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Heart failure self-management behaviors in an indigent population

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Heart Failure Self-Management Behaviors in an Indigent Population

by

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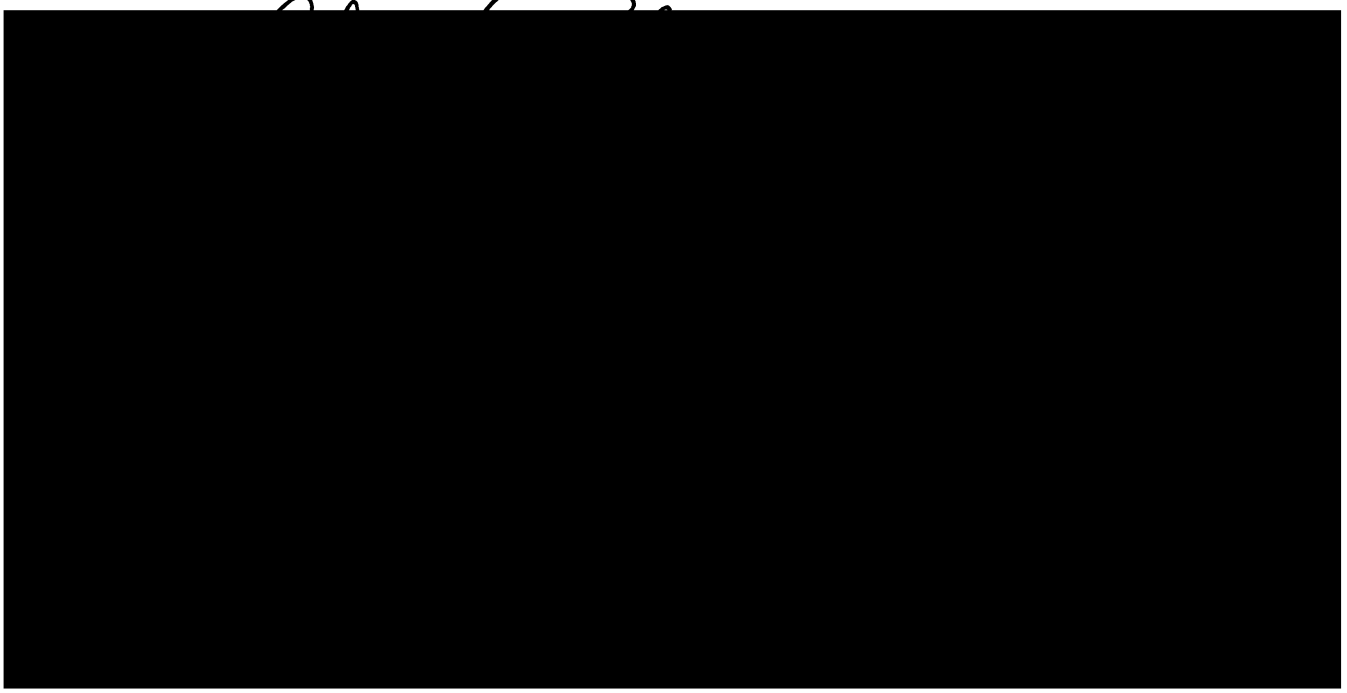

HEART FAILURE SELF-MANAGEMENT BEHAVIORS IN AN INDIGENT POPULATION

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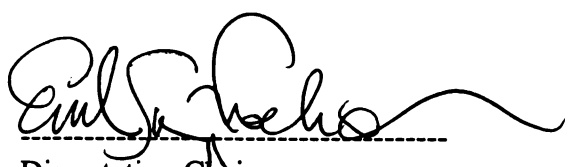
University of California, San Francisco, 2004

Purpose: Heart failure (HF) is a debilitating chronic disease that is continually increasing in incidence and prevalence. The role of patient self-management assumes increasing importance in HF. Recent studies suggest that clinical, socio-economic, and psychosocial variables are related to the performance of self-management behaviors. Little is known about the influence of these variables especially in vulnerable populations of different ethnicities and of lower socioeconomic status who are also uninsured or indigent. The purposes of this study were to: (1) Describe the self-management behaviors of indigent persons with HF with specific interest on clinical and psychosocial variables, as well as their health care utilization; (2) Describe the barriers to self-management behaviors in these patients; and (3) Determine whether demographic, clinical, psychosocial status, and health care utilization predict self-management behaviors. A secondary purpose of this study was to determine if purposes 1-3 differ by gender and race.

Methods: This was a cross-sectional study design utilizing a one-time structured interview. Subjects were recruited from three cardiology clinics and one hospital in central California. Subjects were asked a series of questions from the following instruments: (1) a General Health Perception Question, (2) the Self-Efficacy to Perform Self-Management Behaviors Instrument, (3) the ENRICHD Social Support Instrument, (ESSI), (4) the Center for Epidemiological Studies Depression (CES-D) scale; and (5) the Self-Management in Heart Failure Questionnaire.

Results: The sample consisted of 65 men and women with a mean age of 59±14 (SD), with a majority with less than high school education (57%), unemployed (86%), annual incomes less than $10,000 (56%), and uninsured (52%). A majority of the sample rated themselves as having poor health perception (82%), high self-efficacy in performing HF self-management behaviors (70%), high social support (83%), and depressive symptoms (70%). The performance of HF self-management behaviors was poor (54%). More Whites and females performed good self-management. Based on multiple regression models, symptom severity (New York Heart Association Classification) was the only variable to predict the likelihood of performing HF self-management behaviors.

Conclusions: Performance of HF self-management behaviors was poor despite high self-efficacy and high social support. Gender and racial differences were noted in this largely indigent population.



Dissertation Chair

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It is with my deepest appreciation and gratitude that I write this acknowledgement. This journey has been one I will never forget. It has been one that has been full of significant life changes and life events. It has changed my life and my soul and has put things into perspective for me in realizing what is dear to my heart.

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Glossary of Terms

1) Race/Ethnicity = a classification of individuals by race within the Federal Government's data systems. Five racial groups are identified: American Indian or Alaska Native, Asian, Black or African America, Native Hawaiian or other Pacific Islander, and White. Ethnicity is defined as Hispanic or Latino and non-Hispanic. The Federal Government considers race and Hispanic origin to be two separate and distinct concepts. (Source: CDC, National Center for Health Statistics)

2) Poverty Level = Poverty statistics are based on definitions originally developed by the Social Security Administration. They include a set of money income thresholds that vary by family size and composition. Families or individuals with income below their appropriate thresholds are classified as below the poverty level. According to the U. S. Census Bureau, the average poverty threshold for a family of four was $18,104 annually in 2001.

3) Heart Failure = documentation of an admission diagnosis of HF in the medical record supported with the following patient signs and symptoms: (1) chest x-ray showing pulmonary edema, interstitial fluid, or effusion; or (2) dyspnea, edema, decreased activity tolerance, orthopnea, paroxysmal dyspnea, and weight gain.

4) Clinical variables = physiologic factors which includes left ventricular ejections fraction (LVEF), New York Heart Association (NYHA) functional class, comorbidities (diabetes mellitus, chronic obstructive pulmonary disease (COPD), hyperlipidemia, risk factors (smoking, sedentary lifestyle, obesity, alcohol and drug use), and duration of heart failure.

a.) Left ventricular ejection fraction (LVEF) = documentation of an ejection fraction in the medical record as evidenced by echocardiogram, nuclear study, or heart catheterization (ventriculogram). Study must have been completed within one year of entry into the study.

b.) Low LVEF = ejection fraction of ≤40%

c.) New York Heart Association (NYHA) functional classification = NYHA functional classification as determined by the researcher and/or medical examiner as recorded in the medical record (see Table 1 for specific information regarding NYHA classification). The NYHA classification is a subjective measurement tool used to assess functional status in cardiac patients.

d.) Medical Therapy (pharmacological management) = medications prescribed for HF at the time of hospital discharge. These medications will include ACE-inhibitors, diuretics, digoxin, beta-blockers, angiotensin II receptor blockers, aldosterone inhibitors, nitrates, vasodilators, and calcium channel blockers.

5) Psychosocial variables = set of variables including social support, depressive symptoms, self-efficacy, and health perception.

a) Social support: will be measured using the total score on the ENRICHD Social Support Inventory (ESSI).

b) Depressive symptoms: will be measured using the total score on the Center of Epidemiologic Depression Scale (CES-D).

c) Self-efficacy: will be measured using the total score on the Self-efficacy to perform heart failure self-management behaviors questionnaire.

d) Health perception: will be measured using a health perception question .

6) Self-management behaviors = A set of skilled behaviors an individual engages in to manage his/her illness usually done in collaboration with a health care professional. Behaviors specific for HF patients include: (1) monitoring changes in symptoms, (2) monitoring daily body weights, (3) eating a low sodium diet, (4) exercise, (5) medication compliance, (6) treatment adjustments, (7) evaluating treatment effectiveness, (8) reporting changes to a health care provider. This will be measured the Self-Management of Heart Failure (SMHF) questionnaire.

7) Self-Efficacy = Refers to belief in one's agentive capabilities, that one can produce given levels of attainment. Therefore, it includes both an affirmation of a capability level and the strength of that belief. If differs from the colloquial term "confidence" in that "confidence" refers to strength of belief but does not necessarily specify what the certainty is about. (Bandura, A. Self-efficacy: The Exercise of Control, 1997, p. 382).

8) Health care utilization = will be measured using hospital readmissions (with HF) and emergency room visits. The number of readmission will be measured using the total number of times the patient is readmitted into the hospital (with and without problems related to HF) over the last year or 12 months prior to the study. The number of emergency room visits will be measured using the total number of times the patient visit the emergency room (with or without problems related to HF) over the last year or 12 months prior to the study.

CHAPTER I: STUDY PROBLEM AND SIGNIFICANCE

Background and Significance

Heart failure (HF) is a clinical syndrome in which symptoms of fatigue, dyspnea, exercise intolerance, orthopnea or paroxysmal nocturnal dyspnea are associated with abnormalities of left and right ventricular function and changes in the neurohormonal regulation (Deedwania & Carbajal, 1995). It is a chronic illness that often affects the patients' functional capacity limited to poor cardiac output and reserve. In the United States, more than 4 million people suffer from HF with these symptoms, which results frequently in hospitalizations and poor quality of life. It is one of the leading causes of morbidity and mortality and represents a major public health problem (Funk & Krumholz, 1996).

Heart failure is associated with varying degrees of cardiac disability and, at times, premature death. Despite the major advances in medical and surgical technology in the treatment of HF, the prevalence of HF continues to rise (American Heart Association, 1999). In fact, the past 20 years have witnessed a significant decline in the incidence of myocardial infarction and heart disease-related mortality throughout the world, yet the prevalence of HF has increased dramatically. This is proportionately related to the rapid increase in the number of elderly people in the United States. In 1980, about 12% of the population, or 25.5 million people, were older than 65 years of age. By the year 2020, the number of people over 65 will grow to 35 million, with a projected plateau at 68 million by the year 2040 (Carlton, Rauh, Ventura, & Silver, 1997). Among those patients, 40% will be women (Ghali, Mosley, Danzell, & Eaves, 1998).

Heart failure is the single most common cause of hospitalization for people age 65 and older with hospital discharges for HF rising from 377,000 in 1979 to 870,000 in 1996, a 131 percent increase in 17 years (American Heart Association, 1999). Heart failure is also the most common indication for readmission to the hospital with rates ranging from 29 to 47 percent within 3 to 6 months of initial discharge (Rich et al., 1995). These patients consume an increasing proportion of both inpatient and outpatient medical resources. Nationally, nearly $20 billion are spent on the care of patients with HF making it the most expensive disease in the U. S. medicare system (Lenfant, 1996).

Heart failure is the fastest growing cardiovascular disorder, increasing in incidence, prevalence, and mortality (Garg, Packer, Pitt, & Yusuf, 1993; Yamani & Massie, 1993). The majority of research on heart failure has been done on pathophysiological and pharmacological mechanisms, with some nurse researchers addressing quality of life, social support, and compliance issues (Bennett, Baker, & Huster, 1998; Bennett & Pressler, 1997; Johnson & Dahlen, 1997; Martensson, Karlsson, & Fridlund, 1997; Martensson, Karlsson, & Fridlund, 1998). However, many of these studies have had small sample sizes that are not representative of the population. In particular, many studies have excluded or had an insufficient number of women, non-whites, and older adults.

Epidemiological and clinical trial data suggest potential differences in the natural history and response to therapy between women and men (Adams et al., 1996). Thus, the role of gender is increasingly being acknowledged in the broad spectrum of cardiac disease. There also may be major racial differences which are not evident based on the past research. Furthermore, recent evidence suggests racial and gender-related disparities

in cardiac function, disability, prognosis and treatment. There are many questions that remain unanswered in regards to women, race, and HF.

