THE LIVED EXPERIENCES OF BREATHLESSNESS IN ADULTS WITH CHRONIC HEART FAILURE

by

CECILIA CIPRIANO LIJAUCO

DISSERTATION

Submitted in partial fulfillment of the Requirements
for the degree of Doctor of Philosophy at
The University of Texas at Arlington
College of Nursing and Health Innovation
May 2020

Arlington, Texas

Supervising Committee:

Dr. Donelle Barnes, UTA Supervising Professor
Dr. Yaewon Seo, UTA
Dr. Claudia Beal, Baylor University

ABSTRACT

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Cecilia Cipriano Lijauco, PhD

The University of Texas at Arlington, 2020

Supervising Professor: Donelle Barnes, PhD

Heart failure (HF) is a significant disease condition affecting 6.5 million Americans. Breathlessness is the hallmark symptom of HF impacting affected individual’s functional capacity and quality of life. It is a subjective symptom best described by individuals experiencing it, yet there are very few qualitative studies to understand this phenomenon in HF. The purpose of this study was to explore how adults with HF describe their experiences of breathlessness, determine characteristics, types and patterns, explore the impact of breathlessness on their daily life, and explore how affected individuals manage their breathlessness. Fourteen participants with diagnosis of HF and self-report of breathlessness were interviewed to explore their descriptions of their breathlessness experiences, types and patterns, the impact it had on their daily life and management strategies employed. Thematic analysis was used to analyze the interviews. Five themes were identified to describe the nature of their breathlessness: no air, accompanying symptoms, “just happens”, general shortness of breath vs. cannot breathe, and first reaction. As part of the interview, the participants were asked to draw a graph depicting the severity and duration of their typical episode of breathlessness. Two patterns of episodic breathlessness were identified: group I – quick onset and slow recover and group II – similar time for onset and recovery. Two types of breathlessness episodes were described: triggered episode with predictable response and the triggered or non-triggered wave-like episode. Four themes were identified to describe the impact of breathlessness on their daily life: feeling guilt or self-responsibility, "I used to", helplessness, and forecasting. Adults with HF employ strategies to mitigate the impact of breathlessness on their daily life with four themes identified: stop and breathe, acceptance or carry on, adapting, planning, and new perspective

The study findings reveal the need to educate adults with HF recognize and understand their breathlessness, the need for a multidisciplinary care approach to address the multidimensional impact of this symptom and assist them in developing effective and evidenced-based management strategies.

ACKNOWLEDGEMENTS

All praise and honor to God who has willed for me to take this academic journey. He has been the author of all events in my life. Without His almighty guidance, none of my achievements would have been possible. I thank God for this opportunity.

It is my honor to recognize and acknowledge the people who accompanied me in this journey. To my committee chair, Dr. Donelle Barnes, I am sincerely grateful for your wise counsel, mentorship and dedication to see me succeed. I admire and respect your expertise in qualitative research. To Dr. Yaewon Seo, thank you for your guidance and mentorship. Your research endeavors on dyspnea in heart failure inspired me and motivated me to undertake this topic. To Dr. Claudia Beal, I am sincerely grateful to you for your time and dedication to assist me in this dissertation. You all have played a pivotal role in my development as a nurse scientist. As a Jonas scholar, I am grateful for the financial and intellectual support provided. This research endeavor was also supported by the University of Texas Kyba Nursing Fellowship. To the staff of the heart failure clinics, thank you for accommodating me and my study. To all the study participants, thank you for sharing with me your thoughts and feelings about living with breathlessness and heart failure.

DEDICATION

I dedicate this work to my lifelong friend and husband, Rick Lijauco, who has whole heartedly supported me in this journey. Thank you for your unwavering love and encouragement every step of the way. Your confidence in my abilities inspired me to persevere. To my children, Valerie and Phil, you are precious to me. Thank you for your support and encouragement. It is my hope that with this accomplishment, I may have taught you that nothing is impossible with hard work, belief in yourself, and perseverance. I thank my parents for instilling in me a great appreciation for learning as they would say “education is something no one can ever take away from you”.

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Background and Significance

Heart failure (HF) is a clinical syndrome characterized by structural or functional impairment of the ventricles to fill with or eject blood (Hassenfuss & Mann, 2018; McMurray et al., 2012; Yancy et al., 2013). It is a syndrome involving multi-system impairment including the endocrine, hematologic, musculoskeletal, renal, respiratory, and vascular systems (Pearse & Cowie, 2014). It is a progressive disease requiring lifelong management (Hassenfuss & Mann, 2018).

The most prevalent symptoms experienced by adults with chronic HF are breathlessness and fatigue (Felker & Teerlink, 2018). Breathlessness affects every aspect of a person's life with HF (Walthall et al., 2017). Existing knowledge on breathlessness in HF comes heavily focused on quantitative measurement of the symptom and its clinical management while less is known of the lived experiences of breathlessness in adults with chronic heart failure. Breathlessness has been considered a subjective experience, the interpretation and perception of which differs from one individual to another (Campbell, 2017). Further, there is less known about types and patterns of breathlessness in chronic heart failure as described by those affected. Understanding breathlessness from the lived experiences of affected adults will provide invaluable insight on the experience and its impact on day-to-day life.

Prevalence

HF afflicts 6.5 million Americans (United States Department of Health and Human Services [USDHHS], National Heart, Lung, and Blood Institute, 2018). This prevalence has been estimated to increase by 46% by year 2030 (Heidenreich, et al., 2013). Three possible explanations have been described to explain the increase (Braunwald, 2013). The first is related to medical advances and improved prognoses in the diagnosis and management of many cardiovascular conditions, such as acute coronary syndrome, uncontrolled hypertension, congenital cardiac abnormalities, and many arrhythmias. However, improved prognoses and mortality do not translate to cure, therefore, survivors of these disease conditions remain at risk for possible HF. The second explanation is the increase in the prevalence of cardiac comorbid conditions in an aging population, such as hypertension, type II diabetes mellitus, obesity, chronic kidney disease, chronic obstructive pulmonary disease, and arrhythmias (Braunwald, 2013). The third explanation for increased prevalence is the slow but progressive improvement in HF survival (Mozaffarian et al., 2016).

Economic Impact

HF is an important healthcare issue because of its high prevalence, mortality, morbidity, and cost of care (Heidenreich et al., 2013). The disease is characterized by exacerbating signs and symptoms requiring physician visits, episodic emergency room visits, and even hospitalizations (Mozaffarian et al., 2016). HF costs the nation an estimated $30.7 billion in health care services, medications, and lost wages. By 2030, the total cost is projected to increase to $53 billion (Heidenreich et al., 2013). Survival after the onset of HF in older adults has improved, however, the mortality rate remains high at 29.6% with half of those with HF dying within 5 years (Chen et al., 2011).

Etiology

The multiple etiologies of HF result from disorders of the pericardium, myocardium, endocardium, heart valves, or the great vessels (Hassenfuss & Mann, 2018). The most common etiologies are myocardial infarction, ischemic heart disease, congenital heart disease causing structural heart abnormalities, hypertension, and diabetes. Cardiomyopathies, infection, and prolonged arrhythmias are less prevalent causes of HF (Hassenfusss & Mann, 2018; Kemp & Conte, 2012). Excessive drug or alcohol use, tachycardia, and sleep apnea may also lead to HF (Januzzi & Mann, 2018). Metabolic and other systemic conditions, such as thyrotoxicosis and liver disease, may also cause HF (Pearse & Cowie, 2014). Certain medications may increase the risk for HF, including nonsteroidal anti-inflammatory drugs, cytotoxic agents, and certain antipsychotic drugs (Januzzi & Mann, 2018; Nederend et al., 2015).

Pathophysiology

An index event damaging the heart muscle initiates the progressive disorder in HF. The injury to the heart leads to a loss of critical quantity of functional myocardium affecting cardiac output and venous blood return (Hassenfuss & Mann, 2018). The onset of the index event may be abrupt as in myocardial infarction, or gradual as in hypertension and cardiomyopathies. Regardless of the etiology of the index event, the end result is inadequate cardiac output or inadequate increase on exertion resulting in global hypoperfusion of organs (Kemp & Conte, 2012).

After the initial decline in cardiac output and ventricular function, several compensatory mechanisms are activated to generate adequate stroke volume and cardiac output. These compensatory mechanisms include the Frank-Starling mechanism, neurohormonal activation, and ventricular remodeling (Hassenfuss & Mann, 2018; Kemp & Conte, 2012). Initially, adults with HF may remain asymptomatic because of these compensatory mechanisms, however, over time symptoms develop once the compensatory mechanisms become inadequate (Hassenfuss & Mann, 2018). The underlying pathogenesis of HF also involves silent inflammatory and immune-regulatory responses. Sustained neurohormonal activation leads to further secondary intraventricular end-organ damage, with worsening left ventricular remodeling and hemodynamic decompensation (Hassenfuss & Mann, 2018). The released endotoxins, adhesion molecules, nitric oxide, and various reactive oxygen species have been associated with various pathological characteristics of HF (Hofman & Frantz, 2013)

Classification of Heart Failure

HF can be classified as predominantly left ventricular failure, right ventricular, or biventricular depending on the location of the dysfunction (Jessup et al., 2009). HF is also classified as acute or chronic depending on the time of onset. The term HF generally refers to those with established chronic HF whose symptoms can be classified according to the New York Heart Association (NYHA) functional classification (Januzzi & Mann, 2018). On the other hand, acute HF is generally defined as a rapid onset of new or worsening signs and symptoms (Felker & Teerlink, 2018). The term acute HF also includes those presenting for the first time with typical signs and symptoms of HF (also referred to as de novo HF), and those presenting with worsening of their pre-existing HF, also referred to as acute decompensated HF (Felker & Teerlink, 2018). Clinically, HF is also typically classified into two major types based on the ejection fraction or left ventricular function (Felker & Teerlink, 2018; Yancy et al., 2013). Ejection fraction is a measurement expressed as a percentage of the amount of blood leaving the left ventricle each time it contracts (Lang et al., 2015). The normal ejection fraction in a healthy individual is 52% to 74%. Ejection fraction is important in the categorization of adults with HF because of differences in patient characteristics, prognosis, comorbid conditions, and response to treatments (Dunlay et al., 2012; Kapoor et al., 2016; Tsao et al., 2016). The two major types based on ejection fraction are heart failure with reduced ejection fraction or HFrEF, and heart failure with preserved ejection fraction or HFpEF (Felker & Teerlink, 2018; Yancy et al., 2013). HFpEF is generally defined as left ventricular ejection fraction of 50% or greater, whereas

HFrEF is generally defined as an ejection fraction less than 40% (Kapoor et al., 2016). Most recently, two new subclassifications of HFpEF have been identified in which signs of diastolic dysfunction are combined with an ejection fraction between 41% and 49% (Januzzi & Mann, 2018; Yancy et al., 2017). Regardless of the ejection fraction, the clinical syndrome of HF is present, and the clinical manifestations of reduced stroke volume and cardiac output are similar in all types (Zile & Litwin, 2018). With regards to response to treatment and outcomes, adults with HFrEF respond favorably to standard pharmacological treatment and demonstrate better prognosis. On the other hand, adults with HFpEF have not been shown to respond to standard pharmacological treatments and therefore have poor prognosis (Yancy et al., 2013).

Signs and Symptoms

Breathlessness or dyspnea is the hallmark symptom of chronic HF (Felker & Teerlink, 2018). It is one of the most prevalent and distressing symptoms in adults with chronic HF, associated with hospital admissions and negative health outcomes (DiNino et al., 2015; Parshall et al., 2012; Stevens et al., 2016). Breathlessness is defined as a subjective experience consisting of qualitative distinct sensations of varying intensity regarding breathing. Breathlessness in HF is usually reported as difficulty breathing, chest tightness, or a feeling of inadequate intake of air on inspiration (Kupper et al., 2016). It is derived from multiple factors - physiological, psychological, social, and environmental - that are interacting with each other inducing physiological and behavioral responses (Rose, 1999).

In HF, breathlessness occurs during less than usual exertion, when lying down, or as paroxysmal nocturnal breathlessness. Breathlessness may also be associated with coughing. Adults with HF may feel the need to use more pillows when recumbent or the need to sleep in a chair secondary to breathlessness (Clerkin et al., 2019).

Fatigue, weakness, and/or lethargy are also common secondary to reduced cardiac output and dysfunction of the skeletal, smooth, and cardiac muscles (Clerkin et al., 2019; Perez-Moreno et al., 2014). Signs of late stages of HF include tachycardia, pedal edema, increased jugular venous pressure, abnormal lung sounds (rales or crackles), and S3 gallop. Infrequently, there may be hepatojugular reflux and ascites (Felker & Teerlink, 2018; Kemp & Conte, 2012). The clinical course for most adults with chronic HF tends to be one of gradual decline, often interspersed with episodes of severe deterioration resulting in emergency room admission and/or hospitalization (Alpert et al., 2017). This study will focus on breathlessness as a major symptom that adults with chronic HF must manage.

Breathlessness in Chronic Heart Failure

The sensation of breathlessness has been considered a subjective experience unique to the individual. The perception and interpretation of the experience may vary from individual to another (Campbell, 2017). The description of breathlessness by adults with HF differs from those with pulmonary disease (West et al., 2010). Adults with HF describe their breathlessness as suffocating, feeling the need to breathe faster, instead of describing the increase in the work of breathing as do adults with pulmonary disease (West et al., 2010). Breathlessness impairs the person’s functional capacity and quality of life. Dyspneic adults with HF restrict their physical activity to avoid further breathlessness and fatigue, which may lead to further deconditioning (Chung & Schulze, 2011; Downing & Balady, 2011; Seo et al., 2016). Psychological distress has been reported to accompany breathlessness. The combination of these symptoms may force adults with HF to seek emergency care. As the severity of HF increases, the prevalence of breathlessness increases (Kupper et al., 2016). Therefore, managing breathlessness is imperative to improving functional capacity, quality of life, and overall symptom burden of the disease.

Pathophysiology of Breathlessness

Research into the mechanism of breathlessness has undergone tremendous progress leading to growth in clinicians' knowledge of the neurophysiology of breathlessness, however, such understanding continues to be limited (Parshall et al., 2012). One widely accepted neurophysiological mechanism of breathlessness describes a perceived mismatch or dissociation between the efferent motor activity of the respiratory center in the brain and the incoming afferent signals from mechanical receptors in the airways, lungs, chest wall structures, and chemoreceptors in the blood (Campbell, 2017). Based on this mechanism, the sensation of breathlessness has a lot to do with disjointed interpretation of information and less with the status of the intrinsic respiratory function (Parshall et al., 2012). Another mechanism of breathlessness involves affective processing of corollary discharge sent to the sensory cortex. The activation of the limbic cortical structures evokes the awareness of the respiratory effort producing the sensation of breathlessness (Evans, 2010; Nishino, 2011).

In HF, physiological factors are also important ancillary components of the sensation of breathlessness (Kupper et al., 2016). Activation of the inflammatory response stimulates arteriosclerotic and other abnormal cell processes leading to fibrosis, hypertrophy, cell death, increased mucus production, and bronchoconstriction. Weakness of the main muscle of respiration, the diaphragm, also contributes to breathlessness, brought about by age-related structural and functional changes to the respiratory structures (Alpert et al., 2017; Lowery et al., 2013). Biopsychological factors beyond disease pathology exacerbate the perception of breathlessness. Among adults with HF, the reported severity of breathlessness may not be correlated with objective assessment of their cardiac and respiratory disease conditions (Guglin et al., 2012; Riegel et al., 2018). Regardless of the cardiorespiratory pathophysiology, the sensation of breathlessness can still be very disturbing, causing psychological distress to those experiencing it (West et al., 2010).

The immense burden breathlessness creates in the lives of adults with HF makes improving its management a priority, however, effective management is dependent on greater understanding of this experience. Breathlessness in HF remains a complex phenomenon to grasp. Quantitative explanations of the experience of breathlessness have been inadequate to fully understand this phenomenon (Kupper et al., 2016). Therefore, exploring breathlessness through the lived experiences of adults with HF will maximize the understanding of this experience by both adults with HF and healthcare professionals. Greater understanding will aid affected adults and clinicians toward better assessment of the disease progression and development of effective management strategies to avoid hospitalization and increased mortality risks.

Theory Framework

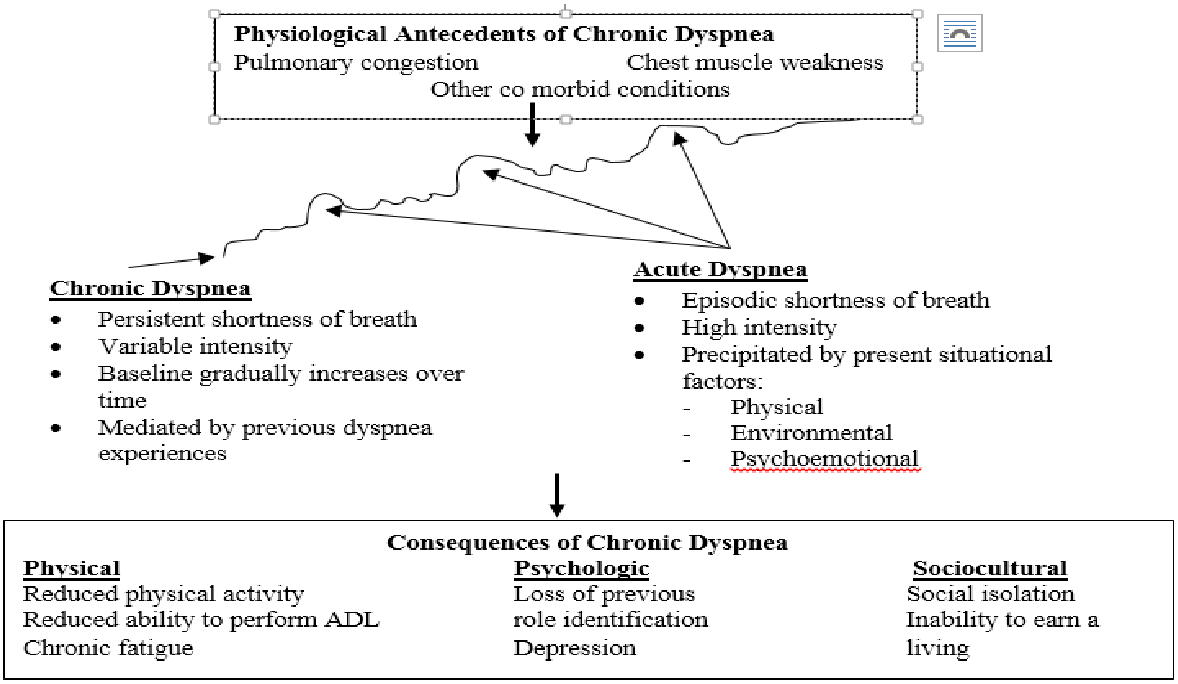
Several models of breathlessness have been proposed, yet there is no single universally accepted theory that can be used to explain the mechanism of breathlessness under all disease conditions. One specific shortfall of the models is the inability to differentiate between acute and chronic breathlessness (McCarley, 1999). In chronic HF, the experience is multi-factorial and the mechanism may arise very differently compared to breathlessness in acute HF (Kupper et al., 2016), therefore a model that pertains to chronic breathlessness will be helpful to understand the experience of dyspneic adults with chronic HF. For this study, the theory of chronic dyspnea (McCarley, 1999) will be adapted.

Physiologic Theory of Chronic Dyspnea

The theory of chronic dyspnea was developed for adults with chronic obstructive pulmonary disease, however, a modified version will be utilized to guide this research on chronic breathlessness in chronic heart failure. McCarley's (1999) model of chronic dyspnea has three components: physiologic antecedents, breathlessness, and consequences (See Figure 1). Breathlessness is seen as a longitudinal experience, varying in intensity from a usual breathlessness state to slowly and greater increases overtime, only to return to the baseline or usual breathlessness state (McCarley, 1999). In chronic obstructive pulmonary disease, the physiologic antecedents include hyperinflation, increased airway resistance, and decreased lung compliance. In HF, the antecedents may include pulmonary congestion, chest muscle weakness, and other co-morbid conditions, such as obesity and other pulmonary diseases. In chronic breathlessness, the antecedents are given less importance as they are often more difficult to treat once chronic breathlessness develops. The focus becomes the ever-presence of breathlessness, described as gradually increasing baseline interspersed with acute breathlessness episodes. The core of the theory is the perception of breathlessness as persistent, varying in intensity, and ever-present (McCarley, 1999). Acute episodes of breathlessness are precipitated by physical, environmental, or emotional factors. The constant possibility of acute breathlessness leads to a cycle of reduced physical activity and worsening physical deconditioning. The consequences of chronic breathlessness are multidimensional affecting every aspect of a person's life (McCarley, 1999). The consequences are divided into physical, such as reduced activity, reduced activities of daily living, and fatigue; psychological, such as role loss and depression; and sociocultural, such as isolation and occupational (Victorson et al., 2009).

