THE ACCURACY OF HEART FAILURE BELIEFS IN RURAL MONTANA AND WYOMING

by

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ABSTRACT

The purpose of this study was to examine the accuracy of illness beliefs of individuals diagnosed with heart failure (HF) in the rural states of Montana and Wyoming. In 2012, 2.4% of the United States population had a diagnosis of HF and this was expected to increase to nearly three percent of the total population by 2030. Accurate heart failure beliefs have been linked to engagement in recommended self-care behaviors leading to better health outcomes. This study used a descriptive design to analyze illness beliefs of Montana and Wyoming residents living with HF. A convenience sample of 50 individuals was recruited from a 300-bed acute care hospital located in Montana. Each participant completed the Survey of Illness Beliefs in HF Instrument, a 14-item survey that measures the accuracy of HF beliefs. The overall sample had inaccurate HF illness beliefs. Rural participants had less accurate heart failure illness beliefs when compared to non-rural participants. Further research is necessary to determine predictors of inaccurate HF beliefs. Nursing interventions targeted at rural dwellers may help to improve the accuracy of illness beliefs.

CHAPTER 1

INTRODUCTION

Heart failure (HF) is a common and severe chronic condition in which the heart has lost the ability to pump enough blood to the body thereby depriving tissues of necessary oxygen and nutrients (Heidenreich et al., 2013). HF develops over time and symptoms may occur suddenly or slowly over many weeks or months. Because of the progressive nature of nature of heart failure, additional cardiac damage can occur even during asymptomatic periods when the disease is undiagnosed and untreated. A diagnosis of HF is confirmed by laboratory and diagnostic tests, including echocardiograms and Doppler flow studies. These diagnostic tests determine abnormalities of the myocardium, heart valves, and the pericardium, assess if ventricular function is preserved or impaired, and identify abnormalities in ventricular structure. Ventricular remodeling, a complex process by which cardiac function is modified by disease, injury, or genetics, leads to decreased pumping ability of the heart, which impairs the body’s ability to provide necessary oxygen and nutrients to the peripheral tissues (Heidenreich, et.al., 2013). The American Heart Association (Ammar et al., 2007; Jessup et al., 2009) defines HF as a chronic disease.

Twenty million people worldwide suffer from HF and the incidence of HF increases as people age (Heidenreich et al., 2013). Twelve percent of the population older than 85 years of age have HF as compared to the total population which has a 2.4% incidence of HF (Heidenreich et al., 2013). By 2030, 25% of all HF cases will be in individuals over eighty years of age and the prevalence of HF, especially in this age group, is projected to increase steadily into the future (Heidenreich et al., 2013). According to the American Heart Association (Heidenreich et al., 2013) HF will continue to be a concerning and significant medical condition because of its high morbidity, mortality, and cost of care. Despite recent advancement in treatment, HF continues to have a poor prognosis and high morbidity (Heidenreich et al., 2013).

One of the most important factors in managing HF is the individual's engagement in self-care activities. Self-care requires individuals to heed the advice of healthcare providers regarding medications, restrictions of sodium and fluid, participate in regular exercise, and actively monitor for signs and symptoms of HF (Riegel et al., 2012). Beliefs and knowledge about an individual's HF illness have been correlated with the level of engagement in self-care behavior (Van der Wal et al., 2005). By understanding the accuracy of HF illness beliefs, health care providers may be able to motivate individuals with HF to actively engage in self-care behavior (Albert & Zeller, 2007).

Significance

In 2012, 2.4% of the United States population had a diagnosis of HF and this is expected to increase to nearly three percent of the total population by 2030 (Rogers et al., 2013). Approximately 600,000 new cases of HF are diagnosed each year and half of these newly diagnosed individuals will die within the first five years after diagnosis; only 25% will live beyond ten years (Rogers et al., 2013). More than half of all individuals with HF who die will die suddenly (U.S. Department of Health and Human Services Centers for

Disease Control and Prevention [CDC], n/d). The morbidity and mortality rate of individuals with heart failure and other comorbid conditions is even higher. Individuals with HF usually have other chronic diseases or comorbidities, and the number of comorbid conditions increases as individuals with HF age. Kidney function naturally declines with age, which increases the likelihood of complications related to diuretic induced electrolyte imbalances as well as increased fluid retention. HF medications can also contribute to further decline in kidney function. Other common comorbid conditions include anemia, chronic obstructive pulmonary disease (COPD), arthritis, depression, and cognitive decline (Rich, 2005).

Risk factors for HF include age, uncontrolled hypertension, diabetes, hyperlipidemia, and obesity (Grandpre et al. 2011; Oser et al. 2007). The incidence of HF increases with age. For example, a 40 year-old male has a lifetime risk of 20% of developing HF. This same male continues to have a 20% lifetime risk of developing heart failure at age 80 even though his life expectancy is much shorter at that point (Roger et al., 2012). The American Heart Association reports that 75% of all HF cases are preceded by hypertension (Roger et al., 2012). Diabetes, hyperlipidemia, and obesity also contribute to the development of HF and are increasing in incidence. Adults with diabetes have heart disease death rates that are two to four times higher than those without diabetes (Grandpre et al., 2011). Obesity is associated with biventricular hypertrophy and HF in the presence or absence of hypertension; hypertension is three times more likely in obese individuals (Eckel, 1997). Hyperlipidemia increases the risk for coronary artery disease, which may result in ischemia of cardiac muscle and in turn may lead to HF.

HF not only results in significant mortality and morbidity, there is also an economic impact associated with the disease. More Medicare dollars are spent on HF care than any other illness in the United States (O’Connell, 2000), and it has been estimated that hospitalization costs of heart failure account for 65% to 70% of total heart failure costs (Dunlay, et al., 2010). HF can be attributed to at least 20% of all hospital admissions for people over age 65 (Jessup & Brozena, 2003), and HF is the most common discharge diagnosis of Medicare beneficiaries (Butler, Marti, Pina, & Defilippi, 2012). Projections show that HF costs will increase from $32 billion in 2013 to over $70 billion by 2030 (Roger et al, 2012).

Purpose

The purpose of this study was to examine the accuracy of illness beliefs of individuals diagnosed with HF in the rural states of Montana and Wyoming. Residents of these states encounter issues which affect self-care that are unique to rural dwellers (Bailey, 2013), and Montana and Wyoming are representative of rural dweller. Illness beliefs have been linked to self-care adherence, decreased hospitalizations, and increased quality of life (MacInnes, 2013; Van der Wal et al., 2005). The research question addressed by this study was: Do individuals living in Montana and Wyoming have accurate HF illness beliefs?

Montana and Wyoming

Montana and Wyoming are geographically large states with wide rural expanses, limited access to health networks, higher rates of chronic disease, and residents are less likely to have adequate health insurance (Bailey, 2013). All of these factors can exacerbate the social and economic burden of HF in rural areas (Bailey, 2013). Forty-eight of the 56 counties in Montana, and 17 of the 23 counties in Wyoming are considered frontier, with less than 6 persons per square mile and more than 60 minutes from a hospital (Grandpre, 2011; Oser et al., 2007); most frontier counties are medically underserved. Of the 56 counties in Montana 52 are designated a medically underserved area or population (MUA/P) as well as a Health Professional Shortage Area (HPSA). Likewise, ten of the twenty-three counties in Wyoming are designated MUA/P and all but one county in Wyoming is designated HPSA (United States Department of Health and Human Services Health Resources and Services Administration [HRSA], n.d.). This shortage of health care providers, combined with large geographical areas and a lack of health insurance coverage, make it challenging to monitor individuals living in rural areas with HF. By understanding the beliefs and attitudes about illness, specifically HF, in rural populations, nursing interventions may be developed specific to rural dwellers living in Montana and Wyoming.