Heart failure represents a complex medical challenge and is one of the most disabling and fatal medical conditions (Adams & Zannad, 1998). Conventional management of complex HF is inadequate and remarkably ineffectual due to suboptimal medical management of effective medications, patients' poor adherence to dietary sodium limitation and optimal drug therapy, and the lack of systematic monitoring of patients after hospitalization in the outpatient or ambulatory care setting (Cardiology Preeminence Roundtable, 1997). In addition, patients often have to adjust their lifestyle by adhering to complex medication regimen, changing their diet and fluid intake, adapting their activities, and monitoring symptoms of worsening heart failure (West et al., 1997).

The concept of self-management in chronic disease, like HF, is changing. It is emphasizing a more proactive role for patients. Effective self-management behaviors include identifying subtle changes in signs and symptoms, evaluating the importance of the changes, choosing a treatment and evaluating the effectiveness of the treatment chosen (Carlson, Riegel, & Moser, 2001). However, self-management behaviors may be difficult for patients who are elderly, with comorbidities, have multiple symptoms, and declining cognitive function (Vinson, Rich, Sperry, Shah, & McNamara, 1990). There is some recent evidence that self-management behaviors also may be difficult for patients who are not working and those with no available support (Naylor et al., 1999; Happ, Naylor & Roe-Prior, 1997; Tsuchihashi et al., 2001). Teaching self-management skills and behaviors can be challenging but can be done with the guidance and commitment of

health care professionals. This education must be tailored to the individual patient to encourage self-efficacy and skill-enhancement elements to ensure success.

There are very few studies that have measured outcomes in terms of self-management behaviors, health status, and psychosocial factors such as social support, self-efficacy and depression (Artinian, Magnan, Sloan, & Lange, 2002; Bennett & Pressler, 1997; Carlson, Riegel & Moser, 2001; Happ, Naylor & Roe-Prior, 1997; Hubbard, Muhlenkamp & Brown, 1984; Jaarsma, Halfens, Tan, Abu-Saad, Dracup & Diederiks, 2000; Lorig et al., 1999). Furthermore, it is also known that teaching self-management can be a successful approach in managing chronic diseases and in reducing frequent hospital readmissions, but little is known about the details of self-management behaviors in patients who have little or no education and little or no financial resources.

As the demographic characteristics of the population changes, we are likely to see greater variations in ethnicities and economic status within the population of adults with HF. It is well known that ethnicity influences socioeconomic status (SES) in the United States (Anderson & Armstead, 1995). Furthermore, a low SES contributes to both the etiology of major illnesses and mortality (Williams, Barefoot, & Kaliff, 1992). Heart failure appears to disproportionately affect vulnerable populations or minority groups. This disparity may be attributable to lower SES influencing health outcomes by affecting not only clinical factors, but psychological and behavioral factors, as well (Anderson, & Armstead, 1995). Persons lower in SES experience more stressful life events and more subjective distress than their higher SES counterparts. Also, the emotional impact of stressful life events is greater in groups of lower SES compared with those higher in SES (Kessler, 1979; McCloud & Kessler, 1990). Furthermore, in addition to greater

vulnerability to stress and subjective distress, lower SES groups are likely to experience other psychological characteristics such as depression, hostility, and external locus of control (Anderson & Armstead, 1995). These psychological and behavioral factors appear to affect health more than clinical risk factors such as cholesterol levels, high blood pressure, sedentary lifestyle, obesity, and smoking (Haan, Kaplan, & Camacho, 1987; McIntyre, Maciver & Sooman, 1993; Lynch, Kaplan & Shema, 1997).

There are a few studies addressing Mexican American population with myocardial infarction (MI) but none were found addressing HF (Espino, Parra & Gabriel, 1994; Herholz et al., 1996). In the MI literature, it was found that Mexican Americans when compared to non-Hispanic whites were found to be younger, less educated, have lower incomes, and have lower-status occupations (Herholz et al., 1996). Mexican American women were more likely to have a history of diabetes mellitus (DM) and hypertension (HTN), the major clinical risk factors leading to HF. Furthermore, among Mexican American, women were also more likely to have in-hospital, acute exacerbations of HF following an MI (Herholz et al., 1996).

Statement of the Problem

Heart failure is a debilitating chronic disease that is continually increasing in incidence and prevalence. It constitutes a large threat to the individual's health status and constitutes a large proportion of health care expenditures. The role of patient self-management assumes increasing importance especially within chronic disease management since it has been shown to improve the patient's overall health and well-being, as well as to reduce hospitalizations and costs (Lorig, Lubeck, Kraines, Seleznick & Holman, 1985; Lorig & Holman, 1989; Goodall & Halford, 1991; Zimmerman, Brown

& Bowman, 1996; Lorig et al., 1999). Most of the research that encompasses the concept of self-management has been done on a wide array of chronic diseases including asthma, arthritis, DM, and HTN. Currently, there is an accumulating body of science addressing HF self-management and its effects on outcomes. Most of this research has been done in urban settings with samples that consist of mostly white males. However, there is also a small body of literature that suggests that clinical, socio-economic, and psychosocial variables are related to the performance of these self-management behaviors. Currently, little is known about the influence of these variables especially in groups of different ethnicities and of lower socioeconomic status, and those who are also uninsured or indigent.

Purposes of the Study

The purposes of this dissertation project were to: (1) Describe the self-management behaviors of indigent persons with HF with specific interest in clinical and psychosocial variables, as well as their health care utilization; (2) Describe the barriers to self-management behaviors in indigent patients; and to (3) Examine the relationships among the above variables and determine whether demographic, clinical, psychosocial status, and health care utilization predicts self-management behaviors. A secondary purpose of this study was to determine whether clinical and psychosocial variables as well as health care utilization differed by gender and race.

The information gathered in this study will provide the ground work for future research to improve self-management behaviors in these patients. Because self-management focuses on patient concerns and problems, a detailed needs assessment must be done for each new topic and population. While many concerns are shared across

different diseases, behaviors, and populations, there may be differences among groups and individuals. Once patient problems have been identified, the next step is to identify the barriers to performing health behaviors so that health care providers can better tailor various interventions to promote the best health outcomes.

Specific Aims

1. Describe the characteristics of indigent HF patients, including their demographic profile, clinical and psychosocial factors, health care utilization, and their self-management behaviors.
2. Describe the difficulties/barriers that patients with HF experience in performing self-management behaviors.
3. Examine the relationships among the above variables and determine whether demographic, clinical, psychosocial status and their health care utilization predict self-management behaviors.

Secondary purpose: A secondary purpose of the study is to describe and compare differences for objectives 1 to 3 by gender and race.

Need for the Study

Widening disparities in health are becoming apparent as medical care is becoming more complex. It has been suggested that poor health in socioeconomically disadvantaged populations results from unfavorable social conditions and ineffective self-management (Haan, Kaplan, & Camacho, 1987; MacIntyre, Maciver & Sooman, 1993; Lynch, Kaplan & Shema, 1997; DeFriese, Woomert, Guild, Steckler & Konard, 1989; Sobel, 1995). Women and persons of lower SES have been shown to have more severe

symptoms, greater functional disability, and more frequent hospitalizations. There is also limited evidence that there may be disparities and variations in the processes and health care utilization in these marginalized groups.

Changes in health care have resulted in an outpatient model for managing chronic diseases. Several reports suggests that increasing access to care and advocating self-management behaviors produces favorable health care outcomes such as decreased hospitalizations and ED visits. However, there are still numerous questions that remain unanswered in regards to self-management with gender and race. There are studies that have examined the differences in African Americans and whites, and the differences between men and women. However, little is still known about these gender differences and even less is known about other racial and ethnic differences in HF. Moreover, very little is known about how psychosocial variables relate to self-management behaviors. It is time to expand our research endeavors to racially diverse groups as important contributions to our knowledge in HF. An important goal of future research should be not only to evaluate the pathophysiological and pharmacological differences across gender and race but also to ascertain information in differences in psychosocial factors, access to care and health care utilization.

Therefore, the purpose of this study was to explore the self-management behaviors, as well as factors that may influence the performance of these behaviors, in indigent patients with HF. This study will also provide the ground work for future research in identifying educational skill building needs of self-management in these patients. By understanding what the barriers are to performing self-management

CHAPTER II: LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Review of the Literature on Gender and Racial Differences and Self-Management Behaviors

Chapter two addresses two parts: (1) a review of the literature on gender and racial differences with demographic, clinical, and psychosocial variables, as well as health care utilization; and (2) a review of the literature pertaining to self-management behaviors. In addition, the conceptual framework used in this study will be provided.

Demographic Characteristics

Epidemiology

There have been several large studies that have examined gender differences in the incidence and prevalence of HF (Table 1). According to the 40-year follow-up of the Framingham Study, the incidence of heart failure is higher in men than in women with the age-adjusted incidence being one-third lower for women than men (Ho, Anderson, Kannel, Grossman, & Levy, 1993). Age-adjusted annual incidence was 2.5 cases per 1000 in women versus 3.7 cases per 1000 in men (Ho, Pinsky, Kannel, & Levy, 1993). The Rochester study, however, revealed an incidence rate of 1.6 cases per 1000 in women versus 0.7 cases per 1000 in men under the age of 75 (Rodeheffer, Jacobsen, & Gersh, 1998). The overall incidence in all age subgroups appears to be fewer women than men with the incidence increasing significantly with age. (Ho, Pinsky, Kannel, & Levy, 1993, Ghali, Mosley, Danzell, & Eaves, 1998, Schocken, Arrieta, Leaverton, & Ross, 1992).

Table 1: Incidence and Prevalence of Heart Failure

Study	Incidence per 1000 patient years		Prevalence per 1000 patients	
	Men	Women	Men	Women
Framingham (1993)				
45-54 yrs	2.0	1.0		
55-64 yrs	4.0	3.0		
65-74 yrs	8.0	6.0		
75-84 yrs	14.0	13.0		
45-74 yrs	3.7	2.5		
Rochester (1998)				
45-54 yrs	0.8		0.8	1.5
55-64 yrs	4.0	1.3	9.7	5.2
65-74 yrs	13.2	7.2	26.8	19.4
0-74 yrs	0.7	1.6	3.3	2.1
Eastern Finland (1992)				
45-54 yrs	1.5	1.2		
55-64 yrs	3.8	2.5		
65-74 yrs	9.1	4.2		
45-74 yrs	4.7	2.4		
Gothenberg (1989)				
50-54 yrs	1.5		21	
55-64 yrs	4.3		32	
61-67 yrs	10.2		130	
United Kingdom (1999)				
25-34 yrs	0.0	0.04		
35-44 yrs	0.2	0.2		
45-54 yrs	0.3	0.1		
55-64 yrs	1.7	0.7		
65-74 yrs	3.9	2.3		
75-84 yrs	9.8	5.9		
85+ yrs	16.8	9.6		
Rotterdam (1999)				
55-64 yrs			0.7	0.6
65-74 yrs			3.7	1.6
75-84 yrs			14.4	12.1
85-94 yrs			5.9	14.0
NHANES (1992)				
55-64 yrs			45	30
65-74 yrs			48	43
25-74 yrs			19	20

Note. NHANES = National Health and Nutrition Examination Survey;

In a more recent study, Senni et al. (1999) reported the incidence of HF between 1981 and 1991 was unchanged; however, men had a higher age-adjusted incidence of HF compared with women. In addition, they too, reported that the incidence increased significantly with advancing age. Furthermore, the incidence among men increased dramatically starting at the seventh decade, whereas, in women this increase was delayed until the eighth decade of life.

Several European studies also report population based incidence rates. A Finnish study reported similar figures to U. S. studies with an annual incidence of 2.4 in women and 4.7 per 1000 individuals in men (Remes, Reunanen, Aromaa, & Pyorala, 1992). The Swedish, Gothenburg study of men reported an average incidence rate of 5.5 per 1000 men aged 50 to 67 years (Eriksson, Svardsudd, & Larsson, 1989). Recently, another population-based study done in the United Kingdom, reported an incidence rate of 1.3 cases per 1000 per year for those aged 25 years and older. Similarly, as reported in the other studies, the incidence rate increased significantly with advancing age ranging from 0.02 cases per 1000 per year in those aged 25 to 34 years to 11.6 in those aged 85 years and over (Cowie et al., 1999).