The model bears some resemblance to Campbell's (2017) dyspnea model. While Campbell (2017) described the relationship between antecedents and reactions to breathlessness in adults with terminal diseases, the model of chronic breathlessness addresses the long-term consequences of breathlessness that affect the person’s quality of life. In contrast to acute breathlessness in which psychological aspects serve as antecedents, in chronic breathlessness psychological aspects are the consequence of living with the constant distress of breathlessness (Victorson et al., 2009). For example, depression is one consequence of chronic breathlessness.

Figure 1. Model of chronic breathlessness (McCarley, 1999)



Application of the Model of Chronic Breathlessness

The use of the model will allow differentiation of chronic breathlessness from acute breathlessness in HF. The model will also allow exploration of antecedents of chronic breathlessness in terms of what triggers the experience, and the consequences in terms of how breathlessness affects the day-to-day life of adults with chronic HF.

Statement of the Purpose

The purpose of this study was to explore how adults with chronic HF describe their experiences of breathlessness, determine characteristics, types and patterns of their breathlessness, how it affects their daily life, and how they adjust to and manage breathlessness and its associated symptoms.

Research Questions

The research questions for this qualitative study were as follows:

1. How do adults with chronic HF describe their experiences of breathlessness?
2. How do adults with HF describe the types and patterns of their breathlessness?
3. How do adults with HF describe the impact of breathlessness in their daily life
4. How do adults with chronic HF adjust to and manage their breathlessness?

Assumptions

1. Adults with chronic HF experiences of breathlessness can be grouped in types and patterns.
2. Adults with chronic HF have limited physical activity, functional capacity, and quality of life because of their breathlessness.
3. Adults with chronic HF strive for control and management of their breathlessness.

Summary

Breathlessness is the hallmark symptom of HF and is the most common cause of HF hospitalization (Felker & Teerlink, 2018). It is a subjective symptom best described by the people experiencing it (Campbell, 2017). Breathlessness in chronic HF can be unrelenting, causing limited physical activity, functional capacity, and quality of life. Assessing breathlessness is the first step in managing it, however, quantitative measures of breathlessness do not always yield richer and more valuable objective data to adequately assess the pathophysiological impairment involved in breathlessness (Banzett & O'Donnell, 2014). In some studies, researchers have found weak correlations of breathlessness with objective hemodynamics measures. Many people who report severe breathlessness may show no corresponding pathophysiology while others who report no breathlessness may inversely show severe pathophysiology (Guglin et al., 2012). Exploring the experiences of breathlessness among adults with chronic HF through qualitative interviews may augment the quantitative data in understanding the breathlessness phenomenon.

Chapter 2

Literature Review

Breathlessness in Chronic Heart Failure

Despite significant progress in the treatment and management of adults with chronic HF, debilitating symptoms, frequent hospitalizations, readmissions and high mortality continue to affect the lives of those afflicted (Stevens et al., 2016). A hallmark symptom of chronic HF is worsening breathlessness (Felker & Teerlink, 2018). Breathlessness is a debilitating symptom with negative impacts on exercise tolerance, functional capacity, and quality of life in adults with chronic HF (Chung & Schulze, 2011; Downing & Balady, 2011; Seo et al., 2016). The purpose of this review is to define and describe HF and describe how breathlessness affects the lives of adults with chronic HF.

Heart Failure

Heart failure (HF) is a clinical syndrome characterized by structural or functional impairment of the ventricles to fill with or eject blood (Hassenfuss & Mann, 2018; McMurray et al., 2012; Yancy et al., 2013). It is a syndrome, rather than a diagnosis, because of the complex multi-system impairment involved including the endocrine, hematologic, musculoskeletal, renal, respiratory, and vascular systems (Pearse & Cowie, 2014). The diagnosis of HF cannot be made based on signs and symptoms alone. An objective measurement of the cardiac structural or functional impairment is an important component of the diagnosis (Mozaffarian et al., 2016; Nederend et al., 2015). The signs and symptoms are dependent on the presence of elevated left-sided or right-sided heart filling pressures, while the impairment may range from normal ventricular size and function to marked ventricular dilatation and dysfunction. Previously called congestive heart failure, this term is no longer preferred, because many adults with HF may not have signs and symptoms of volume overload or overt congestion, but their symptoms may be caused by other factors such as reduced cardiac output (Januzzi & Mann, 2018).

The multiple etiologies of HF result from disorders of the pericardium, myocardium, endocardium, heart valves, or the great vessels. Risk factors for HF include ischemic heart disease, hypertension, myocardial infarction, myocarditis, valvular heart disease, tachycardia, diabetes mellitus, structural heart disease related to congenital heart disease, sleep apnea, excessive drug or alcohol use, and obesity (Januzzi & Mann, 2018). Metabolic and other systemic conditions, such as thyrotoxicosis and liver disease, may also cause HF (Pearse & Cowie, 2014). Cytotoxic agents and certain antipsychotic drugs can also cause HF (Nederend et al., 2015).

Prevalence

HF is an important healthcare issue because of its high prevalence, mortality, morbidity, and cost of care (Heidenrich et al., 2013). HF affects 6.5 million people in the United States. This represents an increase from 5.7 million between 2009 and 2012 (USDHHS, National Heart, Lung, and Blood Institute, 2018). With the projected population growth and aging of the population, more people will be at risk for developing HF. It is projected that the total number of people living with HF will increase by 46% or 8 million by 2030. People 80 years of age and greater will comprise about two million or 26% of those affected (Heidenrich et al., 2013). Significant improvements in the treatment and management of hypertension and other cardiac disorders such as myocardial infarction, valvular heart disease, and arrhythmias, have improved survival and reduced the incidence of sudden cardiac death. Consequently, the overall prevalence of HF is projected to increase to an epidemic proportion (Januzzi & Mann, 2018).

Incidence

There are 915,000 new HF cases annually in the United States with incidence approaching 10 per 1,000 population after 65 years of age (Mozaffarian et al., 2016). HF has been recognized as a disease of the elderly with incidence increasing with age. For the 60-79 year old age group, 6.9% of men and 4.8% of women have HF, while for the 80 and older age group, 12.8% of men and 12% of women have HF (Benjamin et al, 2019).

The age- and sex-adjusted incidence of HF declined from 315.8 per 100,000 in 2000 to 219.3 per 100,000 in 2010. Although HF affects more men than women in all age groups, women constitute at least 50% of the HF cases because of their longer life expectancy. This also contributes to higher prevalence of HF among women than men age 80 and older (Mozaffarian et al., 2016).

The annual incidence of HF is highest in Blacks at 9.1 per 1,000 person-years compared to Whites at six per 1,000 person-years (Mozaffarian et al., 2016). HF is more common among Blacks before 50 years of age compared to Whites. The higher prevalence of risk factors, such as hypertension, obesity, and systolic dysfunction among Blacks, contributes to earlier onset of HF in this population (Sharma et al., 2014). Fifty percent of people diagnosed with HF will die within five years. The mortality rate among adults 65 years and over is 29.6% (Chen et al., 2011).

Economic Impact

HF is debilitating and progressive, with exacerbating signs and symptoms resulting in hospitalizations, high mortality rates, and impaired quality of life. HF costs the nation an estimated $30.7 billion in health care services, medications, and lost wages. By 2030, the total cost is projected to increase to $53 billion (Heidenrich et al., 2013).

HF is one of the leading causes of hospitalizations and readmissions (Ziaeian & Fonarow, 2016). Although it has been reported that age-related incidence of hospitalization for HF has decreased for all race and gender groups (Chen et al., 2011), there were more than 57 million hospital admissions in the United States with HF as the primary or secondary diagnosis between 2001 and 2014. People 65 years and over comprised more than 75% of these admissions and occurred in 53.5% of women (Akitonye et al., 2017).

Equally concerning is the prevailing high rate of readmission after discharge from a HF hospitalization. In a study of the Medicare population hospitalized for HF from 2008 to 2010, the readmission rate was almost 70% and more than 35% died within one year of the index admission (Dharmarajan et al., 2015). An index admission for HF is a significant marker of morbidity and mortality extending beyond 30 days after discharge (Gheorghiade et al., 2013). Important predictors of readmission include severity of orthopnea, renal dysfunction, hemodynamic instability, elevated levels of natriuretic peptides and cardiac troponins, hyponatremia, and presence of associated diagnoses, such as atrial fibrillation and hypotension (Desai & Stevenson, 2012; Hernandez et al., 2013). Demographic predictors of readmission include male gender, advanced age, lack of psychosocial support, low median income, prior admission within six months, medication compliance, and compliance with follow- up visits. Overall level of functional capacity, frailty, or disability, and self-reported quality of life, are also important predictors of readmission (Desai & Stevenson, 2012).

Pathophysiology

HF is a progressive disease requiring lifelong management (Hassenfuss & Mann, 2018). An index event damaging the heart muscle initiates this progressive disorder. The heart muscle damage impairs the heart’s ability to generate force and contract normally to eject blood. The onset of the index event may be abrupt as in myocardial infarction, or gradual as in hypertension and cardiomyopathies. It is important to understand, however, that regardless of the etiology of the index event, the end result is inadequate cardiac output or inadequate increase on exertion resulting in global hypoperfusion of organs (Kemp & Conte, 2012).

After the initial decline in cardiac output and ventricular dysfunction, adults with HF may remain asymptomatic. The symptoms develop after the dysfunction persists for some time. This is thought to be secondary to compensatory mechanisms that are activated in response to the decreased cardiac output. These compensatory mechanisms include the Frank-Starling mechanism, neurohormonal activation, and ventricular remodeling (Hassenfuss & Mann, 2018; Kemp & Conte, 2012).

Frank-Starling mechanism. In the early stage of HF, the Frank-Starling mechanism is an important compensatory mechanism (Hassenfuss & Mann, 2018; Kemp & Conte, 2012). With HF, the blood volume that remains in the left ventricle during diastole is greater than normal. This increased volume increases the stretch of the myocardial fibers thereby increasing the stroke volume or the amount of blood ejection with the ventricular contraction through the Frank-Starling mechanism. This allows better emptying of the enlarged left ventricle and preserves the cardiac output (Hassenfuss & Mann, 2018; Kemp & Conte, 2012).

Neurohormonal activation. Baroreceptors in the carotid bodies and aortic arch respond to low blood perfusion by increasing sympathetic nervous system activity and decreasing parasympathetic activity (Hassenfuss & Mann, 2018). This leads to an increased heart rate and stroke volume or the volume of blood ejected from the left ventricle with each heartbeat. Hypoperfusion of the kidneys leads to increased regulation of the renin-angiotensin-aldosterone pathway resulting in arterial vasoconstriction and the release of norepinephrine and vasopressin (Hassenfuss & Mann, 2018; Pearse & Cowie, 2014). The end result is sodium reabsorption, increased water retention, and vasoconstriction, increasing the mean arterial pressure

(Hassenfuss & Mann, 2018; Kemp & Conte, 2012). Neurohormonal activation in the peripheral vasculature decreases blood supply to the skin, skeletal muscle, gastro-intestinal organs, and kidneys, while preserving circulation to the brain and cardiac structures. The occurring peripheral vasoconstriction activates further sympathetic activation to maintain arterial pressure (Hassenfuss & Mann, 2018).

Ventricular remodeling. The ventricles respond to the chronic changes in hemodynamics by altering its size, shape, structure and function, assuming a less elliptical shape and becoming more spherical to increase the ventricular volume it can accommodate (Hassenfuss & Mann, 2018). The increased ventricular volume allows increased stroke volume and cardiac output. The overall increase in the ventricular wall thickness and mass leads to increased contractility (Kemp & Conte, 2012).

In conditions such as temporal intense physical exertion or bleeding, these compensatory mechanisms are successful in reversing the temporary inadequate cardiac output and other hemodynamics. In HF, however, sustained neurohormonal activation leads to further hemodynamic deterioration (Hassenfuss & Mann, 2018). The ability of the arterial system to vasoconstrict is maximized leading to further deterioration of the ventricular function. The sustained ventricular remodeling leads to disease progression independent of the neurohormonal state of the person. In chronic HF, this vicious cycle results in progressive ventricular dysfunction and death (Hassenfuss &Mann, 2018).

Ejection Fraction

Left ventricular function has been quantified with reference to left ventricular ejection fraction. Ejection fraction is a measurement expressed as a percentage of the amount of blood leaving the left ventricle each time it contracts (Lang et al., 2015). The normal ejection fraction in a healthy individual is 52% to 74%. Ejection fraction is important in the categorization of adults with HF because of differences in patient characteristics, prognosis, comorbid conditions, and response to treatments (Dunlay et al., 2012; Kapoor et al., 2016; Tsao et al., 2016).

Left Ventricular Dysfunction

HF was first understood in terms of reduced ejection fraction secondary to left ventricular failure. Later, researchers discovered that HF with normal ejection fraction was as common as HF with reduced ejection fraction (Jessup et al., 2009). HF categorization was changed to HF with reduced ejection fraction (HFrEF) and HF with preserved ejection fraction (HFpEF) after large randomized trials of different HF therapies were found beneficial for patients with reduced ejection fraction but showed little or no benefit for HF patients with normal or near normal ejection fraction (Yancy et al., 2013). About 55% of adults with HF have HFpEF, and the remainder with HFrEF (Mozaffarian et al., 2016). HFpEF is generally defined as left ventricular ejection fraction of 50% or greater, whereas HFrEF is generally defined as an ejection fraction less than 40% (Kapoor et al., 2016). Regardless of the ejection fraction, the clinical syndrome of HF is present, and the clinical manifestations are similar in both HFrEF and HFpEF (Zile & Litwin, 2018). These include breathlessness on exertion, reduced exercise tolerance, orthopnea, paroxysmal nocturnal breathlessness, peripheral edema, and pulmonary congestion (Dunlay et al., 2012; Zile & Litwin, 2018). Equally similar is the poor five-year survival rate and increased risk for hospitalization related to HF and other cardiovascular events (Shah et al., 2017).

On the other hand, there are clear differences in the response to HF treatment between these two HF phenotypes. Standard HF therapy found to have benefit with adults with HFrEF, do not reduce morbidity and mortality in HFpEF, although updated randomized clinical trials are still needed (Iwano & Little, 2013; Zile & Litwin, 2018). More recently, researchers have turned their attention to adults with HF with ejection fraction between 41% and 49%. Sub classifications of HFpEF have been identified namely: HFpEF with borderline or midrange ejection fraction and HFpEF with improved ejection fraction (Januzzi & Mann, 2018; Yancy et al., 2017). Although, there is no consensus yet on treatment outcomes for HF with borderline ejection fraction (Kapoor et al., 2016), the characteristics, treatment patterns, and outcomes appear similar to those with HFpEF (Yancy et al., 2017). HFpEF with improved ejection fraction is a subset of adults previously with HFrEF but with improvement or recovery in ejection fraction. Further research is needed to define the characteristics of this subset that maybe clinically distinct from those with persistently preserved or reduced ejection fraction (Yancy et al., 2017). This study will limit the HF phenotype descriptions to HFrEF and HFpEF.

Heart failure with reduced ejection fraction. If the ejection fraction is less than 40%, it is considered systolic HF (Pearse & Cowie, 2014). In HFrEF, ventricular contraction and ejection is affected (Singh & Mehta, 2018). The heart may fill well during diastole, but the failing myocardium is unable to eject sufficient blood during systole. Initially, the heart compensates by increasing the force of contraction to restore the cardiac output. Over time, this compensatory mechanism starts to fail and cardiac output decreases with progressive dilatation of the ventricle and stretching of the myocardial fibers (Pearse & Cowie, 2014). The consequence is reduced cardiac output leading to global hypo-perfusion. The increased amount of blood in the left ventricle leads to increased left ventricular end-diastolic pressure. This creates an increased backflow pressure in the left atrium, consequently leading to increased capillary pressure in the lungs. The elevated pressure in the lungs leads to pulmonary congestion which gives rise to the main clinical HF symptom of breathlessness (Kemp & Conte, 2012).

Myocardial ischemia or infarction is the leading cause of HFrEF (Kemp & Conte, 2012).

Other causes include excessive pressure overload with uncontrolled hypertension, increased heart rate, and volume overload secondary to valvular incompetence, cardiotoxins, and cardiotoxic drugs.

Heart failure with preserved ejection fraction. If the ejection fraction is greater than 50%, it is considered diastolic (Pearse & Cowie, 2014). In contrast to HFrEF, the systolic function is preserved with normal or near normal ejection fraction, however, there is inadequate filling of blood during diastole secondary to left ventricular stiffness, abnormality in ventricular relaxation, and concentric remodeling of the left ventricle chamber (Zile & Litwin, 2018). Contrary to the progressive pathophysiology in HFrEF, the pathophysiology in HFpEF remains incompletely studied (Kraigher-Kariner et al., 2014). One hypothesis is that comorbidities such as hypertension, chronic kidney disease, iron deficiency, and chronic obstructive pulmonary disease, cause a proinflammatory state resulting in decreased left ventricular compliance (Erdei et al., 2014). Similar to HFrEF, the end result of HFpEF is decreased cardiac output and organ hypo-perfusion. Under-perfused organs activate the body's baroreceptors triggering a complex neuro-hormonal response resulting in salt and water retention causing increased heart rate and blood pressure. Again, this response is beneficial in the short term, however, when sustained, leads to further heart damage (Pearse & Cowie, 2014). Consequently, left ventricular end diastolic pressure increases, leading to increased backflow pressure into the pulmonary veins. The increased pulmonary vein pressure causes extravasation of fluid into the alveoli creating pulmonary edema (Kemp & Conte, 2012).

Over the past two decades, the prevalence of HFpEF has been steadily increasing, as there has been increased recognition of HFpEF and increased incidence as the population age (Januzzi & Mann, 2018). It is estimated that HFpEF represents more than 50% of HF cases and is estimated to continue to be the dominant type of HF in the near future (Zile & Litwin, 2018). HFpEF patients are usually older and more likely women. Systolic hypertension is the most common antecedent condition in 80% of HFpEF cases. Obesity, coronary artery disease, diabetes, atrial fibrillation, and hyperlipidemia are common comorbid conditions in patients with HFpEF (Yancy et al., 2013). More recently, sleep apnea and anemia have been added as important comorbid conditions (Yancy et al., 2017).

Right Ventricular Failure

As the left ventricular dysfunction progresses, the most common sequela of the increased left atrial pressure and pulmonary congestion is right ventricular failure (Pearse & Cowie, 2014). When the right ventricle fails, the increased amount of blood in the ventricle increases the right atrial pressure and subsequently increases the pressure in the superior and inferior vena cava, which carry venous blood from the body back to the heart. The increased vena cava pressure leads to increased pressure in the liver, the gastrointestinal tract, and lower extremities, giving rise to signs and symptoms of abdominal pain, hepatomegaly, and leg edema (Kemp & Conte, 2012).

Acute, Chronic and Acute Decompensated Heart Failure

The term HF generally refers to those with established chronic HF whose symptoms can be classified according to the NYHA functional classification (Januzzi & Mann, 2018). On the other hand, acute heart failure generally is defined as a rapid onset of new or worsening signs and symptoms (Felker & Teerlink, 2018). This definition includes those presenting for the first time with typical signs and symptoms of HF (also referred to as de novo HF), and also those presenting with worsening of their pre-existing HF, also referred to as acute decompensated HF (Felker & Teerlink, 2018). Both types of acute HF are the most common cause for hospitalization in adults older than 65 years of age (Kurmani & Squire, 2017). Adults in acute HF often present with potentially life threatening condition often precipitated by myocardial ischemia. They present with signs and symptoms of congestion and fluid retention. The decompensation occurs when the compensatory mechanisms have been inadequate or failed to maintain adequate hemodynamics in the setting of worsening left ventricular dysfunction (Felker & Teerlink, 2018). Compared with de novo HF, adults with acute decompensated HF have more comorbidities, higher hospitalization and higher mortality rates during the year after discharge (Tavazzi et al., 2013).

Functional Classification and Disease Progression

The NYHA classification system is commonly used to classify adults into one of four classes based on functional cardiac status (The Criteria Committee of the New York Heart Association, 1994). It is also used as an entry criterion for clinical trials of medications and devices (Kemp & Conte, 2012). NYHA Class I are adults with cardiac disease but without any physical activity limitation or symptoms with ordinary activity. Adults with NYHA Class II have slight limitations in physical activity, are comfortable at rest, but ordinary physical activity will result in fatigue, palpitation, breathlessness, or angina. NYHA Class III adults are comfortable at rest but have marked limitations in physical activity with symptoms occurring with less than ordinary activity. Those with NYHA Class IV have symptoms at rest and are unable to carry out any physical activity without symptoms (The Criteria Committee of the New York Heart Association, 1994).