Montana and Wyoming residents have an increase in mortality due to HF when compared to the United States (US) population, particularly in small rural counties. From 1979 to 2005 overall HF mortality rates increased more rapidly in Montana when compared to US men and women. From 1991 to the present HF mortality in Montana remained higher for both men and women than in the US. HF hospital discharge rates in Montana increased from 197 per 100,000 people in 2001 to 210 per 100,000 people in 2005 (Oser et al. 2007). The total number of discharges with primary diagnosis of HF from Wyoming hospitals in 2008 was 180/100,000 accompanied by healthcare costs of over $17.5 million (Grandpre, Busacker & Ivester, 2011).

Theoretical Framework

The theoretical framework used for this study was the Common-Sense Model of Illness Representation, which is also referred to as the self-regulation model of illness, illness representation model, mental models of illness, or mental representations of illness in the literature (Diefenbach & Leventhal, 1996; Hagger & Orbell, 2010). For purposes of this study it will be referred to as the Common-Sense Model of Illness Representation (CSM). The CSM is derived from Becker’s well-known Health Belief Model (HBM), which was the first model with a systematic approach that included psychological variables to determine health behavior (Diefenbach & Leventhal1996). The HBM has been useful in explaining health behavior in some studies (Baghianimoghadam et al., 2013; DiMatteo, Haskard, & Williams, 2008; van der Wal et al., 2005); however, the use of this model has been primarily limited to the individuals’ perceived costs and benefits of the health behavior in association with the perceived threat of the illness (Diefenbach & Leventhal, 1996).

The HBM postulates that health behavior is a function of four factors associated with certain health behaviors in an effort to avoid the illness or control the threat: (a) perceived susceptibility, (b) perceived severity, (c) perceived benefits, and (d) perceived costs (Diefenbach & Leventhal, 1996). Perceived susceptibility refers to an individual's feelings of vulnerability to a disease or the individual's perception of the likelihood that they may be susceptible to a particular ailment or disease (Diefenbach & Leventhal, 1996). An individual's perceived severity of an illness can be wide ranging, for example from pain to disability, or even death (Diefenbach & Leventhal, 1996). An individual's perceived susceptibility is combined with their perceived severity of the disease threat as a source of motivation for the individual to engage in a particular health behavior. However, the disease alone is not enough for the individual to engage in health promoting behavior. The individual must perceive a sufficient benefit as a result of the perceived cost or effort put forth to decrease susceptibility and/or severity (Diefenbach & Leventhal, 1996). Perceived costs are defined as the time, money, and energy invested in particular health behaviors.

An example illustrating the interplay of the HBM factors follows: A kindergarten teacher may perceive increased susceptibility for catching the common cold because of regular exposure to a classroom full of sniffling children. This teacher may view catching a cold as having substantial severity related to missing work, the inconvenience of being ill, or spreading the illness to the teacher's newborn child at home. Thus this kindergarten teacher may engage in careful and frequent hand washing and clean the classroom equipment often based on this perceived susceptibility. All of these activities are associated with a cost including time, energy, and monetary sacrifice. The individual engaging in self-care health behaviors must perceive a benefit, which may include reducing susceptibility, severity, or progression of the disease. In the case of the teacher, the perceived benefit of keeping a newborn child well, may be enough for the teacher to engage in self-care prevention strategies and accept the associated costs.

The CSM goes beyond the HBM’s simple cost-benefit analysis and postulates that an individual develops illness beliefs based on a number of factors. These factors may include information the individual gathers from healthcare providers, social interaction with friends and relatives, the media, personal experience with the symptoms of the disease, and the perceived effectiveness of engaging in self-care behaviors. The individual processes all information and formulates beliefs that are unique to the individual with regard to his or her diagnosis. These individual beliefs determine the individual’s health behaviors (Leventhal, Meyer, & Nerenz, 1980) and these beliefs may or may not align with evidence based treatment regimens.

Each individual’s experiences with HF and exposures to HF information are unique. Understanding the HF illness representation of an individual or a group of like individuals (i.e. socioeconomic, ethnic, or geographically similar groups) will enable the healthcare provider to tailor interventions based on unique HF beliefs. Through tailored interventions, health behavior can be modified resulting in improved engagement in HF self-care and reduced morbidity and mortality related to HF.

Definitions

Frontier.

A population density of less than 6 persons per square mile and driving time to the hospital of either 60 minutes or severe geographic and/or seasonal climatic conditions (National Rural Health Association, 2008).

Heart failure.

Heart failure (HF) is a syndrome caused by cardiac dysfunction, generally resulting from myocardial muscle dysfunction or loss, and characterized by either left ventricular dilation or hypertrophy or both. Whether the dysfunction is systolic, diastolic, or mixed, it leads to neurohormonal and circulatory abnormalities, usually resulting in characteristic symptoms such as fluid retention, shortness of breath, and fatigue, especially on exertion. In the absence of appropriate therapeutic intervention, HF is usually progressive at the level of both cardiac function and clinical symptoms. The severity of clinical symptoms may vary substantially during the course of the disease process and may not correlate with changes in underlying cardiac function. Although HF is progressive and often fatal, patient can be stabilized and myocardial dysfunction and remodeling may improve, either spontaneously or as a consequence of therapy. In physiologic terms, HF is a syndrome characterized by either or both pulmonary and systemic venous congestion and/or inadequate peripheral oxygen delivery, at rest or during stress, caused by cardiac dysfunction (Lindenfeld, et. al., 2010, p. 480).

Illness belief or representation.

An individual’s expectations about an illness or somatic symptoms based on information gathered from multiple sources, including social communication, cultural knowledge, healthcare providers, close family members and personal experiences. An illness belief or representation consists of the following five attributes:

Identity:

Individual’s belief about an illness relating to the physical symptoms that may be felt or expected.

Timeline:

Individual beliefs about the expected timeframe of the illness. This is in relation to the acuteness or chronicity of the disease.

Consequences:

The believed repercussions of the illness related to personal experiences, economic hardship, or emotional effects.

Cause:

The believed cause of the illness based on experiences of the individual. If the individual has chest pain after meals, he may conclude that eating has caused his chest pain.

Cure or control:

The believed ability to either cure or control a particular illness (Diefenbach & Leventhal, 1996; Leventhal, et al., 1980).

Quality of life.

Physical and mental health perceptions and associated health risks, functional status, social support, and socioeconomic status (Centers for Disease Control and Prevention, 2011).

Rural.

Any county that is not designated as Metropolitan (more than 50,000 people) or Micropolitan (between 10,000 and 50,000 people). Any county with less than 10,000 people (Office of Management and Budget, 2010).