Various sources of epidemiological information on HF indicate an increase in the frequency of HF in the U. S. Data from the Framingham and Rochester studies, both population-based studies mentioned above, revealed that the prevalence of HF also increased with age. The Framingham study revealed that approximately 1% of subjects developed HF in their fifth decade with the risk rising progressively with advancing age, thus, affecting nearly 10% of persons between the ages of 80 and 89 years. Furthermore, the prevalence rose from 0.8% in women 50 to 59 years of age to 7.9% in those aged 80

to 89 years. In men, the prevalence increased from 0.8% in those 50 to 59 years of age to 6.6% in those aged 80 to 89 years of age (Ho, Pinsky, Kannel, & Levy, 1993). The Rochester data also revealed that the prevalence of HF increased dramatically with age but the rates were higher among men (3.3%) than in women (2.1%) (Rodeheffer, Jacobsen, & Gersh, 1998).

Other population-based studies done in Europe add to the information regarding the prevalence of HF. The Gothenburg study reported comparable prevalence rates to that reported in the Framingham study of approximately 13% in men who were 67 years or less (Eriksson, Svardsudd, & Larsson, 1989). The Rotterdam Study with 61% women revealed a prevalence rate of 4.0% in women and 3.7% in men and aged 55 to 95 years (Mosterd, et al., 1999).

The Resource Utilization Among Congestive Heart Failure (REACH), an epidemiological study, showed the annual prevalence rose from 9 to 20 per 1000 patients over 9 years ($p<0.01$). They concluded that this increase can be considered a chronic disease epidemic (McCullough, Cingireddy, Philbin, & Weaver, 1999). However, this study did not differentiate by gender. Other major epidemiological surveys reveal that the overall prevalence is similar in women and men and prevalence increases with age (Schocken, Arrieta, Leaverton, & Ross, 1992; Ho, Pinsky, Kannel, & Levy, 1993; McDonagh, et al., 1997).

The National Health and Nutrition Examination Survey (NHANES- I) reported that the prevalence of HF did not differ greatly between women and men. Based on this U. S. population estimate for the period between 1971 to 1975, the overall prevalence

rate was 2% in women ages 25 to 74 and 1.9% in men of the same ages (Schocken, Arrieta, Leaverton, & Ross, 1992).

Clinical Risk Factors

Gender Differences in Etiology and Pathophysiology

Several studies have suggested that the prevalence of hypertension is greater for women than for men. Hypertension preceded the onset of heart failure in 78% of women and 70% of women and is associated with a two to four-fold increase in the incidence of HF (Levy, Larson, Vasan, & Kannel, 1996). Data from the SOLVD trials found women more likely to have hypertension (55% of women vs. 39% in men, $p<0.001$) (Johnstone et al., 1992). These findings of higher prevalence of hypertension are also seen in blacks (64.2% of women vs. 60.2% of men; $p<0.05$) and whites (42.9% vs. 35.7%; $p<0.05$) (Philbin & DiSalvo, 1998). The difference in the cardiac response to an increase in afterload may be the cause of these differences between men and women (Petrie, Dawson, Murdoch, Davie, & McMurray, 1999)

Coronary artery disease (CAD) was present in 48% of women and 59% of men with heart failure and has been increasing in the incidence among new cases of heart failure. In patients with HF due to CAD, identifiable myocardial infarction (MI) was less frequent in women as compared with men (57% vs. 80%, respectively) (Ho, Anderson, Kannel, Grossman, & Levy, 1993). Women were also more likely to develop heart failure after coronary artery bypass graft (CABG) surgery than men (relative risk 2.71; 95% CI, 1.86 to 3.93) (Hoffman, Psaty, & Kronmal, 1994). Although white women have less CAD than their male counterparts, black women appeared to have more CAD than black men (Philbin & DiSalvo, 1998).

Several studies have suggested that diabetes mellitus (DM) may also be a strong risk factor for developing heart failure, especially in women (Petrie et al., 1999; Croft, Giles, Pollard, Casper, & Anda, 1997; Krumholz, et al., 1997; Shindler et al., 1996; Limacher et al., 1991; Ho, Pinsky, Kannel, & Levy, 1993). Diabetes was more prevalent in women (26%) with HF when compared with men (14%); additionally, the age-adjusted incidence rates suggested that diabetics of both sexes were at far greater risk for HF than were nondiabetics (Kimmelstiel & Goldberg, 1990; Kannel, Hjortland, & Castelli, 1974). Furthermore, the relative risk for diabetic women was more than double that of men and the excess incidence of HF in DM was more predominant in those who required insulin (Kannel, Hjortland, & Castelli, 1974). Additionally, more recent Framingham data have confirmed that younger women with DM have an 8-fold increase in HF incidence (Ho, Pinsky, Kannel, & Levy, 1993). Furthermore, diabetic women with HF have a 70% increase in mortality compared with male diabetics (Ho, Anderson, Kannel, Grossman, & Levy, 1993). Diabetes mellitus and left ventricular hypertrophy seen on the electrocardiogram (ECG) were also associated with an increased incidence of overt HF.

Ghali and associates (1991) found significantly more women with preserved left ventricular systolic function. Many other studies have revealed these findings in women with mild to moderate heart failure (Echeverria, Bilsker, Myerburg, & Kessler, 1983; Dougherty, Naccarelli, Gray, Hicks & Goldstein, 1984; Topol, Trail, & Fortuin, 1985; Bier et al., 1988). According to Erikkson, Kjekshus, Offstad, and Swedberg (1994), there may be a gender-related difference in the degree of underlying left ventricular dysfunction despite the similarity of symptoms. Hence, clinical manifestations of HF may be a result of either systolic and/or diastolic dysfunction.

Signs and Symptoms

Several studies have reported that women have more severe HF symptoms than do men (Fisher et al., 1982; Kennedy, Kaiser, & Fisher, 1981; Kelsey et al., 1993; Jacobs, Kelsey, & Rosen, 1993; DeMaria, 1993) as well as higher prevalence of heart failure symptoms (13% in women vs. 10% in men, p=0.05). It is not known whether the higher prevalence of symptoms is related to their older age and coexisting illnesses or other factors which are unique to women. Perhaps, it could be that women and the elderly may have a greater awareness of their symptoms than do younger male patients (Erikkson, Kjekshus, Offstad, & Swedberg, 1994).

In a subset of patients, nearly one-half of women had recent unstable angina compared with only one-third of the men (p=0.003). In spite of women having more clinical manifestation of HF, the mean LVEF in women was significantly higher than that in men (61% vs. 56%; p=0.0001). In addition, normal LVEF (≥50%) was seen in 79% of women compared with only 69% of men (p=0.0001). According to the authors' findings, being a woman remained an independent predictor of HF such that women had a 1.7 fold higher chance of developing HF symptoms than men (Mendes, Davidoff, Cupples, Ryan, & Jacobs, 1997).

In the Multicenter Investigation of Limitation of Infarct Size (MILIS), prior heart failure was more frequent in women than in men admitted with acute myocardial infarction (12% vs. 7%; p=<0.05), however, the LVEF was significantly higher in women than in men (49% vs. 45%; p<0.05) (Toffler et al., 1987). Other studies have noted similar patterns in the symptoms of heart failure in women despite higher LVEF

(Kennedy, Kaiser, Fisher et al., 1981; Kelsey et al., 1993; Jacobs et al., 1993). In other words, symptoms and objective data of LVEF do not correlate very well.

An analysis by the SOLVD investigators found that women experienced greater shortness of breath on exertion (58% vs. 48% of men, $p<0.001$) and that fewer women were classified as New York Heart Association (NYHA) class I (6% vs. 12%, $p<0.001$) than men (Johnstone et al., 1992). They also found that women had more frequent edema than men (22% vs.15%, respectively), more women than men had an audible third heart sound (17% vs. 11%, $p<0.001$) and an elevated jugular venous pressure (17% vs. 5%, $p<0.001$).

A study comparing women and men with idiopathic dilated cardiomyopathy reported women as having more signs and symptoms and having more functional disability with lower exercise tolerance, as assessed by the NYHA functional class and heart failure signs at entry of the study. Forty eight percent of women were classified as NYHA class III or IV versus 39% of men despite no differences in time of diagnosis of cardiomyopathy (De Maria et al., 1993). However, they found no significant differences in prognosis, although there was a trend toward a worse outcome in women than in men.

Burns et al. (1997) found that more women than men became short of breath walking less than one block (55% vs. 40%, $p<.013$) and had more difficulty performing their activities of daily living (ADLs). In fact, men appeared to be more independent than women in their ADLs and women received formal care more often than men. Additionally, 50% to 75% of the study sample reported their perceived health as fair or poor. This may indicate that women have a more advanced stage of the disease at the time of first presentation for health care (De Maria et al., 1993).

Fatigue is another common physical symptom that is reported by patients with HF. It can be incapacitating because it often interferes with normal daily functioning. A study done by Friedman and King (1995) revealed that fatigue was the primary symptom reported most often by older women with HF and that it increased over time. This increase over time was also related to dyspnea which is the other predominant physical symptom consistent with HF. They also found that perceived stress, satisfaction with life, and optimism did not make a major contribution to current fatigue or the change in fatigue over time. Perhaps, this may be because women tend to adapt to the limitations of their illness.

Survival and Mortality

Mortality risk for patients with HF has been reported to be as high as 50% at 2 years following diagnosis (Johnstone, Abdulla, & Arnold, 1994). According to a study done on a multi-center mortality risk on hospitalized patients by the Clinical Quality Improvement Network Investigators (1996), the overall in-hospital HF mortality rate ranged between 13% to 26% among sites. The average age at death in the total population was 77 years. The mean age at death was 79 years for women and 76 years for men. This study confirmed the results that mortality in HF patients is associated with age. Interestingly, they also reported that the average age of death in patients with HF is approximately 15 years older than the average age of patients surviving acute myocardial infarction. These findings suggest that the HF patients may have a prolonged clinical course after the initial diagnosis of left ventricular dysfunction.

The NHANES-I survey assessed mortality due to HF at two points in time. The 10-year mortality for women and men with clinical HF was 23.8% and 54.4%,

respectively; and for those without HF, mortality rates were much lower (7% for women and 10.2% for men). The 15-year mortality rates in patients 65 to 74 years of age with HF were 51.4% for women and 79.3% in men. Of those without clinical HF, the 15-year mortality rates were 52.1% for women and 37.2% for men (Schocken, Arrieta, Leaverton, & Ross, 1992).

The National Heart, Lung, and Blood Institute's (NHLBI) Framingham Study reported that survival is poorer in men than in women. However, fewer than 20% of women survive longer than 8-12 years. According to Ho, Pinsky, Kannel, and Levy (1993) and the Framingham study, they reported a median survival time after the diagnosis of HF of 3.2 years in women and 1.7 years in men , with 5-year survival rates of 38% in women and 25% in men. After adjusting for age, survival appeared to be better in women than in men. In addition, the mortality rate increased with advancing age. In women, the increase in mortality rate was 61% per decade of age and in men, there was an increase of 27% per decade of age. They concluded that heart failure is associated with a shorter life expectancy than that of many common malignancies.

Jaagosild et al. (1998) found the 90-day survival for women and men to be 72% and 73% respectively, and 1-year survival to be 64% and 57% respectively. They found the results of the Study to Understand Prognosis and Preferences for Outcomes and Risk of Treatments (SUPPORT) survival rates to be similar to the Framingham Heart Study data which reported data from the 1950s to 1980s. According to Senni et al. (1999), overall survival after adjusting for age, sex, and NYHA functional class was not significantly different in patients with HF in 1981 and in 1991. In addition, survival among women and men was similar.

Medication Usage

There have been reports of discrepancies in treatment for HF, acute MI, and cardiovascular risk reduction, particularly in women and in elderly male and female patients (Teo et al., 1996; Montague et al., 1995; Clinical Quality Improvement Network (CQIN) Investigators, 1995). For example, it was found that the use of the only proven efficacious therapy for HF, angiotensin converting enzyme inhibitors (ACE-I), was significantly less frequently prescribed in women and in patients older than 70 years of age (Teo et al., 1996). The Studies of Left Ventricular Dysfunction trial also resulted in very low utilization rates for ACE-I of about 30% (Bourassa et al., 1993).

Several other long-term clinical trials have examined gender differences as well. However, there has been a large under representation of women in these landmark HF trials (Table 2). For example, the Cooperative New Scandinavian Enalapril Survival Study 1 (CONSENSUS 1) provided evidence that angiotensin-converting enzyme inhibitors (ACE-I) such as enalapril prolongs survival in patients with severe heart failure. However, only 30% of patients entered into this study were women and no beneficial effect of enalapril was found among them (The CONSENSUS Trial study group, 1987).

Similarly, the Survival and Ventricular Enlargement (SAVE) trial examined the effects of captopril, another ACE-I, on mortality and morbidity in patients with left ventricular dysfunction post-myocardial infarction. Captopril was found to have much smaller reductions in the risk of death in women compared to men (Pfeffer et al., 1992). In the SOLVD data, men were noted to have a greater benefit from enalapril when compared to women (Limacher et al., 1993). It should be noted, however, that

conclusions about the use of ACE-I in women cannot be drawn due to small representation of women enrolled in the SAVE and SOLVD trials.

