severely debilitated by the exacerbation of this disease. The long-term emotional relief was related to becoming aware they would have the opportunity to experience their lives outside of the hospital once the symptoms resolved.

Participant three, a middle-aged single African American man who has been readmitted multiple times, informed the researcher that he missed a party during this readmission to the hospital but subsequently expresses the realization of what needs to be done to improve his quality of life and ensure he does not miss out on other social events.

Interviewer: ...Were you frustrated, what were your feelings?

Participant: no, I was sad (joking).

Interviewer: you were sad, why were you sad?

Participant: (laughs) because I missed my boy's party. He pulled me over and said come to my party and I was finna (about to) go to his party, it was last Saturday. And he stopped me the Saturday before last to tell me to come to the party, this Saturday that just passed.

Interviewer: oh... aww...

Participant: so but it's cool though, I'll see him on his birthday.

Interviewer: oh. Ok. So do you feel like you missing out on a lot outside when you're in here?

Participant: no, 'cause what's out there gone still be out there, I just gotta (have to) get myself together so I can participate.

Although participant three missed out on a friend's birthday party he had planned to attend, the anticipation of being able to breathe once admitted to the hospital and the recall of being unable to breathe superseded his desire to attend the party. Moreover, it led to a sense of understanding and responsibility he felt in making sure that he does not miss out on events in the future.

When participant seven discussed his feelings about being told he would be readmitted, he said he was relieved because he knew he needed help.

Interviewer: Yeah, anything to help you breathe.

Participant: Like with the chairs like this right here, I couldn't do this I had to bring my feet over and I had to sit up.

Interviewer: Sit up.

Participant: Yeah, it seem like I was suffocating.

Relief from dyspnea during an acute exacerbation of COPD is the ultimate priority for COPD patients. Yet there are other feelings of relief also identified during the interviews with the participants.

The hermeneutic circle metaphor is important for the PI to understand the larger social and cultural contexts and take them into consideration during the interpretation of the data. Five out of 10 participants were either renting a room, living with a friend, living in a board and care, or homeless. Over the last seven years, the city of Los Angeles has had a 75% increase in the homeless population and has the highest prevalence of homelessness in the state of California (Holland, 2018).

Participant eight expressed her relief from not only the dyspnea she experienced with COPD exacerbation, she also discussed her feeling of relief from not sleeping on the streets because of her homelessness. When she was asked her feelings of being readmitted, she expressed relief related to her ability to breathe but also her relief from sleeping on the streets.

Interviewer: So tell me umm when you, when they told you, you were going to admitted how did you feel?

Participant: You going to be shocked about it. It don't bother me

Interviewer: It don't bother you?

Participant: No, I know when I'm in the hospital I'm gone get better. When you been homeless as long as I have you like it. I do.

Interviewer: When you've been homeless?

Participant: For me, even though I got a place to stay now, you still know, to my minds sake, you ain't got to suffer as much cause eventually they gone give you something that's gone help you while you in there.

Interviewer: What if there was a way you could feel better and not have to come to the hospital?

Participant: Either or, with me either or...

For this participant, the desire to feel better and the amenities within the hospital contributed to her acceptance and her ability to cope with being re-hospitalized.

Air is there. Suffering from one or more chronic disease(s), these participants have accepted the diagnosis of COPD and they understand there is no cure, yet lifestyle modifications have not been made to improve their pulmonary health. The feeling of having no other alternative coupled with their recall of the last admission when they were able to receive treatment in order to “get air” from the hospital appears to be a significant contributing factor to their reliance on the hospital in managing their illness. Unlike most chronic diseases, when COPD is exacerbated the dyspnea associated with trapped air and the altered mobility related to anxiety and the feeling of immanent death, understandably, takes precedence.

Participant one recalls her previous admission and how she manages her illness outside of the hospital:

Interviewer: (laughs) I see. Well what about when you were discharged the last time. How did you feel? Like how was your breathing?

Participant: I felt good. I was able to breathe good. I didn't think I was gonna [going to] have to come back this <sic> soon. But after a couple of days, I started feeling like I was getting short of breath more and more.

Interviewer: How do you take care of your COPD when you're at home?

Participant: I mean, what you mean. I take my medicine and that's it. I do not know what else you asking but I take my medicine.

When asked an unrelated question, during this same interview, participant one further expressed and emphasized the trauma experienced when she is unable to breathe and why the hospital is the place to give her air:

Interviewer: Can you briefly tell me what you know about COPD?

Participant: I don't know much but what I do know is that when I can't breathe it's horrible. I mean, horrible.

Although she does not understand her disease, as she clearly states she does not know much, she is able to describe in detail the emotional affects she feels when she is not able to breathe. She goes into further detail by explaining the physical limitations associated with this dyspnea, which will be discussed later in this chapter, as well as her experience of trying to breathe. This attempt to get air, ultimately leads the participant to the location where she believes the air is, the hospital.

Participant four also similarly describes each of her admissions stating she had no choice:

Interviewer: So 5 years ago you quit smoking? 14-50, the age of 14-50?

Participants: (nods head)

Interviewer: Oh Wow that's a long time. So once they told you, you had it [COPD] did anybody tell you how to manage it or take care of it while you're at home?

Participant: No, when I can't breathe I come to the hospital to get air.

In order to breathe, one needs air. Air is vital to life. Participant four also emphasized her need for air during her moments of COPD exacerbation and attempted to describe what she experienced while attempting to draw in the PI into this experience. Initially, she explained how her daughter helps her manage her disease as her daughter works at a clinic:

Participant: She know when thing happen to me, she like right there to help me and try calm me down. And tell me breathe slow, slowly. And sometimes when it happens they ask me if I want to come to the hospital I tell them NO. I try to bear it as much as I can. And when my trach fill up with mucus and blood I got to come to the hospital because I really can't breathe then so they gone give me oxygen or breathing treatment and clean out the trach. This ain't no joke.

Interviewer: Cause you feel like... why do you say it's no joke?

Participant: Do you know what it feel? You can't breathe?

Interviewer: No I can't imagine.

Participant: Please, try not to get no kind of sickness like that, it's terrible. It affect your lungs and everything else. Most of the time water go in my lungs I have to get a dialysis 3 or 4 times or 5 times a week to drain out the water from

my lungs cause when it goes to your lungs it can kill you. And the pneumonia just catch me.

Initially, participant four described the process prior to her making the decision to come to the hospital. She was adamant in letting the researcher know there are actions taken on her end, and the end of her family members, before she makes the ultimate decision to go to the hospital. She is also sure to explain, there are times she is able to avoid returning to the hospital, but she knows the hospital will rescue her from her distress and lack of air.

Participant seven briefly talks about his need to be able to breathe, and why there was an underlying relief in being admitted to the hospital during a time of exacerbation:

Interviewer: So what were your feelings when they said [you would be admitted], how did you feel about that?

Participant: Well they said they said I'm going to get you some what they call it a breathing treatment, I said ok a breathing treatment I said alright. I wanted to come in here anyway 'cause I was tore. [meaning having extreme difficulty breathing and in need of medical assistance.]

Interviewer: So you wanted to be readmitted?

Participant: Man, I couldn't breathe [meaning there was no other alternative]

Instead of admitting he wanted to be admitted, participant seven emphasized, he could not breathe. The underlying meaning of that statement is he had no choice and

everyone knows when you cannot breathe, life can no longer be sustained; therefore, coming to the hospital meant he would soon be able to breathe.

Participant nine also described his need for relief and that being admitted to the hospital made him feel safe. When asked how he felt, this was his response:

Participant: When I knew I was going to be admitted?

Interviewer: Yeah, or when they came to you the doctor or the nurse and said you know we're going to admit you, again, [be]cause you were just discharged.