Self-care.

A naturalistic decision-making process outside of the clinical setting, in which specific behaviors are initiated by an individual with the intention to improve health, prevent disease, and maintain healthy functioning and well-being (Riegal, et. al., 2009; Clark, et. al., 2010).

Ventricular remodeling.

The process by which ventricular size, shape, and function are modified by mechanical, neurohormonal, and genetic factors after acute (e.g. ischemia) or chronic (e.g. uncontrolled hypertension) injury to the heart (Rogers et al., 2012).

CHAPTER 2

REVIEW OF LITERATURE

A review of literature was conducted with regard to HF and HF illness beliefs, the effect of those illness beliefs on health behavior, and the effect of health behavior on outcomes. This review of literature identified that few studies focused on HF illness beliefs in rural areas, and no study compares and contrasts the health beliefs of rural dwellers to those of individuals living in metropolitan areas. Chapter 2 will summarize the literature findings with specific attention to the use of the CSM which has been widely used in studies examining preventative health behavior, sick role behavior, and behavior in chronic illness.

Heart Failure

There is no widely accepted characterization and definition of HF because of the complexity of the syndrome (Lindenfeld, et. al. 2010). The New York Heart Association has categorized HF into four classes (A, B, C, and D) based on the progressive nature of the disease. Class A HF is defined by the presence of risk factors for HF, which includes coronary artery disease, diabetes, or hypertension with no evidence of ventricular dysfunction on an echocardiogram. Class B HF is defined by the presence of ventricular hypertrophy and left ventricular dysfunction in the absence of symptoms such as edema, shortness of breath, or nocturnal dyspnea. Class C HF is defined as the presence of HF symptoms or having experienced HF symptoms in the past. Symptoms include decreased activity tolerance because of dyspnea or fatigue, which can be felt at rest or during activity. Clients may also demonstrate fluid retention evidenced by edema in the extremities, jugular venous distention, and pulmonary infiltrates. Class D HF is the final stage of HF, symptoms are experienced at rest and the outcome is usually death unless a ventricular assistive device is implanted or a heart transplant occurs (Ammar et al., 2007; Jessup, et. al., 2009).

However, most definitions and categorizations of HF fail to capture the complexity of this disease. Thus the Heart Failure Society of America proposed a definition of HF, which demonstrates the complexity and varying physiological components (see full definition on page 9). Part of this definition states: “The severity of clinical symptoms may vary substantially during the course of the disease process and may not correlate with changes in underlying cardiac function” (Lindenfeld et al., 2013, 480). Given the progressive nature of the HF and the fact that symptoms and cardiac function can improve spontaneously with or without treatment or self- care activities it is imperative to recognize the dynamic nature of HF as spontaneously improved or resolved symptoms may influence the formulation of individual HF illness beliefs.

HF is associated with increased mortality, frequent hospitalization, poor quality of life, multiple comorbidities, and complex therapeutic regimes (Lindenfeld et al. 2013). Prognosis among individuals with HF varies, and therefore the course of HF can be difficult to predict and generalize. For example, individuals with cardiac disease such as hypertension or coronary artery disease may never develop cardiac dysfunction or HF, and individuals who have cardiac dysfunction based on diagnostic tests, may never manifest symptoms of HF (Lindenfeld, et. al., 2013). The development of HF symptoms is dependent upon many factors including systemic vascular resistance, renal excretion of sodium, the presence of lung disease, and other comorbidities (Jessup, & Brozena, 2003). There are many potential etiologies of HF and individuals often demonstrate diverse clinical features (Lindenfeld et al. 2013).

In the past it was not uncommon for ventricular remodeling and dilation to lead to the manifestation of HF symptoms. Today, individuals can live with mild to moderate ventricular dysfunction for many years without ever manifesting symptoms of HF. Modern treatments, including low salt diets, moderate exercise, and improved medications, can greatly reduce HF morbidity. Important components of HF treatment include self-care, cardiac rehabilitation, and medication adherence, which have been shown to halt progression of the disease and in some cases reverse cardiac dysfunction (Riegel et al., 2009). Advances in HF treatments have shown a substantial reduction in mortality rate and increased quality of life for individuals with HF (Auduly, Asplund, & Norbergh, 2011; Deaton & Grady, 2004).

Common Sense Model of Illness Representation

The CSM posits that individuals are problem solvers dealing with two factors: the perceived threat of illness and the emotional reaction to this threat. This model was empirically developed and documented that fear messages about acute illnesses led to individuals engaging in healthy behavior. Leventhal et al. (1980) proposed that individuals needed different types of information in relation to their illness in order to engage in healthy behavior. Leventhal et al. (1980) also proposed that healthy behavior changes were often time limited. For example an individual presenting with pneumonia may be given information about the possible deadly effects of cigarette smoking. This information, when coupled with information from the tobacco quit line and a few nicotine patches, may result in abstention from smoking for a few days. However, once this individual starts to feel better and uses all the nicotine patches they may return to smoking. The client's perception of the severity of pneumonia had decreased and he was no longer receiving messages concerning the dangers of smoking, therefore he may no longer be compelled to engage in the self-care behavior of smoking cessation.

Leventhal and colleagues' (1980) developed the CSM to provide a structured model that would aid in understanding how people develop attitudes and beliefs about illness and how these attitudes and beliefs lead to lasting behavioral health changes to cope with illness. Leventhal's group proposed a hierarchy outlining an adaptive system featuring three central tenets. First, the CSM views the individual as an active participant in the illness and the associated health behaviors that are effective in either minimizing symptoms or curing the illness. The individual gathers information about their diagnosis from many sources including previous social communication, cultural knowledge, health care providers, close family members, their own personal experience, and the effectiveness of self-care behaviors. Second, the illness representation that is shaped by this information will in turn guide the individual's perception of illness and their individual coping skills. The third tenet proposes that illness representations are unique to each individual and they may or may not be in accord with medical facts (Diefenbach & Leventhal, 1996; Hagger & Orbell, 2002; Leventhal, et al., 1980).

Illness representations or beliefs have been classified into five categories. These include cause, consequences, identity, timeline, and control or cure. Each individual develops unique illness beliefs with regard to each of these categories and these beliefs are what drives engagement in self-care practices. Individuals may attribute the cause of illness to immune system dysfunction, germs and viruses, emotional factors (stress and depression), environmental factors (pollution and chemicals), and/or psychological factors (overwork, mental attitude, and personality; Hagger & Orbell, 2003). Consequences of an illness relate to an individual’s beliefs regarding the overall effect on quality of life and how the illness will impact daily activities. When an individual is informed of their diagnosis, a mental picture will develop with regard to the impact the illness will have on their life. This may change over time as the individual may realize that the anticipated consequences do align with reality. Illness identity is the association of symptoms to a particular condition. A person with HF may not associate their difficulty breathing with their HF diagnosis but rather with lung disease, pneumonia, or some other comorbidity. Timeline is related to the individual’s beliefs which are related to the acuteness or chronicity of the illness. Control or cure relates to the individuals beliefs regarding the ability to control or cure the illness through health behaviors (Leventhal et al., 1980).