Table 2: Gender Distribution in Heart Failure Trials

Trial	n (Total)	n=women	% women
Captopril-Digoxin	300	51	17
CONSENSUS I	253	75	30
SOLVD (Treatment)	2,569	504	20
SOLVD (Prevention)	4,228	486	11.5
SOLVD Registry	6,063	1,595	26.3
MDC	383	105	27
PROMISE	1,088	235	22
Vesnarinone	477	63	13
RADIANCE	178	42	24
PRAISE	1,153	278	24
DIG	7,788	1,926	24.7
Carvedilol	1,094	256	23
Total	**25,574**	**5,741**	**22**

Note. :CONSENSUS 1 = Cooperative New Scandinavian Enalapril Survival Study 1; SOLVD = Studies of Left Ventricular Dysfunction; MDC = Metoprolol in Dilated Cardiomyopathy; PROMISE = Prospective Randomized Milrinone Survival Evaluation Trial; RADIANCE = Randomized Assessment of the Effect of Digoxin on Inhibitors of the Angiotensin-Converting Enzyme study; PRAISE = Prospective Randomized Amlodipine Survival Evaluation; DIG = Digitalis Study

Note. From "Heart Failure In Women," by J. K. Ghali, L. Mosley, J. Danzell, and B. Eaves, 1998, *Journal of the Louisiana State Medical Society, 150*, p. 89.

Another study done by the Clinical Quality Improvement Network Investigators (1996) reported the ACE-Is were significantly less utilized in women (50%) compared to men (56%), despite the potential benefits. The Agency for Health Care Policy and Research (AHCPR) guidelines for heart failure are recommending that ACE-Is be administered as standard treatment to both men and women with left ventricular dysfunction (Konstam et al., 1994).

The role of beta-blockers in patients with HF has recently been of great interest. Recent studies suggest the usefulness of carvedilol in reducing hospitalization rate and improving ventricular systolic function (Fowler, Gilbert, & Cohn, 1996; Colucci et al., 1996). Gender differences in the use of beta-blockers have not been established and little is known about the efficacy of these drugs in women due to the small minority of women enrolled in the carvedilol studies.

Psychosocial Variables

Psychosocial variables have recently emerged as being important predictors of risk for cardiovascular events among cardiac patients as well as predictors of morbidity and mortality in HF patients. The importance of assessing health perception, self-efficacy, social support, and depression in these patients is imperative to assist clinicians in identifying those at increased risk. The following is a review of the literature in regards to these psychosocial factors.

Health Perception

Heart failure patients frequently have more symptoms and functional impairment. As a result of these troubling symptoms, persons with HF often have diminished quality of life (QOL). However, to date there is only limited data available on quality of life in

heart failure. The research that has been done has used samples composed primarily of men (Bennett, Baker & Huster, 1998).

Past studies have reported that symptoms and health perceptions were the most important predictors of QOL and mortality (Idler & Kasl, 1991; Havranek et al., 2001). A study by Stewart and colleagues (1989) revealed that heart failure patients had among the poorest health perceptions with role and social functioning. Health perception was also found to be a strong predictor of subsequent occurrence of clinical events in patient with HF (Havranek et al., 2001).

Dracup and colleagues (1992) examined QOL in 134 patients with advanced heart failure being evaluated for heart transplantation. In this study, the sample reported their QOL as significantly compromised with feelings of depression, hostility, and decreased functional ability. Muirhead, Meyerowitz & Leedham (1992) also examined QOL in patients awaiting transplantation (n=41). Patients in this study reported fatigue, decreased strength, and shortness of breath as the most frequent physical symptoms, and depression, anxiety, and somatization as the most frequent psychological symptoms. Overall, patients described their health as poor and their QOL as negative. Grady, Jalowiec, Grusk, White-Williams, & Robinson (1992) found fatigue, dyspnea on exertion, and difficulty sleeping as the most frequent symptoms affecting QOL. In these HF patients (n=175), also awaiting transplantation, the symptom distress correlated significantly with greater functional disability, inability to work, higher stress, and lower QOL.

Bennett, Baker, and Huster (1998) conducted a study to describe and examine the relationships among symptoms, perceived health status, perceived social support, and overall quality of life. They found that women who reported high physical symptom

impact, and poor perceived physical health status, also reported impaired QOL. Perceived social support did not strongly correlate with physical symptom impact. However, as physical symptoms worsened, actual support increased. In contrast to previous research, the women in this study reported fairly positive mental health status score. Additionally, an intriguing finding of this study was that emotional symptom impact did not correlate with overall QOL.

More recent studies that have addressed QOL in HF patients have also concluded similar results. Westlake and colleagues (2002) studied 61 advanced HF patients (mean age=56, 74% men, 84% white, 15% Hispanic) awaiting heart transplantation. Their study revealed that subjects reported moderately low levels of neuroticism, moderately high levels of social support, and lower levels of QOL, both in the physical health and mental health components, when compared to the general United States population.

Another study done by Ekman, Fagerberg, and Lundman, (2002) found overall lower levels of QOL in their elderly sample (mean age=81) when compared to healthy controls. Women also appeared to have lower scores in the physical function subscale, when compared with men. Juenger et al. (2002) also reported that HF patients had significantly reduced scores in all aspects of QOL compared with healthy controls but no differences were found between HF patients and those on chronic hemodialysis. Additionally, this study reported that the total HF sample had significantly worse physical health but better mental health. However, those patients with more advanced disease (NYHA class III) had similar scores to patients with major depression. These data are in accord with findings from other studies showing that a large proportion of HF patients suffer from depression, thus, the QOL is significantly reduced.

A study examining gender differences in 1-year survival and QOL among patients who were admitted with HF revealed that women had consistently lower scores on the SF-36 (a health related QOL generic measure) than men at all points (baseline, 2-months, and 1-year). This was especially true for the questions that addressed functional ability. Chin and Goldman (1998) also reported that women, overall, showed less improvement than men after one year and those women tended to require more help after hospitalization. These findings strongly suggest that women have a poorer quality of life than men.

Self-efficacy

Self-efficacy theory is based on the interactive model of human behavior with Bandura's Social Cognitive Theory (Bandura, 1986). In terms of self-management, the impact on health status is based on the person's beliefs in their efficacy to exercise some control over conditions that affect their lives (Bandura, 1986). Self-efficacy influences what people choose to do, their motivation, their perseverance in the face of difficulty, and their vulnerability to stress and depression (Holman & Lorig, 1992). The theory also states that the strength of belief in one's capability is a good predictor of future motivation and behaviors. In addition, one's self-efficacy can be enhanced through performance mastery, modeling, reinterpretation of physiological symptoms and social persuasion. Finally, enhanced self-efficacy leads to improved behaviors, motivation, thinking patterns, and emotional well-being.

Several studies support Bandura's contention that self-efficacy is a powerful determinant of behavior and that self-efficacy is a strong predictor of self-care behaviors (Crabtree, 1986; Godding & Glasgow, 1985; Lorig, Chastain, Ung, Shoor & Holman,

1989; Dilorio, Faherty & Manteuffel, 1992). Additionally, more recent studies have shown that both baseline self-efficacy and changes in self-efficacy are associated with future health status (Lorig et al., 1999). Thus, it appears that enhanced self-efficacy is at least one of the mechanisms responsible for the improvements in health status demonstrated by those attending self-management programs (Lorig & Holman, 2000). Furthermore, it also appears that self-efficacy provides a linking mechanism between psychosocial factors and functional status (Holman & Lorig, 1992).

The goal of self-management in chronic conditions such as HF is retarding the disease progression and improving quality of life. Perhaps, the best model for the self-management of chronic disease utilizing the application of self-efficacy principles was devised by Holman and Lorig (1992). Their research tested the effectiveness of a self-management program in patients with arthritis. Their program was implemented in a community setting in a group format by persons who suffer similar disabilities. It was found that through modeling their success in overcoming their physical debilities, the patients' self-efficacy increased. Furthermore, the higher the perceived self-efficacy, the less they were disabled by their arthritis, the less pain they experiences, and the greater the reduction in the inflammation in their joints (O'Leary, Shoor, Lorig & Holman, 1988). It was also found that patients who believed they could do something about their condition exhibited less depression and less stress.

A 4-year follow-up study was done in the same groups. The results of the study revealed that the effects of the program had either persisted or increased. It was also revealed that there was a 20% reduction in pain and a 40% reduction in physician visits.

Additionally, it was found that during the four years, perceived self-efficacy increased by 29% (Holman, Mazonson & Lorig, 1989).

The results of these studies indicate that health education for self-management utilizing self-efficacy theory, resulted in reduction in pain, depression, and health care utilization while improving patients' physical and social activities (Holman, Mazonson & Lorig, 1989). However, the precise mechanism whereby perceived self-efficacy exerts its effect on patients with other chronic diseases is unknown. In addition, the extent to which this peer model is applicable to a much sicker population remains to be tested.

Social and Emotional Support

Several studies have provided evidence that social relationships are important predictors of morbidity and mortality in patients with CAD (Berkman, Leo-Summer & Horwitz, 1992; Case, Moss, Case, McDermott & Eberly, 1992). However, relatively little attention has been focused on the prognostic importance of these factors in patients with HF.

Krumholz et al. (1998) studied a sample of hospitalized HF patients and performed a comprehensive assessment of psychosocial support in these patients. They found that patients with no social ties had a higher rate of cardiovascular (CV) events than those with ties (p= 0.1) with a more-than-twofold increase in risk of events. This increased risk appeared to be independent of emotional support.

The absence of emotional support was also found to be a strong predictor of cardiovascular events. Patients without emotional support had a more-than-threefold odds ratio of an event in the year after admission compared with patients with emotional support (odds ratio, 2.4; 95% confidence interval, 1.1 to 4.9). Interestingly, this finding

between emotional support and cardiovascular events was very strong in women but absent in men (p=0.01) where the odds ratio for women was 8.2 (95% confidence interval, 2.5 to 27.2) compared with 1.0 (95% confidence interval, 0.3 to 3.3) for men (Krumholz et al., 1998) This association requires further study, however, Krumholz and colleagues (1998) hypothesize that it is possible that there is greater patient adherence to medical therapy and lifestyle recommendations when patients have emotional support.

Other studies have addressed social support in older women with heart failure. Friedman and King (1994) reported in a study of 80 women aged 55 to 92 years, that emotional support was directly related to positive affect and satisfaction with life, but did not buffer the impact of symptom severity on psychological well-being. In addition, they found that another type of support, such as tangible support, affect well-being in situations where the type of support was particularly salient. For example, if a woman received assistance in the home with activities of daily living, and reduced her worry, this tangible support was shown to be psychologically beneficial.

Another study by Friedman (1997) reported that older women with heart failure who lost support sources replaced those sources with other support sources. This suggests that older women attempt to maintain continuity in their social interactions with others. According to Friedman (1997), women that lost support sources experienced more depressed affect and should be assessed for their psychological well-being.

The only qualitative study found was done by Martensson, Karlsson, and Fridlund (1998). They used a phenomenological approach that examined aspects of how female patients conceived their life situation with HF. Their results suggested that a sense of limitation regarding working capacity and being able to support those in their

surroundings caused a great deal of anxiety in the women due to feelings of worthlessness.

Low social support also seems to be associated with increased morbidity and mortality, especially in women (Friedman & King, 1994; Friedman, 1997; Martensson, Karlsson & Fridlund, 1998). In addition, these studies have shown that women who did not have emotional support experienced more depression and that social support also plays an important role in the patient's perception of quality of life.

Depression

Heart failure is a chronic illness that imposes considerable stress on patients and their spouses. As a result, patients with HF have reported increased depression and anxiety (Williams et al., 1998; Havranek, Ware & Lowes, 1999; Hawthorne & Hixon, 1994; Dracup, Walden, Stevenson & Brecht, 1992). Depression has also been found to impede patient adherence to medical therapies, and that failure to adhere could presumably be related to increased risk of developing HF and/or worse outcomes (DiMatteo, Lepper & Croghan, 2000). To date, there is extensive literature that addresses the relationships of depression and coronary heart disease (CHD), but there are only few studies that have looked at depression in HF patients despite its possible effect on outcomes.

A study done by Havranek, Ware, and Lowes (1999) addressed the prevalence of depression in HF. The sample was comprised of 45 HF subjects from a cardiology clinic and 31 control subjects who were being treated for hypertension in the medical clinics. The mean age for the HF subjects was 54 and 58 for the controls. They administered the Center for Epidemiological Studies Depression Scale (CES-D) and found that HF

patients had higher CES-D scores than control subjects (CES-D score 12.0 ± 9.7 vs. 7.3 ±6.4, respectively; p=0.036).