Participant: Well I, yeah but I didn't feel bad about it all, I was praying that I would be admitted because I knew I was to the point to where I had to have some help. So I wasn't discouraged or deterred or angry or anything I felt pretty good that they was going to admit me because now I could get some relief. 'Cause they have the strong lasix you know to drain the fluid, they have everything you need.

Interviewer: So you felt safe?

Participant: Yes, I did.

Participant nine was a single 63-year-old African American male who has a high school diploma and was currently renting a home. He was very open about his need for the hospital and did not hesitate in expressing his need for help and acceptance that the hospital could provide the help he could not provide in managing his breathlessness.

Fear of death. As previously discussed, the feeling of impending doom is often the feeling patients with COPD experience during an acute exacerbation. Individuals with COPD exacerbation experience breathlessness, increased heart rate and anxiety, and a profound feeling of immanent death (Stenzel, Vaske, Kuhl, Kenn, & Rief, 2015). In the

hermeneutic circle, the researcher attempts to interpret the meaning of words and statements through the lens of the cultural contexts of which they exist (Cohen et al., 2000). Being an African American female who grew up in the same community that is being studied, I understand that the fear of dying prematurely is common within this community.

Participant eight expressed her fear of death when she is unable to breathe and explained how it feels when she cannot breathe:

Participant: You feel like you 'bout to die. I kept calling my daughter, my pastor, I said pastor I said imma (I am going to) die.

In the African American community, this fear of death is not solely related to the actual death itself. It is also related to the cultural undertone of religion, and the belief in heaven and hell, which is interwoven into the fabric of the African American culture. Dying prematurely, as is often the case with COPD patients, could likely result in going to hell if you have not had enough time on earth to accept Christ as your savior and live a saved and sanctified life.

Participant five, a married African American male with a strong familial support system, discussed his being told he would die if he did not make the necessary lifestyle changes to manage his disease:

Participant: ...once he told me, said now you gone die. I'm like oh no I'm not finna (going to) die what I need to do? And he sat down and told me. And we situated this meeting and I made the wife go with me you know I made the wife go with me so she would know.

Participant five had a fear of dying, but he also had a strong support system in his wife and three daughters. As a result, his fear of death was not only due to the cultural religious undertone held in the African American community, but also to his commitment to and love for his wife and daughters. Often during the interview, he expressed the importance of COPD patients taking the initiative to understand their illness to manage it better. His fear of death led to him become more accountable for his role in managing his disease and decreasing his risk for premature death. Although he had been readmitted to the hospital, he related his recent admissions to unknowingly being exposed to second hand smoke, which irritated his lungs and led to recent episodes of exacerbation of his COPD.

Weakness in Disease

Another theme identified by the PI was the belief among the participants that acknowledging the symptoms and attempting to seek medical attention before experiencing severe dyspnea was a sign of weakness. Essentially, these participants believed being prematurely admitted to the hospital would indicate a loss in the battle of fighting COPD; therefore, they would fight the symptoms, try to wait until the dyspnea subsided, and, if successful, this would be an indication of a “win.” However, if they fought it, but “lost” the fight, they would be admitted to the hospital. There was an underlying “hope” the symptoms would self-resolve or the participants would somehow begin to feel better if they “stuck it out” as long as they possibly could.

There was a perceived strength in waiting or, as one participant put it, “toughening it out” until the symptoms became unbearable. Attempting to ignore these

acute symptoms while at home decreased the likelihood the participants would seek care from a primary care provider or outpatient clinic. Although many of the participants in this study did not have a primary care provider (PCP), the participants who did have a PCP could have sought out care at the onset of the symptoms of exacerbation and would have been less likely to require readmission to the hospital.

Participant three was asked by the PI if his breathing treatments improved his breathing and he clarified that sometimes it helped him. He further explained his lungs are clear; therefore, he tries to fight wearing his oxygen:

Participant: you know, really. But sometime it get to... like my niece was sitting right there she said, "uncle, why you don't got your oxygen on?", you know... I said, uh, 'cause I don't need it right now... she said, "sound like you need it" but I think I fought it because, you know, I don't want to keep wearing the oxygen if I'm clear, I just want to fight through it and try to advance my breathing because its, its, its, not right, it's not making a lot of sense to me to... it's, it's something wrong, to keep bringing me back. In then, for whatever it is, it's really, really, it really has me nervous and discouraged.

He further provides a specific example when he clearly needed medical intervention, based on his explained symptoms, and yet he did not seek medical care:

Participant: . . .and my brother was like, bruh (brother), you alright? And I was like, I was like, (breathing hard) bruh my breathing is bad... 'look man, you need to shut this down and let's go to the hospital' [his brother said]. I'm like naw

(no), I don't want to go to no hospital, 'well you just need to shut it down and go rest' [his brother said]. I was like, alright, and I just shut it down and I just left.

Reverberating through the interviews is the hope that the severe dyspnea the patients experience will soon dissipate with rest. This is a clear indication there is a knowledge deficit in the management of COPD among these patients. This lack of knowledge and understanding is likely to be contributory to the patients' recurrence and exacerbation of COPD and will be addressed in greater detail later in this chapter.

When participant four was asked about her knowledge of community organizations or places that may be able to help her strengthen her lungs and, ultimately, decrease the exacerbations she experiences, she made it clear she did not need help:

Interviewer: Do you go to any kind of, I know you go for your trach doctor, but do you go to any kind of place that help you practice on making your lungs stronger or help you help you maybe do a little bit of exercise do you do anything like that?

Participant: I help myself like that.

Participant four has not been able to manage her disease effectively and has had multiple readmissions over the last 30 days. She has a tracheostomy which has been in place for over five years and she continues to have repeat hospital admissions. She informed the researcher that her daughters are able to help her; however, they are not healthcare providers and basically assist her in coping with the anxiety she experiences when she is short of breath. Participant four does not ask for help or seek outside help

because it is perceived as a sign of weakness. Being able to help herself would indicate she is strong, not weak, and does not need outside assistance.

Participant seven is a 62-year-old African American male with public medical insurance, who rents a room from a friend. He explained why he did not seek medical care when he noticed his change in condition:

Interviewer: Now tell me tell umm me why didn't you call earlier? Or go to the doctor?

Participant: I thought I could get over it with the with the, cause I had ran out of my little pumps. So I went and got one.

Interviewer: Oh you ran out so you went and got one? Was it yours?

Participant: No, it wasn't mines.

Interviewer: You got somebody else's?

Participant: Yeah, a new one and it wasn't working and then I said something is wrong.

Interviewer: And you were still waiting to see if it was going to go away?

Participant: It wasn't leaving.

Interviewer: After a couple of days.

Participant: Even the ambulance said you wasn't supposed to wait that long. We see on the scale right, you know they read you. [making reference to the pulse oximeter.]

Participant seven acknowledges he needed to intervene once he started experiencing dyspnea and as a result, he obtained an inhaler, which was not prescribed to

him, and tried to see if he would get better. Participant seven, not wanting to engage in a lengthy conversation about obtaining an inhaler that was not prescribed to him, was eager to discuss how long he waited before seeking medical attention as if he were speaking to his ability to tolerate his dyspnea, thereby indicating his strength as it pertains to his illness. After speaking with the researcher about his ability to hold out from seeking medical care and informing the researcher of the conversation he had with the emergency medical team at his home, he was sure to discuss the limitations he experienced as a result of COPD. His recall of the conversation he had with the paramedic while in his home was to inform the researcher of his strength to wait as long as he possibly could before seeking help.