The CSM provides a framework to comprehend how an individual builds an understanding of their disease process and how self-care behaviors are employed. This model may enable healthcare professionals to develop educational and nursing interventions to assist individuals with developing and sustaining appropriate self-care activities when diagnosed with a chronic illness such as HF (Leventhal et al., 1980).

Illness Beliefs and Health Behavior

Beliefs that individuals have about their illness have consistently been related to health behaviors and the actions individuals engage in to deal with illness (Adulv, Asplund & Norbergh, 2011; Ayele, Tesfa, Abebe, Tilahun, & Girma, 2012; Harvey & Lawson, 2008; Hirani & Newman, 2005; Martin, Williams, Haskard, & DiMatteo, 2005). Clark and colleagues (2009) concluded that knowledge alone is not sufficient for individuals to engage in self-care. Healthcare providers must also consider individual beliefs and perceptions about the illness in order to develop effective interventions that result in positive self-care behaviors. A meta-analysis by DiMatteo et al. (2007) linked health beliefs, disease severity, and individual adherence. DiMatteo and colleagues (2007) concluded that individuals who perceived their disease as more serious tended to be more adherent to the prescribed treatment regimen. However, as the health of an individual declined self-care adherence declined as well. Individuals who doubted the efficacy of their treatments because of their declining health did not engage in self-care and they began to doubt their providers' advice and thus had less interaction with them (DiMatteo et al., 2007).

Studies have shown a relationship between illness beliefs and attendance at cardiac rehabilitation sessions, and compliance with medication and treatment regimens

(Ekman et al., 2005; French, Cooper, & Weinman, 2006; Hirani & Newman, 2005; Jin, Sklar, Oh, & Li, 2008; Percival, Cottrell, & Jayasinghe, 2012; van der Wal et al., 2006; Wu, Moser, Chung & Lennie, 2008). French, Cooper, and Weinman (2006) reported that individuals who believed their cardiac condition had potentially serious consequences and the symptoms and disease progression could be managed, were more likely to attend cardiac rehabilitation. Medication adherence directly correlates with an individual's belief that the medication is necessary (Ekman et al., 2005; Percival et al., 2012; Wu, Moser, Chung & Lennie, 2008). Individual beliefs about medication and diet efficacy are both important factors in compliance (Hirani & Newman, 2005; van der Wal et al., 2006). On the contrary, individuals who are fearful of long term or negative side effects of medications were found to be noncompliant with medications (Hirani & Newman, 2005). Cottrell, Denaro, and Emmerton (2013) compared health beliefs of individuals who took their medications regularly to individuals who did not take their medications and reported that beliefs that their medication "affect the heart" [and are] "related to water" (p. 145) promoted compliance with medication regimens. Individuals' beliefs about the causes and meaning of illness, and their motivation to follow treatment recommendations were strongly related to compliance to treatment regimen. Compliance is improved when an individual feels susceptible to the illness, believes the illness could pose serious consequences, and believes the treatment will be effective (Jin et al., 2008).

Goodman, Firouzi, Banya, Lau-Walker, and Cowie (2013) reported that individuals perceiving that the cause of HF was out of their control or that HF was caused by a random factor, were less likely to change their health behaviors and engage in self-care. Understanding what individuals believe to be the cause of their HF may allow the healthcare provider to intervene and help correct any misconceptions, potentially improving self-care behavior. Mulligan et al. (2012) reported that as time passed, accuracy of HF illness beliefs in individuals improved. An increase in the accuracy of HF illness beliefs resulted in an increased quality of life for some and a decrease for others. Individuals who believed that they could control the progression of HF reported an increase in the quality of life while individuals who believed that HF was a chronic, incurable illness reported a decrease in quality of life (Mulligan et al., 2012).

Lau-Walker (2004) studied the relationship between illness representation and self-efficacy by administering an illness perception questionnaire, a general self-efficacy questionnaire, cardiac diet self-efficacy instrument, and a cardiac exercise self-efficacy instrument to individuals diagnosed with either myocardial infarction or angina. Lau-Walker reported a significant relationship between illness perception and self-efficacy; specifically, individuals perceiving greater consequences of their illness had lower general self-efficacy to cope with the condition, and individuals perceiving the time-line of their illness to be longer and more chronic had higher self-efficacy to maintain a change of diet and exercise regime. In contrast, Molloy et al. (2009) conducted a study revealing individuals with HF who believed HF was a chronic condition and had significant consequences on their life were less likely to adhere to medication therapy. It is important to examine an individual’s perception of illness and how this perception influences their attitude towards HF and the ability to cope with the diagnosis as this directly affects self-care behavior.

Illness Beliefs and Outcomes

It has been established that health behavior is predicated on accurate illness beliefs, (Anemma, Luttik, & Jaarsma, 2009; Bosworth et al., 2004; Britz & Dunn, 2010; Jovicic, Leduc, & Straus, 2006; Riegel et al., 2012); therefore, accurate illness beliefs can have positive effects on physical health outcomes. Self-care is defined as the naturalistic decision process of the individual to consciously engage in behaviors that will promote health and prevent disease (Riegel et al., 2012). Individuals with HF who engage in self-care behaviors were much less likely to die or be admitted to the hospital when compared to individuals who did not engage in self- care behaviors (Evangilista & Shinnick, 2008; Jocicic et al., 2006; Riegel et al., 2012). Self-care activities that are essential in successfully managing HF include medication adherence, symptom monitoring, sodium and fluid restriction, alcohol restriction, weight loss, exercise, smoking cessation, and preventive behaviors (Riegal et al., 2012). Annema et al. (2009) identified non-adherence to diet, fluid restriction, or medication as the most important factors contributing to HF hospital readmission.

Engagement in appropriate self-care behavior correlates with increased quality of life and decreased hospitalizations (Bosworth et al., 2004; Britz & Dunn, 2010; Jovicic et al., 2006). Jovicic and colleagues (2006) performed a systematic review of randomized control trials demonstrating the effectiveness of HF management programs. Disease self-management and self-care behaviors decreased all-cause hospital readmissions and HF readmissions resulting in a savings of $1,300 to $7515 per individual annually (Jovicic et al., 2006). Britz and Dunn (2010) stated that individuals who engaged in self-care had greater confidence in their self-care abilities and reported higher quality of life scores. Coping strategies including knowledge, medication compliance, and supporting others with HF contributed to increased quality of life scores (Bosworth et al., 2004). Individuals with HF who felt empowered to engage in self-care behavior, which includes diet, exercise, and medication therapy, also demonstrated higher quality of life scores (While & Kiek, 2009). Ditewig, Blok, Havers, & Van Veenendaal (2010) performed a systematic review of randomized control trials evaluating self-management effectiveness and reported that self-management interventions showed a positive effect on the reduction of hospital readmissions, decrease in mortality, and increase in quality of life.

Illness Beliefs and the Rural Environment

Individuals living in rural areas have been identified as having unique health beliefs (Lee & McDonagh, 2006; Long & Weinert, 1989). Long and Weinert (1989) developed a framework on which others can explore the health seeking behaviors of rural residents. The first two theoretical statements of rural nursing theory describe rural residents' definition of health and their health seeking behaviors. Lee and McDonagh (2006) updated their theory and proposed that rural Montana residents define health as "being able to do what they want to do" (p. 314) and that rural residents are "self-reliant and make decisions to seek care for illness, sickness, or injury depending on their self-assessment of the severity of their present health condition and the resources needed and available" (p. 315).