The most recent study done was a large prospective, population-based study spanning 14 years (Williams et al., 2002). The study was based on data from the Yale Health and Aging Project (YHAP) which is one of the four cohorts of the Established Population for Epidemiological Studies of the Elderly (EPESE) program conducted by the National Institute on Aging. After excluding approximately 300 patients who met the study's definition of preexisting heart failure, the total study population was comprised of 1169 men and 1643 women. The average age was 74. The subjects were recruited from socially and ethnically diverse persons of public and private housing. Depressive symptoms were measured by means of the CES-D. The cut point on the CES-D on this study was a score of ≥21 which denoted "clinical depression" in these subjects. Follow-up time on average was 14 years from 1982 to 1996.

In this population, depressed persons were found to be hypertensive, diabetic, and to have mobility-related functional limitation. Depressed persons were also significantly less likely to be men. At baseline, there were 5.3% (n=56) men who were depressed versus 9.0% (132) women who were depressed. Depressed persons were also significantly less likely to be married and had significantly fewer years of education (Williams et al., 2002). Additionally, a CES-D score ≥21 was also found to be a significant risk factor for incident HF (hazard ratio [HR]=1.69, 95% CI = 1.19, 2.39), and those subjects were more likely to be hospitalized with HF (HR=1.65, 95% CI = 1.02, 2.67. Furthermore, depression was significantly associated with an increased risk of HF in women (HR=1.96, 95% CI = 1.11, 3.46) but not men (HR=0.62, 95% CI = 0.23, 1.71).

Interestingly, this study found that race and social support were neither a significant predictor of HF nor a confounder of the association between depression and HF incidence.

Other previous studies of depression in patients with HF are few. Information found on this topic is found in several studies that measure quality of life, where most HF patients were awaiting heart transplantation. However, these studies may not be applicable to the larger population of HF patients because of the potential selection bias inherent in listing patients for transplant (Havranek, Ware & Lowes, 1999).

Health Care Utilization

Almost all invasive cardiac procedures, most commonly cardiac catheterization, were done twice as often in male patients (7%) than in women (4%) during hospitalizations for heart failure. Several studies have found that women undergoing coronary revascularization have a higher risk of hospital mortality in spite of having better left ventricular ejection fraction (LVEF) (Fisher et al. 1982; Kelsey et al., 1993; O'Connor et al., 1993; Loop et al. 1983). According to the National Heart, Lung, and Blood Institute (NHLBI) coronary angioplasty registry, women who underwent a procedure had a significantly higher mortality than men (Kelsey et al., 1993). Women who underwent CABG had an increased risk of death caused by HF (O'Connor et al., 1993). Furthermore, of those women who underwent CABG, only a small percentage of women (20%) undergo heart transplantation and it has also been reported that when presented with this option, women often decline (Kaye, 1994; Aaronson, Schwartz, Goin, & Mancini, 1995).

The most common non-invasive procedure for women was an echocardiogram (5.5%) (Haldeman, Croft, Giles, & Rashidee, 1999). Both black and white women were less likely to undergo ventriculography, Holter monitoring, and exercise stress testing (Haldeman, Rashidee, & Horswell, 1998).

Philbin and DiSalvo (1998) reported race and gender to be important determinants of lengths of hospital stay, hospital charges, and readmission rates. Hospitalizations have been shown to be higher in women than men and that more women were more likely to require assistance upon discharge. Each year from 1985 to 1995, the number of women hospitalized with HF was higher than for men (Haldeman, Croft, Giles & Rashidee, 1999). Additionally, in 1995, there was a greater proportion of older women patients than older men (85% and 78%, respectively), with the government paying for the hospitalization in 86% of the women patients. Furthermore, women were more likely than men to be discharged to a long-term care facility (21% versus 12%), respectively) (Haldeman, Croft, Giles & Rashidee, 1999). Heart failure admissions were also more frequent in women than in men in the Framingham study. In 1989, there were 8 hospital admissions with the discharge diagnosis of HF per 1000 women, and 6.8 per 1000 in men (Ho, Pinsky, Kannel & Levy, 1993). These frequent hospitalizations in women may be attributed to greater numbers and frequency of symptoms. Women tend to suffer more severe HF symptoms such as unstable angina, fatigue, shortness of breath, dyspnea on exertion, and edema. This high symptom impact can be translated to decreased functional capacity, thus greater functional disability, and lower exercise tolerance. Minority groups were also more likely to be hospitalized and have frequent readmissions. This, perhaps, is related to the differences in socioeconomic and cultural factors, as well as differences in

access to care. Furthermore, groups of lower socioeconomic status have been found to have greater symptom impact and psychological distress.

Review of the Literature on Heart Failure Self-Management Behaviors

Self-management is typically referred to as the patient assuming preventive or therapeutic health care activities in collaboration with a health care professional. It includes a set of skilled behaviors an individual engages in to manage his or her own illness. It also involves a cognitive decision making process undertaken in response to signs and symptoms (Goodall & Halford, 1991; Riegel, Carlson & Glaser, 2000). For patients with HF, self-management may include monitoring changes in symptoms such as fatigue and shortness of breath, as well as performing tasks such as taking their daily body weights, and knowing when to report the changes to a health care provider (Dunbar, Jacobson & Deaton, 1998). In general, self-management includes three major phases: (1) symptom monitoring, (2) symptom interpretation, and (3) treatment adjustments for early intervention in symptom management.

The role of patient self-management assumes increasing importance, especially in HF, since several studies have suggested that there are factors that contribute to the high health care costs that are preventable through improved self-management (Lorig, Lubeck, Kraines, Seleznick & Holman, 1985; Lorig & Holman, 1989; Goodall & Halford, 1991; Zimmerman, Brown & Bowman, 1996; Lorig, et al., 1999). These factors include inadequacies in patient and care-giver education of symptom self-assessment and management skills, discharge planning and follow-up, instruction and guidance, and non-adherence to diet, medications, and activity regimens (Vinson, Rich, Sperry, Shah & McNamara, 1990; Happ, Naylor & Roe-Prior, 1997; Dracup et al., 1994; Rich et al.,

1993). In a review of the self-management literature, the most common studies utilizing self-management as a variable were those done in other chronic diseases such as arthritis, diabetes, asthma, and chronic obstructive pulmonary disease. To date, no studies have addressed self-management in the HF population, and few studies address the indigent population and minority groups. These studies will be reviewed below.

A study by Ni and colleagues (1999) was done to assess the level of knowledge of heart failure and adherence to self-care and to determine associated factors (Ni et al., 1999). They conducted a needs-assessment survey among new patients (N=113) visiting a heart failure clinic to assess how much information they received, how much the patients knew about HF, and their adherence to their treatment regimen. The results of their study revealed that a majority of patients in a heart failure clinic did receive self-care information and advice from health care providers, yet as many as 40% of patients reported knowing little or nothing about HF which suggests a wide gap between receiving and retaining the information. Furthermore, they found that patients with HF had poor adherence to self-care recommendations. This important finding suggests that information alone does not correspond to knowledge or ensure changes in self-care behavior or self-care compliance. Another important finding of the study was that patients who were not married had lower perceived self-efficacy, lacked knowledge of self-care, and those who had no prior hospitalization had lower adherence behavior scores (Ni et al., 1999).

A qualitative study utilizing focus groups was done to describe symptoms and self-care strategies (Bennett, Cordes, Westmoreland, Castro & Donnelly, 2000). This study was done to describe the patients' symptoms, as well as to detail the self-care

strategies used by these patients (n=23, 16 men and 7 women). The most common symptoms found in this group of patients were shortness of breath, swelling of their legs, decreases in concentration, tiredness, chest pain, and trouble sleeping. The authors also reported that women reported emotional symptoms of fear, depression, and sadness more often. In terms of self-care management strategies, many reported changes in activity based on symptoms, breathing assistance measures, medication management, and adherence to a sodium-restricted diet. Many of the subjects who participated in a heart failure clinic reported monitoring their signs and symptoms as a primary strategy. In addition, most of these patients, reported daily weight-taking, edema assessment, and home blood pressure monitoring.

Jaarsma and colleagues (2000) studied the effects of education and support on self-care abilities and self-care behavior, as well as the barriers related to self-care behavior, and how these relate to resource utilization and quality of life (Jaarsma et al., 2000). In this study, patients were randomized to either a control group (usual care) or an intervention group (N=179, mean age=73, 57% men). The intervention group received extra education and support from a nurse guided by a standard nursing care plan during the hospital stay and up to 10 days after discharge. Most patients in the intervention group received an average of 4 visits in the hospital, one telephone call and one home visit. Data was collected at baseline, 1 month, 3 months, and 9 months. They concluded that a supportive educational intervention is effective in enhancing self-care behaviors after hospitalizations. Both groups reported significantly higher self-care behaviors at one month after discharge compared with the baseline scores ($t=6.1$, $p<0.001$, $t=11.4$, $p<0.001$), but self-care behaviors in both groups also decreased over time. Furthermore,

the intervention group still reported complying with more behaviors than control patients at 3 months (12.2 vs. 10.6, t=2.9, p=0.005) but not at 9 months (11.2 vs. 10.3, t=1.6, p=0.11).

A descriptive study by Carlson, Riegel, and Moser (2001) was done to describe self-care behaviors of patients with HF and the difficulties they faced when practicing in self-care. The sample (n=139) were mostly elderly men, retired, unmarried, and earning less than $20,000 annually. Patients were asked about self-care behaviors utilizing the Self-Management of Heart Failure questionnaire. Results of this study revealed that patients had difficulty recognizing symptoms and that recognizing the symptoms importance was evident. In addition, among patients who did experience symptoms, it was found that the more experienced patient was more apt to perform self-care behaviors such as limiting their salt intake, adjusting their diuretic dose, and resting. Self-efficacy to perform self-care was also assessed in this study. The authors found that confidence in recognizing signs and symptoms of HF improved with experience, however, less than half of the group (45.7%) felt confident in their ability to take action to relieve symptoms, and 20% expressed no confidence in their ability to do something to relieve their symptoms. Furthermore, more than half of the patients reported little or no confidence in their ability to evaluate their actions. There were no differences by duration of diagnosis. This study suggests that self-care in HF patients is challenging. Overall, it was found that many patients had misperceptions of troublesome symptoms with many making incorrect judgments regarding their symptoms. Again, this study emphasizes the importance of identifying barriers to self-care in order to provide directions for teaching patients.

Another study by Rockwell and Riegel (2001) utilizing the Self-Management of Heart Failure Instrument was done to identify predictors of self-care in HF patients (Rockwell & Riegel, 2001). The sample (n=209, 51% men and 49% women) used was elderly, predominantly married, had at least a grade school education, and an income less than $20,000. This study revealed that the two predictors of self-care were education and symptom severity. In other words, patients who were better educated were more likely to perform self-care than those who were poorly educated, and that patients with more symptoms had higher self-care scores. A positive association between education and compliance with preventive health care regimens has been found in other studies which have suggested that better-educated persons comply with treatment regimens more consistently (Hayes, Taylor & Sackett, 1979; Burke, Dunbar-Jacob & Hill, 1997). However, this is not to say that less educated persons cannot be taught self-care.

Riegel and Carlson (2002) studied patients' self-care behaviors and potential facilitators and barriers to heart failure self-care. In this study, a sample of 26 patients who were mostly elderly (mean age=74), male (65%), retired, and poor (46% with income level<$20,000) were interviewed on general questions about self-care, support, and hospitalizations. It was found that the common challenges found amongst this group were consistent with other studies such as physical limitations, coping with treatment regimen, lack of knowledge, negative emotions, and other health issues and personal struggles. Patients also stated that they were unable to judge the importance of their symptoms and therefore did not seek assistance. However, learning about HF seemed to facilitate self-care. This study also emphasized the importance of professional support. This type of support appeared to have special meaning and importance to patients.

Another important finding in this elderly, poor group was that most stated they were too preoccupied with major life stresses that their motivation for self-care was decreased. This is important to know since identifying barriers to self-care may facilitate problem-solving.

Artinian, Magnan, Sloan, & Lange (2002) did a descriptive study with predominantly African American males with a mean education level of 11.45 years who reported income levels <$20,000. The purpose of this study was to describe the frequency of performance of self-care behaviors, describe the personal and environmental factors that affect self-care, and the relationships of knowledge and self-care. The authors found that the most frequently performed self-care behaviors were related to taking prescribed medications. The least performed behaviors were those concerning symptom monitoring and symptom management. Additionally, there were several relationships found between sociodemographic factors and specific self-care behaviors. It was found that African Americans were more consistent in seeking medical assistance, but whites were consistent in managing their medicating regimen. Non-married patients were more likely to rest during shortness of breath and those that lived alone were less likely to ask for help or contact a doctor when they noticed symptoms. There was also a negative relationship between weighing behaviors and shortness of breath. Overall, patients in this sample had low levels of HF knowledge, however, low levels of knowledge did not preclude them from performing self-care.