Participant nine acknowledged his symptoms started after he received dialysis. He explained he realized he was having difficulty breathing the night after dialysis but did not seek medical attention. In fact, he waited for more than 24 hours and until he had no other alternative before he decided to call the ambulance. At that point, he was in dire straits and in acute respiratory distress:

Interviewer: And so how did you, did an ambulance bring you here or...?

Participant: Yes, yeah they brought me here Sunday morning 3:00 in the morning. Saturday after I went to dialysis and they took a lot, they took some fluid off but then I started cramping real bad.

Interviewer: After dialysis?

Participant: Well during dialysis. And these are not your normal kind of cramps you know they really are bad cramps. So what it is that had to discontinue the umm, they had to discontinue pulling the water off me but they continue to clean

my blood. But the thing is they left a lot of fluid and when the fluid started to get to my lungs it made me work harder trying to breathe and that aggravated the COPD and that kicked in Saturday night. And I went through all the way through Saturday night and I went through Sunday but then after midnight Sunday night I said I can't, it ain't gone get no better I got to go back in. But by that time I can't lay down I can't lay on back and all because my lungs is in the back so I can't breathe if I lay back like this and I tried laying and I got to a place I couldn't lay on my side and I couldn't breathe any kinda way I did it I just wasn't getting no oxygen. And I know it's bad when the breathing treatments don't work.

Participant nine is aware his usual method to remedy his breathlessness—his breathing treatments—were not working and he understood the remaining fluid left after dialysis contributed to his difficulty breathing. Yet, he did not go to the doctor or the hospital. The PI further queried this participant as she wanted to have a clear understanding of his thought process during this incident:

Interviewer: So tell me, do you feel like if you had done it sooner maybe it wouldn't have been so bad? You think, let's say you know if you would have called the ambulance when you started noticing that you were having difficulty breathing? 'Cause don't do you notice when it's [the disease] starting to kind of act up?

Participant: Yeah I do, I do.

Interviewer: Well, what is it you think in your head?

Participant: I'm, I'm relying on my inhalers and my treatments to try and see if it will cure it or change it any kind of way. But I've never been the type, I'm not really scary, it's a scary thing but I'm not really scary. I just don't run to the doctor because I have those problems. When it gets to the place where nothing's working, and I don't know what else to do then I turn to doctors. But I really don't just run to the doctor 'cause I don't feel good. And I'm just, it's not necessarily a good practice but it's kinda like my problem.

It was evident the struggle experienced by participant nine was perceived as a battle—the battle was between himself and the illness. He considered his exacerbation his problem and if he prematurely went to the doctor because of minor “problems,” it would be an indication of weakness. In hopes the issue would resolve, he felt he should have delayed seeking medical attention until it was his last alternative. If he continued to fight, his chances of winning the battle was slim; however, he would not be considered weak or, as he put it, “scary.” In the case of winning the battle, the symptoms would dissipate and he would resume his normal daily activities, which would indicate that he fought it off and won. However, in the event he lost the battle he would have no choice but to call emergency medical services and accept that he would be admitted to the hospital. Participant nine wanted the researcher to understand he was not afraid of being short of breath and that was why he waited so long; however, his fear of death was obvious as he knew once he could no longer endure the extreme dyspnea, that death would be eminent if he continued to fight this losing battle.

Participants constantly compared the experiences of acute exacerbation as a fight between themselves and COPD. Many of the participants decided to wait to seek medical assistance until there was no other option; they were careful not to involve anyone in their struggle unless it was absolutely necessary. As a result, participants with and without medical insurance did not seek medical attention until they could no longer endure the severe dyspnea. From their perspective, seeking help before they reached the point they could no longer endure the discomfort would be a sign of weakness.

The Unknown Power of Knowing

Low Health Literacy. Low health literacy is associated with unplanned healthcare use within 30 days of a hospital discharge among patients affected with a chronic disease (Cox et al., 2017). More specifically, African Americans have been identified as having lower health literacy than their Caucasian counterparts resulting in poorer mental and physical health among this population (Hoover et al., 2015). Prior to interviewing the participants for this study, I predicted the participants would identify a lack of knowledge of COPD as one of the fundamental reasons they were not able to effectively manage their disease and prevent rehospitalization. In addition, I expected there would be an identification of a need in the community for resources that would help them not only manage their disease but also provide education and outpatient follow-up specifically regarding their disease. To the contrary, not only did the participants lack knowledge regarding their disease process, they accepted their lack of knowledge as it was not identified as a barrier to disease management but rather an expectation since they were not healthcare professionals.

Moreover, there appeared to be a social acceptance of the knowledge deficit the participants had regarding management of their disease and an acceptance of not knowing or clearly understanding COPD. The participants in this study provided valuable insights, from the patient's perspective, of the detrimental effects of low health literacy on chronic disease management that ultimately led to increased hospital admissions among these participants. The participants not only had low health literacy regarding COPD, most participants were disinterested in learning about their disease. The purpose of this study was not to explore levels of literacy among the participants; however, there was a glaring undertone during the interviews that the participants did not understand their disease nor did they realize how obtaining an understanding and gaining knowledge about their disease could help them better manage their illness and decrease their risk of being readmitted.

Participant three is a 51-year-old African American male who lives in a recuperative care facility. He stated he has a lot of support from both the staff at the recuperative care facility and his family. On the other hand, he has limited knowledge of COPD and how to manage the disease at home. When asked about his knowledge of the disease, participant three responded as follows:

Participant: I know that COPD comes from, uh, smoking...

Interviewer: Do you still smoke right now?

Participant: Nah, I don't smoke... I smoke, I smoke, one joint a day.

Interviewer: ok, is.. do you smoke any cigarettes?

Participant: nah, I don't touch 'em [them].

Interviewer: ok, so one joint a day.

Participant: I have a lot of friends that respect me, if they come and sit down and they smoking, they like, 'Oh! Let me get away from you with this cigarette,' and they will leave me, go smoke and then they will come back and sit with me ... and, I respect that...

Interviewer: yeah, so you know it's from smoking... what else do you know?

Participant: ummm, I carry my uh... my inhaler...

Interviewer: uh huh...

Participant: ummm I think, to me, personally, I think the weather has a lot to do with it.

Participant three is able to attribute smoking to his COPD diagnosis. Moreover, he stated he uses his inhaler as an attempt to inform the interviewer that he understands how to manage his disease. He stated he does not smoke anymore but does not attribute his smoking marijuana as a potential contributor to the exacerbation of COPD. From his perspective, smoking cigarettes, specifically, is the cause of his COPD and not smoking marijuana. By not knowing that smoking marijuana could also exacerbate his COPD and potentially contribute to him returning to the hospital, participant three is, by default, relinquishing his power in knowing how to effectively manage his disease. As a result, he increases the likelihood he will continue to seek management of his disease within the hospital setting.

When asked, participant three did express his desire to know more about his disease.

Interviewer: ...Do you feel like you could know more about your disease?

Participant: yeah. Uh, I would like to know more.

In stating he would like to know more, participant three made the researcher feel as if it is a desire but not a priority for him. It is something he wants and it is likely if someone were to educate him about the disease he would be receptive to learning; however, he would not likely be proactive in obtaining the information on his own. This was confirmed later in the conversation with participant three when he was asked questions about COPD as well as his comorbidities, congestive heart failure (CHF) and asthma, and the disease process. The researcher attributed his willingness to ask her questions to his level of comfort and familiarity with the researcher.

Participant seven was also asked his level of knowledge and understanding about COPD:

Interviewer: What do you know about it? What do you know about the disease?

Participant: I know you limited on a lot of stuff.

Interviewer: But what is it? Why do you have it? What do you know about the disease?

Participant: What do I know about the disease?

Interviewer: Like just about COPD what do you know about it?

Participant: About COPD?