In 2001, the American College of Cardiology (ACC) and the American Heart Association (AHA) developed a rating system to evaluate the progression of HF symptoms (Hunt et al., 2001). This classification system recognizes established risk factors for HF and structural prerequisites for the development of HF (Yancy et al., 2018). Adults with Stage A HF are at high risk of developing HF but do not have structural disorders of the heart. Those with Stage B HF have structural disorder without any symptoms of HF. Stage C HF includes past or current symptoms which are associated with underlying structural heart disease. Those with Stage D HF have end-stage HF that requires specialized treatment strategies (Yancy et al., 2018). There are some overlaps with the two classification systems, whereas Stage A corresponds to pre-HF, Stage B to NYHA Class I, Stage C to NYHA Class II and III, and Stage D to NYHA Class IV (Kemp & Conte, 2012).

Signs and Symptoms

While the onset of symptoms is rapid in acute HF, chronic HF presents with gradual increase and worsening of signs and symptoms as the disease progresses (Alpert et al., 2017). The signs and symptoms of HF are related to volume overload and hypoperfusion (Felker & Teerlink). Breathlessness is the common presenting symptom (Felker & Teerlink, 2018). Breathlessness in acute heart failure occurs as shortness of breath on (less than usual) exertion. It can also occur as shortness of breath when recumbent (orthopnea) secondary to increased venous return from lower extremities and increased pulmonary pressures. Adults may complain of the need to use more pillows when recumbent or the need to sleep in a chair due to breathlessness. There may also be complaint of paroxysmal nocturnal breathlessness and/or coughing at night waking the individual from sleep (Clerkin et al., 2019). Adults with chronic HF most often describe their breathlessness experience in two stages: first, when HF symptoms start with very acute onset of breathlessness, and second, daily occurrence of breathlessness as the disease progresses into the chronic stages (Walthall et al., 2017). Rales may be heard during lung auscultation and pleural effusion may be evident on chest radiograph (Felker & Teerlink, 2018). Other symptoms related to volume overload include foot and leg discomfort. Lower extremity edema occurs in the presence of inefficient systemic venous return secondary to right ventricular failure (Kemp & Conte, 2012). Signs of volume overload also include ascites, increased abdominal girth, right upper quadrant pain or discomfort, hepatomegaly, splenomegaly, scleral icterus, increased weight, elevated jugular venous pressure, and increasing third heart sound or S3 (Felker & Teerlink, 2018)

Fatigue is also a common symptom resulting from decreased cardiac output (Clerkin et al., 2019). Dysfunction of the skeletal, smooth, and cardiac muscles secondary to hypoperfusion gives rise to the symptom of fatigue (Perez-Moreno et al., 2014). Fatigue can be debilitating in HF. It may affect the person’s ability to perform the activities of daily living and may contribute to decreased physical ability and social isolation (Jones et al., 2012). Fatigue has also been found to be related to depressive symptoms (Smith et al., 2012). The skeletal muscle dysfunction may lead to loss of pharyngeal muscle tone contributing to obstructive sleep apnea and central sleep apnea, which are common and predominant in adults with more severe HF (Pearse & Cowie, 2014). Adults with HF may have chest pain if the cause of HF is coronary heart disease. As the body conserves blood consumption to major organs such as the heart and brain, a low perfusion state may occur in other organs such as the gastrointestinal tract and kidneys. This may result to nausea, lack of appetite, anorexia, poor intestinal absorption, renal impairment, functional iron deficiency, and anemia. Malnutrition may cause a general loss of fat, lean, and bony tissue leading to cardiac cachexia, contributing to further fatigue (Clerkin et al., 2019).

Other signs and symptoms of hypoperfusion include altered mental status, daytime drowsiness, confusion, difficulty concentrating, as well as dizziness, syncope or presyncope.

Adults with HF may appear pale, with dusky skin discoloration and extremities are cool to touch (Felker & Teerlink, 2018). The clinical course for most adults with chronic HF tends to be one of gradual decline, often interspersed with episodes of severe deterioration resulting in emergency room admission and/or hospitalization. Towards the advanced stage, the symptoms worsen with limiting breathlessness on minimal exertion, or even at rest. At this stage, the focus of treatment becomes the relief of symptoms (Alpert et al., 2017).

Treatment Modalities

HF is an incurable clinical condition needing lifelong treatment. The goal of treatment is to improve the debilitating signs and symptoms, to extend life expectancy, and to reduce complications (Kemp & Conte, 2012). Treatment guidelines developed by ACC/AHA include three modalities: pharmacological, devices or surgery, and non-pharmacological (Yancy et al., 2017). One important point to remember when considering the ACC/AHA HF guidelines is that although the topics pertain to all adults with HF, the pathway recommendations apply only to patients with HFrEF since efficacious therapies for HFpEF remain investigational. Further, the recommendations are applicable mainly with the management of adults with chronic ambulatory HFrEF with some recommendations for adults hospitalized with acute HF (Yancy et al., 2017).

Pharmacological therapy. Several medications are recommended to counteract the negative effects of the neurohormonal adaptive responses responsible for the many signs and symptoms of HF (Yancy et al., 2017). The 2017 update to the ACC/AHA treatment guidelines include algorithms to enable all healthcare practitioners to accomplish optimal therapy for adults with HF. Beta blockers and either angiotensin converting enzyme inhibitors (ACEIs) or angiotensin receptor blockers (ARBs) are the cornerstone medications for HFrEF (Yancy et al., 2017). The use of ACE1 is recommended for all HF stages. This drug blocks the conversion of angiotensin I to angiotensin II, thereby, reducing the activation of the renin-angiotensin-aldosterone system responsible for vasoconstriction, sodium retention, and thirst in HF. Angiotensin receptor blockers (ARB) may be used on adults who cannot tolerate ACEIs. Beta-blockers are used to protect the heart from the effects of sympathetic nervous system overstimulation, thereby slowing the heart rate for more efficient ventricular contraction. In general, when initiating treatment for HF, ACEIs/ARBs may be better suited for adults with HF with volume overload, whereas beta blockers may be preferred for those without excess fluid (Yancy et al., 2017). Beta blockers and ACEIs/ARBs may be initiated simultaneously, but patients must be monitored for hypotension. Aldosterone antagonists also directly inhibit the renin-angiotensin-aldosterone system (Yancy et al., 2017). The updated guidelines also emphasize the need to titrate HF medications to the most effective dose. In general, higher doses of beta blockers and ACEIs/ARBs result in better hospitalization and mortality outcomes (Yancy et al., 2017).

There is a new angiotensin receptor blocker, combined with a Neprilysin inhibitor, called ARNI for adults with Class II or III HF despite beta blocker and ACEI/ARBs (Yancy et al., 2017). Inhibiting Neprilysin generates vasoactive peptides that are helpful in regulating ventricular remodeling, endothelial dysfunction, and vascular inflammation. The drug is recommended to further reduce morbidity and mortality in adults with symptomatic HFrEF with NYHA class II or III who tolerate ACEI or ARB. However, ARNI should not be used concomitantly with ACE inhibitor or within 36 hours of the last ACE inhibitor dose and is contraindicated for patients with a history of angioedema (Yancy et al., 2017). Ivabradine is another new drug with moderate (Class IIa) benefit that is recommended to decrease the risk for HF hospitalization on adults with persistent HF symptoms not fully controlled by beta blockers.

An anti-hypertensive agent, isosorbide dinitrate has been underutilized to control hypertension among African Americans but is strongly recommended for this population group after they have been established on beta blockers and ACEI/ARB. Digoxin is another drug that counteracts the effects of sympathetic nervous system activation and has been used in HF for more than 200 years. Diuretics relieve fluid retention and improve exercise tolerance. More recent recommendations on diuretics allow dosing changes to be flexible based on actual HF symptoms. Lastly, inotropic drugs allow the myocardium to increase contractility (Yancy et al., 2017).

Medical treatment of hypertension, dyslipidemia, diabetes, and arrhythmias are also important components of the treatment (Kemp & Conte, 2012). There are also guidelines on the management of atrial fibrillation, detection of atrial fibrillation in patients with implanted cardiac electronic devices, and weight loss (January et al., 2019).

Devices and surgery. Surgical interventions that may be used in the advanced stages of HF include ventricular remodeling, cardiac resynchronization therapy, coronary revascularization, implantation of ventricular assist device, and heart transplantation (Kemp & Conte, 2012). Ventricular remodeling surgically restores the normal anatomy of the ventricles. Reversing ischemic heart disease improves myocardial function and pumping efficiency. Resynchronization therapy improves ventricular efficiency by pacing the right and left ventricles simultaneously, while ventricular assist devices improves the cardiac output, and heart transplantation replaces the failing heart with a new functional organ (Kemp & Conte, 2012).

Non-pharmacological therapy. Self-management is an important cornerstone in managing HF symptoms. Adults in all stages of HF should weight themselves daily, maintain a healthy weight, improve their physical condition through regular exercise as tolerated, and abstain from tobacco and alcohol use (Inamdar, & Inamdar, 2016). They should restrict sodium and water intake with symptomatic HF. Immunizations for influenza and pneumonia are also important (Kemp & Conte, 2012). Other non-pharmacologic recommendations include stress reduction and depression screening (Heart Failure Society of America, 2016). Different breathing and respiratory muscle training, such as diaphragmatic breathing, slow breathing, and inspiratory and expiratory muscle training, are gaining attention as non-pharmacological approaches to manage the symptom of breathlessness in heart failure (Cahalin & Arena, 2015).

Breathlessness

Breathlessness is the hallmark symptom of chronic HF (Felker & Teerlink, 2018). It is usually reported as difficulty breathing, chest tightness, or a feeling of inadequate intake of air on inspiration (Kupper et al., 2016). Breathlessness has been considered a subjective experience unique to the individual so perception and interpretation of breathlessness may vary (Campbell, 2017). Breathlessness should be differentiated from other respiratory variations such as tachypnea, hyperventilation, and hyperpnea. These respiratory variations may not always be associated with breathlessness (Whited & Graham, 2018).

In a large population based study, the prevalence of breathlessness among adults with respiratory and cardiovascular conditions was 27% (Grønseth et al., 2014). Predictors of breathlessness included female gender, increasing age, lower educational attainment, obesity and underweight, current and past smoking history, occupational dust exposure, hypertension, heart disease, diabetes, tuberculosis, prior lung surgery, hospitalization for breathing problem as a child, and reduced forced expiratory volume in one second/forced vital capacity ratio and decreased forced vital capacity (Grønseth et l., 2014). Among adults aged 45 to 64 years in the United States, without prevalent cardiopulmonary diseases, the prevalence of breathlessness was 22% (Santos et al., 2016). Older age, female gender, higher body mass index, and active smoking were significantly associated with breathlessness.

Breathlessness is one of the most prevalent and distressing symptoms in chronic HF (DiNino et al., 2015; Parshall et al., 2012). It is the most common complaint of adults with HF presenting for hospital admission (DiNino et al., 2015; Parshall et al., 2012) and is associated with greater risk for negative outcomes (Stevens et al., 2016). Mild breathlessness is associated with a higher risk of HF [adjusted Hazard Ratio (HR) 1.30, 95% confidence interval (CI): 1.16-1.46], myocardial infarction [adjusted HR 1.34, 95% CI 1.20-1.50, and death [adjusted HR 1.16, 95% CI 1.06-1.26]. With moderate breathlessness, the risk is heightened: adjusted HR 2.14. 95% CI 1.59-2.89 for HF, adjusted HR 1.93, 95% CI 1.41-2.56 for myocardial infraction, and adjusted HR 1.96, 95% CI 1.55-2.48 for death (Santos et al., 2016). As the severity of HF increases, the prevalence of breathlessness increases (Kupper et al., 2016). Up to 88% of adults with advanced heart disease experience breathlessness in their last year of life (Moens et al., 2014).

Quantitative studies on breathlessness in HF are valuable in understanding the physiological impact of the symptom, however, it has been reported that among HF adults the reported severity of breathlessness may not be correlated with objective assessment of their cardiac and respiratory disease conditions (Guglin et al., 2012; Riegel et al., 2018). Many people who report severe breathlessness may show no corresponding pathophysiology while others who report no breathlessness may inversely show severe pathophysiology (Guglin et al., 2012; Riegel et al., 2018). Further, regardless of the cardiorespiratory pathophysiology, the sensation of breathlessness can still be very disturbing to those experiencing it. Psychological distress has been reported to accompany breathlessness (West et al., 2010).

Breathlessness is defined as a subjective experience consisting of qualitative distinct sensations of varying intensity derived from multiple factors: physiological, psychological, social, and environmental; that are interacting with each other inducing physiological and behavioral responses (Rose, 1999). In as much as breathlessness is a subjective experience (Campbell, 2017), studying it qualitatively is also a suitable approach. However, there are few qualitative studies on the experience of breathlessness among the general population and studies specific to the breathlessness experience of adults with chronic HF are even fewer.

Pathophysiology of Breathlessness

A brief review of the normal mechanics of respiration is necessary in order to understand the pathophysiology of breathlessness (Campbell, 2017). The function of respiration is both autonomic and voluntary. Autonomic control is regulated by the respiratory centers in the pons and medulla oblongata of the brainstem. Chemoreceptors in the brain, carotid, aortic arch, and throughout the arteries, as well as mechanical receptors in the joints, tendons, and muscles of the chest, provide a closed-loop exchange of information between the respiratory center and the ventilator muscles. The chemoreceptors send afferent or sensory information regarding any changes in the partial pressure levels of oxygen, carbon dioxide, and hydrogen ions in the blood, while the mechanical receptors send afferent information on the stretch and tension of the respiratory muscles. The respiratory center responds by sending efferent or motor signals to the ventilator muscles regulating the rate and depth of breathing (Nishino, 2011). These autonomic controls are involuntary, continuous, and can override conscious or voluntary controls (Campbell, 2017). Voluntary control of breathing is a function of the cerebral cortex (Coccia et al., 2016). Relative to this voluntary control, a person can change his/her breathing rate by breathing faster or holding the breath in preparation for vigorous exertion or effort (Coccia et al., 2016).

The three components - afferent signals, efferent signals and brain information processing - are the mechanisms involved in breathlessness (Nishino, 2011). One widely accepted neurophysiological mechanism of breathlessness involves a mismatch or dissociation between incoming afferent information from the receptors and the descending efferent motor command. The sensation of breathlessness arises when afferent information to adjust the rate and depth of breathing is not met with efferent commands for effective pulmonary ventilation (Campbell, 2017). Another mechanism of breathlessness involves affective processing of respiratory sensations. When motor signals are sent to the chest wall, a corollary discharge is also sent to the sensory cortex. The activation of the limbic cortical structures evokes the awareness of the respiratory effort producing the sensation of breathlessness (Evans, 2010; Nishino, 2011).

Etiology of Breathlessness in HF

In HF, breathlessness is commonly caused by pulmonary congestion as a sequela of left ventricular dysfunction causing an increase in pulmonary venous pressure (Kupper et al., 2016). Pulmonary congestion decreases lung compliance impairing the work of breathing. In chronic HF, activation of the inflammatory response stimulates arteriosclerotic and other abnormal cell processes leading to fibrosis, hypertrophy, and cell death. The inflammatory response also stimulates mucus production and bronchoconstriction (Kupper et al., 2016). The left ventricular dysfunction contributes to decreased exercise tolerance, and leads to increased breathlessness while performing the activities of daily living (Wong et al., 2011).

Weakness of diaphragm, a muscle, also contributes to breathlessness (Alpert et al., 2017). The reduced respiratory muscle strength may worsen breathlessness on exertion and contributes to early fatigue in chronic HF (Wong et al., 2011). Chronic HF leads to alterations in structure and function of the respiratory muscles particularly the inspiratory muscles, namely the diaphragm and the external intercostal muscles (Chung & Schulze, 2011; Verissimo et al., 2015; Wong et al., 2011). Age related structural and functional changes to the spine, muscles, ribs, and respiratory muscles impacting normal lung function further contribute to breathlessness (Lowery et al., 2013).

Maximal inspiratory pressure, a measure of the strength of the inspiratory muscles, begins to decrease at age 40-60 years and progressively declines with age (Pessoa et al., 2014; (Verissimo et al., 2015). Chronic HF heightens the inspiratory muscle impairment secondary to age (Kelley & Ferreira, 2017). In a large cohort of adults with HFrEF, inspiratory muscle strength was inversely correlated with NYHA functional class with severe inspiratory muscle weakness more prevalent in adults with NYHA class III and IV (Filusch et al., 2011). The prevalence of inspiratory muscle weakness is 30-50% in individuals with chronic HF (Wong et al., 2011). The result of inspiratory muscle weakness in chronic HF is the sensation of breathlessness, inability to increase ventilation during physical activity, and exercise intolerance (Cahalin et al., 2013; Woods et al., 2010). Expiratory muscle weakness has also been found in adults with both HFrEF and HFpEF. Among HFrEF, breathlessness is associated with expiratory muscle weakness (Cahalin et al., 2013).

The loss of inspiratory muscle function leads to adoption of shallow breathing as a compensatory mechanism (Woods et al., 2010). Sustained neurohormonal activation in HF to increase the cardiac output leads to worsening of the cardiovascular autonomic dysfunction manifested as impaired baroreflex sensitivity, impaired heart rate variability, and respiratory weakness (Russo et al., 2017). Shallow breathing is characterized as increased respiratory rate without an increase in the tidal volume, or the amount of air transported in and out of the lungs with each respiratory cycle. As a consequence, the ratio of dead space to tidal volume is increased, compromising alveolar ventilation and gas exchange. Dead space refers to the amount of air in the alveoli that does not participate in gas exchange. (Woods et al., 2010). As a result, shallow breathing further increases sympathetic activity predisposing adults with HF to cardiac arrhythmias, further respiratory muscle dysfunction, and increases risk for mortality (Del Rio et al., 2013).

Treatment Approaches for Breathlessness

Information on breathlessness management with advanced heart disease is limited while majority of the randomized controlled trials have focused on adults with chronic obstructive pulmonary disease (Mahler et al., 2010). Treatment approaches to relieve breathlessness in adults include both pharmacological and non-pharmacological interventions (Booth et al., 2011; Bolzani et al., 2017). Pharmacological interventions for adults include opioids, benzodiazepines and oxygen, however, according to large systematic reviews and meta-analyses, the use of these agents is at times limited as adverse effects are a constant possibility with use and the need for careful titration. In lieu of pharmacological interventions, different non-pharmacological interventions are important part of the treatment of breathlessness (Bolzani et al., 2017). Different breathing exercises such as diaphragmatic breathing, inspiratory muscle training and use of handheld fan to deliver cool air have been examined and described in HF and have shown to be effective in improving the overall burden of breathlessness and many pathophysiological manifestations of HF (Cahalin & Arena, 2015). Further, as anxiety and depression have been known to frequently accompany breathlessness, it has been recommended by the American College of Chest Physicians that evaluation of anxiety and depression be part of the treatment plan (Mahler et al., 2010).

The Lived Experiences of Breathlessness Among Adults with Heart Failure

There is a scarcity of qualitative studies on breathlessness in heart failure, while a larger body of qualitative studies exist on breathlessness in chronic obstructive pulmonary disease and cancer (Gysels & Higginson, 2011; Walthall et al., 2017). Walthall and Floegel (2019) performed a synthesis of the qualitative studies published between 2017 and 2018 on the lived experiences of breathlessness in people with HF and found three studies. The authors found the experience of breathlessness and people's understanding of the experience differed from one person to another. Adults with HF have described breathlessness in the context of the way they experience the symptom, their emotional response, its impact on their activities of daily living, psychological impact, and coping strategies to reduce the impact. Regardless of the variations in the descriptions, the descriptions were found consistent with the American Thoracic Society definition of breathlessness as multifactorial, and a phenomenon that has to be understood in the context of a person's daily life (Walthall et al., 2017).

Development of breathlessness in HF has been described as gradual or subtle that adults with HF could not identify the first time they experience the symptom in their disease trajectory (Gysels & Higginson, 2011). Walthall et al. (2017) described two distinct stages of breathlessness presentation: first during initial presentation with acute heart failure and second, during acute decompensation. Breathlessness can occur with minimal exertion or at rest, is common in HF with NYHA functional class II and higher, however, is also reported by adults in HF with NYHA functional class I or those reporting with no limitations in ordinary physical activity (Alpert et al., 2017).