HF is a serious and chronic condition with a unique set of self-care practices, and it is important that individuals diagnosed with HF understand the seriousness of their condition in order for them to engage in appropriate self-care. This self-care includes the ability to recognize the need to seek professional help when they are experiencing deteriorating symptoms. The second theoretical statement of rural nursing theory addresses self-reliance and self-assessment concerning the severity of the disease (Lee & McDonagh, 2006). An individual’s beliefs about the severity of their HF are important determinants of whether or not self-care behavior will be employed.

To date, only one research study examined the accuracy of HF beliefs by race and individual characteristics (Albert, Throchelman, Meyer, & Nutter, 2009). No studies have examined the accuracy of HF beliefs in rural populations. Obtaining knowledge about the illness beliefs of individuals with HF, specifically in the rural states of Montana and Wyoming, may help to inform the development of nursing interventions to positively impact self-care behaviors of rural dwellers living with HF.

It is important to study the illness beliefs of rural residents with HF. Rural residents with HF may not be experiencing symptoms of HF consistently because they are “able to do what they want to do” (Lee & McDonagh, 2006, p. 314). Therefore, rural dwellers may perceive HF as being cured, which may in turn lead to noncompliance with daily self-care behaviors. Self-care adherence is essential, even in the absence of symptoms, to improving quality of life and decreasing mortality. Assessing HF illness beliefs of rural residents may allow healthcare professionals to understand the accuracy of clients’ beliefs with regard to cause, consequences, timeline, identity, and cure/control.

Montana and Wyoming have a larger proportion of Native Americans (NA) per capita at 6.4% and 2.6% respectively when compared to the United States at 1.2% as a whole (Grandpre et al., 2011; Oser et al., 2007). It is important to explore HF illness beliefs of the NA population because of the higher incidence of diabetes, hypertension, obesity, and hyperlipidemia in NA, compared to the general population (Oser et al., 2005). These comorbidities increase the risk of cardiovascular disease and the development of HF. Although this study is not focused specifically on the NA population, it is assumed that a representative proportion of NAs may be included since Montana has seven Indian reservations and Wyoming has one Indian reservation that is the 7th most populated reservation in the country.

CHAPTER 3

METHODS

Study Design and Sample

This study used a descriptive design to analyze illness beliefs of Montana and Wyoming residents living with HF. A convenience sample of individuals was recruited from a 300-bed acute care hospital located in Montana, which serves individuals living in south central Montana and northern Wyoming. Inclusion criteria included hospitalized adults 21 years and older, who could speak English, and who had a primary or secondary diagnosis of HF. Individuals who had a diagnosis of dementia and those discharged to a long-term care facility were excluded from the study. It was expected that the sample would include individuals living in both urban and rural areas of Montana and Wyoming as well as a proportionate representation of minority populations living in the region.

Setting

The healthcare facility from which the sample was derived has a variety of cardiac services including cardiodiagnostics, cardiac catheterization, cardiac surgical services, cardiac intensive care, telemetry, and cardiopulmonary rehabilitation (CR). The most recent additions to cardiovascular services include a hybrid operating room as well as providing minimally invasive valve replacement. Associated with the hospital are 13 medical practice clinics, as well as 19 specialty medical practice clinics, including a heart and vascular center. The heart and vascular center provides consultative and diagnostic cardiac and vascular services and is staffed by physicians specializing in adult cardiac surgery, general thoracic surgery, and vascular surgery.

Procedures

The step-by-step procedures included:

- A list of potential study participants was generated from the hospital database. The list included name, contact number, primary or secondary diagnosis of heart failure, date of birth and hospital discharge date. Exclusion criteria included individuals with a diagnosis of dementia, those younger than 21, those who cannot speak English, and those discharged to a long-term care facility.
- The list was provided to the St. Vincent Healthcare call center registered nurses (RN).
- The call center RNs attempted up to three calls to each individual on the list and this is consistent with the call center's protocol in contacting individuals for satisfaction surveys.
- A script (Appendix A) was used by the call center RNs to ensure consistent use of Institutional Review board approved language for informed consent and data collection for the Survey of Illness Beliefs in HF instrument (Appendix B).
- The registered nurses at the call center entered the data into a computer program at the hospital and kept all data on a password-protected computer.

The principal investigator checked in with the director of the call center on a weekly basis to address questions or concerns and to pick up the data collected to date.

- At the end of data collection a report was generated for the principal investigator which included de-identified demographic data and the participants' responses to the Survey of Illness Beliefs in HF statements.

Each call center RN received a $10 gift card to the hospital coffee shop in appreciation of their assistance with data collection. Participants in the study did not receive any compensation or payment for survey participation.

Data Collection and Instruments

Demographic and socioeconomic data collected included sex, age, race, ethnicity, income level, city and county of residence, marital status, education level, and employment status. The Survey of Illness Beliefs in HF Instrument (Albert & Zeller, 2007) instrument is a 14-item survey that measures the accuracy of HF beliefs and was also used during data collection. The reliability of the Survey of Illness Beliefs in HF instrument has been established with a reported Chronbach's alpha of 0.73 (Albert & Zeller, 2007). Each item refers to one of four categories of illness beliefs: consequences, identity, timeline, and control. The fifth category, cause, is not addressed by this survey. The Survey of Illness Beliefs in HF instrument uses a four-point Likert scale with choices ranging from strongly agree to strongly disagree. Seven items were worded accurately and seven were worded inaccurately. Each item was scored separately assigning a score of 1, 2, 3, or 4 to each item based on the correct answer using the following scoring: (a) strongly disagree - 4 points, (b) disagree - 3 points, (c) agree - 2 points, and (d) Strongly agree 1 point.

Human Subjects Considerations

Montana State University and St. Vincent Healthcare Institutional Review Boards granted approval for this study. The call center RNs read the following script to all potential participants: "Participation in the study is voluntary, and you can choose to not answer any question that you do not want to answer, and you can stop at any time." The individual was then asked, "Are you willing to participate in this study which should take less than 10 minutes?" No individual was coerced in any way to participate in the study. Individuals maintained the right to refuse participation in the survey and the rights, privacy, and dignity of each qualified potential and participating individual was protected at all times.

Data Analysis

The data was entered into an excel spreadsheet and the mean score of the 14 items on the questionnaire was calculated. Scoring was reversed for inaccurately worded items so a mean score of 3 or higher indicated accurate health beliefs (Albert & Zeller 2007). A p-value of less than or equal to 0.05 was considered statistically significant. An overall score above 3.0 indicated accurate beliefs. Deviation from the mean score of 3 indicates the level of certainty or uncertainty in individual illness beliefs. Overall beliefs were calculated and reported, along with the accuracy of each individual illness belief category (consequences, identity, timeline, and control). Responses were analyzed for accuracy of HF beliefs comparing rural/frontier and non-rural subgroups. These rural and non-rural subgroups were further analyzed comparing the accuracy of illness beliefs of rural male vs. rural female, rural single vs. rural married, rural participants with no college vs. rural participants with at least some college and rural participants younger than age 70 vs. rural participants age 70 and older. Non-rural subgroups were similarly compared.