Artinian, Magnan, Christian, and Lange (2002) performed another study describing the knowledge levels of HF in 123 participants. The sample was mostly male (72%) and African American (74.6%) and very similar to the study previously described.

In this study, the authors revealed that this group had a low level of HF knowledge, however, a majority of the sample (>50%) was able to recognize symptoms of HF, understood recommended alcohol restrictions and reasons for taking diuretics, were able to identify foods high in sodium, and correctly define an advance directive. In addition, they found that higher levels of education were associated with higher knowledge levels (r=.272, p=.002), and being older was associated with lower levels of knowledge (r=-.20, p=0.27). Those persons who were attending a HF clinic or support group also had higher knowledge scores than those who did not.

Most of the studies reviewed above have been descriptive in nature with small to moderate sample sizes. The samples consisted mostly of low-income white males with a couple of studies representing African Americans. In summary, the literature presented reveals that most HF patients have very low levels of HF knowledge and that they have trouble with self-management, especially in areas of symptom monitoring and symptom management. Additionally, it was found that level of education correlated with effectively managing the treatment regimen, including taking medications. Moreover, those who were more symptomatic had higher self-management scores. Gender and racial issues were not well explored, nor differentiated. However, in a study by Bennett, Baker & Huster (1998), women were found to have more emotional symptoms including fear and depression.

These issues are considered limitations to the earlier reports. The previous studies did not include Hispanics, and few included females. They did, however, describe populations of lower socioeconomic status. It is imperative that research include those of other ethnicities, especially Hispanics, since they appear to be the largest growing

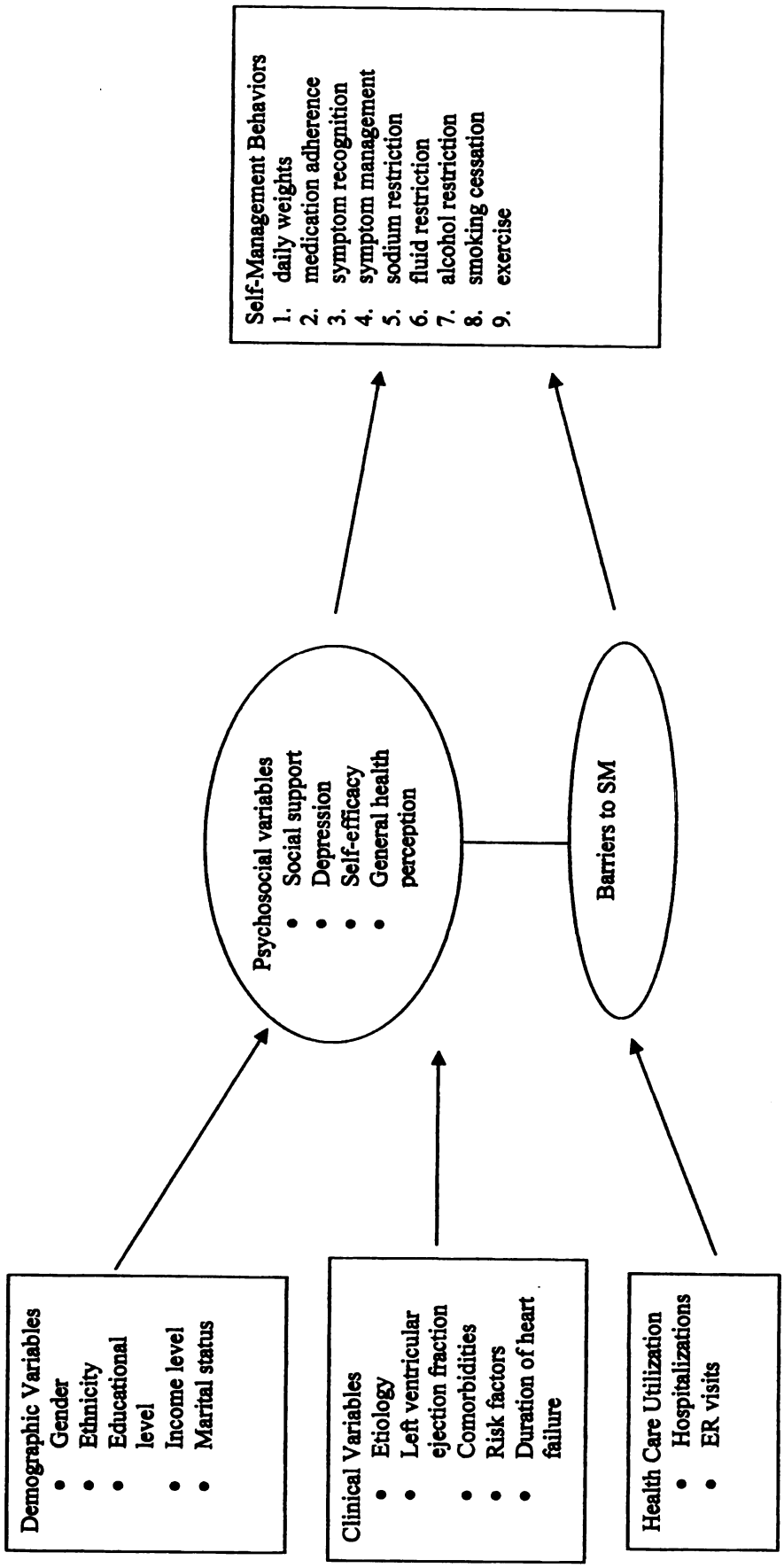
minority group in the U. S. Furthermore, because of the increasing prevalence of women and HF, it is time to include and describe them as well.

Conceptual Framework

Performing self-management behaviors is essential in the successful management of heart failure and the avoidance of the progression and exacerbation of symptoms. However, there are many factors that may improve or impede the performance of these skills. Coping with the challenges of heart failure not only requires knowledge and skills but also the motivation and belief that one can use these skills to produce the desired outcomes such as improvement in their symptoms. Therefore, a central concept in self-management is self-efficacy which is the confidence to carry out certain behaviors necessary to reach a desired goal. There are numerous studies that support Bandura's (1986) contention that self-efficacy is a powerful determinant of behavior and that self-efficacy is a strong predictor of self-care behaviors (Bandura, 1986; Holman & Lorig, 1992; Crabtree, 1986; Godding & Glasgow, 1985; Lorig, Chastain, Ung, Shoor & Holman, 1989; Dilorio, Faherty & Manteuffel, 1992; Lorig et al., 1999).

The conceptual framework shown in Figure 1 represents a model of self-management. This was adapted and modified from Lorig's work and model of self-management which evolved from Bandura's self-efficacy theory to suit the requirements and needs of the present study. Self-efficacy theory states that an individual's perception of ability can affect behavior, level of motivation, thought patterns and emotional reactions in response to exacerbations of disease (Bandura, 1986). In order to prevent the ravages of disease, one must exercise control over one's health habits and environmental conditions that impair physical well-being. Additionally, it also states that enhanced self-

Figure 1: Conceptual Framework



CHAPTER III: RESEARCH DESIGN & METHODS

General Study Design

This was a cross-sectional study design proposed to (1) describe the self-management behaviors of indigent persons with HF with specific interest in clinical and psychosocial variables, as well as their health care utilization; (2) describe and compare the barriers to self-management behaviors; and (3) to determine whether demographic, clinical, psychosocial status, and health care utilization predicts self-management behaviors. A secondary purpose of this study was to determine whether clinical and psychosocial variables as well as health care utilization differ by gender and race.

Sample and Setting

The study population was a convenience sample of women and men who have been identified with a primary or secondary diagnosis of heart failure or cardiomyopathy. Subjects were recruited from the Cardiology clinics of the University Medical Center – Fresno (UMC), Sierra Adult Health Clinic, Cardiovascular Care Consultants Heart Center, and Fresno Community Hospital. Inpatients ready for hospital discharge were recruited, as well as patients who had clinic appointments at any of the above clinic sites.

Sample Size

Description of this sample was a major focus of this study. For feasibility purposes, all patients meeting inclusion criteria who agreed to participate in the study were recruited for a total sample of 65 patients. Data from all four sites were pooled for analyses.

Inclusion/Exclusion Criteria

Inclusion criteria were: (1) women or men patients over the age of 18 with a primary or secondary diagnosis of heart failure or cardiomyopathy diagnosed within the last two years; (2) concurrence of admitting or primary physician to enroll patient; (3) patient alert and oriented; and (4) able to speak, understand, and read English.

Exclusion criteria were patients who are discharged to a long term care facility, and patients whose anticipated survival was less than three months as determined by their primary care physician. Heart failure in children (<18 years) is rare and of different etiology which would require a different conceptualization than adults and, therefore, children were excluded.

Human Subject Assurance

The investigator ensured that the subject was given full and adequate verbal and written information about the nature, purpose, possible risk and benefit of the study. Subjects were free to discontinue their participation in the study at any time. The subjects were given the opportunity to ask questions and time for consideration. Written consent was obtained. Human subject approval was obtained from the Committee on Human Research at the University of California San Francisco and the Community Medical Centers Institutional Review Board in Fresno, California.

Data Collection Procedure and Measurements

Data collection took place over the 6-month period from October 2003 to March 2004. Potential subjects were screened for eligibility by the researcher during scheduled clinic visits or in the patient's hospital room. Eligible patients were given information on

the study and a consent form for participation was signed (Appendix A). Patients identified eligible during their hospital admission were approached just prior to hospital discharge.

Baseline demographical and clinical information were taken from the medical chart and/or the patient during the interview and was documented on the medical abstraction form (Appendix B). Data collection was performed using a structured interview format by the investigator. The questions that were asked during the interview came from the following instruments: (1) a General Health Perception Question, (2) the Self-Efficacy to Perform Self-Management Behaviors Instrument, (3) the ENRICHD Social Support Instrument, (ESSI), (4) the Center for Epidemiological Studies Depression (CES-D) scale; and (5) the Self-Management in Heart Failure Questionnaire. A summary of these instruments are provided in Appendix C. Family members, if present, were also approached to provide additional information. Data collection took approximately 40 to 60 minutes of the respondent's time.

Instruments

Patient Demographics

Age, gender, ethnicity, socioeconomic status as denoted by income level and educational level, insurance carrier classification, social/family history, and other co-morbidities were included in demographics and recorded using a medical record abstraction form. Clinical variables included etiology of HF, ejection fraction (EF) (%), cardiac risk factors, and functional status as measured by the New York Heart Association (NYHA) Functional Classification system were also collected. The NYHA Classification was delineated further in Table 3. Information on signs and symptoms

related to HF such as dyspnea, orthopnea, paroxysmal nocturnal dyspnea, and/or lower extremity edema, as well as information on medications, hospitalizations, and exercise, were recorded using this medical record abstraction form.

Table 3: New York Heart Association (NYHA) Functional Classification

Class I	Patients with cardiac disease without concomitant limitations of physical activity. Ordinary activity does not cause undue fatigue, palpitations, dyspnea, or anginal pain.
Class II	Patients with cardiac disease that results in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitations, dyspnea, or anginal pain.
Class III	Patients with cardiac disease that results in marked limitation of physical activity. They are comfortable at rest. Less than ordinary physical activity causes fatigue, palpitations, dyspnea, or anginal pain.
Class IV	Patients with cardiac disease that results in inability to carry on any physical activity without discomfort. Symptoms of cardiac insufficiency or of the anginal syndrome may be present even at rest. In any physical activity is undertaken, discomfort is increased.

Note. Criteria Committee of the New York Heart Association. *Disease of the heart and blood vessels. Nomenclature and criteria for diagnosis*. 6th ed. Boston: Little, Brown 1984, p. 111-114, 286.

According to the Criteria Committee of the New York Heart Association (1984), NYHA functional class is an approximate estimate of the patient's ability to perform physical activity ranging from an asymptomatic state (Class I) to complete disability (Class IV). However, because the provider infers this information from the history and/or by observation of the patient in certain forms of physical activity, it is considered a subjective measure of function, and thus generally unsupported by objective evaluation. However, despite its obvious flaws, it has served researchers well in a crude categorization of subjects.

Health Perception Question

Health perception refers to personal beliefs and evaluations of general health status and where people see themselves along a continuum of well to unwell, healthy to unhealthy. These perceptions differ from other measures of health in that they are subjective and general rather than focused specifically on one component of health (i.e. physical, mental or social health). Health perception has been demonstrated repeatedly to be a significant predictor of mortality and health care resource use, even after controlling for clinical factors that influence these perceptions (Idler & Kasl, 1991; Connelly, Philbrick, Smith, Kaiser & Wymer, 1989).