Adults with HF experience breathlessness on a daily basis (Walthall et al., 2017), however, they do not always report their breathlessness to their healthcare provider (Gysels &

Higginson, 2011; Walthall & Floegel, 2019). Although they would seek acute or urgent care due to breathlessness, they would also delay seeking care because they did not equate worsening of their breathlessness with deterioration of their HF (Reeder et al., 2015). Most interestingly, HF adults would delay seeking care because they do not recognize breathlessness as a critical symptom (Walthall and Floegel, 2019). Some adults with HF do not always report their breathlessness because they do not see this as the role of the healthcare provider. One patient was even afraid to give the impression of only imagining the symptom and be given a label of being a “hypochondriac” (Gysels & Higginson, 2011, p. 6).

The disabling effects of breathlessness is common to all conditions, however, there are differences in people’s experience of breathlessness in different disease conditions. Adults with COPD perceive their breathlessness as self-inflicted. Adults with cancer perceive their breathlessness as a reminder of their mortality despite therapies, surgery and new drugs, while adults with HF perceive their breathlessness as contributing factor to the disabling effects of their disease (Gysels & Higginson, 2011).

Breathlessness impairs the person’s functional capacity and quality of life. Dyspneic adults with HF restrict their physical activity to avoid further breathlessness and fatigue, which may lead to further deconditioning (Seo et al., 2016). Impaired quality of life includes limited physical ability, psychological burdens, and social life barriers (Ahmadi et al., 2014). When asked to rate their breathlessness, most adults with HF were able to describe their breathlessness vividly but found it difficult to provide a meaningful rating. With the daily limiting symptom of breathlessness, they were unclear how or on what basis they could make the comparison to rate their breathlessness (Walthall et al., 2017). Experiencing breathlessness daily and its limiting effect on their daily activities make adults with HF uncertain of the future and if life is worth living (Gysels & Higginson, 2011; Walthall et al., 2017).

Breathlessness also affects adults with HF emotionally and socially. Some find embarrassed to be in the company of other people when breathless, leading to feelings of isolation and loneliness. They may feel angry and frustrated with the limitation imposed by breathlessness creating anxiety and stress. Breathlessness sometimes occur as a response to exertion, however some adults with HF experience breathlessness without an identifiable cause. Uncertain of what makes them breathless and when it may occur creates worry and panic (Walthall et al., 2017).

Similar physical and emotional consequences of breathlessness were found, however, the strategies used to manage the experience varied from one individual to another. Symptom tolerance, adaptation, and hoping the symptom will pass have been described as coping mechanisms (Taylor et al., 2017). The quality of their interaction with their health care provider have somehow determined the management strategies that were adopted. Accordingly, healthcare providers do not ask HF patients to describe their breathlessness or give advice on coping strategies. In the absence of concern and advice from healthcare professionals, HF adults with breathlessness resorted to avoidance strategies to cope with the symptom (Gysels & Higginson, 2011). On the basis of these findings, researchers have concluded that appropriate education is needed to recognize breathlessness as a critical symptom and adequate communication between patients and providers is needed to support management of the syndrome (Walthall & Floegel, 2019).

There is little known about patterns and types of episodes of breathlessness in HF. Simon at al., (2013) explored episodic breathlessness among adults with advanced diseases in order to describe types and patterns. Using an interview topic guide, participants with chronic obstructive pulmonary disease (COPD), heart failure, motor neuron disease, and cancer were asked about characteristics, triggers and patterns of their breathlessness episodes. As part of the qualitative interviews, the participants were also asked to draw a graph depicting the pattern of their typical breathlessness episode. Five patterns emerged as the authors grouped the graphs based on the characteristics of the onset and recovery patterns. From the descriptions, the authors determined five types of breathlessness episodes. A similar exploration focused on breathlessness in HF is needed to better understand this phenomenon in HF.

Summary

Breathlessness is a complex phenomenon that can only be perceived and interpreted by adults experiencing the symptom (Rose, 1999). It is a subjective experience best described by the people experiencing it (Campbell, 2017). Appropriate management of breathlessness in HF and other advanced diseases requires better understanding of the multidimensional nature of breathlessness phenomenon. Better understanding will inform HF adults and clinicians toward better assessment, diagnosis, and development of effective management strategies. In as much as breathlessness is a subjective experience makes it an appropriate subject in a qualitative study. Further, quantitative measures of breathlessness may not correlate with the severity of the symptom (Guglin et al., 2012; Riegel et al., 2018). To explore the experiences of breathlessness among adults with chronic HF with qualitative approach will provide a much valuable insight on its characteristics, types and patterns, its impact on daily life, and coping and management strategies being utilized.

Chapter 3

Methods and Procedures

The purpose of this study was to qualitatively explore the experiences of breathlessness in adults with chronic heart failure in order to understand the general experience, characteristics, types, patterns, its impact on daily living, and strategies used to cope and manage this syndrome. Phenomenology is the qualitative method that was used to accomplish this aim. In addition, participants were asked to draw a typical episode of their breathlessness using a coordinate graph template (see Appendix D).

Phenomenology

Phenomenology has been described as both a philosophy and a method of inquiry to reflectively examine and describe a phenomena or event and the meanings of the event as experienced and perceived from the first person point of view as opposed to the event as it exists externally to (outside of) that person (Smith, 2013). With phenomenology, various types of experiences including perception thought, memory, imagination, emotion, desire, volition, communication, and social activity can be studied (Smith, 2013). Phenomenology emphasizes the centrality of the human context in understanding the individual's life-world (Bloor & Wood, 2011). The term life-world as developed by Edmund Husserl, refers to the day-today experiences of people's lives, however, the focus of phenomenology is not on the individual nor the world they live in, but rather on the meanings or essences of their experiences while living in the world (Eddles-Hirsch, 2015). The foremost goal of phenomenology is to use the life-world as a source of evidence providing rich textured description of the lived experiences or phenomenon (Bloor & Wood, 2011).

As a philosophy, the aim of a phenomenological study is to describe, understand, and interpret the meanings of human lived experiences (Reeder, 2010). The key concepts of phenomenology include consciousness, embodiment, natural attitude, and perception (Munhall, 2012). Consciousness refers to existence in the world through the body and is the starting point in building one's knowledge of reality. Embodiment is the awareness of being in-the-world through our consciousness and is essential in individual interpretation of the experiences. Natural attitude refers to the interpretations of the experiences as experienced by the individual. Natural attitude can also be ingrained or as have been handed down from previous generations, becoming part of the individual's consciousness. Lastly, perception is the individual's interpretation of his/her reality. Reality is not what the researcher perceives as what is happening but as the individual perceives it. Phenomenology considers the individual's interpretation and unique perception of an event as critical. (Munhall, 2012).

As a research methodology, essential steps included bracketing, existential inquiry, phenomenological contextual processing, and analysis. All of these steps occurred prior to writing the phenomenological narrative and meanings (Munhall, 2012). Bracketing is the process whereby the researcher reflects and sets aside his/her assumptions, biases, intuitions, motives and beliefs about a phenomenon. In this step, it was essential for the researcher to adopt a perspective of "unknowing and decentering" which is essential in formulating the research questions (Munhall, 2012, p. 136). Bracketing began prior to data collection and is maintained during data analysis. In this step, it was essential for the researcher to identify her personal judgments and prejudices so as not to impair the analysis process (Padilla-Diaz, 2015). This is also a useful method to demonstrate validity in phenomenology (Chan et al., 2013).

The existential inquiry step required attentiveness, intuitiveness, constant reflection on decentering, active listening, interviews, and recording descriptive expressions from the person and others engaged in the experience (Munhall, 2012). Phenomenological contextual processing occurred concurrently with existential inquiry. In this step, the researcher presents his/her thoughts about the materials gathered in existential inquiry in order to describe to the readers the situated contexts of the study participants.

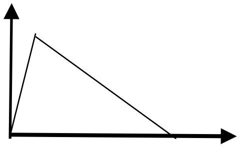
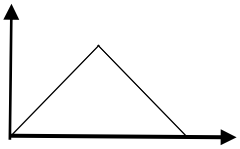
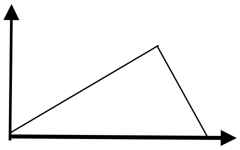
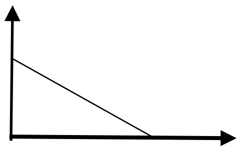
In the analysis step, the researcher sorted through individual transcripts to identify patterns, relationships, and commonalities in the meanings. In this step, dwelling and horizontalization were essential. Dwelling through empathic immersion and reflection is the process of allowing the phenomenon to reveal itself and speak into the phenomenologist's understanding (Finlay, 2014). Horizontalization is the process of finding and listing significant statements (in the data) about how the participants are experiencing the phenomena. The significant statements were grouped into larger units of information called meanings or themes that emerge from the data. The data analysis culminated in the identification of the essence of the phenomenon from the textual and structural analysis (Creswell, 2013). The final essential steps were writing the phenomenological narrative and meanings including the relationships between the themes that were identified during the analysis. The rich descriptions provided by the researcher describe the lived experiences and reconstructed as the reality with the essences and meanings contribute to greater understanding and knowledge of the phenomenon (Munhall, 2012).

Graphs

In addition to the descriptions of their breathlessness episodes, the participants were also asked to draw a graph of their typical breathlessness episodes using a graph template. The graph was used as a visualization method to depict the onset, progression and recovery of the participants' typical breathlessness episode (Browder et al., 2011). This graph only has positive number values and has two perpendicular lines called axes. The graph had a horizontal or *x* axis depicting the duration of the breathlessness episode. The participants were allowed to define the duration whether unit is in minutes, hours, or days. The vertical or *y* axis depicts the severity of their typical breathlessness episodes. The participants were allowed to define the severity whether mild, moderate, and severe. The axes intersect near the bottom of the *y* axis and the left end of the *x* axis.

The graphs were grouped according to the four different patterns (see figure 2) described by Simon et al. (2013). The groupings were based on the characteristics of the onset and recovery, whether quick or slow (see figure 2).

Figure 2. Patterns of Episodic Breathlessness (Simon et al., 2013)

Group	Graph	Characteristics
I		Quick onset Slow recovery
II		Onset and recovery the same
III		Slow onset Quick recovery
IV		Recovery only

Based on these group patterns and descriptions of their participants' general breathlessness experiences and characteristics, Simon et al. (2103) described five types of episodic breathlessness. These five types are: Type 1 – triggered episodes with normal levels of breathlessness, Type 2 – triggered episodes with predictable response, Type 3 – triggered episodes with unpredictable response, Type 4 – non-triggered, unpredictable attack-like episodes, and Type 5 – triggered or non-triggered wave-like episodes in COPD (Simon et al., 2013).

Appropriateness of Qualitative Research Method

Qualitative research is done in the social or natural setting in order to understand the phenomenon of inquiry (Creswell, 2013). The goal of phenomenology is to use the life-world as a source of evidence providing rich textured descriptions of the lived experiences or phenomenon. From the rich textured descriptions of the life-world of individuals, researchers and consumers of research can attain a fuller understanding of the essential qualities and nature of the human experiences (Bloor & Wood, 2011). The use of phenomenology was most appropriate to study the lived experiences of breathlessness of adults with chronic heart failure. It offered a method for a deeper understanding of the nature and the meaning of the breathlessness phenomenon as lived by adults with chronic heart failure.

Population and Sample

A purposive sample of adults aged greater than 18 years of age who have been diagnosed with chronic heart failure was asked to participate. A sample size of 20 men and women were sought, or until saturation of themes was reached. Participants were recruited from the heart failure clinic of a large teaching hospital in Dallas, Texas and a smaller affiliate community hospital in Irving Texas. The potential participants were approached by the researcher during their visit to the heart failure clinic utilizing a recruitment script (see Appendix 1).

Eligibility criteria were 18 years of age or older, diagnosis of heart failure (as reported by the patient and confirmed by a cardiologist from the HF clinic record), an experience with breathlessness by self-report, and the ability to speak and read English. There were no eligibility criteria set for type of treatment the participants were receiving for their HF and breathlessness, and maximal variability were sought with regards to ethnicity and NYHA functional classification. Exclusion criteria were cognitive impairment or incompetence as judged by the investigator, lack of capacity to give informed consent, recent (within past 6 months or less) cardiac surgery, resynchronization, or device implantation, and severe breathlessness or any condition precluding participation in the interview. To assess the participants' cognitive ability, the researcher spent one to two minutes engaging the participant in general conversation. This offered an opportunity to build rapport with the participants as well as assess their broad cognitive processing, general mood, and communication ability. The investigator assessed how quickly the participants responded to the general questions and their engagement in the general conversation.

Setting

The participants were interviewed in a private consult room in the outpatient heart failure clinic located in the campus of a large teaching hospital in Dallas, Texas and a smaller campus in Irving, Texas. The two clinic provides comprehensive care to approximately 1,200 adults with heart failure from evaluation to diagnosis and treatment. The clinic offers highly specialized services including extensive education on medications, diet and lifestyle changes, exercise and cardiac rehabilitation, inotropic medications, and evaluation for surgical options such as ventricular assist device or heart transplant. The heart transplant program of the hospital is the largest in Texas and the second largest in the nation in terms of volumes.

Both hospitals are not-for-profit hospitals nationally accredited by The Joint Commission and offers a variety of heart and vascular services with several other acute care services. The Dallas hospital is licensed for 921 beds and the Irving hospital is licensed for 293 beds. The Dallas hospital is the nation’s first hospital to receive the Gold Seal of Approval from The Joint Commission for the Ventricular Assist Device program. In partnership with the Baylor Scott and White Research Institute and Baylor Scott and White Heart and Vascular Hospital, the hospital coordinates more than 50 studies involving cardiac surgery, cardiology, cardiac and vascular intervention, electrophysiology, vascular surgery and cardiovascular disease prevention.

Data Collection Method

An exploratory qualitative approach using in-depth interviews was utilized for this study. The use of semi-structured interviews facilitated exploration of the experiences of breathlessness in adults living with heart failure, their description of the characteristics, types and patterns of breathlessness, as well as strategies used to manage the breathlessness syndrome in the context of their daily lives. Using the recruitment script, the researcher approached potential participants after they were checked in the HF clinic exam room and were waiting to be seen by their HF clinic provider. The researcher engaged the potential participants in general conversation and questioned them about their breathlessness experience. After ascertaining if the potential participants met the inclusion and exclusion criteria, the researcher introduced the study, its purpose and the interview process. Potential participants who expressed willingness to participate were asked to meet the researcher at the conclusion of their clinic visit, in a private consult room located next to the heart failure clinic exit door.

The consent process and individual interviews took place in the private consult room.

The researcher conducted one face-to-face semi-structured interview with each consenting participant lasting no more than an hour. An interview guide (see Appendix C) was utilized to allow the participants to tell their own story of living with breathlessness. The interview guide included open-ended questions to explore the breathlessness experiences of the participants, characteristics, types, patterns, its impact on daily living, and strategies used to cope and manage this syndrome. Prompts, probes, and follow up questions were used as appropriate to fully explore the participants' point of view. An example of specific open-ended interview question was "What specific circumstances make you short of breath? [Probe: triggers, activities] [Prompts: What activities are you usually doing when you feel short of breath?]. To ensure proper understanding of the responses and meanings, key ideas and themes were summarized back to the participants as appropriate. Questions also were asked for the participants to describe the severity and the duration of their typical breathlessness episode. For example, participants where asked, "When you get short of breath, how would you describe the severity from start to finish?" and "How long do you feel short of breath before you can breathe normally again? Is there a pattern of start and stop time?" As part of the interview, the participants were asked to draw at least one graph to illustrate patterns of their breathlessness episodes in terms of its onset, duration and recovery.

Procedure

After a brief introduction, the purpose of the study was explained to each participant. The study protocol for the interview was explained to each participant. The participants were given ample time to ask questions or discuss their concerns. The participant were given a copy of the consent. The consent was reviewed by reading through it together. Ample time was given to each participant to ask questions and seek clarifications about the consent and the study. The participants were asked to sign the form if they agreed to participate. Before commencing the interview, demographic and clinical data were obtained using the demographic and clinical data tool (see Appendix B). Demographic data were collected including age, gender, ethnicity, highest level of education obtained, living situation (whether living alone, with spouse, with other family member), and the perceived level of support available to them. Clinical data including etiology of HF, NYHA classification, and comorbidities including but not limited to diabetes mellitus, cancer, COPD, and asthma were collected. The demographic data were collected as self-report by the participants, while the clinical data were collected from the HF clinic record after obtaining permission from the participants.

Each interview was audio-recorded, and notations were made on behaviors and reactions observed during the interview process. Further questioning and probing were used to elicit additional information, provide focus to the discussion on breathlessness in heart failure, or clarify information. Each interview lasted no more than an hour. Narrative interviews were conducted until no new information emerged and saturation was achieved. As part of the interview, the participants were asked to draw a graph to illustrate the typical patterns of their breathlessness episodes.

Ethical Considerations

The study was submitted for approval to the Nursing Research Council of the facility and the health care system. Following the approval of these two research councils, the study was submitted to the hospital system Institutional Review Board (IRB) and the University of Texas at Arlington Institutional Review Board for approval prior to study initiation.

Each potential participant was verbally informed of the purpose of the study prior to enrollment. Participants were provided a copy of the study consent and the content was read verbatim to the participants. Each participant were given ample time to ask questions and discuss their concerns before the consent was signed. Each participant was given the assurance that the care they receive at the heart failure clinic will not be altered or affected whether they consent to participate or not. The procedure for withdrawal from the study with no penalty was also explained. The participants were assured their demographic and clinical information as well as the interview responses will be treated with extreme confidentiality. The responses the participants provided to the interview questions were only used in the reporting of the findings to provide context to the themes that were identified.

There is minimal risk associated with the interview process. Participants may feel slightly anxious when recalling their breathlessness experience. Participants were assured that they do not have to answer any particular questions if they do not feel comfortable responding. If they feel upset, the participants were allowed to stop the interview process at any time. The potential risks in this study are outweighed by the potential benefits.

Any information that were obtained in connection with this study and any patient identifier information were treated with extreme confidentiality. Confidentiality was maintained by use of code numbers instead of subjects' names. The investigator did not use any patient identifier in the conduct of or reporting of this study. Any information that can identify individual subjects were and will not be released to anyone outside the study without the subject's consent. Data were coded to remove direct identifiers. The link to the codes were saved in a flash drive accessible only via password and was kept in a locked drawer. Audio files were for transcription purposes only and were permanently destroyed as soon as transcription is complete. Transcription was done by the primary investigator. Retention and destruction of all forms of information obtained on the subjects in the conduct of this study are handled according to the IRB protocol.

Method of Data Analysis

Thematic Analysis

Interviews were audio-recorded, transcribed in verbatim, and rigorously analyzed using thematic analysis or qualitative content analysis by the Principal Investigator. The first step of this method is referred to as familiarization, which entailed reading and rereading the interview transcripts. Familiarization encourages seeing individual differences inherent in the transcripts to better identify within-and between participant differences. Early impressions that emerged and any specifics the researcher wanted to remember for later are jotted on one side of the paper transcript. The next step was to identify emerging themes or codes (Creswell, 2013). The codes and categories were compared, contrasted (between and within the participants) and sorted until no new categories and codes emerged. Phenomenological data analysis continued through horizontalization or the process of finding and listing significant statements (in the data) about how the participants were experiencing the phenomenon. The significant statements were grouped into larger units of information called meanings or themes. The data analysis culminated in the identification of the essence and the meanings ascribed to the phenomenon by the participants (Creswell, 2013).

Types and Patterns of Breathlessness

As each participant drew the graph, the researcher asked each participant to describe the pattern by going through their descriptions of their breathlessness experiences again. This allowed the researcher to confirm with the participants the pattern that was drawn.

Delimitations

This descriptive qualitative study focused on the experiences of breathlessness among adults with chronic HF and the semi-structured interviews elicited retrospective recollection of their breathlessness episodes. Purposive and convenience sampling of men and women greater than 18 years of age of White, Hispanic, African American and Asian ethnicity was utilized.

Summary

The purpose of this study was to explore the experiences of breathlessness in adults with chronic heart failure in order to understand the general experience, characteristics, types, patterns, and triggers of breathlessness, impact on daily living, and strategies used to manage this syndrome. A descriptive qualitative design using descriptive phenomenology was used for this study. Interpretation and analysis of findings using the thematic analysis method provided a method of demonstrating rigor and trustworthiness in data obtained through the qualitative methodology. The findings of this study will assist patients and clinicians to inform them of the progression of the HF and in the development of management strategies and individualized care plans to assist adults with HF manage their breathlessness.