CHAPTER 4

RESULTS

Sample

Approximately 300 patients discharged from the health care facility between September 1, 2013 and November 30, 2013 met the inclusion criteria for the study. Call center RNs made 119 phone calls to potential participants from the list and sixteen phone numbers were not in service, two phone numbers were incorrect, and 14 phone calls were not answered. A total of 15 potential participants refused to participate in the study, eight potential participants did not meet the study inclusion criteria (due to their residing in a long-term care facility) and 14 potential participants had died since discharge from the hospital. Due to time constraints, the call center discontinued calls once 50 surveys were obtained.

Illness beliefs of participants with a diagnosis of HF were collected from 50 participants and the demographics of the sample are reflected in Tables 1 and 2. A total of 29 participants resided in rural areas of less than 10,000 people and 21 participants resided in non-rural areas with 10,000 or more people. The average age for participants ranged from 38 to 98 years with 38% of the sample in their 70's. The sample was almost evenly divided between males (52%) and females (48%) and the sample was primarily Caucasian, non-Hispanic, and non-Latino (96%). Four percent of the sample was Native American. Fifty eight percent of the sample was married or had a domestic partner and 56% of the sample reported living with their spouse or domestic partner. Seventy percent of the sample was retired and 66% reported an annual income of $29,999 or less. Forty eight percent of the sample reported having at least some college or technical education with 18% of the total sample reporting a four year degree or higher.

The rural group (n=29) was predominately female (59%), single (55%), had not attended college (52%) and were 70 years or older (62%). The non-rural group was predominately male (67%), married (76%), had not attended college (52%) and were 70 years or older (67%) (Table 3).

Table 1. Age, Gender, City/Town Population of Sample

Participants		**Number of Cases**	**% of total sample**
Age	30-39	1	2%
	40-49	1	2%
	50-59	5	10%
	60-69	11	22%
	70-79	19	38%
	80-89	9	18%
	90-99	4	8%
Gender	Male	26	52%
	Female	24	48%
City/Town Population	Less than 10,000	29	58%
	More than 10,000	21	42%

Table 2. Relationship status, living arrangements, employment status, race, education, and household income of sample. n=50

Response		**Number of Cases**	**% of total sample**
Relationship status	Single	4	8%
	Married/Dom partner	29	58%
	Widowed	11	22%
	Divorced	5	10%
	Separated	1	2%

Table 2. Relationship status, living arrangements, employment status, race, education, and household income of sample. n=50, continued

Participants		**Number of Cases**	**% of total sample**
Living arrangements	Alone	15	30%
	With Family	7	14%
	With spouse	28	56%
Employment status	Employed for wages	3	6%
	Homemaker	4	8%
	Unable to work	8	16%
	Retired	35	70%
Race	White	48	96%
	Native American	2	4%
Highest level of Education	Some high school	7	14%
	High school graduate	19	38%
	Some college	15	30%
	College 4 years	7	14%
	More than 4 years	2	4%
Household Income	Under 10,000	10	20%
	10,000-19,999	12	24%
	20,000-29,999	11	22%
	30,000-39,999	5	10%
	40,000-49,999	3	6%
	50,000-74,999	4	8%
	75,000-higher	2	4%
	Did not answer	3	6%

Table 3. Rural and Non-rural Subgroup Demographics

		Rural		***Non-Rural***	
Variable	Total	*n*	%	*n*	%
Gender					
Male	26	12	41%	14	67%
Female	24	17	59%	7	33%
Relationship					
Married	29	13	45%	16	76%
Single	21	16	55%	5	24%
Level of education					
No College	26	15	52%	11	52%
Some College	24	14	48%	10	48%
Age					
Younger than 70	18	11	38%	7	33%
70 or older	32	18	62%	14	67%

Accuracy of Illness Beliefs

The overall sample had inaccurate HF illness beliefs with the mean Illness Belief sum score of 2.86. Rural participants had less accurate heart failure illness beliefs (mean sum score of 2.73) when compared to non-rural participants (mean sum score of 2.91). This result was statistically significant with a p-value of 0.018 (Table 4).

Table 4. Illness Beliefs Sum Scores by Setting

	Total		**Rural**		**Non Rural**	
n	Mean (SD)	*N*	Mean (SD)	*N*	Mean (SD)	*p* value
50	2.86 (0.47)	29	2.73 (0.23)	21	2.91 (0.28)	0.018*

Note. T-tests for unequal variance were used (rural vs. non rural).
*Statistical significance p = < 0.05.

Examining the specific attributes of illness beliefs including control, timeline, consequences, and identity, demonstrated that rural participants had less accurate heart failure beliefs within each attribute with the exception of timeline where the mean illness belief sum score was similar in both rural and non rural residents (see Table 5). Illness beliefs for the attributes of control and consequences reached statistical significance when comparing rural residents to non-rural residents (Table 5). Rural participants tended to inaccurately believe that their illness could not be influenced by their behavior, requires them to drink fluids (water, juice, etc.) when thirsty, does not always need treatment, and could improve or even be cured. The most frequent inaccurate HF belief in both rural and non-rural participants was that their heart function could improve over time with pharmaceutical drug therapy prescribed by a health care provider.

Table 5. Individual Illness Beliefs Mean Scores (Mean < 3.0 indicates inaccurate beliefs), by Population

Illness Beliefs attribute based on the Common Sense Model of Illness	Rural	Non Rural	*p*-value
Control	2.69 ± 0.31	2.91 ± 0.37	0.029*
Timeline	2.81 ± 0.47	2.81 ± 0.46	0.995
Consequences	2.68 ± 0.26	2.90 ± 0.31	0.014*
Identity	2.86 ± 0.52	3.05 ± 0.44	0.180

Note. Rural n=29 Non rural n =21
*A *p*-value of ≤ 0.05 indicates statistical significance.

Comparing rural and non-rural groups within specific demographic groups indicated that rural males and non-rural males had slightly less accurate illness beliefs when compared to their female counterparts. Married participants had slightly more accurate beliefs than non-married participants (including divorce, widowed, separated, and single). Those with at least some college had more accurate beliefs than participants with some high school or those who were high school graduates. Rural participants younger than age 70 had slightly less accurate beliefs than those 70 years and older and non-rural participants younger than age 70 had slightly more accurate beliefs than those 70 years and older (Table 6).

Table 6. Illness Beliefs Sum Scores Comparing Rural and Non rural within Specific Demographic Groups

	Rural	**Non Rural**
Gender		
Male	2.70 ± 0.27	2.89 ± 0.31
Female	2.75 ± 0.22	2.96 ± 0.21
p-value	0.623	0.539
Relationship		
Married	2.77 ± 0.15	2.92 ± 0.29
Single	2.70 ± 0.28	2.87 ± 0.24
p-value	0.380	0.695
Level of Education		
No College	2.70 ± 0.26	2.88 ± 0.268
At least some college	2.76 ± 0.19	2.94 ± 0.30
p-value	0.485	0.637
Age		
Younger than 70	2.67 ± 0.16	3.04 ± 0.31
70 years or older	2.77 ± 0.26	2.85 ± 0.24
p-value	0.225	0.183

Note. A *p*-value of ≤ 0.05 indicates statistical significance.