Interviewer: Like what it is what causes it and all that?

Participant: I heard it come from stress, umm paint, welding, mechanics all that, asbestos...

Interviewer: Asbestos?

(about 4 second silence)

Interviewer: And smoking right?

Participant: And smoking, the main thing.

When asked what he knew about COPD, initially, participant seven spoke about his personal experience in the confines of the physical limitations he has as a result of the disease. He did not answer the question asked by the interviewer about his knowledge of the disease; instead, he delayed his response by asking the question that was asked of him. It is clear participant seven lacks a clear understanding of COPD but he was not willing to inform the interviewer of this. He eventually spoke of what he heard causes COPD (he did not attribute that to anyone) but did not speak of the primary cause of COPD until prompted by the interviewer. This participant may have been nervous when asked the question of his knowledge of his disease; however, based on the field notes and recall from the researcher, she felt the participant truly had no knowledge of his disease and could only speak of what he heard about the disease and not what he knew.

Participant 10 is a 55-year-old divorced female who currently lives with a friend. Although she no longer smokes cigarettes, the friend with whom she lives does smoke cigarettes. When the researcher asked participant 10 about her understanding and knowledge of her medications and COPD, she made it clear that she was compliant with taking her medication but she could not name which medication she was taking and for which chronic illness.

Interviewer: How do you usually manage your disease? How do you take care of the disease when you're at home? Do you take medication?

Participant: I take medication, the medication that the doctor prescribed for me.

Interviewer: Do you know what medications you take?

Participant: I sure don't.

Interviewer: Can you describe how you take it? Is it an inhaler, is it pills?

Participant: Sometimes I take the inhaler, but it's pills mostly for my heart, for my kidneys and liver. I have liver problems. Blood pressure and things like that.

Participant 10 was not able to describe or list the medications prescribed to her to manage her COPD. The researcher asked her if she used an inhaler and the participant answered yes; however, she prioritized the pills that she took for her other chronic illnesses over her COPD medication as she stated she mostly takes her pills and does not use the inhaler as much. Not knowing the medication that is prescribed for management of her illness is a contributing factor to the multiple readmissions she has had over the last 30 days. Moreover, because she did not know which inhaler she was prescribed, the researcher concluded that the participant most likely assumed that all inhalers were the same.

Poor Self Efficacy. Participant eight is a 50-year-old female who was officially diagnosed with COPD a year ago. Participant eight has a history of asthma and therefore, did not go to the doctor due to her breathing difficulties because she believed it was her asthma during the times she experienced the dyspnea:

Interviewer: So all these years you were having a hard time breathing you thought that it was asthma?

Participant: Yeah I knew it was still asthma then not too long ago I think they said you got COPD. I said oh, I would just look at the little flyers they gave me but I never had to put oxygen to it.

Interviewer: Did anybody teach you about COPD?

Participant: No, they would just give me the flyers.

Interviewer: So nobody taught you how to even...

Participant: Manage it? I just started managing it like asthma. And it wasn't as bad.

Interviewer: But that was a year ago, so you do you feel like it's getting worse?

Participant: Yeah, I'm on oxygen, I mean can I get off of it or I don't know? I don't know a lot about it. I guess I got so much major stuff going to now it's major to me 'cause I can't breathe. At first it wasn't as major.

It was unclear the specific actions taken by participant eight to manage her asthma because she did not explain how she manages it. However, it was clear she lacks knowledge about COPD, lacks a true understanding of how this disease physiologically affects her breathing, which is not the same as asthma, and lacks the confidence that she would be able to successfully manage her disease on her own. She did state she received flyers but did not state she read them or what she learned from them. Moreover, later in the conversation, she admitted she really does not know a lot about COPD and attributed that to her focus on her other chronic diseases.

The interviewer, while interviewing participant eight, noticed the participant did not express an interest in obtaining knowledge even when it was identified she lacked

understanding of COPD. She further explained that COPD did not become significant to her until she experienced severe dyspnea. The disconnect in this conversation, from the researcher's perspective, is that the patient did not understand that her unknowing and mismanagement of COPD were contributors to the exacerbation she was currently experiencing. Considering that participant eight is homeless, has other chronic conditions, and lives in a medically underserved area, her prioritizing and focusing on what is required for survival has increased her likelihood for continued readmissions.

Patient Activation. Of the ten participants, only one spoke of the significance in understanding his disease and the importance of involving his wife in understanding the disease process to properly manage his COPD. Patient activation refers to a patient's willingness and ability to gain knowledge, skills, understanding, and confidence in their ability to manage their health and care (Hibbard and Gilbert, 2014). Participant five spoke of the significance in understanding his disease and the importance of involving his wife in understanding the disease process in order to better manage COPD.

Participant five is a 55-year-old married, uninsured male who is the father of three adult daughters. He stated he is very close to his daughters and he is the primary breadwinner for his wife and himself. He was diagnosed with COPD 14 years ago and, until recently, was never admitted to the hospital since his initial diagnosis. Participant five attributed his ability to effectively manage his disease with his decision to learn as much as possible about his disease and by his taking ownership in seeking out opportunities to learn more about COPD. The researcher and participant five discussed the lack of community resources for understanding disease management in patients with

COPD, which ultimately led to a discussion about accountability and the power in knowing:

Participant: We need, we need it, I understand that I understand that but once you're diagnosed you got to go find out where it is so you can learn, and that's what I did I helped myself we didn't have it there then but I went and found it. So I mean you, I mean you know umm yeah, I understand we need it here in the community because it's a lot of people out here that's born in LA with COPD because of the bad smog and that has a lot do it with it too. Ummm yeah, you know, I went out and learned, me and the wife, she went with me she knows about it.

He further explained the steps he took once he received information from the physician who was managing his COPD at the time, as well as his proactivity in ensuring that he had in-depth knowledge and understanding of the new normal that he and his family would now have to adjust to.

Participant: I educated myself after I found out and the doctor gave me information [and] gave me some tips, gave me a phone number or two and I followed through and I went because it was a change in my life, yeah sure absolutely yeah. The biggest change, the biggest change was just getting adjusted to it. Using equipment that I've never used before that I was kinda [kind of] scared of at first, cause it's taking me out of my element. I had to do certain things at certain times and I had to take those breathing treatments and all that good stuff, so yeah I learned, yeah, yeah, yeah I went through it.

As discussed earlier in this analysis, participant five was informed that he could die a premature death if he did not make the necessary lifestyle changes. Moreover, he was provided resources in order to educate himself and his wife on management of his illness. He refused to accept premature death as his reality and that ignited a desire and passion in participant five to take control of his circumstances. This participant was very confident and fully aware that the next steps he took after being diagnosed could potentially have a detrimental impact on himself as well as his family if he did not make better health-related choices. As a result, he received the information that was provided by the physician and sought out additional resources, even if they were not conveniently located within the community in which he resides.

Contrary to the other nine participants, it is clear there is power in knowing and understanding COPD to manage it and decrease the likelihood of multiple readmissions. Participant five informed the researcher that patient activation coupled with family support is vital in decreasing readmission rates. Although patient five was readmitted to the hospital within 30 days, prior to these admissions, he had not suffered from COPD exacerbation since he was initially diagnosed with this chronic disease 14 years prior to this interview. Also significant, his admission was a result of unknown exposure to secondhand smoke that compromised his lungs and led to COPD exacerbation, which, the patient believes, was not fully resolved from the previous admission.

Limitations in Activities of Daily Living

The participants in this study expressed severe physical limitations immediately prior to their readmission. They spoke about the increased shortness of breath and the impact this breathlessness had on normal activities such as getting dressed, walking, and

carrying lightweight items. The participants spoke of the difficulty they experienced and, in that moment, their increased desire to get better. The researcher was particularly interested in how these symptoms were unexpected by the participants, although none of the participants were newly diagnosed, and how surprised the participants were that they could experience such physical limitations as their illness progressed.

