



Congestive heart failure : perceptions and practice
by Monica Lyn Maher

A thesis submitted in partial fulfillment of the requirements for the degree of Masters of Nursing
Montana State University
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Abstract:

The purpose of this qualitative research study was to explore how persons with heart failure in south-central Montana manage their illness. Exploring the illness experience and self-care practices while assessing symptom recognition and resource availability and utilization of persons with heart failure may enable the health care practitioner to better participate in caring for those with heart failure.

Qualitative research methods and rural nursing theory provided the underlying framework for this study. Semi-structured interviews were conducted with a purposeful sample of 10 people age 38 to 87 years with heart failure from an urban cardiac specialty medical center.

Nine themes emerged from the data analysis of symptom recognition, illness experience, and resource utilization. These themes were difficulty with breathing, identification of effects of fluid imbalance, health within illness, trust in providers, management of symptoms based on knowledge and experience, making choices, perseverance, resources commonly utilized, and resources not commonly utilized.

The implications of the study for nursing practice include the following: (a) educate patients regarding symptoms of heart failure, (b) a need for health care providers to utilize appropriate referrals to improve outcomes, (c) utilize an integrated care conference in the care of persons with heart failure, (d) provide written information and instructions to patients regarding illness self-management, and (e) utilize a telephone case management approach to reduce exacerbations and costs of treating exacerbations.

Implications for nursing research include the following: (a) explore the relationship between symptoms at presentation and diagnosis of heart failure, (b) explore health care providers' patterns of referrals, (c) evaluate the effectiveness of an integrated care approach, (d) determine benefits and cost effectiveness of telephone case management for rural dwellers, (e) repeat this study with a larger sample size, and (f) continue to develop a strong theory base for rural nursing, as well as evidence-based, cost-effective health care for rural dwellers.

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A thesis submitted in partial fulfillment
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This thesis has been read by each member of the thesis committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

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ABSTRACT

The purpose of this qualitative research study was to explore how persons with heart failure in south-central Montana manage their illness. Exploring the illness experience and self-care practices while assessing symptom recognition and resource availability and utilization of persons with heart failure may enable the health care practitioner to better participate in caring for those with heart failure.

Qualitative research methods and rural nursing theory provided the underlying framework for this study. Semi-structured interviews were conducted with a purposeful sample of 10 people age 38 to 87 years with heart failure from an urban cardiac specialty medical center.

Nine themes emerged from the data analysis of symptom recognition, illness experience, and resource utilization. These themes were difficulty with breathing, identification of effects of fluid imbalance, health within illness, trust in providers, management of symptoms based on knowledge and experience, making choices, perseverance, resources commonly utilized, and resources not commonly utilized.

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CHAPTER 1

INTRODUCTION

Heart failure is a growing problem in the United States. In 2002, nearly five million Americans were living with heart failure. That same year, 550,000 new cases of heart failure were diagnosed (American Heart Association [AHA], 2002). Heart failure is the single most common cause of hospitalization for persons older than 65 years of age in the United States, accounting for approximately one million hospitalizations in the year 2000. This is an increase in hospitalizations of 155% since 1979 (AHA, 2002). Facts presented in the AHA Heart and Stroke Statistical Update (2003) indicate that the total estimated cost of heart failure in the United States for 2003 will be \$24.3 billion. Even with treatment, 50% of those with heart failure die within five years of diagnosis (National Heart, Lung, and Blood Institute [NHLBI], 2002). In 2002, heart failure claimed the lives of 285,000 Americans (AHA, 2002).

The increase in prevalence of heart failure observed over the last two decades is likely to continue. The rise in heart failure has been attributed to several factors: the increasing proportion of elderly individuals in the population, improved short-term survival of patients with myocardial infarction (MI), better treatment of hypertension, and heightened awareness of heart failure resulting in increased diagnosis and reporting (Skrabal, Stading, Behmer-Miller, & Hilleman, 2000; Ghali, Cooper, & Ford, 1990). The expected rise in the number of persons living with heart failure supports the need to

explore the self-care activities that can potentially improve the quality of life for these individuals.

The ability to implement self-care strategies is an important factor in chronic illness management (Winters, 1997; Braden 1990). Self-care for persons with heart failure includes reducing risk factors, controlling symptoms, managing medications and treatments, making lifestyle and dietary changes, and adapting to physical, psychological, and social change (ACC/AHA, 2001; Bennett, Cordes, Westmoreland, Castro, & Donnelly, 2000; Riegel et al., 2002).

Some people learn to self-manage their own illness during the non-acute stages; others demonstrate a helplessness or passive response to self-management (Braden, 1993). A learned self-care response represents an informed process of facing definable, manageable adversities by maintaining control of everyday problems (Robinson, 1982). Learned helplessness, the opposite response, is characterized by an uninformed process of withdrawing from definable, manageable adversities by succumbing to everyday problems (Braden, 1990). Learning to recognize and respond to changing symptoms are priorities of care for people with heart failure. The self-care activities utilized by people with heart failure should promote a healthier illness experience while reducing the exacerbations and expenses. The process of identifying exacerbation begins with recognizing which symptoms signify decompensation.

The ability of persons with heart failure to recognize symptoms related to decompensation of their condition can prevent serious complications and hospitalization. Symptoms of heart failure decompensation can contribute to a diminished quality of life,

increased morbidity, and increased mortality (Bennett et al., 2000). Some of the most common symptoms experienced by persons with heart failure are increasing dyspnea, weight gain, and fatigue (Tierney, McPhee, & Papadakis, 2002).

Persons with heart failure often experience negative emotional symptoms along with the physical symptoms. Bennett et al. (2000) reported that physical and emotional symptoms associated with heart failure, as well as the treatments for heart failure, are commonly reported as troublesome and can negatively affect the outcome for the affected person. By learning what persons with heart failure do either to improve their illness state or reduce exacerbations, nurses can develop appropriate resources to assist individuals in achieving the best possible outcome.