Chapter 4

Findings

The research questions for this study are: (1) How do adults with chronic HF describe their experiences of breathlessness? (2) How do adults with HF describe the types and patterns of their breathlessness? (3) How do adults with HF describe the impact of breathlessness in their daily life, and (4) How do adults with chronic HF adjust to and manage their breathlessness? The data for the study was collected through semi-structured interviews with 14 participants. Interviews were conducted between January through March 2020. Each interview lasted between 17 to 46 minutes and was transcribed verbatim.

Findings begin with the description of the participants' socio-demographic and clinical characteristics, followed by the findings extracted from line-by-line coding of transcribed interviews. These are presented as themes and subthemes assigned to the four research questions. Themes and subthemes are described in detail and supported with quotes.

Participants' Demographics and Clinical Characteristics

Demographic and clinical information were obtained using the demographic and clinical data survey tool found in Appendix B. Categorical socio-demographic characteristics of the study sample are presented in Table 1. Among the 14 participants, eight (57%) were males and seven (50%) were White. The mean age was 67 (± standard deviation [SD] = 10.6 years), and the range was 50 to 88 years. Five (36%) participants had completed college. Twelve (86%) participants lived with a spouse or other family members and 12 (86%) reported receiving very good level of support.

Table 1. Demographic Characteristics of the Study Sample

Characteristics	n (%)
Gender	
Male	8 (57%)
Female	6 (43%)
Age (years)	
Range	50-88
(Mean± SD)	(67.43 ± 10.64)
Ethnic Group	
White	7 (50%)
Black	4 (29%)
Hispanic	3 (21%)
Education	
Grade School	1 (7%)
Some High School	1 (7%)
Graduated High School	3 (21%)
Some College	4 (29%)
Graduated College	2 (14%)
Master	3 (21%)
Lives with	
Alone	2 (14%)
Spouse	8 (57%)
Children or other family member	4 (29%)
Satisfaction with support from family and friends	
Satisfactory	1 (7%)
Good	1 (7%)
Very good	12 (86%)

Clinical characteristics of the participants are presented in Table 2. Non-ischemic and dilated cardiomyopathy ranked as the most documented etiology of HF in eight (57%) participants. When asked about their NYHA classification, most of the participants reported not knowing this information or had not been told of this information by their HF provider. However, based on the review of their HF clinic record, six (43%) participants had NYHA Class III while another six (43%) did not have the NYHA classification documented on their HF clinic record. Eight (57%) participants had an ejection fraction of ≤ 40% and six (43%) had an ejection fraction of ≥ 50%, and the range was 15% to 69%. Twelve (86%) participants had two or more co-morbid conditions, the three most common being hypertension in 10 (71%), diabetes in eight (57%), and kidney disease in seven (50%) participants.

Table 2. Clinical Characteristics of the Study Sample

Characteristics	n (%)
Etiology of HF	
Ischemic	5 (36%)
Cardiomyopathy	8 (57%)
Hypertensive	1 (7%)
NYHA Classification	
Class II	2 (14%)
Class III	6 (43%)
Not Documented	6 (43%)
Ejection Fraction	
40% or less	8 (57%)
50% or greater	6 (43%)
Comorbidities	
Diabetes	8 (57%)

Cancer	3 (21%)
COPD	2 (14%)
Asthma	2 (14%)
Pulmonary Hypertension/Fibrosis	4 (29%)
Kidney Disease	7 (50%)
Hypertension	10 (71%)
Sleep Apnea	1 (7%)
Irregular Heartbeat	5 (36%)

When participants were asked of other symptoms they experienced with their breathlessness, seven (50%) participants reported fatigue and the other seven participants (50%) reported at least one of the following symptoms: dizziness, irregular heart-beat, leg pain, chest pain, gastric pain, and confusion.

Thematic Analysis

Findings extracted from line-by-line coding of transcribed interviews are presented as themes assigned to the four research questions exploring the following four main categories: nature of breathlessness, types and patterns, impact of breathlessness on daily life, and management strategies employed by the participants.

Nature of Breathlessness

The first research question explored how adults with chronic HF describe their experiences of breathlessness. Most of the participants experienced breathlessness before receiving the HF diagnosis. It was their breathlessness that prompted them to see a physician, however some described delaying to see a physician. One participant described going to an urgent care center because of her breathlessness. The physician told her, based on her chest X-ray, that she had congestive HF, yet she was allowed to go home without treatment and only with the instruction to see her primary physician. From the urgent care center, she then went to a hospital emergency room where she was immediately admitted to the hospital and started on HF medications. One participant was diagnosed with HF after his failed coronary artery bypass and is currently on the waiting list for a heart transplant. Some of the participants have improved their breathlessness after their HF diagnosis, while some continue with episodes of breathlessness despite their HF regimen. Analysis of data revealed five themes: “no air”, accompanying symptoms, “just happens”, general shortness of breath versus cannot breathe, and first reaction.

No air. This theme embodies the participants’ descriptions and perceptions of what it feels like to be short of breath. Participants have vividly described their breathlessness as “not being able to breathe”, “running out of breath”, “not getting enough oxygen”, and “a compressed feeling in the chest making it difficult to get their breath” into their lungs. Participants also described their shortness of breath as a compressed feeling as if being pulled down or the body is shutting down. One participant described how it feels to be short of breath in this manner: “I can’t breathe… like the air is cut off, like there is no air to breathe or no air coming out”.

Accompanying symptoms. The theme of accompanying symptoms embodies how participants have also described their breathlessness in terms of other symptoms they experience during the breathlessness episode. Fatigue has been described as the most common accompanying symptom.

> Yeah, that’s probably my main thing right now. Umm, I get fatigued pretty easily just from short walks you know, moving around the house. It is not bad, but if I go around the house on a short walk, I get pretty fatigued pretty easily.

Fatigue has been described as an overwhelming sense of being tired or exhaustion, feeling significantly weak or debilitated, lack of energy, and reduced physical strength. “I was tired a lot. I would be talking to my friends on the phone and would be falling asleep. I was going through everyday feeling tired." "You can feel it in your muscles, you can feel it everywhere. It is like something is pulling you down."

> To think about it, I was huffing and puffing but it was accompanied by lack of energy to complete what I was doing. Like this one time, I was going to do the laundry. It was not far from where I live, it was like kind of just a little further than that door [points to the door of the room]. I could not make it. So, I just sat down on the lawn and prayed that somebody would help me just get it there.

A participant who was recently admitted to the hospital secondary to an acute decompensation episode provided this description of his breathlessness and its accompanying symptoms.

> Oh yeah, I can't lay flat on my back without serious issues. When it is really bad, there is pain in the center of my chest and… I would say the confusion was probably the final stage where I was mentally screwed up. It was kind of gradual. At first it was just fatigue and out of breath and then the chest pain and then the confusion was the final stage but each episode, the breaths got harder and harder in each one of those stages.

Just happens. This theme describes the unpredictable nature of breathlessness and the variability of its occurrence. Exertional breathlessness has been described by most of the participants, however the occurrence varies among those with exertional breathlessness. Some participants experience exertional dyspnea on a daily basis, and they can predict it with any exertion, while others have described being breathless only in some activities and not breathless in other activities. Those with unpredictable exertional breathlessness described not knowing what activity would cause shortness of breath and what activity would not. In performing their daily activities of living, some participants described being breathless on some days while on other days they are without breathlessness doing the same activities. These participants have denied anticipating they will get short of breath. "It just happens" was how one participant described it. "I don't anticipate it, but it happens. It was just out of the clear blue, then I felt it was coming." "I never know when I may get short of breath. Like I said some days I walk around the house okay and other days I get short of breath."

> You never really know when it is going to happen. There is no set time or day. Some activity I am doing, it will crop out and then I may have whole day with no problem, you see, and then the next day I am doing the same thing then I may have to sit down for a couple of minutes before I can go on.

General shortness of breath versus cannot breathe. This theme refers to how participants would describe a lower severity of breathlessness as general shortness of breath compared to a more severe episode as not being able to breathe. Participants with exertional breathlessness have differentiated between general shortness of breath and cannot breathe by how quickly recovery ensues after stopping the exertion that caused the breathlessness. General shortness of breath has been described as "normal" shortness of breath from exertion and is characterized by quick recovery once the participant stops the exertion, while "cannot breathe" refers to exertional breathlessness without the ability to quickly recover despite stopping the exertion.

> It is just general shortness of breath, you know, with exertion. It's normal shortness of breath, not like when I have to stop and lean against the wall. And if I am short of breath from that, the minute I stop, ahh, from running around, you know, to catch my breath, I will begin to recover, and so that starts immediately. And now that is not the case when I do something, you know like when I have to walk long distance or when I have to stand for a long period of time. I, ah, you know, when I finally get the chance to sit down or lie down, I don't… the thing that concerns me is I don't begin to recover right away.

First reaction. This theme embodies the initial reaction adults with HF have when they first experience shortness of breath. It also embodies their attempt to identify a reason for their shortness of breath and explain the reason for its occurrence. Participants have verbalized not recognizing the symptom and the reason for their shortness of breath. They have described initial denial reactions which may have delayed seeking medical help, as well as being in a state of shock when they cannot explain the reason for their breathlessness.

> I guess you could say I was not recognizing I was short of breath! That is exactly right. I am kind of stubborn. When it comes to my health, I am kind of stubborn. I would just tell myself, "You are not sick, there is nothing you cannot do." Like I was telling myself,

> I can make this work. It was really hard. I guess you can say I was determined not to accept that I was sick. Come to think of it, I had worked as what the doctor said, “You have worked up to the very day”, and I say, “I know, what was I thinking. But I had no idea, I really didn’t”.
>
> Umm…. frightening, umm…because you do not know what is causing this. The shortness of breath, when you finally get it in ease and under control, then you got that, everything is ok. But then you know, you get up, then it starts all over again. When that continues, then you continue to feel like it’s… I mean it… it’s really shocking to you especially if is not anything to explain what would cause something like that. When you discover it, it is like…wow, what is going on?

Many participants initially thought something was wrong, however many tried to attribute their breathlessness to other reasons such as being overworked, overweight, a change in the weather, allergy, or even bronchitis.

> Yeah, yeah, it started slow and was noticeable, but it wasn’t like you can pinpoint why, why this is coming about. And as the time went, it got a little worse, then, a little more badly. Then like I said that day, I thought “man if I couldn’t walk 100 feet, then I know there has got to be something wrong.
>
> When it basically started… I was just… I don’t know, … just like the weather has changed and so I thought my allergy was acting up. That was when I thought it could be asthma. It’s like um… it is like a slow thing… but you feel it is happening because you feel like you can’t do anything, like you can’t walk down the hall without being short of breath. It started to increase a little bit. So, I just took allergy pill, which I normally do.
>
> No, I thought I had bronchitis at the time. It was the confusion… and ahh… hiccups actually. [Wife chimes in – and the pressure]. Yeah there was pressure in my chest, which was a lot different than bronchitis. The shortness of breath I thought was just regular bronchitis or flu, so I thought I was coming down with bronchitis because I was also coughing a little bit.

The lack of recognition and understanding was stressful and distressing to the participants.

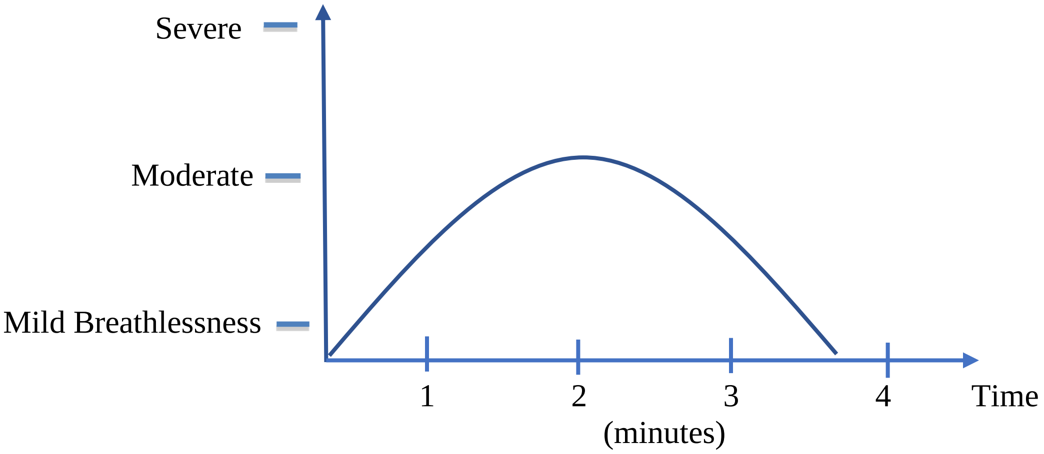
> It was very stressful and distressing because in your brain, you think you can do the things you used to do but then you start doing it then your body tells you no. Like there is a fight going on and you cannot seem to understand it in your head.

Types and Patterns of Breathlessness

The second research question explored how adults with HF describe the types and patterns of their breathlessness. Using the semi-structured interview guide, participants were asked to describe the patterns of their breathlessness including triggers, the severity and the duration. With the use of a graph template with the *x*-axis to illustrate the duration and the *y*-axis to illustrate the severity, participants were asked to draw at least one graph to illustrate the pattern of a typical episode of their breathlessness. Participants were asked to define the duration units whether in minutes, hours or days. Thirteen of 14 participants were able to draw the description of their typical breathlessness episode on the graph. One participant received a phone call while the graph was being explained to her then she had to leave without completing the graph.

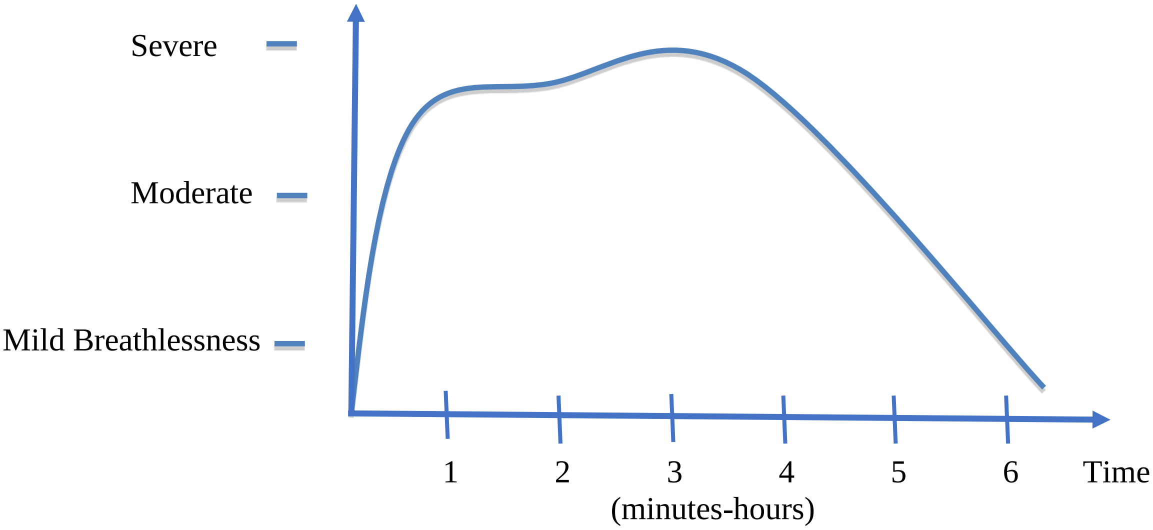
The types and patterns described by Simon et al. (2013) were used to guide the analysis of the graphs in this study. In this current study, 10 graphs depicted a pattern with similar time for onset and recovery or group II, while three graphs depicted a pattern with quick onset and slow recovery or group I. Majority of the participants described a Type 2 or triggered episodic breathlessness with predictable response (see Figure 3). This type was typical for those with exertional dyspnea. The activity (exertion) was both the trigger and the worsening factor. With this type, the participants described their breathlessness to be always triggered by a certain level of activity, followed by a gradual increase with a predictable level of severity that continued to increase unless they stopped the trigger (activity). Most participants described the peak severity of their breathlessness as moderate because they immediately stopped whatever they were doing to catch their breath and recover. These participants have learned that if they do not stop, the breathlessness gets worse. Many described a gradual increase and a gradual decrease in their breathlessness severity after stopping the activity that triggered the breathlessness. These participants described the duration of their breathlessness varying between one to two minutes after stopping their activity. There were variations in the characteristic of their recovery from their episodic breathlessness. Some have returned to baseline pre-breathlessness level while some remained with mild breathlessness for a short while before returning to normal breathing.

Figure 3. Type 2-Triggered episode with predictable response



Some participants described a type of episodic breathlessness with a quick onset and increasing to severe intensity immediately before gradually decreasing to normal breathing levels. This type of breathlessness corresponds to type 5 which can be triggered or non-triggered wave-like episode (see Figure 4). Unlike type 2, this episodic breathlessness has been described to have a quick onset, higher severity and longer duration. This type may not be related to activity and participants have drawn this type as a wave which corresponds to the severity lasting for several minutes or even hours. One participant described feeling short of breath all of a sudden and the severity intensifying immediately. Her breathlessness remained severe as she pushed herself to walk farther (which was the triggering activity) before gradually tapering down to recovery level. The duration of her breathlessness episode lasted seven minutes even after she has stopped walking. She gradually recovered to normal breathing but had another breathlessness episode once she started walking again. Another participant described experiencing breathlessness "out of the blue" and was uncertain what activity triggered the breathlessness. Another participant described this type of breathlessness while he was resting and the duration lasting for four minutes.

Figure 4. Type 5-Triggered or non-triggered wave-like episode



Impact of Breathlessness

The third research question explored how adults with chronic HF describe the impact of breathlessness in their daily life. Participants have described the impact of their breathlessness on their lifestyle, their activities of daily living including sleeping and walking, as well as the impact on their emotional and social life. Analysis of data revealed the following themes: feeling guilt or self-responsibility, “I used to”, helplessness, and forecasting.

Feeling guilt or self-responsibility. This theme describes how the participants attempt to rationalize or examine their role for developing breathlessness and HF. In the process, participants have described feeling guilt or feeling responsible for their breathlessness. Some participants have attributed their shortness of breath from being overweight, their unhealthy lifestyle, or habits such as smoking, not exercising or being active, and failing to take care of their bodies.

> I do not know why I get short of breath. So, I am trying to fight it. For me, I was still making excuses, like, ‘Oh you are overweight.’ Is it something I have been doing, like I am responsible for myself and for getting short of breath? In my mind, I make up stuff like, you know, you need to walk more. The doctors tell me that I still have to walk even

> when I get short of breath but how can I walk more when I cannot walk because I am short of breath? You kind of give yourself a reason why you feel short of breath.

Another participant stated, "I have heart failure because of a lot of things combined, you know? I used to smoke, I didn't exercise, I didn't eat right. I did not take any meds. I just didn't take care of my body."

"I used to". This theme describes the impact of breathlessness on their lifestyle, social life, ability to work, hobbies, and interests. The participants described feeling restricted in their mobility and losing independence and autonomy to do previously enjoyed activities. Participants described longing for the time in their life when they were able to do whatever they wanted to do, when they wanted to do it, and the pleasure and enjoyment they derived from doing the activities. This loss of activity leads to feelings of sadness, distress, and anger.

> I used to be able to do whatever I wanted to do, whenever I wanted to, the way I wanted to do it, and I just cannot do that anymore. I used to go play racquetball, but I cannot do that anymore as I can't breathe, and I can't keep my balance. I used to just rollerblade and then ride my mountain bike… It makes me really sad [change in tone of voice as if one can tell the sadness in her voice], you know like, like these past few days, in the afternoon it is just gorgeous outside. And so you know, when I was working and I came home and it was just like that (gorgeous), I, you know, I grab my bike and my music and just go for a ride. I just wish I could still do the things I used to do.
> Well, I wasn't near as active, so the shortness of breath was better but then I was giving up my lifestyle too to go with that. I mean I could not continue to be active because the shortness of breath kept coming on so that at the very beginning it was like, 'Man, this is terrible because I got things to do, I got places to go, I got people to see.' I've got too much to do and this is bothering me, just really bothering.

Breathlessness has forced the participants to lead a less active life at home and at work, and unable to enjoy activities with their family.

> Oh, I'd like to do more. I guess you can say I have always been a blue-collar worker. I have always done physical work. I have been a house inspector for 29 years, lots of, you know, checking on houses, climbing up attics, climbing up roofs. I have been very active as far as doing things. I now I have to sit at home a lot, … my wife won't let me do a lot of things anymore. But I don't do much stuff, I don't do that anymore really. I stay pretty close to the house.

> Oh yeah, it was frightening. It kept me from getting out in the yard and doing gardening. Umm… it kept me from walking from my car into a soccer field to watch my grandsons play. It kept me from doing a lot of things. I could not go dancing… and… I love dancing but I got to the point where I cannot even dance to the whole song.
> Then I was like…man…I am out of breath, I'm tired, I got to sit down.