Participant one was a 55-year-old female who rents a room from a friend and speaks defiantly of her physical limitations during her moments of COPD exacerbation. Her frustration of these limitations is obvious during the interview as she expressed her unknowing and lack of understanding of COPD. The researcher asked her about her knowledge of COPD and how she manages it and rather than answer the question, she spoke of the physical limitations she experiences as a result of her illness:

Interviewer: Can you briefly tell me what you know about COPD?

Participant: I don't know much but what I do know is that when I can't breathe it's horrible. I mean, horrible. I be tryna [trying to] catch my breath, can't walk, can't talk, can't do nothing but try to get air. So... that's all I can tell you.

Participant one is expressing her frustration of her physical limitations as a result of her disease; moreover, the researcher observed that participant one was very specific and provided examples about the limitations she experiences when her COPD exacerbates. She identified the most basic activities such as walking and talking, which in normal circumstances would require minimal effort, as difficult tasks for her during an episode of exacerbation. Although she is uninformed about the disease itself, she is aware of the frightening and distressing symptoms she experiences as a result of COPD.

Participant three spoke of his inability to eat when he experiences breathlessness:

Participant: ... You know, I got to the point where my health had gotten so bad, I wasn't even eating. Sometimes, I wouldn't even eat for four days...

Participant three suffered from other chronic conditions such as CHF and end-stage renal disease and, as a result, the researcher queried the participant to gain insight as to how he is able to attribute the shortness of breath he experiences to COPD and not the other illnesses:

Interviewer: ... Or, do you basically know, it's breathing, and... when my breathing gets bad, I know it's my COPD?

Participant: yeah. (silence 5 seconds) I know it's my COPD, when it get bad. Uh, and there is another thing I know when it's getting bad, like when I walk back from the bathroom here and I sit back down... and you see me doing this, (audible breathing in and out) cause I'll be doing this in a minute... (pointed to his chest, can visibly see mild labored breathing)... that mean its bothering me. But I'll be clear.

This participant was not able to address the interviewer's question specifically. His response was based on what the researcher stated and not his own knowledge. He expressed his ability to identify the breathlessness he experienced as a direct result of COPD based on the severity. He addressed limitations in simple tasks such as walking to the bathroom. Moreover, he illustrated his breathing pattern, which he believes proves it is exacerbation of his COPD.

While interviewing participant four, she expressed the difficulty she experienced attempting to talk and breathe:

Participant: It's very hard. Like now, I'm straining to breathe and talk.

Participant five expressed his physical limitations when he was asked how he felt when he thought he would be readmitted.

Participant: Girl, please I was laying down in the backseat of the car. I knew I was going to stay, I couldn't breathe... I knew they just weren't going to come in here and see me and give me a prescription and send me out of there.

As participant five stated, he was not able to sit upright in the car during his episode of exacerbation. As a result, he knew that he would be admitted and that he was experiencing a severe exacerbation of his illness.

Participant seven is a 62-year-old male who rents a room from a close friend. He considers himself fairly active and admits since his initial diagnosis of COPD, he has noticed that physically his health has declined. Participant five uses public transportation to get to the doctor and other places but during an acute exacerbation, he is not able to walk due to his breathlessness:

Interviewer: So you were here umm less than 30 days ago, what, what you think led you to come back?

Participant: Same thing again, it happened all over. Well this time I'm walking, well this time what happened on this, I was in the rain walking in the rain late at night coming home and I got that cough, I thought it was a cold, but it was, what

they said I had? Pneumonia. And I tried to walk to the store, and the store is about from here to the end of the grey building right there, took me almost about an hour to get there cause I had to rest and stuff, it was messing with my breathing.

Participant seven admitted that he quit smoking only two months ago, although he was diagnosed about three or four years ago with COPD. He stated he stopped smoking because he realized he would not get better if he continued to smoke. He painted a picture for the interviewer of how limited he had become physically by showing her how, during an exacerbation, he could not walk 100 feet (to the grey building he referred to during the interview). Later in the conversation, he told the interviewer what the emergency medication technician informed him once they arrived at his home and also addressed his frustration with the limitations he experiences:

Participant: No, they said you waited too much long you might not even be here to talk. This COPD ain't no joke, can't, you limited on everything. You pick up something heavy, its HEAVY. Can't do nothing. Can't move nothing.

He also explained how his physical limitations has affected his ability to help those around him:

Interviewer: So what do you do to manage it at home then?

Participant: Slow down on whatever I'm doing. I don't do to, nothing too strenuous. Yeah. See like it stops you. See I be liking to do a lot of stuff. Like a few days about a week ago I went to help a neighbor move something, <sic> that

was out the question. I woulda [would have] did that I boy I probably woulda [would have] been in here earlier than that. See that's the COPD, eliminates your breathing, taking your breathing from you.

Participant seven lived an active lifestyle prior to being diagnosed with COPD. He used to help out friends and neighbors and considered himself to be very independent. Once diagnosed with COPD, the lifestyle he was accustomed to changed drastically. This significant change led to feelings of frustration due to his new physical limitations as a result of his illness.

Participant nine also provided an illustration of the detrimental effects of COPD and the physical limitations he experienced. He provided an example of his physical abilities when his illness is not exacerbated versus when it is exacerbated:

Participant: Yeah sometimes I can walk a mile as long as it's not aggravated. When its aggravated, I couldn't walk from here to that far wall over here without resting, it gets that bad.

His physical limitation varies contingent upon the severity of his breathlessness. Providing a comparison of his physical abilities prior to an episode of exacerbation, he described how severe his limitations are.

The feeling of being physically limited as a result of COPD permeated throughout the interviews with the participants. It was expressed by most participants in detail, through specific examples, or extracted from unrelated participants' statements. Experiencing physical limitations is ultimately what triggered the participants to seek

medical attention during episodes of exacerbation. Ironically, using those triggers as a gauge for seeking medical help was always too late.

Summary

This chapter provided in-depth descriptions of each participant's lived experience of being readmitted with COPD to a safety-net hospital within 30 days. During the interviews, the researcher explored the feeling of the phenomenon with the participants initially during data collection in the field and through the narrative text as she interpreted the data for the reader. The researcher captured and communicated the participants' feelings of being readmitted and extracted four primary themes: The COPD Effect, Weakness in Disease, The Unknown Power in Knowing (Health Literacy), and Limitations in Activities of Daily Living. It was apparent based on the information gathered during the interviews that the participants experienced substantial social, cultural, and environmental difficulties that may have perpetuated the likelihood of them being readmitted. More specifically, many of them did not have a high school diploma or GED and were living with friends or in transitional housing. This is an indication of their socioeconomical status and potential lack of access to medical resources. Lacking educational attainment, coupled with a lack of knowledge or health literacy about COPD, are social considerations that should be considered when developing strategies to decrease readmission rates within this vulnerable population.

Chapter 5

Discussion of Findings

The lived experience of readmitted African American patients with COPD was uncovered with the use of the hermeneutic phenomenological approach. In this chapter, the findings that evolved from in-depth interviews of 10 African American men and women who were readmitted to the hospital within 30 days of a previous discharge are discussed. Issues pertaining to the experience will be considered while simultaneously examining contextual, socio-cultural, and environmental influences within the African American culture. A sample appraisal and description of the characteristics of the participants will be discussed with descriptive summaries of the participants' experiences provided.