Access to a health care provider (HCP) for maintenance of heart failure and symptom management as well as supportive services, such as case management and cardiac rehabilitation programs, can enhance illness management and improve quality of life (Fonarow et al., 1997). Resources commonly available for urban persons with heart failure include dietitians, cardiac rehabilitation experts, Internet resources, and health library resources. A majority of the research available on heart failure management has been done on urban populations. Little is known about the resources available to rural persons with heart failure.

Today, approximately one-quarter of the nation's population, roughly 51 million people, live in rural areas (Rural Information Center, 2003). The percent of persons living in rural areas is even greater in Montana, with 47.5% of Montanans living in designated rural areas (Montana Office of Rural Health, 2002). Forty-one of Montana's

56 counties are designated as health provider shortage areas (HPSA) (Health Resources and Services Administration, 2000). Primary care HPSAs are defined by the Department of Health and Human Services (2003) as an area of more than 3500 people per primary care provider, or a ratio of 3000:1 in high-risk or high-need areas. Without adequate numbers of health care providers, access to health care and health care resources is limited. Other issues compounding rural persons' access to health care are isolation, environmental conditions, and distance (Lee, Hollis, & McClain, 1998; Henson, Sadler, & Walton, 1998; Bushy, 1991). Rural persons often have to travel long distances to regional health care centers over poorly maintained roads to receive the care readily available to their urban counterparts. In south-central Montana, the city of Billings serves as a regional center for specialized health care to persons from eastern Montana, western North Dakota, and northern Wyoming.

Although there is an increasing amount of literature addressing health behaviors in rural people, little information is available on the patterns of responses of rural people to symptom occurrence signifying actual or potential health problems (Buehler, Malone, & Majerus, 1998). Likewise, little is known about resource utilization and self-care development for rural dwellers managing heart failure. These gaps in the research are the justification for this study. A better understanding of these issues will assist nurses and other health care providers in providing effective care for their rural patients.

Purpose

The purpose of this study was to explore how persons with heart failure living in

south-central Montana manage their illness. The specific aims of this study were to (a) explore the illness experience and self-care practices of persons with heart failure, (b) assess symptom recognition and responses of persons with heart failure, and (c) assess resource availability and utilization by persons with heart failure living in south-central Montana.

Theoretical Perspective

A qualitative approach and rural nursing theory were used to explore illness experiences, symptom recognition, and resource utilization of persons with heart failure living in south-central Montana. Qualitative health research focuses on the experiences of people in relation to health and illness (Orb, Eisenhauer, & Wynaden, 2001).

Qualitative research is a systematic approach used to describe life experiences and give them meaning (Burns & Grove, 2001). By utilizing a qualitative method, one can explore and examine people and their natural environments with the purpose of describing a phenomenon from the participants' point of view through interviews and observations.

In qualitative research, descriptions from participant observation, structured and unstructured interviews, and written and oral retrospective accounts are studied for themes. These themes are stated in the language of the researcher, a significant shift in discourse because it moves the description of the meaning of the researched phenomenon from the subject's language to the language of the science (Parse, Coyne, & Smith, 1985; Polit & Hungler, 1999).

Rural nursing theory attempts to guide nursing practice, education, and research specifically related to caring for the unique needs of rural dwellers. Rural nursing theory development has emphasized defining and understanding health from a rural perspective (Weinert & Long, 1991). Several key concepts have been identified in relation to understanding rural health needs and rural nursing practice. These concepts are work beliefs and health beliefs, isolation and distance, self-reliance, lack of anonymity, outsider/insider, and old timer/newcomer (Long & Weinert, 1989). Qualitative methods were used to formulate these important concepts regarding rural dwellers and rural health care providers. Subsequent studies can strengthen and add to the development of the rural nursing theory (Long & Weinert, 1989). It is essential to develop an understanding of rural persons and their self-defined needs and preferences in order to develop beneficial and effective rural health care models.

Issues related to and potentially unique to rural nursing can be effectively explored utilizing a qualitative method. The knowledge gained through interviews with individuals can affect the understanding of the human experience, including the rural experience (Chenitz & Swanson, 1986; Orb et al., 2001). By including individuals who live in rural Montana, the exploration of the unique needs and qualities related to being rural can be examined.

Assumptions

Three assumptions underly this work. First, urban areas in rural states serve as regional centers for specialty medical care serving both urban and rural dwellers.

Therefore, it was assumed patients receiving care from a regional medical clinic will include Montanans living in rural and urban areas. Secondly, because an individual's experience is best understood from the context in which the experience occurs, it was assumed a qualitative method was an appropriate approach for the purpose of this study. Thirdly, it was assumed the individuals participating would be willing and able to provide information regarding their experience with heart failure, symptom recognition, self-care practices, as well as knowledge and utilization of resources.

Definitions

Heart failure: a complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the ventricle to fill or eject blood (ACC/AHA, 2001).

Illness experience: the process of living with chronic heart failure as viewed by the person living through it. This experience can include periods of health as well as a decline in wellness. It is the perception of the events of the individual living with heart failure.

Resource availability: formal and informal sources reported as being accessible.

Resource utilization: formal and informal sources accessed to answer questions or provide support; the seeking and acquiring of information that may be instrumental in determining health outcome.

Rural: a community with a population equal to or less than 2,500 and 40 or more miles from a community of 50,000 people with a regional health care center.

Urban: a community with a regional health care center and a population of 50,000 or more people.

Self-care: behaviors to maintain health, prevent and/or alleviate treatment side effects or complications of heart failure.

Symptom recognition: awareness of a change in health status that may indicate a deterioration in management. Some of the more common changes noted by people with heart failure are weight gain, progressive dyspnea, fatigue, exercise intolerance, chronic nonproductive cough, peripheral edema, abdominal pain, and decreased appetite.

CHAPTER 2

REVIEW OF LITERATURE

Three areas of literature were reviewed for this study. The areas reviewed include heart failure, illness experience, and rural nursing theory. The heart failure literature reviewed included pathophysiology, epidemiology, classification systems, symptoms, and economic impact. Regarding the illness experience, the areas of self-care, symptom recognition, and resource utilization were explored. The literature review concluded with a review of the rural nursing theory literature.