Participants have also described increasing dependence on family members as they find themselves unable to complete tasks they previously carried out for themselves. Participants find this limitation to be frustrating. When doing things with their friends, participants find themselves unable to keep up with the activity as they find the need to slow down or stop to relieve their breathlessness. Participants react to this change by isolating themselves.

> Well, I know if I do not stop, it just keeps getting worse. Like, you know, when I bring in heavy stuff, like when I had to get a case of water… I got it out of the car but can't get it to the house. My sister was home, and I just say, you know, 'Could you please help me?' And she was like 'Sure!'
>
> It is just frustrating when I am going and doing things with friends, you know when we are walking and things. I always say, "Just go, don't worry about it. I just had to stop and catch my breath. Then I have to try to walk slow and not let it happen again. If I try to hurry up, I will get short of breath again.
>
> If I want to do something outside, you know if I have to do quite a bit of walking there, kind of limit me. I… I don't really want to burden my wife or my friend when I have to go somewhere. I… I just stay home because I don't want to be holding them back if there is quite a bit of movement or whatever. You know, I try to consider if I can do it or not especially if other people are involved, I just let them go on.

Participants described their ability to do things to be as variable and unpredictable as their breathlessness.

> And you know, some days are not as bad as the others, but then there are days that are like, you know when I have done so much for that day, the next day, I just stay at home. I don't do anything because I just feel wiped out. And so, that is physical, but then it makes me sad because I can't do what I used to.

Participants also described negative feeling about other people's perceptions and behaviors towards them and their breathlessness. Family members and co-workers may be perceived as lacking understanding of their shortness of breath instead of being a source of support and assistance. The perception over the change in the relationship adds to the sense of loss and sadness.

> Yeah, and you know, even some family members. We went on a family vacation, and we went to this great resort in Tennessee called Blackberry Farm. It was wonderful, it was lovely, it was in the foothills in Tennessee and there were so many of us we rented this huge house and so I just can't do well with the steps. My niece was there with her husband and their little girl and she just… she just kind of… we have always been very close, and you know, she seem like she was disgusted with me because I couldn't do what I used to do. And I was kind of surprised that she acted like that! And so, I feel more comfortable asking some family members for help than I do others. And so, she was here for Christmas, and you know, there were some things I needed her help me do and I find somebody else to help me because of the way she kind of act sometimes. And so, we were so close when she was growing up and so it just kind of make me sad. You know, I wish the relationship could be like when she was young. [Clears throat]

Helplessness. This theme describes the beliefs and perceptions of the participants of not having any control over their breathlessness or having the ability to do anything to help their breathlessness. This also refers to their perception that their HF provider cannot do anything with their breathlessness or are not helpful with their breathlessness. "It is like a slow thing, and you feel it is happening because you feel like you can't do anything, like you can't walk down the hall without being short of breath." "Nothing! There is nothing you can do. Actually, when it comes to your heart, there is nothing you can do besides to rest." "My wife tries to encourage me, but I cannot do more walking if I cannot breathe, and I feel that there is nothing that my doctor can do to help my shortness of breath."

> "Like I said, information from the doctor about my heart failure. I did not have any information to know about heart failure and why I was short of breath. Not until I got to this clinic. That was very frustrating for me. I was not getting any information from my doctor where I live."

Forecasting. Another theme identified as an impact of breathlessness is forecasting. This theme describes the uncertainty the participants feel about the future given the chronic recurrence of breathlessness and declining functional capacity. None have used the word deterioration but have expressed their condition is progressing to the point they may become completely dependent on others as if to acknowledge that HF is incurable, and death is inescapable. On the other hand, some participants are aware of the precariousness of their condition yet remain hopeful of a cure.

> …it kind of worries me sometimes that… is there a day when I just can't recover. So, it makes me, you know, concerned because slowly but surely, things are progressing to the point where I feel like I can just do a little bit less and a little bit less.
>
> Well, now I know it is something they can't cure but I have not been smoking or drinking. I know I have lung issue, but it is not because of something I did that I should have not been doing. I just hope they can find something to help. I mean being short of breath…it is a frightening experience… because… typically have this feeling that your breathing is something just… ahh… involuntary… just taken cared of. But when you have shortness of breath you then focus on how can I force the proper volume of air even when I do not necessarily have any control of it.

Management Strategies

The fourth question explored different strategies participants employ to manage their breathlessness. All participants described at least one strategy to manage their episodes of breathlessness. Several coping strategies and active interventions were described. Six themes emerged from the data: stop and breathe, acceptance or carry on, adapting, planning, new perspective.

Stop and breathe. This theme describes the need to stop whatever the activity that caused the breathlessness in order to find relief from it. Many participants have become aware when they feel short of breath, and most often they have described stopping when it happens to rest and catch their breath and then complete what they were doing. Many participants have employed this management strategy regularly knowing their breathlessness will not improve if they do not stop. “In my case, I had to stop and sit down, get myself breathing easier again, before I can continue.”

> Resting! You need to stop, put everything down. That means you sit down. It may last only ten minutes, but it may last an hour or longer if you do not stop. There is no winning, you will continue to be short of breath if you do not stop.
>
> It will get better once I stop and rest. You got to rest; otherwise, you will continue to be short of breath. You got to sit down for a while. "Then when I had to stop, it would take about 2 minutes at the most before I feel I can breathe normal again.

Some participants have described the use of deep breathing to overcome the episodes of breathlessness, however, the technique was described as a way to calm them by taking deep breaths, particularly when they become aware they are breathing fast to overcome their breathlessness. "Not necessarily deep breathing but when I was in the hospital, I learned there... I guess calm myself so that I was not breathing fast and maybe taking more deep breaths." Only a few participants have described it as method formally learned from pulmonary rehabilitation class or taught by a licensed physical or respiratory therapist.

> And so sometimes, I just have to sit there and do absolutely nothing or you know, like they taught us a technique in pulmonary rehab to use when we are short of breath, you know, you inhale like to the count of two, umm… just breathing in through your nose, and then you breath out to the count of four.

Acceptance or carry on. This theme describes how the participants have gradually began to accommodate their breathlessness and the limitations it has imposed on their lives. As a coping mechanism, they have learned to focus less on the breathlessness but more on what they can do despite the breathlessness and their limitations.

> What I am just saying is like if I have to run to catch the bus, I will not be able to do that. I know I will get short of breath. I guess you can say, that is how I am managing it also is knowing what I am capable of. I just know any kind of exertion will make me short of breath.
>
> You know, probably not in a month but probably in the last three or four months. I can tell I get fatigued pretty easier and I have to think something before I do it. I just… I have learned….mentally what is not good, and I just pace myself.

This code also describes how the participants maintain a strong will to keep their independence and physical autonomy to overcome the limitations breathlessness has created in their lives. Participants gradually began to change the way they did things and their lifestyle in order to take control of the limitations their breathlessness has imposed on them. They have described not dwelling or focusing on the symptom but rather continue to live as normal life as possible. “I always say, “Just go, don’t worry about it. So then, I would get up and go again. I am not letting this stupid shortness of breath keep me from going.” They continue to make plans as if not letting their breathlessness dictate what they can do. “We are planning this trip to Quebec and I say I am not letting this stupid shortness of breath keep me from going.” Participants think focusing on their breathlessness may push them to disability. “I don’t think about it. Yeah, you know, if you think about it, it will probably put you on a wheelchair. Just get up and go do what you do.”

Adapting. This code describes the different modifications adults with HF employ when they carry on an activity. To manage their breathlessness, some participants avoid doing the activity that would cause them to be breathless, while some participants simply take time to complete the activities or do things “in slow motion.” They have experienced breathlessness in the past when doing things in a hurry or at a faster pace. They have learned to be flexible in order to accommodate breathlessness in their day-today-life. Besides slowing down, they also have learned to modify how they perform certain activities and their lifestyle so they can live with their breathlessness.

> In terms of what I would do to help myself, I would just be limiting the number of things I would have to do and a lot of times we just have to play it by ear like are we going to be able to go out today. Sometimes, we don’t know until I know how I feel at that time, you know. I have to be flexible.
>
> I would go through what I have to do… in slow motion. I would get up to the bathroom, wash my face, brush my teeth, you know, in slow motion. Then I would still prepare my own food because I am watching my sodium and stuff so I thought it would be better if I prepare my own food.

> I just kept going but I know I was working on things harder. Like I was not doing a lot of singing during my choir practice, but I was doing a lot of instructing. My shortness of breath affected my voice, but I was not going to stay home and not go.

Some participants expressed the inability to lie supine. To manage their breathlessness at night, adapting meant sleeping on a chair, a recliner, or a bed with a control to raise the head of the bed. "Hard to breathe. I could not sleep lying down. I got me one of those wedges, you know, to sleep up. Now I got me one of those beds you can raise your head."

> Yeah. It's kind of when I am up I am okay, when I am sitting up I am okay… but when I lay down at night, I don't know if is just putting pressure in my chest or something, I just feel like I have shortness of breath like I can't breathe good enough. I am telling you, there are times, when I, and I am still awake, it is like I am suffocating like I can't catch my breaths. Mostly, like claustrophobic type feeling that I have. I try to fight it because I want to lie in the bed all night, but I can't get a good night sleep and what happens I end up in the chair. I am in that chair, four, five, six hours at night. I sleep in the chair and that is just how it is.

> I cannot lie on my back at all. I get short of breath when I lie down. I feel suffocated I end up sleeping in a chair. I have a nice recliner next to my bed. It is an electric recliner and I get there at night. I'll end up in that recliner five or six hours straight. Sometimes I find myself slumped, but I can breathe better when I am on that chair.

Planning. This code describes how the participants would plan and organize how they go about doing what they want to do and the modifications their family members have to do for them, such as determining the next spot to stop or sit down, or their family member dropping them off at the nearest entrance instead of walking the distance from the parking lot. "I go a lot of places with my sister and so what they'll do if there are no handicap places, they'll drop me off. And I go inside and wait for them." By planning, participants were able to carry on whatever activities they planned to do and still accommodate their breathlessness.

> Well, I just always pick out the next seat [laughs] so I can tell where I can sit again. I said, well I would just go to the mall and I did that. [With excited tone] Well, I got to one store and right away I had to find a place to sit down.

> I don't do anything like, where I go, like where people go to the mall to walk. I try to park close to the entrance of a restaurant or if we go to a movie, she'll drop me off at the

> curve, you know, where I can walk right in. It is the long walk, even in a very slow pace, as slow as I can go, I still get winded on a short distance.

Participants also described strategies they employ as they strive for quality of life. They leverage what they learned to be important, such as exercise for physical health, seeking information to better understand their condition, as well as attitudes and mindset they adapt to preserve their mental and emotional health. For example, as the participants understand the physiological causes of breathlessness, such as weight gain and fluid retention, they begin to understand the importance of watching their salt and fluid intake. As they understand the relationship between physical fitness and fatigue, they begin to understand the importance of exercise. The increased understanding motivates them to make the lifestyle changes needed and increased their compliance with their treatment.

> I started walking on the treadmill five minutes a day then slowly got up to 40 minutes a day. I really just made myself do it. As hard as it is, I made myself, literally. And that you don’t need to put salt on it.
>
> Well, one is to really watch what you eat. You start reading food labels. It forces you to think what you are doing. Two, I had to completely stay away from drinking. Three, I had to make sure I take the medications and learn all I can learn you know about how food and medications interact to make sure the medications can act the way it should act.

For their mental and emotional well-being, participants have described assuming a positive attitude of dealing with their condition, not focusing on what they have lost and not feeling sorry for themselves. The support of family members is one motivation for them to maintain a positive attitude. “I try to think positive and… my wife, she is just a wonderful person. She tries to do everything she can to help me, you know.”

> And you know I am human and so there are times when I feel sorry for myself and then other times when I kind of have some self-talk and say, you know, just a minute here, things could be a hell of a lot worse, and so don’t focus on what you don’t have or what you have lost. Focus on what you do have, and so, [clears throat] I, I… I feel fortunate, you know, because I think things could be a lot worse.

> I think I have the skill set and I think it is not, like what I said, it is not all physical. It's … there are spirituality in there, there's the mental health aspect and so I try not to break things apart and just keep it all together and say all things considered I can deal with this.

When asked about what things they think they need to learn to help them live with their breathlessness, many participants described receiving inadequate information from their health care providers about their symptom and other questions they have about HF particularly during the initial onset of their breathlessness. This is information that would have been helpful in their understanding and management of their symptom. "Like I said, information from the doctor about my heart failure. I did not have any information to know about heart failure and why I was short of breath." One participant felt asking a lot of questions irritated her physician. "None of the doctors in my hometown, they never told me anything. My local doctor, did not tell me a whole lot but I asked a lot of questions which I think irritated him.

> Yes. I did not want to forego anymore not knowing what is wrong because I knew there has got to be some kind of a problem causing my shortness of breath but finding out what that problem was, that was their job. I just had to do that and that for me was how I managed my shortness of breath.

Summary

This chapter presented the lived experiences of breathlessness of 14 participants with chronic HF. The demographic and clinical characteristics of the participants and the themes identified through thematic analysis were presented. Participants have described the nature of their breathlessness experience, the types and patterns of their breathlessness episodes, the impact of breathlessness in their daily life, and strategies they employ to manage their breathlessness.

Chapter 5

Discussion

The findings of the study are informative of the experiences of breathlessness by adults with chronic HF, the types and patterns of their breathlessness episodes, the impact it has on their daily lives, and the many ways they manage this symptom to minimize its impact.

Nature of Breathlessness

The vivid descriptions given by the participants support the definition of breathlessness by the American Thoracic Society, as a subjective sensation of work or effort to breathe, tightness, and inadequate air intake or inspiration (Parshall et al., 2012). The descriptions of breathlessness by the study participants are also consistent with the characterization of chronic dyspnea described in the model of chronic dyspnea (McCarley, 1999). In this model, chronic dyspnea is characterized as ever present, of varying intensity, and gradually increasing over time.

Different reactions emerged when the participants first experienced breathlessness. Some participants were shocked, some were frightened, and some were in denial. Some of these reactions contributed to a delay in seeking medical attention. This finding aligns with the American Thoracic Society’s definition of dyspnea as a subjective sensation that may induce secondary physiological and behavioral responses (Parshall et al., 2012). .

After being diagnosed with HF, some participants suggested their own reasons for why they developed the condition while others were not given an explanation. Some participants developed HF after having coronary artery bypass graft surgery or after receiving treatment for lymphoma. These participants were not told of the possibility of them developing HF at the time of these medical conditions. It was not until after they developed HF they were told their previous medical condition contributed to their HF. Taylor et al. (2017) found similar findings. Many of their participants had a history of previous cardiovascular disease, such as myocardial infarction, yet the participants were initially unaware that their symptom could be due to heart failure. These findings may provide direction to clinicians to educate patients that HF can be a possible sequela of other disease conditions.

Normalization of symptoms is a sociological phenomenon described by Bunn et al. (2012). It refers to a process through which people perceive symptoms as being less problematic. Taylor et al. (2017) found participants took their HF symptoms seriously only once their activities of daily living were impacted. Many of their HF participants did not recognize their breathlessness was due to HF. In the current study, participants did not recognize and understand their initial episodes of breathlessness, which led them to delay in recognizing the symptom and seeking medical attention. This finding may inform clinicians to educate adults to identify breathlessness as a significant symptom of HF.

Types and Patterns of Breathlessness Episodes

The graphs drawn by the participants in the current study depicted only two patterns: group 1 with quick onset and slow recovery and group 2 with similar time for onset and recovery. Simon et al. (2013) did not analyze the graphs based on the diagnosis of their participants. However, group 1 was the most common pattern identified followed by group 2.

The two types described by the participants are similar to the two most common types found by Simon et al. (2013). Fourteen of their 15 participants with HF described the triggered predictable type or Type 2 typical for exertional breathlessness, and only one participant described the unpredictable or wave-like type 5. Type 5 was described by majority of patients with chronic obstructive pulmonary disease. Simon et al. (2013) also found three other types described by a few of their patients with HF, whereas, in the current study, only type 2 and type 5 were described.

Simon at al. (2013) did not find strong relation between the four groups of graphs and the five types of episodic breathlessness. However, according to the authors, there was a tendency for the triggered predictable episode type 2 to be more often related to group II – similar time for onset and recovery, and the attack-like type 4 episodes to group I – quick onset slow recovery. In the current study, the group 1 pattern was representative of the Type 5 triggered non triggered wave-like attack and the group 2 pattern was representative of the triggered predictable type 2 described by the participants.

Lovell et al. (2019) found the types and patterns of breathlessness episodes determined how affected individuals coped and sought help. Coping and help-seeking behaviors of individuals with unpredictable episodes are likely to be different, especially in the context of a chronic illness as HF. Unpredictable episodes are experienced with higher unpleasant intensity compared to predictable episodes (Linde et al., 2018). Understanding that coping and help-seeking behaviors are dependent of types and patterns of breathlessness may assist clinicians to tailor management strategies and enhance coping for individuals affected.

Impact of Breathlessness

The study findings on the physiological, psychological, and sociocultural impact of breathlessness are consistent with the multidimensional consequences in the model of chronic dyspnea by McCarley (1999). Physiologic impact was described in terms of reduced physical function, activity restriction, and reduced mobility. Psychologic impact was described in terms of loss of previous life and distress over inability to perform activities they previously enjoyed. Socio-cultural impact was described in terms of changes in relationships and isolation. Hutchinson et al. (2018) and Lovell et al. (2019) similarly reported widespread effects of breathlessness. The authors have stated that the multidimensional (physical, physiological and social) impact of breathlessness is common irrespective of medical condition causing breathlessness. Furthermore, Hutchinson et al. (2018) explained effective management of breathlessness should be based on a holistic understanding of the many ways it can impact the lives of those suffering from it. Specific to HF, Walthall et al. (2017) reported how breathlessness impacted normal activities of daily living such as sleeping, walking, eating, and talking. Similar to the current study findings, participants in the Walthall et al. (2017) study were also unable to function fully in their own homes and unable to carry out activities they previously were able to do. Compared with the current study, the participants in the Walthall et al. (2017) study had greater HF acuity with 68% of the participants were NYHA Class IV. This difference possibly demonstrates that the impact of breathlessness on the lives of adults with chronic HF transcends HF severity. Participants spoke about declining functional ability and increasing uncertainty about their future because of the recurrent nature of their breathlessness. The decrease in their physical performance created frustration and a sense of dependence on family members. Paturzo et al. (2016) found similar findings of decreased physical function as well as other important life changes including employment, sexuality and lifestyle changes.

Management of Breathlessness

Qualitative studies describing how adults with chronic HF manage and cope with their breathlessness are very sparse. It is evident from the findings of the current study that adults with chronic HF develop strategies to manage their breathlessness and reduce its impact on their lives. However, it was also clear that several of the strategies employed by the participants were self-imposed and lacked guidance from health care providers. Many participants verbalized receiving inadequate to no information and education from their healthcare providers that could have helped them better understand and cope with their breathlessness. These findings raise concerns for how effective the strategies are without guidance from healthcare providers, as well as emphasize the important role healthcare providers play in helping adults with chronic HF manage their breathlessness.

Despite the multifaceted ways breathlessness has impacted the lives of adults with chronic HF, most of the participants maintained the will to live, perhaps motivated by family affection and bonds. Most participants described having very good support from family and friends. This study finding emphasizes the importance of social support in managing breathlessness. Interventions to manage breathlessness need to include family members or sources of social support. Hutchinson et al. (2018) found family members and carers also experience the impact of breathlessness on their lives. The way that their family member suffering from breathlessness copes and manages breathlessness can cause extra burden on the carer. In addition, the carers also experience isolation and helplessness if there is absent or inadequate response from healthcare providers in managing the breathlessness (Hutchinson et al., 2018).