The research question that guided this study was *what is the human experience of patients discharged from the hospital and then subsequently readmitted within 30 days?* Thematic analysis of the participants' description of the feeling of being readmitted led to the emergence of four core categories: (a) The COPD effect, (b) Weakness in Disease, (c) The Unknown Power in Knowing (Health Literacy), and (d) Limitations in Activities of Daily Living. Through the analysis and exploration of the data using a hermeneutical lens, in the presence of social, environmental, and contextual constructs, the experiences of readmitted African American patients with COPD were captured. A review and interpretation of the findings and the significance of these findings to the current body of literature as they apply to policy, research, and practice will be discussed.

Sample Appraisal

Ten African American participants with COPD, five women and five men between the ages of 50 and 63, were interviewed. Each participant had been previously admitted to the hospital within 30 days of the interviewed-admission with a primary or secondary diagnosis of COPD at the time of each admission. In addition to being diagnosed with COPD, nine out of 10 participants suffered from comorbidities of CHF, kidney failure, diabetes, hypertension, asthma, and/or high cholesterol. Three participants rented their own home/apartment, six either rented a room, lived in alternative housing such as recuperative or board and care, or lived with a friend, and 1 participant self-identified as homeless. Seven participants had public medical insurance, Medi-Cal, Medicare, or both, and three participants were uninsured. Fifty percent of the participants had less than a high school diploma and two had some college education with one of those obtaining an Associate of Arts Degree. Four participants were single or divorced, three participants were married, one was estranged, and two resided with their spouses at the time of their interviews.

Hermeneutical Lens

The hermeneutic circle metaphor is important for the PI to understand the larger social and cultural contexts and take them into consideration during the interpretation of the data. The participants in this study have high rates of homelessness and reside in a medically underserved community with increased rates of poverty. Hermeneutic phenomenology allows the researcher to explore the meanings of the participants' experiences while attempting to describe, explain, or interpret the phenomena (Cohen et al., 2000). The lived-experience of being readmitted can be captured based upon the

understanding of the experience interpreted by the researcher to the reader (Cohen et al., 2000).

The COPD Effect

Chronic Obstructive Pulmonary Disease exacerbation has been defined by the Global Initiative for Chronic Obstructive Lung Disease (GOLD) as “an acute event characterized by worsening of the patient’s respiratory symptoms that is beyond normal day-to-day variations and leads to a change in medications.” (Rabe et al., 2011). Recurrent episodes of COPD exacerbations have been associated with poor quality of life, anxiety and depression, physical limitations, and increased risk for mortality (Alahmari et al., 2014; DiBonaventura et al., 2012; Piquet et al., 2013; Vestbo et al., 2013). The current findings derived from the participants interviewed support existing literature on how patients with COPD attempt to cope with episodes of exacerbation and who are more likely to be readmitted compared to other chronic diseases, with the exception of CHF (Kanel, Elster, & Vrbin, 2010). The participants in this study were more likely to go to the hospital to seek relief from symptoms of breathlessness. It was clear in the participants’ narratives at the time of the previous hospital discharge that the participants were feeling better and had improved lung functionality. This improvement led to a feeling of contentment and resolve by the participants at the time of discharge and also provided a sense of comfort in knowing that going to the hospital would lead to relief in their episode of breathlessness. Three subcategories emerged during data analysis: The feeling of relief, air is there, and fear of death.

The feeling of relief. Participants expressed a feeling of relief once they were informed by a healthcare professional they would be readmitted to the hospital. This was

an unexpected finding by the researcher as there was an expectation the participants would feel some level of frustration as they were unexpectedly admitted again for the same reason they were previously admitted. In reality, the participants expressed feelings of relief because there would soon be some resolution in their dyspneic attack. Moreover, they were relieved because they would receive care from those who had better knowledge and understanding of their disease.

Air is there. Dyspnea is a major symptom associated with acute exacerbation of COPD and is also associated with increased airflow limitation (Müllerová, Lu, Li, & Tabberer, 2014). Although a subjective experience, the feeling of breathlessness is echoed throughout the interviews. During the interviews, the participants continued to express the feeling of being winded and unable to manage their disease effectively while at home. The feeling of having no other alternative led these participants to return to the hospital. Similarly, one qualitative study that explored readmissions in Chinese patients with COPD, found the participants preferred to remain in the comfort of their own homes during an acute exacerbation and only considered hospital admission when all options had been exhausted (Tang and Lee, 2016).

Fear of death. Having no other alternative, the participants sought help only after they discovered their two options were death or going to the hospital to seek medical treatment. Religion is a cornerstone in the African American culture and has been found to lead to positive health outcomes in this community (Debnam, Holt, Clark, Roth, & Southward, 2011). One of the participants, during an AECOPD episode, spoke of calling her pastor to inform him she was afraid because she felt she was going to die. Through careful analysis and reflection and reviewing field notes, the researcher believes

this participant was seeking divine intervention. Likely this intervention would occur in the form of prayer from the pastor or positive encouraging words, yielding a feeling of relief, as the pastor is often seen as the gatekeeper between the participant and God. This participant also expressed her ability to seek relief during most times of her exacerbation when she prays to God. She stated that with prayer, she feels a sense of calm and she is able to breathe better. In the event she is unable to be relieved of her breathlessness after prayer, she goes to the emergency department for relief.

Religion is interwoven within the fabric of the African American culture. Fear of premature death is not uncommon in those who believe they have not achieved their purpose in life, or those who have not given their lives to their Lord and Savior. Being afraid to die coupled with strong religious beliefs, increased the likelihood participants would go to the hospital during an AECOPD episode.

Summary

A dominant symptom of acute COPD exacerbation is breathlessness. This feeling of respiratory distress coupled with the desire for relief, the need for oxygen, and the fear of dying led participants in this study to readily seek medical care once all attempts to resolve the dyspneic episode at home had been exhausted. The researcher summarized these sub-themes under the category of the COPD effect.

Weakness in Disease

Prior to feeling the only alternative to seeking medical attention is death, the participants in this study spoke of the battle between themselves and the respiratory distress they experienced. Because the patients being interviewed had a previous hospital admission, they were able to recall the relief they experienced once they were admitted;

however, it was clear there were no objective boundaries set by the participants to gauge the point in which the fight was lost. Trying to stick it out or fight it off was the common experience of the participants immediately before the decision was made to seek emergency medical attention. The researcher attributes this delay in seeking care to the low health literacy of this community, which will be discussed later in this chapter. Lacking a clear understanding of a chronic illness versus an acute illness is likely to be a key missing component in improving utilization of primary care clinics and seeking early treatment for COPD exacerbation in this population.

The Unknown Power of Knowing

Health Literacy. The Roundtable on Health Literacy (2013) defined health literacy as, “the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” The researcher in this study had preconceived expectations that participants interviewed would express concern due to a lack of knowledge of their disease and identify a need to have available community resources to better understand their illness and improve home-management of COPD. In contrast, most participants were aware of the knowledge deficit possessed but appeared to be unconcerned with their inability to manage their disease. This lack of concern, the researcher believes, is attributed to the general consensus among this community that there is no need to understand their disease because they can go to the hospital as needed to be helped. Contextually, this community has been identified as medically underserved with limited access to medical providers and even less access to culturally adept healthcare providers. Similar findings have shown African Americans have lower health literacy compared to their Caucasian counterparts and that educational attainment and

health literacy leads to poorer health outcomes among African Americans (Gupta et al., 2016; Shupe, Pohlig, Kuczmarski, Zonderma, & Evans, 2018). The perception of disease management among this community appears to be related to the knowledge gap between understanding acute versus chronic diseases and truly understanding how to effectively manage COPD outside of the hospital.