Heart Failure

The pathophysiology of heart failure is complex, multidimensional, and not completely understood. The most common causes of heart failure are coronary heart disease and hypertension. Valvular heart disease may also result in heart failure in older individuals (Rich, 1997). Clinically, heart failure can be defined as impaired cardiac performance resulting in an inability to meet the energy requirements of the body (McCance & Huether, 1998). Heart failure is generally categorized as systolic or diastolic dysfunction, with both conditions having relatively poor long-term prognoses. The prevalence of heart failure appears to be rising as the population ages, while mortality from heart failure declines. In 2000, the six-year mortality rate was 84% for men and 77% for women (O'Connell & Bristow, 2000). The recommended treatment for

heart failure is multifaceted. Heart failure management involves a collaborative effort between the health care provider and the person with heart failure. Depending on the severity of the heart failure, treatment includes, but is not limited to, daily medications to regulate the heart's functioning, lifestyle changes that include exercise and dietary restrictions, and, in some cases, surgical intervention (ACC/AHA, 2001).

Several organizations have developed tools to categorize heart failure based on the severity of the failure, the impact it has on daily life, and the effects experienced by the individual with heart failure. The most commonly used system to classify heart failure is the New York Heart Association (NYHA) Functional Classification. Heart failure is classified according to the way the condition affects the performance of normal physiology. There are four categories of heart failure within the NYHA functional classification system (NYHA, 2002).

Table 1. NYHA Functional Classification.

<u>Class I</u>	<u>Class II</u>	<u>Class III</u>	<u>Class IV</u>
Presence of cardiac disease without limitations in physical activity.	Presence of cardiac disease resulting in slight limitation in physical activity.	Presence of cardiac disease resulting in marked limitation of physical activity.	Presence of cardiac disease resulting in inability to carry out any activity without discomfort.
Ordinary physical activity does not cause undue fatigue, palpitations, dyspnea, or angina.	Comfortable at rest. Ordinary physical activity results in fatigue, palpitations, dyspnea, or angina.	Comfortable at rest. Less than ordinary activity results in fatigue, palpitations, dyspnea, or angina.	Symptoms of cardiac insufficiency or angina present at rest and increase with physical activity.

It is estimated that approximately one-third of patients suffering with heart failure are categorized in NYHA functional class III or IV. Class III and IV heart failure lead to

progressive deterioration and frequent hospital admissions (Fonarow et al., 1997). Because of the continued increase in the number of persons with heart failure, the effects of this illness can be felt in nearly every community in this country.

Heart failure has become a significant public health problem in the United States, currently afflicting more than five million Americans. The cost of heart failure is high, both financially and emotionally. According to the NHLBI (2002), heart failure is the most common cause of hospital admissions in people over the age of 65. Estimates of annual expenditures on heart failure in the United States range from \$10 to \$40 billion. The AHA estimates the cost for 2003 to be \$24.3 billion (AHA, 2002). Because of the significant impact on resources, many investigators are looking for ways to improve outcomes related to heart failure. Some of the areas being explored are pharmaceutical therapies, comprehensive multidisciplinary disease management, heart failure clinics, community outreach clinics, and telephone case management (Fonarow et al., 1997; Massie & Shah, 1997; Shah, Der, Ruggiero, Heidenreich & Massie, 1998; Stewart, Pearson, & Horowitz, 1998; Riegel et al., 2002).

Several studies have been conducted utilizing telephone case management interventions (Fonarow et al., 1997; Weinberger, Oddone, & Henderson, 1996; Riegel et al., 2002; Shah et al., 1998; Stewart et al., 1998). Fonarow et al. (1997) assessed the impact of a comprehensive management program on 214 persons with NYHA functional class III and IV heart failure. The program included a systematic approach to drug therapy; patient education about diet, exercise and illness self-management; and regular

contact with a heart failure team. This intensive approach to symptom management was shown to reduce costs and symptoms in persons with heart failure while reducing the hospital admission rate by 85%. This approach also improved the functional status of transplant patients in this study. The investigators concluded a referral to a heart failure program might be appropriate for medical management of persistent functional class III and IV heart failure.

When assessing whether or not increased access to primary care altered the admission rates of 1396 chronically ill patients (diabetes, chronic obstructive pulmonary disease, and heart failure), Weinberger, Oddone, and Henderson (1996) concluded the intervention population (those that received more intensive primary care than the controls) was noted to have an increase in admissions and no change in their quality-of-life scores when compared to the control group. The main difference they noted was improved satisfaction with care received in the intervention group versus the control group. Other studies have gone beyond primary care access to evaluate the effectiveness of a means of care for individuals outside of a health care setting. This care setting is home monitoring.

Home monitoring has been studied as a means to manage patient symptoms, prevent complications, and improve quality of life. Riegel et al. (2002) explored the effectiveness of a standardized telephone case management intervention in reducing resources used by 130 persons with heart failure. The results of this study showed that early, standardized nurse case management achieved significant cost savings, reductions

in resource use, and increases in patient satisfaction. Shah et al. (1998) designed a home monitoring program for patients with heart failure and utilized education, phone contact, and a pager system to generate computer-based messages to remind the study patients when to take medications, monitor their blood pressure, and weigh themselves. The monitoring service would notify physicians when study participants reported changes in their conditions or symptoms. Shah et al. found an overall reduction in hospitalizations, as well as increased patient satisfaction and acceptance of regimens.

A study conducted by Stewart et al. (1998) utilized a home visit by a nurse and pharmacist, intense medical follow-up, and caregiver vigilance in a study of 49 people with heart failure. The results from this study showed a reduced frequency of unplanned readmissions, as well as a reduction in out-of-hospital deaths within the six-month time frame of the study.

Heart failure is a multidimensional and complex condition that significantly affects millions of Americans. The findings from the studies reported here highlight the complex nature of heart failure management.