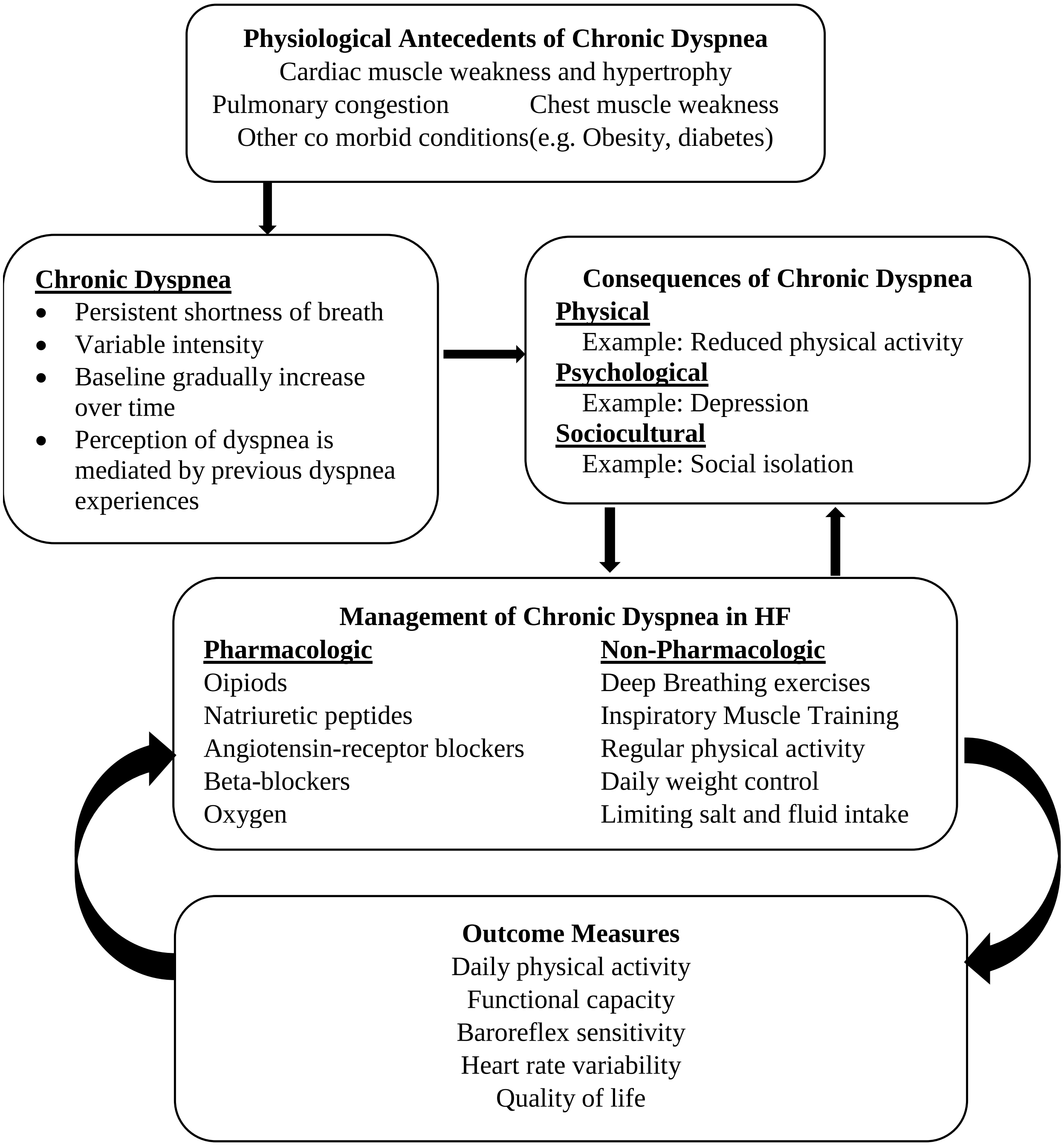
Self-care Management: Importance of Patient Education

Self-care behaviors including dietary adherence, medication taking, symptom monitoring, fluid restriction, and regular physical activity, have shown to significantly improve HF-related quality of life (Jonkman et al., 2016). Being able to manage HF symptoms increases the sense of control over their disease condition. The perceived sense of control determines an individual's capacity to manage and cope with disease-related events and achieve favorable outcomes (Hjelm et al., 2019). One barrier to self-care is insufficient or unclear information about HF and its symptoms (Herber et al., 2017). Several participants in the current study verbalized not receiving information about their breathlessness and HF from their healthcare providers. The lack of information made them feel frustrated and created a sense of helplessness. Besides frustration, Hutchinson et al. (2018) found the lack of information made participants feel there was nothing their healthcare providers could do for their breathlessness. In addition, it left them feeling abandoned and unable to access breathlessness specific interventions. Walthall et al. (2017) found the lack of information made adults with chronic HF feel they were left on their own to manage their breathlessness. The findings of the current study are informative of the need for adults with HF to receive information from their health care providers so they can better understand and manage their breathlessness.

Evaluation of the Model of Chronic Dyspnea

McCarley's model of chronic dyspnea provides insights into the study sample descriptions of their chronic breathlessness as defined in the model as persistent, of variable intensity, with the baseline gradually increasing on over time, and mediated by previous dyspnea experiences. The model's inclusion of mediation by previous dyspnea experiences in its definition would support the need to add management strategies to the model. Effective management strategies may lessen, if not eliminate, the disabling consequences of chronic dyspnea on the functional capacity and quality of life of individuals. Evaluation of the management strategies will also need to be added to the model. This can be represented by different outcome measures to evaluate the effect of the management interventions on physical activity, functional capacity, baroreflex sensitivity, heart rate variability, and quality of life. This new proposed model of chronic dyspnea is depicted in figure 5.

Figure 5. Proposed Model of Chronic Dyspnea in HF



Implications for Practice

In as much as breathlessness is a subjective sensation best perceived by persons experiencing it (Parshall, 2016), proper assessment of breathlessness by listening to what affected individuals have to say about their experiences cannot be overemphasized. Affected individual's own descriptions of their breathlessness episodes, the different emotions that accompanies it, the different types and patterns of breathlessness, the multidimensional impact of breathlessness in their day-to-day life, and they ways they employ to minimize its impact have to be included in assessing the symptom. This qualitative assessment can be used in conjunction with a quantitative measurement for a fuller understanding of this symptom. This more robust assessment will provide direction in developing algorithms to detect changes in the nature and severity of breathlessness that both affected individuals and clinicians can use. It can also provide guidance in developing appropriate and type-specific interventions. Such algorithms will enable adults with chronic HF know when to manage breathlessness by themselves and when to call for help.

The study findings suggest that adults with chronic HF look to their healthcare providers for information and education about breathlessness and HF. They also look for information about how to best manage their breathlessness. The findings of this study provide guidance to clinicians in the development of educational materials and programs to address breathlessness among adults with chronic HF. The findings of this study provide evidence for a need for a multidisciplinary care approach to help adults with chronic HF manage their breathlessness. A multidisciplinary team is essential to address the multidimensional impact of breathlessness. The findings of the study can provide guidance as the multidisciplinary team plan and teach adults with chronic HF effective self-care management activities. A multidisciplinary team approach may enhance the effectiveness of adults with chronic HF as they alter their lifestyle and behaviors to manage their breathlessness and HF.

Implications for Research

As the prevalence of HF increases and improvement in life-prolonging treatments continue, the burden of breathlessness will continue to be a concern for adults with chronic HF. Most participants experienced the onset of breathlessness before they were diagnosed with HF. Future research should address the lack of public understanding of chronic breathlessness and HF. Qualitative research on breathlessness in chronic HF remains sparse. For further understanding of this phenomenon specific to HF, more qualitative research is needed. Qualitative studies exploring nurses' and other healthcare providers' knowledge of breathlessness and HF are needed. Research studies should also be conducted to explore the impact of the breathlessness experiences of HF adults on the lives of their family, loved ones and care givers. Although not explored in this study, there is some evidence that chronic breathlessness also impacts the physical, mental health and social lives of people close and significant to adults with chronic HF (Hutchinson et al., (2018). As evidenced by the multidimensional impact of breathlessness, research on the use and effectiveness of a multidisciplinary care approach to manage breathlessness need to be conducted.

Further well-designed and rigorous nursing research studies to describe the different types and patterns of breathlessness need be conducted. Such studies may provide insight on the need for individualized care approach specific to the types and patterns of breathlessness episodes. To date, there are no randomized controlled trials that explore the effectiveness of non-pharmacological management interventions for breathlessness in HF. Such studies will strengthen the evidence on its effectiveness. The utility of the proposed model of chronic dyspnea in exploring the breathlessness experiences among adults with chronic HF needs to be studied using quantitative measures of breathlessness, its impact and outcomes of different interventions. Finally, future studies considering the impact of other variables such as co-morbid conditions, length of heart failure diagnosis, and social support have on breathlessness should be considered.

Strengths

The qualitative methodology was a strength of this study because it made exploration of the breathlessness phenomenon among adults with chronic HF possible. Participants that were interviewed provided vivid descriptions of their breathlessness experiences, its impact on their daily lives and ways they have employed to minimize its impact. Participants were not inconvenienced or pressured into participation. They were rather very willing to share their lived experiences with breathlessness. All efforts to maintain their privacy and confidentiality were upheld.

Limitations

The study was limited by the use of a convenient sample. Although the participants were residents from different Dallas-Fort Worth areas and surrounding states, recruitment was limited only to adults with HF from two outpatient HF clinics, therefore, the findings of the study cannot be generalized to populations. Although efforts were made to obtain a race-diverse sample, Whites represented 50% of the sample. The narratives and graphs of the participants were not analyzed according to other variables such as age, gender, ejection fraction, years of living with HF, comorbidities, and HF medication or HF treatment modalities. The experiences of breathlessness among those of younger age, male gender, with preserved ejection fraction, or newly diagnosed HF maybe different from those who are older, female gender, with reduced ejection fraction or had been living with HF for longer years.

Conclusions

In summary, this study explored the lived experiences of chronic breathlessness among adults with chronic HF. The study findings provided vivid descriptions of what it feels to be breathless. The types and patterns of breathlessness episodes, the impact of breathlessness on the daily lives of adults with chronic HF and the many ways they employed to manage breathlessness and minimize its impact were described. This study adds to a very limited body of evidence that explored the lived experiences of breathlessness among adults with chronic HF. MaCarley's (1999) model of chronic dyspnea could help clinicians to understand how adults with chronic HF experiences breathlessness and how it affects their lives in a multidimensional way. It was identified that adults with chronic HF need information and education on breathlessness and HF from their healthcare providers. It was also identified that adults with chronic HF develop multiple ways to deal with their breathlessness to minimize its impact on their daily lives. However, it was evident that the interventions employed by adults with chronic HF were self-imposed and lacked guidance from healthcare professionals. The need for further research to evaluate what is considered as self-care interventions was identified. The new proposed model of chronic dyspnea can guide research to explore management strategies of breathlessness and outcomes of these interventions. Finally, a multidisciplinary approach may help to address the multidimensional impacts of breathlessness. Such approach may lead to better assessment and design of interventions most effective for adults with chronic HF to use to manage their breathlessness.

APPENDIX 1

RECRUITMENT SCRIPT

(P= Potential Participant; I= Interviewer)

I: My name is Cecilia Lijauco and I am a doctoral student at the University of Texas at Arlington. I am currently conducting a study on the experience of breathlessness in adults with heart failure, under the supervision of my research chair, Dr. Donelle Barnes. The primary objective of the study is to obtain a greater understanding of the experience of breathlessness in adults with heart failure in order to describe the pattern and types, as well as to gain an understanding of how they manage this symptom. I am conducting interviews to discover the perspectives of adults with heart failure on this experience. I would like to invite you to participate in this interview. Is this a convenient time to give you further information about the study?

P: No, I do not have time today (agree on a more convenient time to call the person)

OR

P- Yes, could you provide me with some information regarding the interviews you will be conducting:

I: (Give the following background information)

- We can go in the consult room and I can give you more information about the study and do the interview.
- The interview will last about one hour.
- Participation in this interview is entirely voluntary and there are no known or anticipated risks to participation.
- The questions are quite general (for example, describe to me what it is like to feel short of breath.

- You may decline to answer any of the interview questions you do not wish to answer and may terminate the interview at any time. With your permission, the interview will be tape-recorded to facilitate collection of information and transcription for analysis.
- All information you provide will be treated with extreme confidentiality. There will be no personal information that can identify you in the writing, reporting or publishing of this study. The data collected will be kept in a secured location and disposed in three years.
- I would like to assure you that this study has been reviewed and received clearance through the Baylor Scott and White Institutional Review Board. However, the final decision about participation is yours.

I: Are you willing to participate? Do you have any question before we continue?

P: No thank you.

OR

P: Sure

I: (At the conclusion of the interview). Thank you very much for your participation. Please do not hesitate to call me if you have any further question or concern. My cell phone number is 214-558-1721. Do you need help to get out of the building?

P: No, I will be fine.

OR Yes, I need assistance with a wheelchair (arrange transportation assistance or assist to the front door if assistance is needed).

APPENDIX 2

DEMOGRAPHIC AND CLINICAL DATA SURVEY TOOL

Demographic Data ***(To be obtained by self-report)***	
Participant ID:	
How old are you?	
With what ethnic group do you identify?	
• White	
• Black	
• Hispanic	
• Asian	
• American Indian	
• Other	
How much formal education have you completed?	
• Some High School	
• Graduated High School	
• Some College	
• Graduated College	
Who do you live with?	
• Lives alone	
• Lives with spouse	
• Lives with children or other family member	
How satisfied are you with the support you receive from family and friends?	
• Satisfactory	
• Good	
• Very good	
Clinical Data ***(To be obtained from the clinic record with the participant's consent)***	
Etiology of HF:	
• Ischemic heart disease	
• Cardiomyopathy	
• Valvular	
• Hypertension	
• Arrhythmia	
NYHA Classification	
• I	

• II	
• III	
• IV	
Comorbidities	
Diabetes Mellitus	
Cancer	
Chronic Obstructive Disease	
Asthma	
Kidney Disease	
Other (list here)	
None	

APPENDIX 3

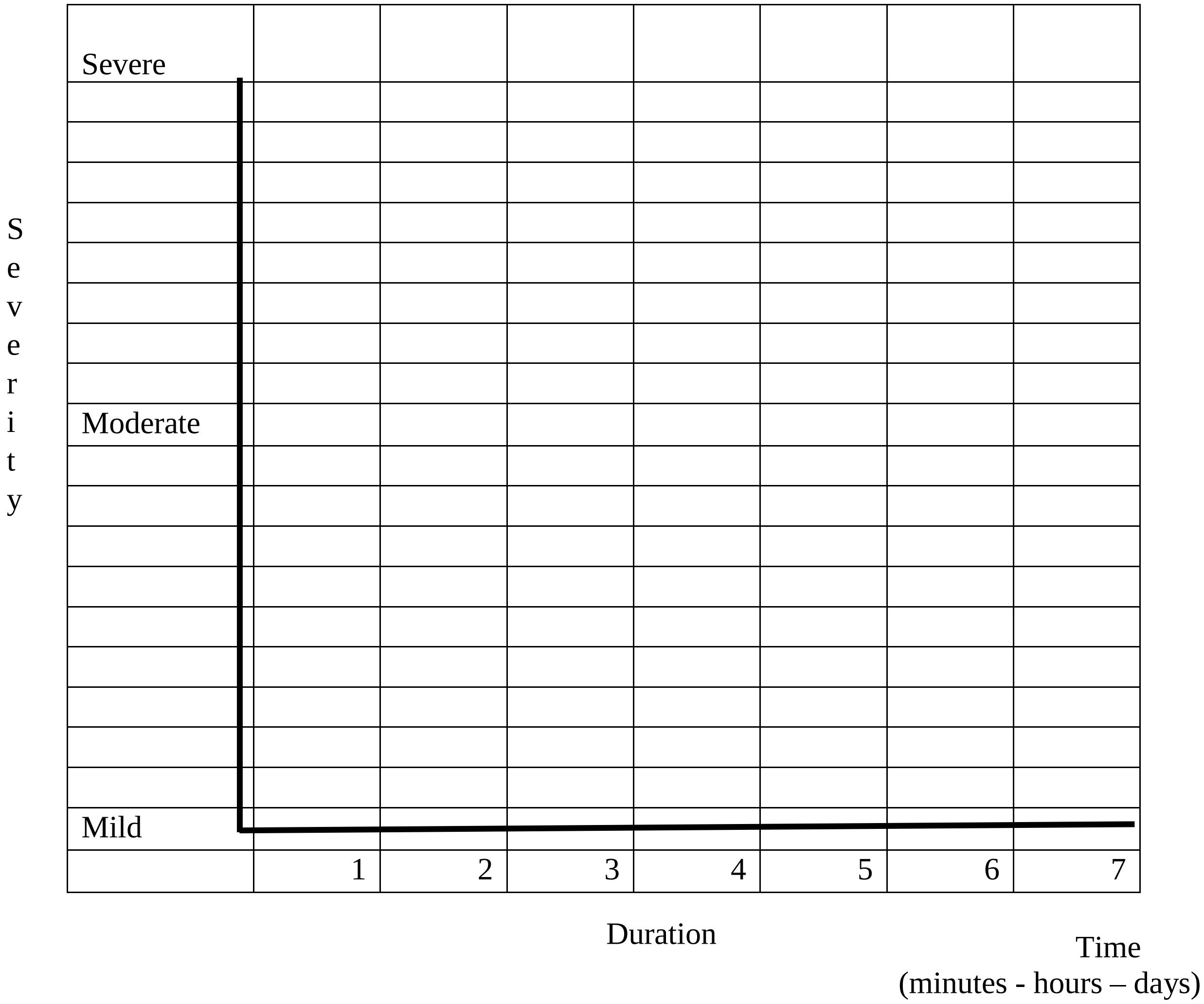
INTERVIEW GUIDE

1. Please describe what it is like to feel short of breath. [Inclusion criteria for the study is that they have SOB.]
2. What are some characteristics you may give to describe your shortness of breath? [Probe: predictable, with exertion, at rest, preventable]
3. What specific circumstances make you short of breath? [Probe: triggers, activities] [Prompts: What activities are you usually doing when you feel short of breath?]
4. When you feel short of breath, does it occur suddenly or does the sensation slowly build up?
5. How often do you feel short of breath in a day? In a week?
6. When you get short of breath, how would you describe the severity from start to finish?
7. How long do you feel short of breath before you can breathe normally again? Is there a pattern of start and stop time?
8. Can you draw on the graph what you have just described?
9. What other symptoms do you feel when you are short of breath? [Prompts: physical: fatigue, inability to sleep or psychological: anxiety, fear, depression]
10. What makes your shortness of breath worse?
11. What makes your shortness of breath better?
12. Has there been a change in the pattern of when and how you experience shortness of breath over the past month? If so, please describe it.
13. Many people find shortness of breath distressing. How does it affect you on that level?

14. When you get short of breath, how does it change or limit what you do? [Prompts: leave house, do errands, play with children/grandchildren or pets, clean house, cook]
15. How do you manage chores like (washing the car, mowing the lawn (for men) washing clothes, cooking (for women)?
16. How do you manage leaving the house, such as grocery shopping or going to the bank?
17. How does it make you feel when you feel limited in what you can do because of your shortness of breath?
18. What do you do to help manage your shortness of breath? What helps?
19. What may get in the way of managing your shortness of breath?
20. What other things do you think you need to learn to help you live with your shortness of breath?