Poor Self-Efficacy. Defined as the belief in an individual's capabilities to produce a desired result, self-efficacy has been shown to improve health outcomes and reduce hospital readmissions and has been vital in self-management of chronic conditions (Bandura, 1994; Katch & Mead, 2010). The participants in this study appeared to view COPD as a complex condition they could not effectively manage on their own. During the interviews, participants either attempted to explain their condition, even if the explanation was incorrect, or they would state they did not know about COPD or how to manage it. The researcher, through careful reflection and analysis of the interviews and field notes, also attributed the acceptance of their known knowledge deficit to a lack of self-efficacy in their ability to manage COPD and an overall lower health literacy, which has been identified as a concern in the African American community (Hoover et al., 2015). Most participants were willing to take the medications prescribed by their physician; however, only one of the 10 participants took the initiative to utilize community resources to understand treatment modalities to help manage their disease. Eight of the 10 participants denied having any knowledge of community resources and had not sought out information to assist them with disease management. This is likely due to a lack of community involvement in public health activities and a lack of available community resources in poverty-stricken areas.

Krauskopf et al. (2015) found over 50% of patients with COPD are nonadherent to their COPD medications and when stratified based on ethnicity, African Americans were found to more likely be nonadherent than their Caucasian counterparts. The African Americans in this study stated they were compliant with their medication regimen but were unable to name their medications. One participant stated that during his AECOPD he obtained an inhaler that did not belong to him. Not being able to understand the different mechanisms of action for different inhaler medications indicates this participant would not be able to effectively manage his illness outside of the hospital. The participants were more likely to be compliant during times of extreme respiratory distress, less likely to seek outside assistance or modify their current lifestyle when they were at their baseline level of health, and less likely to effectively manage their disease outside the hospital if they lacked the confidence to effectively manage it.

Patient Activation. The patient activation measure is a 22-item tool that assesses a patient's knowledge, skill, and confidence for self-management of their disease (Hibbard, Mahoney, Stockard, & Tusler, 2005). For the purposes of this study, the researcher used this term to describe participants who believed they could effectively manage COPD at home and sought assistance beyond the hospital to manage their illness. This was identified as a sub-theme, not due to its presence among the study's participants, rather this sub-theme was identified due to its absence. Of the 10 participants, only one revealed a level of activation in managing the disease and obtaining information regarding their illness that led to improved outcomes. The lack of patient activation has led to multiple hospital rehospitalizations among the participants and poorer prognosis compared to the participant who was identified as being "activated."

Out of the 10 participants, the activated participant had been diagnosed with COPD longer than the other participants and had significantly less readmissions—only two since being diagnosed 14 years prior. There were also social influences that, in tandem, likely improved the identified patient's activation. Some of those influences were likely due to the support he received from his wife, his educational attainment as he attended some college, and his environment as he was employed and living in his own home with his wife.

Summary

Living in a medically underserved community, the African Americans in this study have lower health literacy, poor self-efficacy, and an absence of patient activation. These themes are vital to effectively managing chronic conditions such as COPD outside of the hospital setting. The African Americans in this study appeared to be unaware that a lack of knowledge and understanding of their illness, and the management of it, by default relinquishes their power and leads to poorer quality of life, increased recurrence of AECOPD, and preventable rehospitalizations.

Limitations in Activities of Daily Living

Studies on quality of life in COPD patients show that patients suffering from respiratory distress and breathlessness experience profound limitations in their usual activities of daily living (DiBonaventura et al., 2012; Gullick & Stainton, 2007). In this study, the participants expressed their perceived physical limitations prior to being readmitted. In interviews, the patients were unable to explain COPD; however, they were able to express their understanding of the dyspneic episode leading up to their readmission by the limitations they experienced in basic activities of daily living. Several

participants in the study received confirmation they were in AECOPD based on the breathlessness they were experiencing but also because they were unable to perform certain tasks such as walking to the room or bathroom or being able to pick up lightweight objects. During the interview, the participants expressed these physical limitations to the researcher in order to explain how burdensome these limitations were to them. The participants gauged the severity of their exacerbations based on their physical limitations and their struggle to breathe. In the event there was physiological distress and extreme dyspnea, the participants would seek emergency medical attention.

Significance

The Centers for Medicaid and Medicare Services (CMS) established the Hospital Readmissions Reduction Program (HRRP) to improve quality as well as reduce hospital readmissions and decrease the economic burden caused by certain conditions on the U. S. healthcare system (CMS, 2016). Under the HRRP, hospitals with excess rates of readmissions for identified conditions, including COPD, will be penalized up to 3% of total reimbursements (CMS, 2016). The participants in this study revealed the complexities regarding readmissions in a community that is medically underserved and impoverished. There are many facets that should be taken into consideration prior to penalizing hospitals and one of these is the consideration of the community in which the care is provided. Specifically, safety-net hospitals, which provide care to individuals regardless of their ability to pay and provide care to racial/ethnic minority populations, are at increased risk for financial penalties compared to non-safety-net hospitals (Joynt et al., 2011). The communities served by safety-net hospitals have higher healthcare utilization, higher emergency department usage, lower socioeconomic status, low health

literacy, and have complex social and medical concerns (Joynt et al., 2011; Shaya et al., 2009). As discovered in this study, unmet basic needs lead to increased vulnerability and increased readmissions in lower-income communities, which extends the reach of the hospital (Shaya et al., 2009; Williams et al., 2016).

An unexpected discovery while collecting demographical data from the participants was the increased homelessness, or alternative living conditions, as well as the lack of educational attainment and lack of social support among the participants. According to Henry and colleagues (2018), the state of California has the highest prevalence of unsheltered homeless people in the country. Moreover, Los Angeles County, where this study's participants reside, has the highest rate of homelessness compared to other counties within the state of California (Los Angeles Homeless Services Authority, 2017). Studies have shown that homelessness is an independent risk factor for chronic conditions. This leads to increased readmissions due to the inability to effectively manage health conditions and results in high usage of emergency services in lieu of primary care clinics (Kushel, 2016; Lam, Arora, & Menchine, 2016; Shalen et al., 2016). Considering the increased readmission rates among African Americans and their lower socioeconomic status compared to their societal counterparts, it is imperative that interventions be grounded with a clear, scientific understanding of the risks of the most vulnerable.

Implications for Policy

The HRRP is designed to improve quality and reduce hospital readmissions for conditions such as COPD; however, based on the participant interviews, this study reveals that factors beyond hospital walls also play an important role in readmission rates.

The participants in this study denied knowledge of any community resources or organizations within their community where they could learn about their chronic condition. The community in which people live has been linked to the health of vulnerable populations and has been shown to affect the health of communities (DeGuzman & Kulbok, 2012). The criteria for reimbursement penalties should consider the demographics of the population and extant factors that may be contributory to mismanagement of chronic conditions yielding increased rates of AECOPD.

Implications for Nursing

Transitional Care Model

The transitional care model (TCM) is a nurse-led intervention that targets patients during a hospitalization who are at risk for rehospitalization and poor outcomes as a result of multiple chronic conditions and old age (Naylor & Sochalski, 2010). The TCM comprises 10 core components that involve assisting patients with transitioning from the hospital setting to home. The nurse and the patient together are at the center of the model while providers simultaneously collaborate to design and implement a streamlined plan of care to reduce avoidable hospital readmissions (Hirschman et al., 2015). The elements of this model have been effective in reducing hospital readmissions in older adults with multiple chronic conditions (Hirschman et al., 2015). Based on the participant interviews in this study, the elements of TCM—screening, staffing, maintaining relationships, engaging patients and caregivers, assessing/managing risks and symptoms, educating/promoting self-management, collaborating, promoting continuity, and fostering coordination—would likely reduce hospital readmissions and improve understanding and knowledge of COPD among the participants if social conditions, such

as living in medically underserved areas, homelessness, and healthcare disparities, were also considered.