Illness Experience and Self-Management

Living with a chronic illness is an experience that is unique to the individual experiencing it. Understanding how persons experience and respond to their illness can help health care providers direct appropriate care and resources. Living with heart failure involves living with uncertainty, change, conflict, and significant personal, medical, and

family issues. Winters (1997) noted that persons living with chronic heart disease wanted to care for themselves yet recognized the need for complex medical care. In a study of 10 individuals living with heart disease, Winters recognized that those with heart failure often moved between periods of certainty and uncertainty and feeling in control and feeling out of control. When these individuals felt stable and in control of their illness, they were able to do things in their lives without letting their heart disease dictate if and when they could.

Mishel and Braden (1988) explored the antecedents of uncertainty in 61 women being treated for gynecologic cancers. The researchers found adequate social support from involved persons, a trustworthy authority for assistance in managing the disease, and access to education and information contributed to a sense of certainty. Having access to necessary resources can assist individuals to feel in control of their illness process. Along with certainty and uncertainty, researchers are exploring how persons respond to a chronic illness and how they come to that response.

One aspect of learning to live with the chronicity of heart failure is learning to reshape one's thinking about health. The idea of health within illness has been explored as an outcome of living with heart failure. Winters (1997, 1999) found when individuals were initially diagnosed with heart failure, they thought of themselves as ill. The individuals also viewed themselves as ill during exacerbations. Over time, people with heart failure were able to view themselves as stable or healthy. Health care providers are an important resource for persons with heart failure and are ideally positioned to help their patients develop a health-within-illness view. Finding out what an individual does

to promote health and then supporting those activities will allow health care providers to assist persons with heart failure in achieving their desired outcomes.

Braden's Self-Help Model attempts to explain a person's response to chronic illness. Braden's model was generated to describe the dynamics of learned response to chronic illness. Braden's model is based on the assumption that adjustment is a learned, rather than an inherited, capacity or personality trait (Braden, 1990). Braden has demonstrated that people inherently learn something from their illness. Most people learn self-help promoting skills; however, some learn to become helpless, becoming overly dependent on others and the health care system. Braden (1990, 1993) also recognized that enabling skills are positive coping mechanisms that help people with chronic illness in several ways. Enabling skills allow the individual to continue to stay involved in valued adult role activities (self-help), engage in activities that promote wellness and manage side effects/symptoms of disease (self-care), and maintain stable psychological adjustment and overall satisfaction with quality of life, despite the uncertainties associated with illness and its treatment.

Researchers are also looking into how people respond to their symptoms and their illness and what they do to manage the illness process. Bennett et al. (2000) found that patients with heart failure used a variety of self-care strategies to manage their symptoms. Changing the level of physical activity, especially decreasing activity, was a common response to help alleviate several of the symptoms reported by patients. Bennett et al. also found that along with physical symptom management, distraction, family

support, and positive self-talk were all reported by patients as strategies for managing their emotional symptoms.

Information seeking is an antecedent to health care decision making and necessary for individuals to actively participate in their own care. Information seeking is compatible with nursing theories that acknowledge a person's ability and right to make conscious, independent health decisions and advocate for active participation by the ill individual (Lenz, 1984). Active participation in one's own care is an integral part of chronic illness management. Access to information and health care resources is essential to self-care of chronic illness (Lenz, 1984; Mishel & Braden, 1988). Self-care behaviors (those things people do for themselves) are common among rural individuals (Bartlome, Bartlome, & Bradham, 1992; Bushy, 1994; Veitch, 1995). Bushy (1994) maintained that rural individuals preferred informal support networks to formal networks. They tended to look for networks in their own communities, relying on neighbors or acquaintances that have experienced, or know someone who has experienced, a similar situation. It did not matter if these individuals had a health care background. The philosophy, "if you want something done, do it yourself," appears to be prominent in rural persons.

Symptom Recognition

The many symptoms associated with heart failure are well documented in the literature. Patients with heart failure report a number of troubling symptoms, including dyspnea, fatigue, peripheral edema, weight gain, depression, memory loss, sleeplessness, and attention deficit (Grady, Jalowiec, Grusk, White-Williams, & Robinson, 1992;

Bennett et al., 2000; McCance & Huether, 1998). The troublesome symptoms experienced by patients with chronic heart failure are associated with diminished quality of life, frequent hospitalizations, and increased mortality. Bennett et al. (2000) noted that recognition and treatment of symptoms are priorities of care for patients with chronic illnesses, such as heart failure. Prompt recognition of symptoms can minimize complications, as well as reduce the severity of the complications. The ability to recognize symptoms quickly and correctly also promoted and strengthened self-care management strategies and the ability to live with heart failure (Bennett et al. 2000).

Symptom recognition can affect outcomes and quality of life in individuals with heart failure. Jalowiec, Grady, and White-Williams (1994) found that symptoms of exacerbation were the most frequent stressors identified by 175 persons with heart failure awaiting transplantation. Regarding quality of life, Grady et al. (2000) found that symptoms were the most significant predictor of quality of life. According to a study by Bennett et al. (2000), in addition to diminished quality of life, worsening symptoms were strongly associated with morbidity and mortality in patients with heart failure. The most common symptoms reported by Bennett et al. were weight gain, shortness of breath, edema, fatigue, dizziness, and hypotension. These symptoms were commonly self-managed by the person without a clinic visit but required a change in diuretics and/or cardiac medication to reduce symptoms.

Resource Utilization

Access and availability of health information, health care resources, and health care providers, and the willingness to use them, impact health and illness outcomes. Rosenbaum's theory of learned resourcefulness (Rosenbaum 1990; Kennett & Stedwill, 1996) identifies resourcefulness as the driving force behind a person's willingness to seek information to enhance knowledge or understanding. Rosenbaum describes one's level of resourcefulness as a personality variable that promotes health. Resourcefulness can vary from low to high levels. Those with high levels of resourcefulness tend to seek information and utilize self-change more effectively. If individuals are utilizing resourcefulness, they will be motivated to find the gatekeepers to the information they are seeking.

With the advent of the Internet, access to information is a keystroke away. Recent surveys indicated that in 2001, 100 million individuals sought health information online (Taylor & Leitman, 2001). Peterson and Fretz (2003) found in their study of 139 people that older persons were among the increasing numbers of persons who access health information online. Peterson and Fretz also found that people from rural areas of less than 1,000 population used the Internet to the same degree as their urban counterparts.