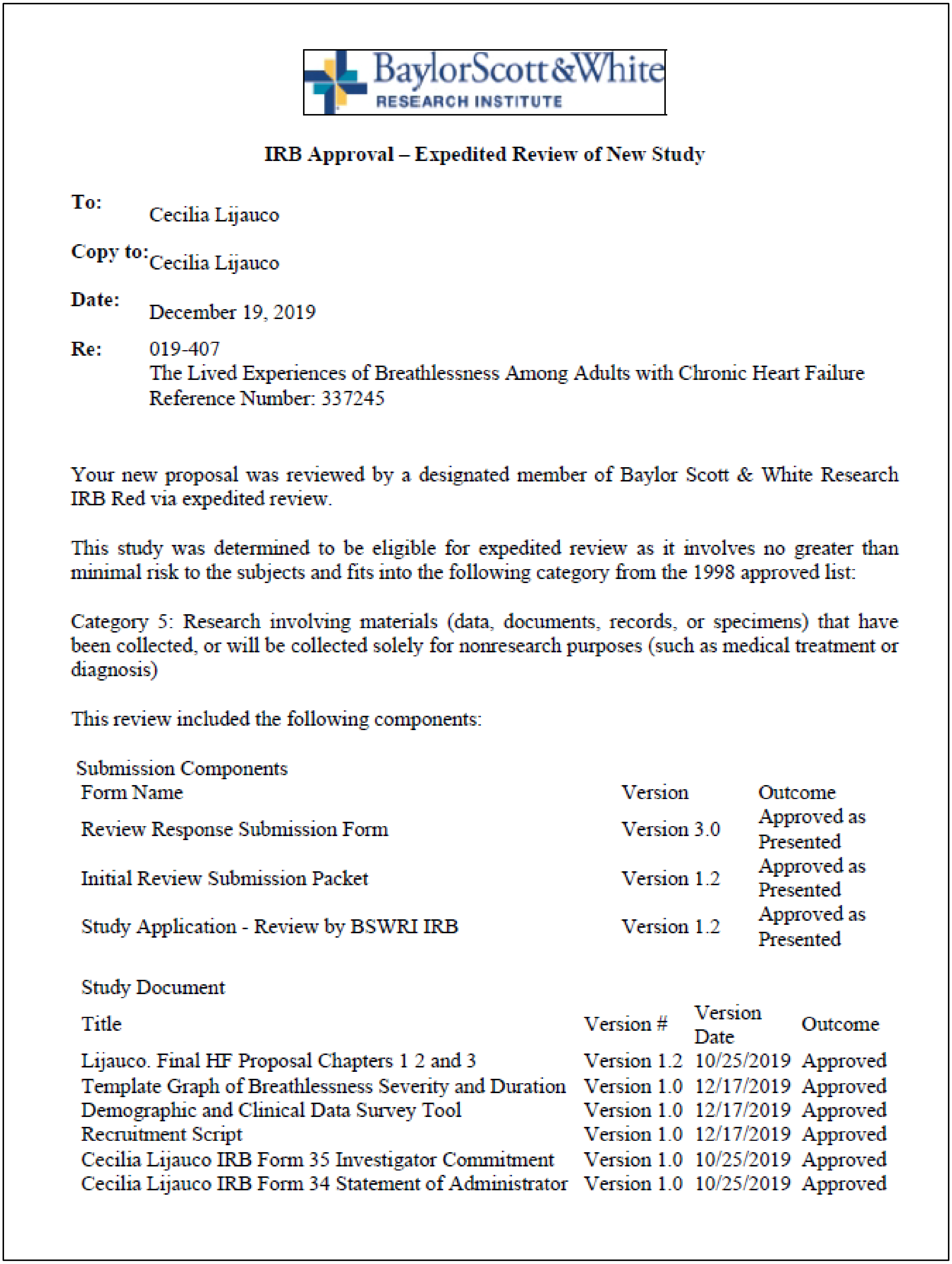
APPENDIX 4

TEMPLATE GRAPH OF BREATHLESSNESS SEVERITY AND DURATION


Severe
S
e
v
e
r
i
t
y
Moderate
Mild
1
2
3
4
5
6
7
Duration
Time
(minutes - hours – days)

APPENDIX 5

HEALTHCARE SYSTEM INSTITUTIONAL REVIEW BOARD APPROVAL LETTER



BaylorScott&White RESEARCH INSTITUTE

IRB Approval – Expedited Review of New Study

To: Cecilia Lijauco

Copy to: Cecilia Lijauco

Date: December 19, 2019

Re: 019-407
The Lived Experiences of Breathlessness Among Adults with Chronic Heart Failure
Reference Number: 337245

Your new proposal was reviewed by a designated member of Baylor Scott & White Research IRB Red via expedited review.

This study was determined to be eligible for expedited review as it involves no greater than minimal risk to the subjects and fits into the following category from the 1998 approved list:

Category 5: Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis)

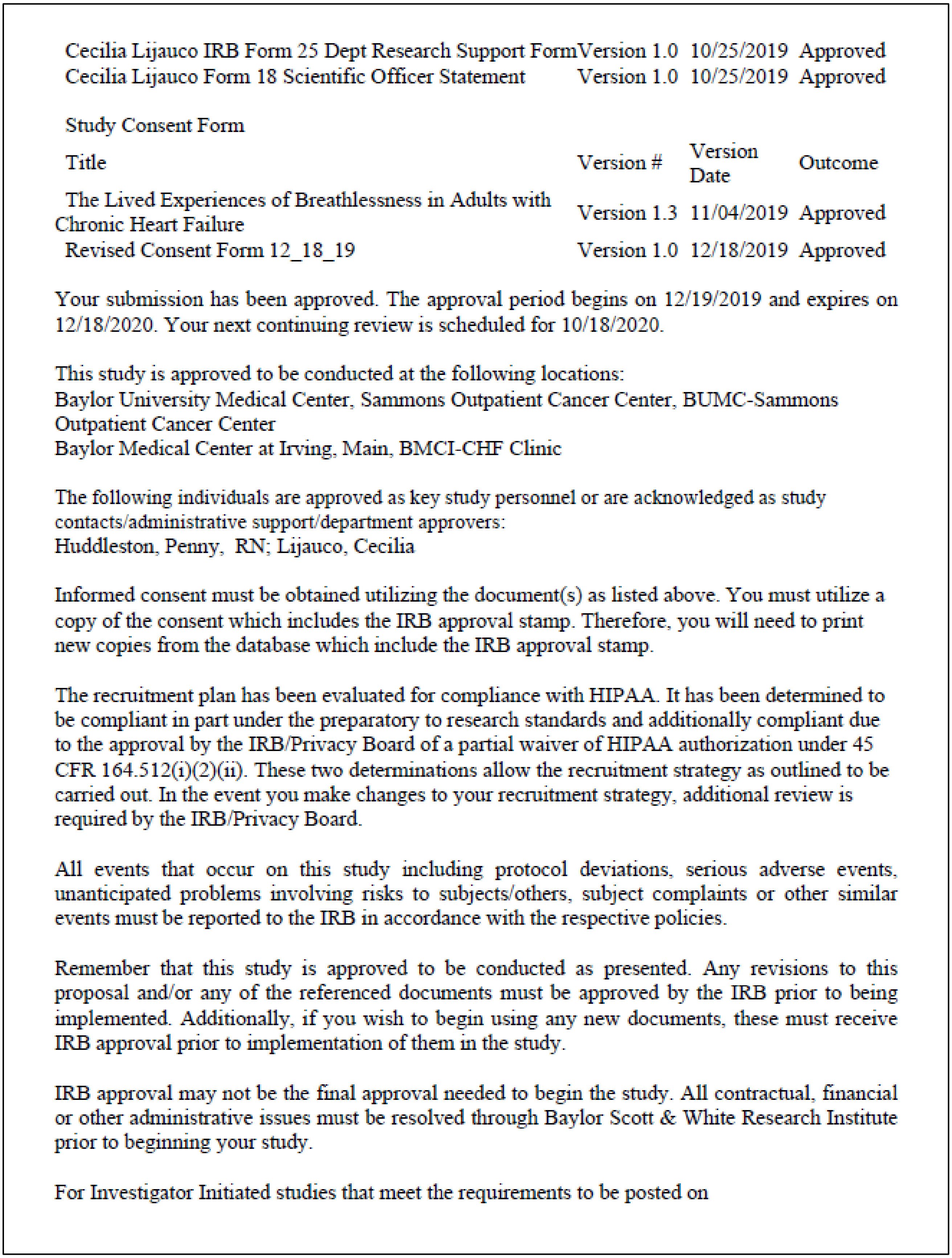
This review included the following components:

Submission Components

Form Name	Version	Outcome
Review Response Submission Form	Version 3.0	Approved as Presented
Initial Review Submission Packet	Version 1.2	Approved as Presented
Study Application - Review by BSWRI IRB	Version 1.2	Approved as Presented

Study Document

Title	Version #	Version Date	Outcome
Lijauco. Final HF Proposal Chapters 1 2 and 3	Version 1.2	10/25/2019	Approved
Template Graph of Breathlessness Severity and Duration	Version 1.0	12/17/2019	Approved
Demographic and Clinical Data Survey Tool	Version 1.0	12/17/2019	Approved
Recruitment Script	Version 1.0	12/17/2019	Approved
Cecilia Lijauco IRB Form 35 Investigator Commitment	Version 1.0	10/25/2019	Approved
Cecilia Lijauco IRB Form 34 Statement of Administrator	Version 1.0	10/25/2019	Approved



Cecilia Lijauco IRB Form 25 Dept Research Support Form	Version 1.0	10/25/2019	Approved
Cecilia Lijauco Form 18 Scientific Officer Statement	Version 1.0	10/25/2019	Approved

Study Consent Form

Title	Version #	Version Date	Outcome
The Lived Experiences of Breathlessness in Adults with Chronic Heart Failure	Version 1.3	11/04/2019	Approved
Revised Consent Form 12_18_19	Version 1.0	12/18/2019	Approved

Your submission has been approved. The approval period begins on 12/19/2019 and expires on 12/18/2020. Your next continuing review is scheduled for 10/18/2020.

This study is approved to be conducted at the following locations:
Baylor University Medical Center, Sammons Outpatient Cancer Center, BUMC-Sammons Outpatient Cancer Center
Baylor Medical Center at Irving, Main, BMCI-CHF Clinic

The following individuals are approved as key study personnel or are acknowledged as study contacts/administrative support/department approvers:
Huddleston, Penny, RN; Lijauco, Cecilia

Informed consent must be obtained utilizing the document(s) as listed above. You must utilize a copy of the consent which includes the IRB approval stamp. Therefore, you will need to print new copies from the database which include the IRB approval stamp.

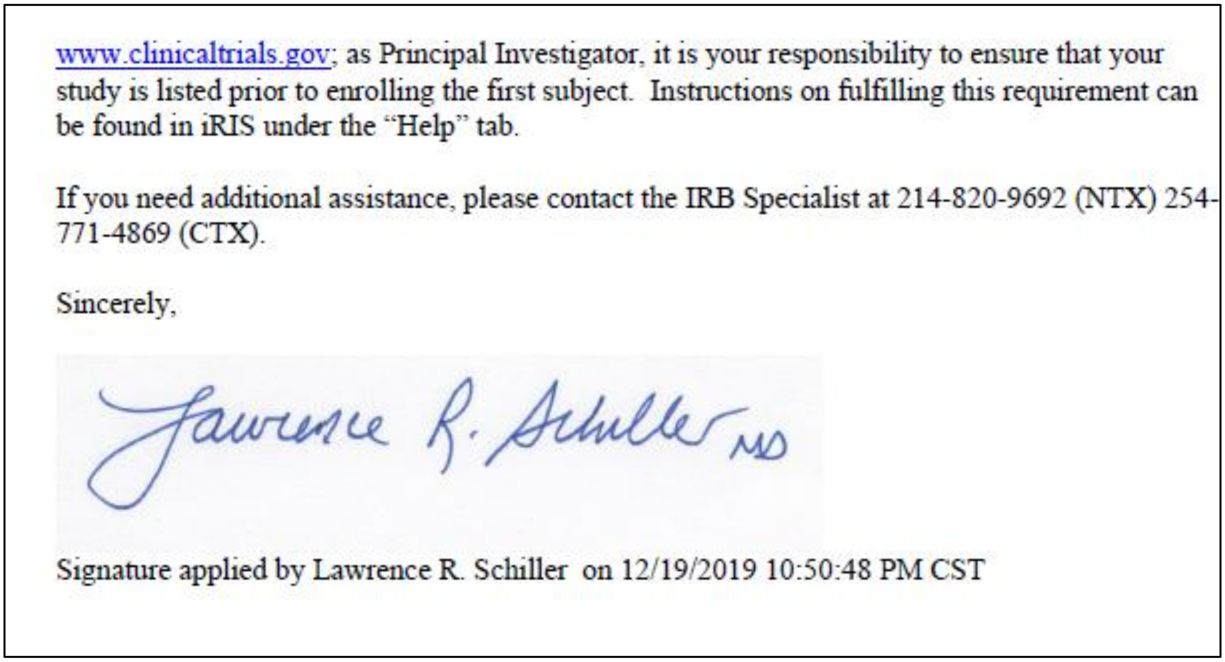
The recruitment plan has been evaluated for compliance with HIPAA. It has been determined to be compliant in part under the preparatory to research standards and additionally compliant due to the approval by the IRB/Privacy Board of a partial waiver of HIPAA authorization under 45 CFR 164.512(i)(2)(ii). These two determinations allow the recruitment strategy as outlined to be carried out. In the event you make changes to your recruitment strategy, additional review is required by the IRB/Privacy Board.

All events that occur on this study including protocol deviations, serious adverse events, unanticipated problems involving risks to subjects/others, subject complaints or other similar events must be reported to the IRB in accordance with the respective policies.

Remember that this study is approved to be conducted as presented. Any revisions to this proposal and/or any of the referenced documents must be approved by the IRB prior to being implemented. Additionally, if you wish to begin using any new documents, these must receive IRB approval prior to implementation of them in the study.

IRB approval may not be the final approval needed to begin the study. All contractual, financial or other administrative issues must be resolved through Baylor Scott & White Research Institute prior to beginning your study.

For Investigator Initiated studies that meet the requirements to be posted on



www.clinicaltrials.gov; as Principal Investigator, it is your responsibility to ensure that your study is listed prior to enrolling the first subject. Instructions on fulfilling this requirement can be found in iRIS under the "Help" tab.

If you need additional assistance, please contact the IRB Specialist at 214-820-9692 (NTX) 254-771-4869 (CTX).

Sincerely,

Lawrence R. Schiller MD

Signature applied by Lawrence R. Schiller on 12/19/2019 10:50:48 PM CST

APPENDIX 6

UNIVERSITY INSTITUTIONAL REVIEW BOARD AUTHORIZATION AGREEMENT AND RELIANCE APPROVAL

UNIVERSITY OF
TEXAS
ARLINGTON
OFFICE OF RESEARCH ADMINISTRATION
REGULATORY SERVICES

January 21, 2020

Cecilia Lijauco
The University of Texas at Arlington

RELIANCE APPROVAL

UTA Protocol No.: 2020-0190
Protocol Title: *The Lived Experiences of Breathlessness in Adults with Chronic Heart Failure*

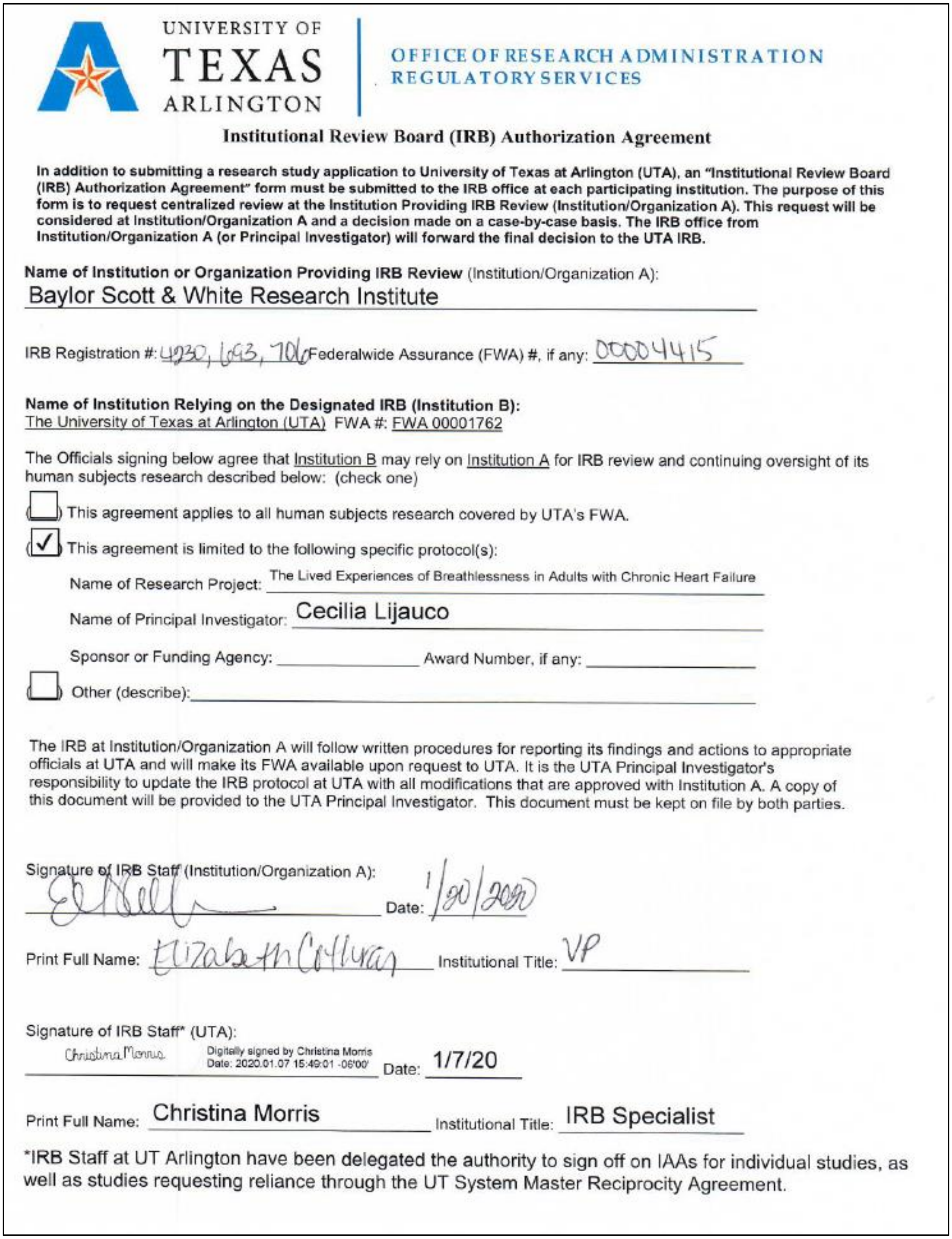
The UT Arlington Office of Research Administration - Regulatory Services and Institutional Review Board (IRB) are pleased to acknowledge your engagement in this research protocol involving human subjects which has been approved by the IRB at Baylor Scott & White Research Institute. The Baylor IRB is noted as the "IRB of record" for this protocol. An IRB of record assumes IRB responsibilities for another institution as specified in each institution's Federalwide Assurance (FWA), and has an agreement of reliability on file. Having met the conditions for approval set forth by the IRB at Baylor, and in compliance with applicable regulations, acknowledgment of such approval has been granted by the UTA IRB or designee.

Baylor IRB No: 337245
Review Level: Expedited
Approval Date: December 19, 2019

Please note that you are responsible for providing UT Arlington's IRB with a copies of official notifications or approvals from the IRB of record, including but not limited to: approval letters for continuing reviews, approval letters for protocol modifications, incident or adverse event reports, audit or monitoring reports, or study closures.

The UT Arlington IRB and the Office of Research Administration - Regulatory Services appreciate your continuing commitment to the protection of human subjects engaged in research and wish you all the best in your research endeavors. Should you have questions or require further assistance, please contact Regulatory Services at regulatoryservices@uta.edu or 817-272-3723.

REGULATORY SERVICES
SERVICES
The University of Texas at Arlington, Center for Innovation
202 E. Border Street, Ste. 201, Arlington, Texas 76010, Box#19188
(T) 817-272-3723 (F) 817-272-5808 (E) regulatoryservices@uta.edu (W) www.uta.edu/rs



UNIVERSITY OF TEXAS ARLINGTON

OFFICE OF RESEARCH ADMINISTRATION
REGULATORY SERVICES

Institutional Review Board (IRB) Authorization Agreement

In addition to submitting a research study application to University of Texas at Arlington (UTA), an "Institutional Review Board (IRB) Authorization Agreement" form must be submitted to the IRB office at each participating institution. The purpose of this form is to request centralized review at the Institution Providing IRB Review (Institution/Organization A). This request will be considered at Institution/Organization A and a decision made on a case-by-case basis. The IRB office from Institution/Organization A (or Principal Investigator) will forward the final decision to the UTA IRB.

Name of Institution or Organization Providing IRB Review (Institution/Organization A):
Baylor Scott & White Research Institute

IRB Registration #: 4930, 693, 706 Federalwide Assurance (FWA) #, if any: 00004415

Name of Institution Relying on the Designated IRB (Institution B):
The University of Texas at Arlington (UTA) FWA #: FWA 00001762

The Officials signing below agree that Institution B may rely on Institution A for IRB review and continuing oversight of its human subjects research described below: (check one)

☐ This agreement applies to all human subjects research covered by UTA's FWA.

☑ This agreement is limited to the following specific protocol(s):

Name of Research Project: The Lived Experiences of Breathlessness in Adults with Chronic Heart Failure

Name of Principal Investigator: Cecilia Lijauco

Sponsor or Funding Agency: ______ Award Number, if any: ______

☐ Other (describe): ______

The IRB at Institution/Organization A will follow written procedures for reporting its findings and actions to appropriate officials at UTA and will make its FWA available upon request to UTA. It is the UTA Principal Investigator's responsibility to update the IRB protocol at UTA with all modifications that are approved with Institution A. A copy of this document will be provided to the UTA Principal Investigator. This document must be kept on file by both parties.

Signature of IRB Staff (Institution/Organization A): ______ Date: 1/20/2020

Print Full Name: Elizabeth Collvran Institutional Title: VP

Signature of IRB Staff* (UTA): Christina Morris Digitally signed by Christina Morris Date: 2020.01.07 15:49:01 -06'00' Date: 1/7/20

Print Full Name: Christina Morris Institutional Title: IRB Specialist

*IRB Staff at UT Arlington have been delegated the authority to sign off on IAAs for individual studies, as well as studies requesting reliance through the UT System Master Reciprocity Agreement.

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