The most common method of assessing health perception is through self-report responses to general health questions like: "For your age, in general, would you say your health is excellent, good, fair, poor, or bad?". More objective measures of health perceptions have not been adequate surrogate measures since health perceptions are purely subjective and verifiability is irrelevant (Deaton, Exner, Schron, Riegel, & Prevost, 2001) (Appendix D).

Self- Efficacy to Perform Self-Management Behaviors Questionnaire

Self-efficacy in dealing with heart failure is not only knowing what to do (knowledge) but, rather, it reflects a capability to organize and integrate certain information to perform certain behavioral skills. Self-efficacy to perform self-management behaviors will be measured by using the Self-Efficacy to Perform Self-Management Behaviors Questionnaire (Appendix E). This instrument was derived from the Chronic Disease Self-Management Study (Lorig et al., 1996).

The self-efficacy scales utilized a multi-item Likert scale using multitrait scaling. The authors of the instrument used multitrait scaling analysis because it allowed to test whether the items in the hypothesized efficacy scales were highly related to the parallel behavior or outcome. Furthermore, it provided a confirmatory approach that tests the adequacy of a hypothesized scale structure. They reported that all items in these scales met the criteria of item convergence and item discrimination. All the items in the final self-efficacy scale exceeded 0.50. Reliability for multi-item scales were tested using internal consistency and test-retest methods. Ten day test-retest reliability revealed coefficients for the self-efficacy measures ranging from 0.82 to 0.89, and internal consistency coefficients from 0.77 to 0.92. The validity scores for self-efficacy measures ranged from 0.14 to 0.68, where the largest correlations were between self-efficacy for managing symptoms and managing depression ($r=0.68$). The correlations between the general self-efficacy to manage the disease index and the specific scales ranged from 0.36 to 0.77. The absolute magnitude of correlations for health status measures ranged from 0.14 to 0.90, with the largest correlations between depression and the psychological well-being distress index.

Scoring for the self-efficacy questionnaire was divided into three subscales: (1) self-efficacy to get information about HF; (2) self-efficacy to manage signs and symptoms and (3) self-efficacy to manage the disease in general. Bandura (1995) recommended that individuals rate the strength of their belief for each item on a self-efficacy scale from 0 to 100 or 0 to 10 with 10-unit intervals from 0 (cannot do the behavior); through intermediate degrees of certainty 5 or 50 (moderately sure can do); to complete confidence, 10 or 100 (completely sure can do). For each scale, the mean of the scores of the items were obtained. If more than two items were missing in each section, the value of the score for the scale was set to missing. The numbers were summed and divided by the total number of items to get total scores. The total scores for each scale range from 1 to 10 or 0 to 100, with higher scores indicating greater levels of self-efficacy. Previous research has used a cut point of ≥70% indicating those with greater likelihood to perform a certain behavior.

ENRICHD Social Support Instrument (ESSI)

There have been several studies that report social support as an important predictor of compliance and positive health practices. In addition, the effects of social support has been implicated to decrease hospital readmissions and improve patient outcomes (Hayes, Taylor, & Sackett, 1979; Krumholz et al.1998; Freidman & King, 1994; Hubbard, Muhlenkamp, & Brown, 1984)

Social support was measured using the Enhancing Recovery in Coronary Heart Disease (ENRICHD) Social Support Inventory (ESSI) (Appendix F) (ENRICHD Investigators, 2000; ENRICHD Investigators, 2001). The ESSI was developed to measure perceived emotional support for use in the ENRICHD study. The ENRICHD study was

done to investigate the effects of a psychosocial intervention on depression and/or low social support on survival and reinfarction in patients who were at risk for recurrent cardiac events (ENRICHD Investigators, 2000; ENRICHD Investigators, 2001)

The ESSI consists of 7 items which were developed from scales and items from prior studies that were predictive of acute myocardial infarction (AMI), hence, documenting predictive validity. Response categories ranged from 1 (none of the time) to 5 (all of the time). A score of ≤ 3 on 2 or more of the items and a total score of ≤ 18 suggests low perceived social support (ENRICHD Investigators, 2000; ENRICHD Investigators, 2001)

Cronbach α for the ESSI from the pilot study was 0.86. The ESSI was also shown to have a positive correlation with the Perceived Social Support Scale (Pearson coefficient = 0.62), and with the Inventory of Socially Supported Behaviors (Pearson coefficient = 0.35), and negatively with the Beck Depression Inventory (Pearson coefficient = -0.39).

Center for Epidemiologic Studies Depression (CES-D)

Depression is a condition that causes significant functional limitation in patients with chronic medical conditions and has been associated with a greater risk of heart failure (Williams, Kasl, Heiat, Abramson, Krumholz & Vaccarino, 2002). In addition, depression has also been associated with increasing symptoms, such as fatigue, and increased morbidity and mortality (Havranek, Ware, & Lowes, 1999; Radloff, 1977) Furthermore, in the presence of depressive symptoms, persons are less likely to engage in health promoting activities such as weight monitoring and cardiac rehabilitation. Radloff (1977) states that persons of lower socioeconomic groups report more physical symptoms

while persons of higher socioeconomic groups express depression affectively (Radloff, 1977). The Center for Epidemiological Studies Depression (CES-D) scale is a very well known survey instrument for identifying symptoms of depression. It has been used extensively in large trials and is applicable across age and sociodemographic groups. Furthermore, published norms are available from samples of different socioeconomic and minority groups.

Depressive symptoms was measured using the CES-D scale (Appendix G). The CES-D contains 20 items selected from previously validated scales of depression. These items consist of six components: depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance. Respondents rated how often they experienced symptoms within the last week on a scale of 0 to 3; 0 = "rarely or none of the time", 1 = "some or little of the time", 2 = "occasionally or moderate amount of time", and 3 = "most or all of the time"; except for the four positive questions. The four positive questions (questions 4, 8, 12, and 16) were worded positively to discourage a response set. The scores of these questions were reversed by subtracting the score from 3. The scores for the 20 items were then summed, resulting in potential total score ranging from 0 to 60. If more than four items on the scale were missing, a score was generally not calculated. Although there was no standard cut point for the use of this scale, a cut point of $\geq$16 was considered having depressive symptoms within the last week (Radloff, 1977). Scores used in another research study used a cut point of $\geq$21 to indicate symptom severity that approximated a clinical diagnosis of depression (Williams et al., 2002). When compared with a clinical diagnosis of depression based on DSM-III-R criteria, a score of 21 or more on the CES-D

had a high sensitivity (92%) and specificity (87%) (Lynnes et al., 1997). A score of ≥16 was chosen for this study because it is not a nurse's role to diagnose, but rather to make some assessment of patients experiencing depressive symptoms.

Reliability and validity of the scale have been tested in general and clinical populations, as well as in other ethnic populations and in the elderly, yielding very good internal consistency with an alpha of 0.85 for the general population and 0.90 for a psychiatric population. Convergent validity was supported by significant correlations with other scales that measure depression. Test-retest reliability was satisfactory ranging from 0.51 to 0.67 over a 2- to 8-week period and 0.32 to 0.54 over a 3- to 12-month period (Radloff, 1977).

Self-Management of Heart Failure Questionnaire (SMHF)

The Self-Management of Heart Failure (SMHF) questionnaire was developed to evaluate the self-management behaviors of heart failure patients (Appendix H) (Riegel, Carlson, & Glaser, 2000). *Self-care maintenance* was measured using seven behaviors agreed upon by experts in heart failure as being essential routine necessary behaviors (i.e. monitoring daily weights, low sodium diet, exercise, medication compliance, weight management, prophylactic immunization, and routine medical follow-up). These self-care maintenance items were assessed on a 4-point Likert scale with (1=*never or rarely*; 4=*always*). *Self-care management* was also measured with four subscales: (1) recognition, (2) evaluation of sign/symptom importance, (3) action, and (4) evaluation of treatment effectiveness.

Preliminary testing on the SMHF instrument revealed an alpha coefficient of 0.65 for the *self-care maintenance* scale. However, the behavioral items as described above

were poorly correlated with the medical items such as taking medications and preventive immunizations. Subscale alpha coefficients for the *self-care management* scale were reported according to the four subscales described previously.

In the *recognition* subscale that consisted of 1 item, 94% of the sample had experienced shortness of breath in the past three months. Of these patients, 55.1% failed to recognize it as a symptom of heart failure. Riegel and associates (2000) performed a discriminant function analysis which revealed the ability to recognize shortness of breath and it could also be discriminated by actions, ability to evaluate the effectiveness of treatments, and self-efficacy. In other words, those with poor symptom recognition were those who also failed to take action, had difficulty evaluating treatment effectiveness, and had low self-efficacy (Riegel, Carlson, & Glaser, 2000). The alpha coefficient of the *evaluating importance* subscales was 0.87. The authors also reported that scores on this subscale were poorly related to those on the other subscales. The next subscale, *action*, had five choices (three active items and two passive items). Correlations among the five choices were moderate (0.40 to 0.57). The three active choices were then evaluated as a subscale and the alpha coefficient for this subscale was 0.70. In the *evaluation* subscale, only 15.2% of respondents were unable to evaluate the effectiveness of their actions.

These preliminary analyses of the internal consistency of the SMHF instrument was adequate and supported further use. However, since the original development of the SMHF, it has been revised by the authors (Reigel, Carlson, Moser & Sheposh, 2001). The revised version of the SMHF had a total of 22 items evaluated on a 4-point response scale. In a pilot test with a sample of 97 patients, this revised scale had an alpha coefficient of 0.60. Factor analysis revealed two factors explaining 50.2% of the variance

in self-care maintenance: health behaviors (29.7% of the variance) and medication compliance (20.5% of the variance). The alpha coefficient of the health behaviors was alpha =0.65. Preliminary validity testing on this instrument was done using discriminant validity and concurrent validity testing.

Discriminant validity testing showed that patients who readily recognized shortness of breath (SOB) (n=31) were significantly more likely to implement a treatment (p=.004) and higher self-efficacy (p=.008) than those who failed to recognize the symptoms (n=48).

Concurrent validity testing was done also using discriminate analysis to determine how decision-making abilities of HF patients predicted self-management behaviors. Self-management scores ranged from 4.43 to 19 out of a total possible score of 20. Those who found decision-making easiest (n=16) had the highest scores (mean 13.2±1.83). Patients who found decision making most difficult (n=45) had scores of 11.1±3.35 on average (Riegel, Carlson, Moser & Sheposh, 2001)

Additionally, the SMHF questionnaire was also further revised for the purpose of this study. As a result of these modifications, information on the scoring of the modified SMHF for this study was non-existent. Hence, a cut point was created based on the median of the total scores of the subscales. Due to the ease and recent update of the SMHF, it will be used in this study to further validate its effectiveness in measuring self-care behaviors of heart failure patients (Riegel, Carlson, Moser, & Sheposh, 2001).

Data Management

All materials were labeled with identification numbers and placed in individual folders. All subjects were given an identification number which were recoded on their

data collection forms to assure the correct information was linked with the appropriate subject, in case the forms became accidentally separated. The data from the instruments were coded numerically and entered into an SPSS program file. Labeled data was entered by the researcher and then verified by the researcher a second time to confirm that the data was entered correctly. Subject data was kept in a locked cabinet and was only be accessible to the student and dissertation adviser.

Data Analysis

The Statistical Package for the Social Sciences (SPSS) Version 11 (Chicago, Illinois) was used for data management and analysis (Statistical Package for the Social Sciences). Descriptive statistics were used to evaluate all data and were expressed as mean values, standard deviations, medians, ranges for continuous variables, and frequencies for dichotomous and nominal variables. Chi- square test was used to describe in proportions of all categorical and nominal variables. To investigate the associations between variables and self-management behaviors, we used all variables with a $p<.30$ as candidate variables and entered these in a multiple logistic regression model. Odds ratio with 95% confidence intervals were reported for all independent variables with respect to self-management behaviors treated as the dependent variable.. The level of statistical significance was set at $p<0.05$.

AIM 1.

Describe the demographic profile, clinical and psychosocial factors, health care utilization, and the self-management behavior of indigent HF subjects.

Descriptive statistics including frequency distributions, measures of central tendency (means, medians, and modes), and measures of dispersion (ranges, quartiles, standard deviations) were used to accomplish this objective.

AIM 2.

Describe the challenges, difficulties, and barriers that subjects with HF experience in performing self-management behaviors.

The following descriptive statistics were used: frequency distributions, measures of central tendency (means, medians, and modes), and measures of dispersion (ranges, quartiles, standard deviations) were used to accomplish this objective.

AIM 3.