One of the questions in the survey used by Peterson and Fretz queried participants about using a clinic computer for self-education. More than 60% of those in the survey who currently used a computer to some extent responded that they would utilize a clinic computer for self-education. However, only 15% of those who did not currently use a computer responded that they would use the clinic-setting computer to access

information. Along with accessing health information via the Internet, many educational materials are available from health care providers. Pamphlets, individualized handouts, and plans of care may prove beneficial, if one can access the health care provider.

According to the Agency for Healthcare Research and Quality [AHRQ] (2002), roughly one in five Americans is living in areas classified as rural. Compared to their urban counterparts, clients in a family practice setting were more likely to be older, to be in poorer health, and to face longer distances to health care services, especially specialty care. Even though rural dwellers tend to be older and face longer distances to health care, in a study of 1,230 people in a family practice setting, Crabtree (2001) reported that rural dwellers tended to receive more preventative services (clinical breast exams, family history assessment, cholesterol screening, and administration of the influenza vaccine) than their urban counterparts.

A variety of health care providers practice in the urban areas of south-central Montana. These providers include pharmacists, nurses, physicians, primary care providers, medical specialists, dieticians, cardiac rehabilitation experts, and alternative medicine providers. In contrast, health care services in rural areas are often limited to primary health care providers and, on occasion, an outreach clinic staffed by a visiting specialty care provider.

Rural

The United States Census Bureau [USCB] (2000) defines rural as a community with a population of less than 2,500 people. Health researchers, on the other hand, often define rural in terms of population density, distance, availability of health care services, and time required to travel to a regional health care center (Koehler, 1998; Bales, 2002). For this study, rural was defined as a community with a population of 2,500 people or less, and 40 miles from a community of 50,000 or more people with a regional health care center. This study was conducted using both urban and rural areas. The urban area in which this study was conducted had a population of 100,317 and is a regional center for specialized medical care (USCB, 2000). The urban area provides medical services for eastern and south-central Montana, western North Dakota, and northern Wyoming. The three rural communities used in this study had populations of 3,384 (distance of 54 miles), 1,748 (distance of 45 miles), and 1,650 (distance of 80 miles).

According to the Congressional Rural Caucus (2001), nearly 22 million rural residents live in federally designated Health Professions Shortage Areas (HPSA) or Medically Underserved Areas. The criteria for the designation of HPSA are based on geographic area, population, and availability of facilities. The basic criterion for designation of a HPSA is 3,500 or more people served by a single primary care physician. In areas of high need or high risk indicators, this ratio drops to 3000:1. In Montana, 41 of the 56 counties are currently designated HPSA. With this large percentage of the population affected, it becomes imperative that research on the effects of diminished access to health care continues.

A growing body of literature addresses rural health. The basis for much of this work has been the belief that health issues of rural dwellers are different than those of urban dwellers and that these differences have not been adequately explored. Rural health authors and researchers have identified a variety of concepts and factors thought to be unique to rural people. Researchers are also exploring factors that may impact access to care for rural dwellers. These factors include, but are not limited to, distance, weather, economic hardship, lack of transportation, poor road conditions, and the increasing number of elderly living in rural areas, who may have a more difficult time with travel (Ballantyne, 1998; Bushy 1991). It is clear that rural dwellers face challenges when accessing care, but it is unclear as to whether or not these challenges prevent access to care.

Summary

A growing number of individuals are living with heart failure. Because of this growth, the cost for managing this chronic illness continues to climb. The literature reviewed regarding heart failure focused on pathophysiology, epidemiology, heart failure classification systems, symptoms, and economic impact. Regarding the illness experience, the areas of self-care, symptom recognition, and resource utilization were explored. The literature review concluded with a discussion of the rural health care literature relevant to this study.

There is an expanding body of literature regarding heart failure management and treatment availability. However, little documentation exists on rural persons' responses and management of heart failure.

CHAPTER 3

METHODOLOGY

Qualitative research methods were used for this study. The qualitative method of research is a systematic and objective approach utilized to analyze subjective data. The qualitative method is used to describe life experiences and give them meaning (Burns & Grove, 2001). Qualitative analysis is the non-numerical organization and interpretation of data from interviews and open-ended questionnaires (Wilson, 1985) in order to discover patterns, themes, and qualities.

In this study, predetermined categories with open-ended questions were utilized to illicit responses from persons with heart failure about their illness experience. Participants were asked about their symptoms, illness management strategies, and resource utilization. Chapter 3 includes a description of the research methods used in this study.

Sampling

Purposeful sampling was utilized, and participant selection occurred through a regional cardiac center in south-central Montana. Eligible participants were residents of Montana, at least 21 years of age, English speaking, and diagnosed with NYHA Functional Class I, II, or III heart failure. People with Class IV heart failure were

excluded due to the severity of their disease and their requirement for intensive management. Eligible participants may have co-morbidities related to heart failure.

The sample consisted of four men and six women. Seven participants were from an urban community, and three were from rural communities in south-central Montana. Initial contact with each potential participant was made by the staff from the regional cardiac center. After an in-service on inclusion and exclusion criteria, staff approached eligible persons about the study and asked permission to share their name and phone number with the investigator. Protection of human subjects was ensured, as the Montana State University-Bozeman Human Subjects Committee as well as the Inter-Institutional Review Board from the urban health care center approved the study.

Data Collection

Persons expressing an interest in the study were contacted by the investigator. Once eligibility was confirmed and consent to participate obtained, an interview time was arranged. Eight face-to-face and two telephone interviews were conducted. Informed written consent was obtained from each participant. The consent form included the purpose of the study, a description of the expectations for participating, permission to audiotape the interview, discussion of the risks and benefits, and the process for maintaining confidentiality. Participants were encouraged to ask questions. The consent form was signed prior to the interview and the participants were given a copy (see Appendix A).

For the two interviews conducted over the phone, consent forms were mailed to each individual. Once the investigator received the signed consent form, a copy was returned to the participant, and the audiotaped phone interview took place, utilizing the same process as the face-to-face interviews. The interviews were conducted during March, 2003. Each interview lasted from 20 minutes to one hour.