This study revealed African American patients with COPD could benefit from additional involvement in their care through a creation of trust and cultivation of relationships between the nurse and the patient. Participants were asked if they were interested in having a healthcare professional explain their illness or provide information about community resources to help learn about their illness. Most participants said no. The TCM could improve communication between the participant and the nurse if trust is established during the hospital admission. Moreover, considering that at least half of the participants were in temporary housing, renting a room, or homeless, the TCM should include interventions that expands its reach beyond vulnerable elderly populations to include minority and/or medically underserved groups. In order to decrease hospital readmissions, additional studies should modify scientifically sound models, such as the TCM, to identify if these models are effective in lower socioeconomic groups.

Limitations

The participants in this study were conveniently selected based upon their willingness to participate in the study. It is possible the participants who chose to be interviewed may have managed their illness differently than other COPD patients. The participants in this study were not randomly selected and the interpretation of the data was based on the subjective experience of the researcher. Since the participants were all African American, the study is not generalizable to other ethnic minority groups within the same community as it is a qualitative study with a convenience sample. Although measures were taken to attempt to control these limitations, qualitative studies are

vulnerable to researcher and participant biases that can skew the results. The participants' answers to the posed questions were based on the recollection of the participants' experiences. Considering the participants were inpatients during the time of the interview, their recall may have been altered. The researcher, being a member of the community being studied, attempted to interpret the lived experience of the participants based on the interviews; however, subconscious biases may have affected the interpretation of the data. In spite of these limitations, new insight is gained in understanding prehospitalization in African Americans with COPD.

Conclusion

Effectively managing COPD within the community is key to preventing hospital readmissions within this population. This study revealed, through phenomenological explorations, the impact of existential contributory factors such as poverty, homelessness, lower socioeconomic status, and low health literacy on readmission rates. Being a member of this community, the researcher would like to prevent misconstrued interpretation of the data and exclaim that health is perceived as valuable within this population; however, the challenges are largely due to social and economic constraints taking precedence and leading to a decreased desire to seek education and resources as other more pressing issues take priority. Exploring this phenomenon from the patients' perspective provided insight on the overall feeling of relief when being readmitting during a breathless episode and the lack of resources within the surrounding community to educate and inform the participants of proper disease management. This study provided insight at the individual level of factors that could lead to increased readmissions in African American COPD patients. Moreover, considerations should be

given to hospitals that provide healthcare to these populations as community support and resources in lower income areas are scarce. In order to safely and effectively reduce readmission rates among African Americans with COPD, interventions identifying a patient's psychosocial and economic support systems prior to their discharge from the initial hospitalization should be identified. The feeling of being readmitted circumvents the expected feelings of inconvenience of being hospitalized in a community that is scarce in resources and high in low-health literacy and is instead associated with feelings of relief, resolve, and rescue from the breathless experience.

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Appendix A

USD IRB



Jan 4, 2019 8:52 AM PST

Kiiyonna White
Hahn School of Nursing & Health Science

Re: Renewal - IRB-2018-210 The Lived Experience of Discharged and Readmitted African American patients with Chronic Obstructive Pulmonary Disease (COPD) to a Safety-Net Hospital

Dear Dr. Kiiyonna White:

The Institutional Review Board has rendered the decision below for IRB-2018-210, The Lived Experience of Discharged and Readmitted African American patients with Chronic Obstructive Pulmonary Disease (COPD) to a Safety-Net Hospital.

Decision: Approved

Findings: None

Research Notes:

Internal Notes:

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited or exempt review at any time.

Sincerely,

*Dr. Thomas R. Herrinton
Administrator, Institutional Review Board*

**Office of the Vice President and Provost
Hughes Administration Center, Room 214
5998 Alcalá Park, San Diego, CA 92110-2492
Phone (619) 260-4553 • Fax (619) 260-2210 • www.sandiego.edu**

Appendix B

Research Participant Consent Form

For the research study entitled:

The Lived Experience of Discharged and Readmitted African Americans with Chronic Obstructive Pulmonary Disease (COPD) to a Safety-Net Hospital

I. Purpose of the research study

Kiiyonna L. White is a student in the Hahn School of Nursing at the University of San Diego. You are invited to participate in a research study she is conducting. The reason for this research study is: explore your feeling of being readmitted to the hospital after being discharged less than 30 days ago.

II. What you will be asked to do

If you decide to be in this study, you will be asked to:

1. Complete a form that asks about your age, ethnicity and your illness.
2. Speak with the researcher about your feelings of why you think you needed to come back to the hospital.
3. Speak with the researcher about what you feel you need outside of the hospital to prevent you from being readmitted.
4. Allow the researcher to record your discussion (all of the conversation will be private and none of your personal information will be disclosed).

Your participation in this study will take a total of 20 - 30 minutes, or at any point you choose to end the conversation.

III. Foreseeable risks or discomforts

Sometimes when people are asked to think about their feelings, they feel sad or anxious. If you would like to talk to someone about your feelings at any time, you can call toll-free, 24 hours a day: Los Angeles County Mental Health Hotline at 1-800-854-7771.

IV. Benefits

- a.) While there may be no direct benefit to you from participating in this study, the indirect benefit of participating will be knowing that you helped researchers better understand the feelings patients with COPD experience when they find out that they will be readmitted to the hospital.
- b.) For your participation in this study, you will receive a \$25 Visa card as a small token of appreciation.

V. Confidentiality

Any information provided and/or identifying records will remain confidential and kept in a locked file and/or password-protected computer file in the researcher's office for a minimum of five years. All data collected from you will be coded with a number or pseudonym (fake name). Your real name will not be used. The results of this research project may be made public and information quoted in professional journals and meetings, but information from this study will only be reported as a group, and not individually.

VI. Compensation

If you participate in the study, the researcher will give you a \$25 Visa gift card in the following way: personally
You will receive this compensation even if you decide not to complete the entire interview session.

VII. Voluntary Nature of this Research

Participation in this study is entirely voluntary. You do not have to do this, and you can refuse to answer any question or quit at any time. Deciding not to participate or not answering any of the questions will have no effect on any benefits you're entitled to, like your health care.

**** You can withdraw from this study at any time without penalty****

VIII. Contact Information

If you have any questions about this research, you may contact either:

1) Kiiyonna White

Email: kiiyonwhite@sandiego.edu

Phone: (310) 654- 9047

2) Dr. Jane Georges

Email: jgeorges@sandiego.edu

Phone: (619) 260-4566

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records.

Signature of Participant

Date

Name of Participant (Print)

Signature of Investigator

Date

Appendix C

Demographic Data Form

Gender: Male Female

Age: _____

Race:

African American/Black

Marital Status:

Single Divorced Widowed/Widower

Never Married

Housing Status:

Own home Rent home Rent room Live in Shelter

Live with family member(s) Homeless Other: _____

Highest Education Completed:

Less than Middle/Junior High School Bachelors Degree

Less than High School Masters Degree

High School Diploma or GED Doctoral Degree

Do you currently have medical insurance? Yes No

If yes, do you have Medicaid or Medicare? Yes No

Appendix D

Interview Guide

- 1) Tell me how you felt when you realized you needed to come back to the Emergency Department?
- 2) Tell me how you felt when the health care team, doctor or nurse, informed you that you were going to be readmitted?
- 3) When you were discharged from the hospital the first time, tell me how you felt being at home with COPD?
- 4) How do you manage your disease outside of the hospital?
- 5) Do you have any assistance from family or can do you have someone to call to ask question about your illness?
- 6) Tell me how you feel about the support you receive to manage your disease in your home and in this community.