CHAPTER 5

DISCUSSION

The conceptual framework used in this study, the Common Sense Model of Illness, proposed that individuals react to their illness based on their perception or beliefs surrounding their illness. The CSM provides a model to understand how people develop attitudes and beliefs about their illness and how these beliefs affect the individual's engagement in lasting behavioral health changes in order to cope with their illness. The Survey of Illness Beliefs in HF instrument was designed to assess the accuracy of beliefs developed by individuals with HF. The survey assessed the accuracy of beliefs in four of the five categories of illness beliefs proposed in the CSM framework consequences, control, identity, and timeline. Understanding an individual's illness beliefs is important as these illness beliefs have been associated with the promotion of behavioral health changes such as self-care adherence leading to decreased hospitalization and increased quality of life (van der Wal et al., 2005; MacInnes, 2013).

The results of this study demonstrated that HF beliefs were inaccurate with rural participants demonstrating statistically significant less accurate HF beliefs when compared to the non-rural participants, ($p = 0.018$); specifically in the categories of consequences ($p =0.014.$) and control ($p = 0.029$). The findings of this study support the findings of a previous study conducted by Albert et al (2009) indicating overall individuals have inaccurate HF beliefs. Most individuals recognized that HF could worsen by lifestyle behavior and that HF is a threat to their health. Based on the findings in the literature review, the overall inaccurate beliefs, especially demonstrated in the rural subgroup in this sample, may lead to inadequate self-care behaviors resulting in HF symptom exacerbations.

Limitations

Due to data collection from a small convenience sample using self-report methods for illness beliefs of HF, there is the possibility of sample bias or self-report errors. The generalizability of the study findings is limited due to a small sample size recruited from one site over a short time period. The small sample size did not provide the ability to calculate predictors of HF illness beliefs.

Many potential participants were unable to be contacted due to disconnected phone numbers. This may have excluded lower socioeconomic groups without phones as well as people with cell phones and no home phones. The requirement of having a phone may have affected the representation of Native American participants as well. Four percent of Native Americans were represented in this study which is slightly below the 5.9% of Native Americans in Montana. In addition many individuals were excluded due to nursing home admission and death; these individuals may likely have been in the end stages of their illness. Excluding this group of individuals' likely negatively impacted study results. These individuals may have known about their HF diagnosis for a longer period of time. Because of this they may view their symptoms differently and they may have experienced different outcomes as a result of their self-care behaviors.. The study did not consider the presence of any comorbidities, access to specialized cardiology care, or details about the time frame since the diagnosis of HF which may be determinates or predictors of the accuracy of illness beliefs.

Implications

This study has implications for research, practice and education. It is important to identify HF beliefs of individuals, including both rural and non-rural residents, and more research is needed with larger sample sizes and more ethnic and racial diversity. To date, little research has been performed with regard to the accuracy of HF illness beliefs, especially in the rural population. Albert (2009) conducted a study which determined some predictors of illness beliefs and identified the accuracy/inaccuracy of HF beliefs. Further research regarding the HF illness beliefs of rural residents living with HF is needed to determine predictors of inaccurate beliefs. Determining the cause of inaccurate beliefs may help health care providers develop programs targeted at rural individuals to increase the accuracy of their beliefs, thus potentially leading to increased adherence to self care, decreased hospitalizations, and increased quality of life. Research with a larger sample size would allow the determination of predictors of accurate HF illness beliefs. Future research is also needed to examine variables such as comorbidities, length of time since the HF diagnosis, lifestyle behaviors, availability of health insurance and access to medical care, to determine if these factors affect the accuracy of HF illness beliefs. Further studies examining the effect of the accuracy of HF beliefs on As noted by Molloy et al., (2009) more accurate beliefs with regard to timeline and consequences actually led to decreased engagement in medication adherence resulting in poor health outcomes. The accuracy of beliefs should be further examined to determine the effect of individual HF beliefs on individual outcomes.

Current health care practices, especially in urban healthcare centers, may not address the healthcare needs specific to rural residents living with HF. It is important to identify reasons causing inaccurate HF beliefs in the rural population. Rural dwellers have a tendency to be under insured, have less access to healthcare, and higher rates of chronic disease (Bailey, 2013). Rural dwellers also have a unique development of health beliefs turning to trusted sources such as family, neighbors, and friends for healthcare advices even though these sources may not be the most accurate (Winters & Lee, 2010).

Rural dwellers are known to be less likely to trust and heed to advice provided by healthcare professionals who are considered outsiders. Healthcare advice and help is more likely to be sought through informal healthcare systems including family, friends, and neighbors rather than formal systems (Winters & Lee, 2010).-The CSM also recognizes these informal healthcare systems as contributing to the formation of illness beliefs (Leventhal et al, 1980). Although the cultural barrier preventing rural dwellers from seeking care through formal healthcare sources is changing, the principle of self-reliance remains a characteristic of rural dwellers and their care seeking behavior (Winters & Lee, 2010). By identifying the sources rural dwellers seek for healthcare advice, targeted education could be provided to these individuals that rural dwellers know and trust including family, friends, and rural healthcare providers. These individuals could play a pivotal role in promoting accurate HF beliefs in the rural population. Interventions focused on increasing evidence based HF knowledge within this informal network of healthcare may help to increase the accuracy of HF beliefs. It may also be beneficial to target healthcare provider within the rural communities to increase their knowledge of best practices regarding HF care. Educating rural local health care providers, who are considered insiders and have gained trust and credibility within the rural community, may help to increase the accuracy of HF beliefs of rural residents.

The results of this study support a need for nursing education pertaining to rural health beliefs and how they are determined, especially in urban healthcare facilities that serve rural residents. Over half of the population sampled were rural dwellers and they were all discharged from an urban hospital. Rural dwellers overall had inaccurate heart failure beliefs especially in the categories of control and consequences. Lee & McDonagh (2006) state that rural residents define health as “being able to do what they want to do” (p. 314) and older rural residents define health in a functional manner, as being able “to work, to be productive, and to do usual tasks” (p. 314). HF can limit the ability to function, especially with regard to working productively and the ability to engage in usual tasks. Health care providers should consider describing the effects of HF exacerbations in terms of limiting functional capacity and decreasing the ability to engage in daily activities, therefore promoting self-care practices as measures of preventing these limitations. If rural dwellers believe they have the ability to control their illness and limit functional decline (consequences), they may be more likely to engage in self-care. Also, if rural dwellers understand they may not be able to “do what they want to do” (Lee & McDonagh, 2006, p. 314) as a consequence of their illness, they may be more likely to engage in self-care activities that will slow the progression of the disease leading to this consequence.

In conclusion, the literature suggests that inaccurate HF beliefs may contribute to increased hospital admissions and decreased quality of life. Targeting research to determine the predictors of inaccurate HF illness beliefs may help to identify individuals who need a better understanding of their illness. It is important for health care professionals to support rural dwellers to better understand their illness. In addition nursing educators should develop educational programs to address the lack of knowledge pertaining to how rural dwellers form health beliefs. These efforts may help to increase the accuracy of HF illness beliefs. Recognizing the unique characteristics of the rural population and applying this knowledge to develop targeted education for this population may aid to increase the accuracy of HF beliefs. Increasing the accuracy of HF beliefs in the rural population will potentially lead to increased HF self-care adherence.