Each face-to-face and telephone interview was audiotaped for transcription and coding purposes; once transcribed, the audiotapes were destroyed. The names of the participants were not part of the transcript. Each participant was assigned an identification number known only to the investigator. Demographic data collected at the beginning of each interview was transcribed separately from the interview and assigned the corresponding identification number. The demographic information will be reported in summary tables in all reports of this study.

The participants received no benefit from their participation in this study. As discussed with each participant, a potential risk exists that participants may be recognized through their verbalized experiences when data are reported. Participants were therefore offered a copy of the transcribed interview to review and were encouraged to report any miscommunications or errors in the transcript. The participants were also assured they could withdraw consent to participate at any time during the study. The participants were made aware that the investigator might contact them in the month following the interview to clarify data or confirm understanding of what they said.

The interview process began with the collection of demographic information. The information collected included year of birth, gender, years of education, current

occupation, marital status, insurance status, years in the community, size of the community, and location and distance to health care (see Appendix B).

An interview schedule with predetermined categories and open-ended questions (Appendix C) was utilized to guide each interview. The questions were intended to elicit information regarding the nature of the participants' heart condition, their illness experience, their ability to recognize and respond to symptoms, and the resources they utilize to maintain their health. Participants were allowed to answer however they wanted. Prompts were used to develop clearer and fuller data.

Data Analysis

The qualitative data were analyzed for common themes. The transcribed interviews were first read in their entirety. The interviews were then reread and coded. This coding process began by highlighting certain words or phrases the participant used to convey meaning. Data analysis continued by looking for common themes that emerged from the coding process. The data were analyzed until no new codes, or themes, were discovered (Burns & Grove, 2001; Polit & Hungler, 1999). Once recurrent themes were noted, the sample size was determined to be adequate. The interview transcripts were reviewed by the thesis committee chairperson who agreed with the emerging themes.

The demographic data were analyzed by reviewing the responses to the personal and geographic information. The ranges for year of birth, years of education, years in the community, and distance to health care were calculated by hand. The other information

collected, such as location of health care services, marital status, health insurance status, and gender, was all noted for frequency. The results are presented in Chapter 4.

CHAPTER 4

FINDINGS OF THE STUDY

The findings from the study are reported in Chapter 4. The demographic information collected from the participants is presented first, followed by a discussion of the common themes related to the illness experience, self-care management practices, symptom recognition, and resource utilization

Demographics

The sample consisted of six women and four men ranging in age from 38 to 87 years. The mean age was 63.2 years. The age categories and gender are presented in the following table.

Table 2. Age and Gender Categories of Sample Group (N = 10).

Age Categories *	Male (n)	Female (n)	Total (n)
30-39		1	1
40-49	1		1
50-59		2	2
60-69	1	1	2
70-79	1	2	3
80-89	1		1

* Mean age of 63.2 years

Years of education ranged from 10 to 17 years (M = 13.1 years). The participant with 10 years of education had 2 years of English before he started school, and then he

completed through the eighth grade. Twenty percent of the participants have a Bachelor's degree (n=2). This is slightly lower than the 24.4% of Montanans with a Bachelor's degree (USCB, 2000). Table 3 contains the information regarding education level for this sample.

Table 3. Education Levels of Sample Group (N = 10).

Years of education *	(n)
Two years of English + eighth grade = 10 years	1
Through 11 th grade	1
High school graduate	3
High school + one year of college	1
High school + two years of college	2
Bachelor's degree	1
Bachelor's degree + one year internship	1

* Mean years of education = 13.1 years

With regard to employment, six of the participants were retired or no longer worked. Two of the participants continued to work full-time, while two participants worked part-time. Regarding marital status, six of the participants were married, one was divorced, two stated they were widowed, and one participant was single but living with a significant other. All of the participants stated they had good support systems within their network of family and friends. Two of the study participants are African-American; the remainder are Caucasian. The religious preferences were Catholic (2), Presbyterian (1), Lutheran (2), Congregational (1), Protestant (1), Methodist (1), and no preference (2).

Eight of the participants had health insurance, while two stated they did not. Each participant's community of residence had at least one family practice clinic staffed by either a physician, a physician assistant (PA), or a nurse practitioner (NP). All of the

participants utilized a regional health care center as their cardiac specialty clinic for managing their heart failure. All participants also noted that they would seek emergency care within their own community, accessing their local ambulance crew if needed. Table 4 contains travel and distance information for health care.

Table 4. Distance to Cardiac Specialty Health Care (N = 10).

<u>Community</u>	<u>(n)</u>	<u>Mileage to specialty health care</u>
1 (urban center)	7	N/A
2	1	45 miles
3	1	80 miles
4	1	54 miles

The length of time participants had lived in their current communities varied from 2 to 78 years ($M = 33.4$ years). Some of the respondents noted they were born in Montana, left for a few years, and then returned to be closer to family.

Emerging Themes

The aims of this study were to explore symptom recognition, illness experiences, self-care practices, and resource availability and utilization by persons with heart failure living in south-central Montana. Predetermined categories and open-ended questions were utilized to illicit responses from the participants regarding symptom recognition, illness experiences, self-care management practices, and resource utilization. The responses were then analyzed for emerging themes within these categories. The major themes are presented below.

Symptom Recognition

Two themes regarding symptom recognition emerged from the data. These themes were difficulty with breathing and identifying effects of fluid imbalance.

Difficulty With Breathing. Difficulty with breathing is defined as any alteration in breathing pattern noted during symptom exacerbation. All of the participants noted an effect on their breathing, which ranged from shortness of breath to dyspnea on exertion to orthopnea (difficulty breathing when laying down). The participants also noted a frequent non-productive cough. These symptoms occurred prior to initial diagnosis, as well as with exacerbations of their heart failure.

The following comments were noted regarding the initial symptoms the participants encountered that cued them to seek health care.

I couldn't breathe. My breathing got so bad that I had like a seizure and I shook so bad that I couldn't control myself.

I couldn't breathe so I went in on Christmas morning and they gave me some tests. It was liquid on the lungs. I could hear it crackling when I breathed and I couldn't catch my breath.

I was having trouble breathing. Nobody seemed to know what it was. They were treating me for asthma.

The following are comments regarding symptoms experienced during illness exacerbation:

I notice an increase in shortness of breath and coughing. If I do something a little more strenuous when I'm not doing well, it is not unusual for me to have a coughing fit afterwards.

I have trouble breathing, and I run out of breath walking.

I get to where I'm not able to sleep at night because I can't breathe.

Identifying Effects of Fluid Imbalance. Other symptoms noted by the participants correlate with what the literature reports as common with heart failure and fluid volume imbalance. Peripheral edema, nocturnal urination, weight gain, and fatigue were common symptoms of exacerbation experienced by the study participants.

My ankles are swollen to a certain extent anyways, but they will be worse when I'm having troubles.

I get to where I can't sleep at night because of the shortness of breath and having to urinate frequently at night.

I get tired, really tired. I just go home and put my feet up.

Really tired.

Lack of energy. Tired.

I can gain six pounds overnight, and I never seem to lose it all.

Illness Experience and Self-Care Management

Several themes emerged from the data regarding the participants' illness experience and self-care management practices. The themes were health within illness, trust in providers, management of symptoms based on knowledge and experience, making choices, and perseverance.

Health within Illness. The definition of health within illness is viewing one's self as healthy or well while living with a chronic illness. Being able to do those things that were important to the participants on a daily basis and being able to continue functioning as they wanted to contributed to the investigator's designation of health within illness.

During periods of time when they were free of exacerbating symptoms, participants thought of themselves as healthy. During an exacerbation of their heart failure, the participants defined themselves as ill.

When the participants were free from symptom exacerbations, they described their state of health as being similar to what they experienced prior to being diagnosed with heart failure. The majority of participants also reported that their current state of health was less functional than prior to the diagnosis, but they still did not consider themselves "ill." The participants incorporated their medications, doctor appointments, and health-related procedures into their daily routine. Some of the comments noted when asked how their heart condition affected their lives were as follows:

Well, now it [heart failure] doesn't [affect daily activities].

I still work full time. I take my medications, try and exercise everyday, and watch my salt intake. That keeps me on track.

Well, I have high blood pressure and I take medicines for that. I have diabetes and I take medicine for that. I get a gout attack about every two months, I take a little colchicine and it goes away. The treatments have made me feel better. My activity level is better now than before.

During periods of exacerbations, participants experienced a change in their level of functioning. They were no longer able to do what they had been doing on a daily basis. Often, this meant unanticipated visits to their health care provider, changes in their medication routine, and changes in activity level. Some of the comments noted from these participants are listed below.

When I'm not feeling well, it slows me up.

I get really tired. I get really short of breath. I can't seem to get my housework done because I have to sit down and rest quite a bit. Then I just get behind on everything and can't keep up.

I like working outside, but when I'm not feeling well, I can't.

Trust In Providers. Trust in providers is defined as a bond or relationship that developed between the participants and their health care provider. Some of the participants were misdiagnosed as having pneumonia or a cold. Once they were directed to the specialist able to make the correct diagnosis, a trusting relationship was formed. Even with this delay in diagnosis, all participants reported some degree of trust in their current health care provider to manage their chronic illness.

The participants expressed trust in their health care providers' knowledge in providing the correct information and treatment regimes. This trust led the participants to develop comfort in utilizing the information the providers gave them to manage their illness. This trust also affected the participants' assessment of their progress; if the provider stated things were going well, the participants believed things were going well.

[The health care provider] really saved my life. Just trust your doctor. They know what they are doing for you. If you don't trust them, why waste their time and your money?

See a good doctor and do what they tell you.

My treatments are working. I thought I was feeling better and I went to [the health care provider] and he said I was doing fine. He thinks that I am tolerating [the treatment] pretty well. I've done what they told me and I haven't really had any problems since they have gotten me regulated and everything.

Management of Symptoms Based on Knowledge and Experience. Over time, participants learned to recognize changes in their symptoms and how to correctly manage them. Once a diagnosis and tolerable treatment plan was established, the participants reported that they altered their treatment regimes to manage their illness and to prevent worsening of symptoms and exacerbations.

The group acknowledged there was an initial period of learning when they tried different strategies to correct the exacerbating symptoms. Once they were able to correlate a symptom with an intervention that worked for them, they could institute the action and achieve their goal. Some of the symptoms the participants were able to self manage with a treatment alteration were shortness of breath, weight gain, dyspnea with exertion, and decreased stamina. Below are a few of their comments.

One time we ate at a Chinese restaurant and we ended up in the emergency room. So now I'm more strict with my diet. I take a Maxzide when I need it. If the Maxzide doesn't work, I take a Demadex too.

I take a diuretic if I think I have too much fluid. If I'm winded, I take a diuretic. I take Demadex.

I don't add salt to anything I eat, but of course there is salt in so much of it. I usually take another water pill and then potassium too, if I need to.

Making Choices. Making choices is defined as deciding which lifestyle change to make regarding heart failure management. Often participants knew what the correct course of action should be but choose not to comply or make the change, regardless of the possible repercussions. When participants received education on recommended lifestyle changes, many chose not to comply with some of these changes, at least not initially. The lifestyle changes required of persons managing heart failure can include

dieting, food, salt, and fluid restrictions, and implementing an exercise program. The magnitude of change required by some may be overwhelming or too much to do at once. Moderation tended to be the key for many of the participants in incorporating the lifestyle changes, choosing which of the changes they were willing to tackle at any given time.

I do not have an exercise routine. Nothing real structured. It's always been do what you feel like you can do. And I'm a terrible dieter. It probably would have helped me to lose more weight.

I try to watch my salt. I'm not too good at it, but I try. I do try and exercise 30 minutes a day.

I'm not as good as I could be. It seems like I can't eat anything. I do eat stuff that I'm not supposed to. I try to exercise. I have a bicycle that I try to ride. Usually I'm just too tired to even do that. I know I shouldn't eat salt, I just can't leave dill pickles alone.