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APPENDICES

APPENDIX A

CALLER SCRIPT

Caller Script
Administering Survey of Illness Beliefs in Heart Failure
Instructions are in italics

Good morning.
My name is ___________________________ and I am calling from the Call Center at St Vincent Hospital.
Is this Mr./Ms. _______________________. *Caller will verify correct party on the phone.*

You have been selected to participate in a graduate nursing student's research study examining beliefs and understanding about heart failure. The study involves providing some basic demographic data as well as answering 14 short survey questions about what heart failure means to you.

Participation in the study is voluntary, and you can choose to not answer any question that you do not want to answer, and you can stop at any time. The survey will take less than 10 minutes and there is no direct benefit provided to you for your participation. The information you provide is confidential and no identifying data will be associated with your responses. All study results will be anonymous.

Are you willing to participate in this research study, which should take less than 10 minutes? Is this a good time?

Individual opts out or hangs up at any time during the call = phone call ends. Please record the number of individuals called who opt out of the survey and all data recorded up to the termination of the call.

Individual agrees to continue = proceed with the questions below.

Once verbal consent is received, the survey is administered beginning with demographic data. Read the question and record the individual's answers.

Before we begin, do you have any questions about the study?

1.) What is your age? _______
2.) What is your gender? ______Male ______Female
3.) In what city/town do you live? ______________________________
In what county do you live? _____________________________
4.) What is your relationship status?
______Single, never married ______Married or domestic partnership
______Widowed ______Divorced
______Separated
5.) What best describes your living arrangements?
______Live alone ______Live with spouse or significant other
______Live with family member ______Live with friend or roommate

6.) What is your employment status?
______Employed for wages ______Self-employed
______Out of work – looking ______Out of work - not currently looking
______Homemaker ______Retired ______Unable to work
7.) What is your race?
______White ______African American
______Native American
______Asian ______Native Hawaiian/Pacific Islander
8.) Are you Hispanic?
______Yes ______No
9.) Are you Latino?
______Yes ______No
10.) What is your highest level of education?
______Some high school ______High school graduate
______Some college or technical school ______College 4 years (Bachelor's degree)
______More than 4 years of college (Master's degree or higher)
11.) What best describes your current household income?
______Under $10,000 ______$10,000-19,999 ______$20,000-29,999
______$30,000-39,999 ______$40,000-49,999 ______$50,000-74,999
______$75,000-99,999 ______$100,000-149,999 ______Over $150,000

The survey will be administered reading the directions first, fully reading each statement and providing the four possible responses after each statement.

This survey provides 14 statements that might describe what heart failure means to you, including your beliefs and understanding about heart failure. The purpose is to learn what you believe about heart failure.

I will read each statement to you and I would like you to respond with strongly disagree, disagree, agree, or strongly agree. Choose strongly disagree or strongly agree if you are very certain that the statement is something you believe.

Answer each statement as best as you can. It is important for you to respond to each statement based on your actual beliefs and not on how you think you should respond to each statement.

Read each statement to the individual and provide the answer choices "strongly disagree, disagree, agree, and strongly agree" after each statement. Record the individual's answer.

1. Question number 1: Heart failure is an illness that I cannot influence by my behavior.

   Strongly disagree

   Disagree

   Agree

   Strongly agree

2. Question number 2: Heart failure is something I go “in” and “out” of.

   Strongly disagree

   Disagree

   Agree

   Strongly agree

3. Question number 3: Heart failure is present only when symptoms are present.

   Strongly disagree

   Disagree

   Agree

   Strongly agree

4. Question number 4: Heart failure can be cured with drugs and other therapies.

Strongly disagree

Disagree

Agree

Strongly agree

5. Question number 5: Heart failure requires me to drink fluids, especially when I feel thirsty.

Strongly disagree

Disagree

Agree

Strongly agree

6. Question number 6: Can occur silently (without signs or symptoms)

Strongly disagree

Disagree

Agree

Strongly agree

7. Question number 7: Heart failure is likely to shorten my life (cause premature death).

Strongly disagree

Disagree

Agree

Strongly agree

8. Question number 8: Heart failure drugs work best when I have symptoms.

   Strongly disagree

   Disagree

   Agree

   Strongly agree

9. Question number 9: Heart failure can get worse by my lifestyle behaviors or actions.

   Strongly disagree

   Disagree

   Agree

   Strongly agree

10. Question number 10: Heart failure can be disabling.

    Strongly disagree

    Disagree

    Agree

    Strongly agree

11. Question number 11: Heart failure is a threat to my health.

    Strongly disagree

    Disagree

    Agree

    Strongly agree

12. Question number 12: Heart failure needs treatment even if I feel fine.

    Strongly disagree

    Disagree

    Agree

    Strongly agree

13. Question number 13: Heart failure may improve with drugs and a lot of time.

    Strongly disagree

    Disagree

    Agree

    Strongly agree

14. Question number 14: Heart failure plan of care (drugs, diet…) must be followed forever.

    Strongly disagree

    Disagree

    Agree

    Strongly agree

Thank you for your time to complete this survey.
Do you have a pen and paper close because I would like to provide you with a contact number in case you have any questions about the research study.
Principal investigator contact name and number: Jan Ostermiller, 406-690-6693.
Montana State University, Institutional Review Board, Mark Quinn, 406-994-4707

APPENDIX B

SURVEY OF ILLNESS BELIEFS IN HEART FAILURE

Survey of Illness Beliefs in Heart Failure

Directions: This survey provides 14 statements that might describe what heart failure means to you, including your beliefs and understanding about heart failure. The purpose is to learn what you believe about heart failure. Read each statement then circle the best response:

strongly disagree (SD) disagree (D) agree (A) or strongly agree (SA)

Choose *strongly* disagree or *strongly* agree if you are very certain that the statement is something you believe.

Answer each statement as best as you can. It is important for you to respond to each statement based on <u>your actual beliefs</u> and not on how you think you should respond to each statement.

Heart failure….	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
1. Is an illness that I cannot influence by my behavior.	SD	D	A	SA
2. Is something I go "in" and "out" of.	SD	D	A	SA
3. Is present only when symptoms are present.	SD	D	A	SA
4. Can be cured with drugs and other therapies.	SD	D	A	SA
5. Requires me to drink fluids, especially when I feel thirsty.	SD	D	A	SA
6. Can occur silently (without signs or symptoms).	SD	D	A	SA
7. Is likely to shorten my life (cause premature death).	SD	D	A	SA
8. Drugs work best when I have symptoms.	SD	D	A	SA
9. Can get worse by my lifestyle behaviors or actions.	SD	D	A	SA
10. Can be disabling.	SD	D	A	SA
11. Is a threat to my health.	SD	D	A	SA
12. Needs treatment even if I feel fine.	SD	D	A	SA
13. May improve with drugs and a lot of time.	SD	D	A	SA
14. Plan of care (drugs, diet…) must be followed forever.	SD	D	A	SA

Thank you for completing this survey.