Perseverance. Perseverance is defined as the persistence, strong will, and inner strength needed to get through the illness process. Continuing to work full time even though they have a chronic illness, or pushing themselves through their routines because they feel they must complete something are two examples of perseverance exhibited by participants.

Persistence, inner strength, and strong will were qualities that helped participants get through difficult and often life-altering changes in daily routines. Sometimes, perseverance was very similar to stubbornness, which initially resulted in a delay in seeking care and worsening of symptoms. However, the same participant that displayed stubbornness displayed perseverance in the recovery process and utilized inner strength and strong will to recover and continue on with life. Perseverance is exemplified by the following quotes from participants.

I was just being stubborn and I knew that I didn't feel well and I kept on doing what needed to get done, and that's the reason I'm here [extended care facility]. I have to forget the past and just work at the future. I will get back home very soon.

I'm still at work. I refuse to let it [heart failure] interfere with my work.

Even when I didn't know for sure what my diagnosis was, I kept working full time, I wasn't dead and I had things I needed to get done.

Just push yourself or you won't get well. I had a stroke during my valve surgery and I had to keep pushing or I wouldn't have gotten through it.

Resource Utilization

Resource utilization is defined as the services or information sources used by the participants as part of their management of heart failure. Participants were asked about their use of specific resources (see Appendix A). The data were analyzed and separated into resources commonly used by the participants and resources not commonly utilized. The commonly used resources were categorized as formal and informal.

Commonly Utilized Resources. Participants utilized several formal resources. The formal resources included health care providers, dieticians, and written and oral information.

The participant's health care provider was the primary source of information. The participants accessed varying numbers of health care providers to assist with their heart failure management. One participant utilized only a cardiologist. The remainder of the participants utilized a cardiologist and a primary care provider. Two of the participants also had cardiovascular surgeons in their loop of providers. Regardless of the number of

providers utilized, the respondents relied on their health care providers and the providers' staff members for information.

When I have questions, I ask down at the nurse's desk [in the extended care Facility]. They are pretty well informed down there.

When I have a question regarding my heart condition, I call my doctor's office. They are real good. They usually get the information right back to me.

A majority of the participants utilized a dietician as a source of information after receiving a referral from their health care provider. Contact with the dietician was made during the initial treatment of the heart failure. Information retained by participants from their contact with the dietician was to limit salt. Three of the participants in this study were not offered a consult with a dietician.

I don't remember for sure what all the dietician told me, but she did give me a pamphlet and told me to cut back on salt.

The dietician at the hospital when I was first diagnosed talked with me about reducing my salt intake. I've been doing it on my own since then.

I did get some information from the dietician. I also went with my mom when she was going and I learned a lot more through her dietician. I got some handouts.

Other resources used by participants were pamphlets or written information obtained from their health care provider's office. The pamphlets were either on display and available in the provider's waiting rooms or presented to them by a health care provider. Two of the women were also noted to be active learners. These women had attended various classes about their heart failure held at a health care facility.

There is a lot of reading material out there. I pick up different things.

I get pamphlets from the doctor's office, they're convenient and it's a good way to remember the information, I just pull it out again to review it.

I've gone to a couple of the small classes at the hospitals dealing with heart disease. I might like to see a dietician for more information though.

The informal resources used by the participants were family members and other persons with heart failure. Family support, whether from one family member or several, was noted by all of the participants as being important. Participants also relied on persons diagnosed with heart failure.

My sister helps me get information when I need it. My brother is a pharmacist in Missoula and he gives me all kinds of information regarding my medications. They are very helpful.

There are other residents here [assisted living facility] that are going through the same thing as me. We talk about what works for us (our treatments) and if we have questions, we can ask the nurse at the front desk, they're pretty well informed about things like this.

My mother has congestive heart failure also so when I'm concerned about something, I can her and ask her what she thinks.

Resources Not Commonly Utilized. Cardiac rehabilitation programs were seldom utilized, even though they were locally available to all but two of the participants. Six of the participants were never given the option of this service. One participant even noted preferring membership at a local fitness center over the cardiac rehabilitation program. Only two of the respondents had utilized a cardiac rehabilitation program.

I did have therapy [cardiac rehab], but I don't now. I couldn't see paying for something that I could do on my own.

I joined 24-Hour Fitness once my doctor let me. I have a personal trainer that makes sure that I don't do something I shouldn't.

I was supposed to go to cardiac rehab. I had a nurse working with me for several weeks after I got out of the hospital. I can't remember why I didn't go. Something came up and I never got back to it.

Very few participants utilized the Internet as a source of support or information, and even fewer utilized a library. Three of the participants stated they did not have computer access in their homes. Of the remaining participants, only three responded that they or their spouse utilized the Internet for information.

- I know it's [the Internet] out there. But no, I haven't used it. I just don't seem to have time to get on the Internet or go to the library.

Every now and then I look [at an Internet site], but not real big time. We use the Internet right now because of the problem we are running into now is our insurance. They have to pre-approve everything. Fortunately my wife is real good at that kind of stuff. I'm not as assertive as she is.

I don't have a computer and I wouldn't know how to use one.

One of the interview questions related to utilization of alternative therapies.

Participants were asked if they used alternative or herbal medications, message therapy, acupuncture, and other therapies to manage their illness. With the exception of one person who utilized massage therapy on a rare occasion, participants did not use these forms of therapy. I did note the participants were aware that some alternative medications could cause an adverse reaction if taken with their current prescribed medications.

I do not use any herbal or alternative medicines. I only use what the doctor gives me.

I am not supposed to take herbal medications with my Coumadin.

My husband was after me to do this [utilize alternative therapies]. We have a masseuse that comes in every week to give us massages, but I don't usually work on Fridays so I've only gotten a couple of them. He sells some product and they have really been pushing me to get on that. I'm a little leery to get on that and it is quite expensive. It's supposed to help my diabetes and it's supposed to help my heart failure. It's like \$300.00 a month. I can't afford that plus all my pills and