Examine the relationships among the above variables and determine whether demographic, clinical, psychosocial status, predicts the subjects' self-management behaviors and health care utilization.

Analysis of covariance, using baseline demographic, clinical, psychosocial status and health care utilization as covariates, was used to examine the effects of these variables on the dependent variable (HF self-management behaviors).To estimate the predictive value of the independent variables for HF self-management behaviors, logistic regression was used to estimate the independent contribution from among a set of variables. Logistic regression analyzed the relationships between multiple independent variables (continuous and dichotomous) and the categorical dependent variable, self-management behaviors (Munro, 1997). Furthermore, logistic regression models was used to estimate the odds ratio and 95% confidence interval for the independent effects of a set

of potential predictor variables such as social support, depression, self-efficacy, and health perception with the performance of self-management behaviors.

Secondary purposes are to:

(a) Describe and compare differences for objectives 1 to 3 by gender and race.

The objective of the first secondary aim was to describe and compare men and women with respect to the above study aims 1-3. T-tests were used to detect differences between the groups. Gender and race was used as the independent variables for the t-test. Self-management behavior was used for the dependent variable. Significance for the *p* value was set at 0.05 for all statistical tests.

Chapter IV: ANALYSIS AND RESULTS

Data were collected from 65 subjects between October 2003 and March 2004 from three cardiology clinics and one hospital in Central California. All analyses were conducted with SPSS version 11.

Analysis to Aim 1

To answer Aim 1 of this study, data was collected to *describe the demographic profile, clinical and psychosocial factors, health care utilization and self-management behaviors of indigent HF subjects.* Descriptive statistics for demographics, clinical risk factors and heart failure characteristics, health care utilization and self-management behaviors for the total sample of 65 are presented. Chi-square tests were used to describe in proportions of all categorical and nominal variables.

Demographic Characteristics

Demographic data are described in Table 4. Of the total sample (N=65), there were 55% women and 45% men. Of those 65% were white and 35% were non-Whites which included African Americans, Asians, and other. The ages ranged from 27 to 90 years old with a mean (SD) age of 59(±14).

Over half of the sample (57%) had a high school education or less. Of those, 64% were women and 48% were men. Sixty-two per cent of Whites had less than a high school education as compared to 48% of non-Whites. Forty-three per cent of the sample reported having at least some college education, and of those 36% were women and 52% were men; 38% of Whites and 52% of non-Whites.

Table 4: Gender and Racial Differences in Characteristics of Participants

CHARACTERISTICS	TOTAL % (N)	FEMALES % (n)	MALES % (n)	WHITE % (n)	NON-WHITES % (n)
	100 (65)	**55 (36)**	**45 (29)**	**65 (42)**	**35 (23)**
Age					
<65	72 (47)	69 (25)	76 (22)	71 (30)	74 (17)
≥65	28 (18)	31 (11)	24 (7)	29 (12)	26 (6)
Education					
≤HS Education	57 (37)	64 (23)	48 (14)	62 (26)	48 (11)
Some college or more	43 (28)	36 (13)	52 (15)	38 (16)	52 (12)
Unemployed	86 (56)	75 (27)	100 (29)	90 (38)	78 (18)
Living Alone‡	56 (36)	69 (25)	39 (11)	57 (24)	55 (12)
Annual income					
≤$10,000	56 (36)	69 (24)	41 (12)	50 (21)	68 (15)
>$10,000	44 (28)	32 (11)	59 (17)	50 (21)	32 (7)
Insurance Type					
Medicare	32 (21)	36 (13)	28 (8)	33 (14)	30 (7)
Medicaid	26 (17)	28 (10)	24 (7)	21 (9)	35 (8)
None	26 (17)	25 (9)	28 (8)	24 (10)	30 (7)
Other (Private)	15 (10)	11 (4)	21 (6)	21 (9)	4 (1)

Note. ‡ Living alone is not reported for 1

Overall, 56% reported living alone. Of those, more women than men were living alone (69% vs. 39%, respectively). There were no significant differences in Whites and non-Whites living alone (57% vs. 55%, respectively).

Eighty-six per cent of the total sample reported being unemployed with 75% of those being women compared with 100% of those being men. More Whites reported being unemployed than non-Whites (90% vs. 78%, respectively). Thus, over half (56%) reported having annual incomes of less than $10,000 and 44% reported incomes >$10,000 annually. More women (69%) and non-Whites (68%) reported income levels of <$10,000 than men (41%) and Whites (50%).

Of the total sample, 52% had either Medicaid or were uninsured. 32% had Medicare and 15% had some form of private insurance such as Blue Cross or HealthNet. Of those, there were more non-Whites (65%) who had Medicaid or were uninsured when compared to Whites (45%).

Clinical Risk Factors

Clinical risk factors for the sample were also obtained and described in detail in Table 5. Of the total sample, 7.7% reported drinking alcohol with the majority being men comprising 14% but only one woman (3%). Twenty per cent reported using tobacco with a majority being men (27.6%). One man and one woman reported using illicit drugs (3.1%). More non-Whites than Whites reported using alcohol, tobacco, and illicit drugs (9% vs. 7%; 22% vs. 19%; 4% vs. 2%, respectively).

Of the total sample, 46% were diabetic, with more women (64%) than men (24%) being diabetic and more Whites than non-Whites (48% vs. 44%, respectively). Seventy-seven percent of the total sample reported having HTN. Of those, 75% were women and

79% were men and 83% were non-White. Almost half of the subjects (49%) reported having had a myocardial infraction (MI) with more males and Whites (59% vs. 62%, respectively) than women and non-whites (42% vs. 26%, respectively). Twenty three percent of subjects reported having hyperlipidemia. Of those, 28% were women and 26% were non-Whites as compared to 17% men and 21% Whites.

When asked if the subject adhered to a special diet, 38% stated they did. Of those who adhered to a diet, 19% maintained a low sodium diet, 11% maintained a low cholesterol diet, and 9% maintained a diabetic diet. Some form of daily exercise was performed by 42% of the sample and only one woman had received any formal cardiac rehabilitation and no men.

There were numerous other comorbidities associated with this sample as described in Table 5. However, of note, 29% had asthma, 22% had chronic obstructive pulmonary disease (COPD), and 12% had renal disease.

When asked about any prior cardiac procedures or surgeries, only 33% of the total sample had either percutaneous transluminal coronary angioplasty (PTCA)/ stent placement or coronary artery bypass graft surgery (CABG). Among those who had any procedures or surgeries, 22% of women had a PTCA/stent and 26% of Whites versus only 14% of males and 4% of non-Whites. Additionally, more males than females (17% vs. 11%, respectively) and more Whites than non-Whites (17% vs. 9%, respectively) had cardiac surgery.

Table 5: Gender and Racial Differences in Clinical Risk Factors

	TOTAL % (N) 100 (65)	**FEMALE % (n) 55 (36)**	**MALE % (n) 45 (29)**	**WHITES % (n) 65 (42)**	**NON-WHITES % (n) 35 (23)**
CARDIAC RISK FACTORS					
Alcohol	8 (5)	3 (1)	14 (4)	7 (3)	9 (2)
Tobacco	20 (13)	14 (5)	28 (8)	19 (8)	22 (5)
Drugs	3 (2)	3 (1)	3 (1)	2 (1)	4 (1)
Diabetes	46 (30)	64 (23)*	24 (7)*	48 (20)	44 (10)
HTN	77 (50)	75 (27)	79 (23)	74 (31)	83 (19)
MI	49 (32)	42 (15)	59 (17)	62 (26)**	26 (6)**
Angina	19 (12)	19 (7)	17 (5)	19 (8)	17 (4)
Hyperlipidemia	23 (15)	28 (10)	17 (5)	21 (9)	26 (6)
DIET ADHERENCE	38 (25)	39 (14)	38 (11)	38 (16)	39 (9)
Low-Sodium	19 (12)	36 (5)	64 (7)	38 (6)	67 (6)
Low Cholesterol	11 (7)	21 (3)	36 (4)	25 (4)	33 (3)
Diabetic	9 (6)	17 (6)	0	38 (6)	0
EXERCISE	42 (27)	44 (16)	38 (11)	36 (15)	52 (12)
CARDIAC REHAB	2 (1)	3(1)	0	2 (1)	0
COMORBIDITIES					
Asthma	29 (19)	36 (13)	21 (6)	21 (9)	44 (10)
COPD	22 (14)	25 (9)	17 (5)	24 (10)	17 (4)
PVD	8 (5)	6 (2)	10 (3)	10 (4)	4 (1)
Renal Disease	12 (8)	17 (6)	7 (2)	12 (5)	13 (3)
Thyroid Disease	6 (4)	11 (4)	0	5 (2)	9 (2)
Valvular Disease	11 (7)	11 (4)	10 (3)	10 (4)	13 (3)
PROCEDURES					
PTCA/Stent	19(12)	22 (8)	14 (4)	26 (11)†	4 (1)†
CABG	14 (9)	11 (4)	17 (5)	17 (7)	9 (2)
Pacemaker	3 (2)	0	7 (2)	5 (2)	0

Note. HTN=Hypertension; COPD=Chronic Obstructive Pulmonary Disease; MI=Myocardial Infarction; PVD= Peripheral Vascular Disease; PTCA=Percutaneous transluminal coronary angioplasty; CABG=coronary artery bypass graft surgery

* p=.002; ** p=.009; † p=.04

Heart Failure Characteristics

Heart failure characteristics are described in detail in Table 6. Of the total sample, 25% were diagnosed with heart failure (HF) within the last year; 12% had HF for 1-2 years, 35% had HF for 2-5 years and 26% had HF for more than 5 years.

A majority of the sample (45%) had ischemia as the etiology for their HF and 40% had either nonischemic reasons or HTN. Other etiologies of HF were drugs, chemotherapy, or peri-partum cardiomyopathy which comprised 15% of the total sample. There were less women than men who had ischemia as the etiology of their HF (39% vs. 52%). In addition, Whites were more likely to have an ischemic etiology for their HF (57% vs. 22%, respectively).

Ejection fractions (EF) of less than 20% were seen in 14% of the total sample with 59% having an EF between 20-40% and 27% having an EF between 40-45%. When comparing women to men, it appeared they had similar distributions of EFs but more males (21%) had EFs of less than 20%. Furthermore, more non-Whites had EFs of <20% when compared to Whites (17% vs. 12%, respectively). New York Heart Association Functional Classifications (NYHA) were obtained and a majority of the sample (60%) were classified as Class III – IV with more women than men in those classes (64% vs. 56% respectively). Whites and non-Whites had similar distributions in NYHA class (60% vs. 61%).

Table 6: Gender and Racial Differences in Heart Failure Characteristics

	TOTAL % (N) 100 (65)	FEMALE % (n) 56 (36)	MALE % (n) 44 (29)	WHITES % (n) 65 (42)	NON-WHITES % (n) 35 (23)
DURATION OF HF[a]					
<6 months	22 (14)	22 (8)	21 (6)	21 (9)	22 (5)
6-12 months	3 (2)	6(2)	0	0	9 (2)
1-2 years	12 (8)	14 (5)	10 (3)	17 (7)	4 (1)
2-5 years	35 (23)	39 (14)	31 (9)	36 (15)	35 (8)
>5 years	26 (17)	17 (6)	38 (11)	26 (11)	26 (6)
ETIOLOGY					
Ischemic	45 (29)	39 (14)	52 (15)	57 (24)	22 (5)
Non-ischemic	8 (5)	6 (2)	10 (3)	7 (3)	9 (2)
HTN	26 (17)	33 (12)	17 (5)	21 (9)	35 (8)
Idiopathic	5 (3)	6 (2)	3 (1)	5 (2)	4 (1)
Valvular	2 (1)	3 (1)	0	0	4 (1)
Other	15 (10)	14 (5)	17 (5)	10 (4)	26 (6)
EF[a]					
<10%	5 (3)	3 (1)	7 (2)	5 (2)	4 (1)
11-20%	9 (6)	6 (2)	14 (4)	7 (3)	13 (3)
21-30%	34 (22)	36 (13)	32 (9)	29 (12)	44 (10)
31-40%	25 (16)	25 (9)	25 (7)	27 (11)	22 (5)
40-45%	27 (17)	31 (11)	21 (6)	32 (13)	17 (4)
NYHA CLASS					
I	5 (3)	0	10 (3)	5 (2)	4 (1)
II	35 (23)	36 (13)	35 (10)	36 (15)	35 (8)
III	37 (24)	39 (14)	35 (10)	31 (13)	48 (11)
IV	23 (15)	25 (9)	21 (6)	29 (12)	13 (3)

Medication Usage

A list of medications were obtained either during the interview or from the medical record. Detailed information on medications are listed in Table 7. Of the total sample, 67% were prescribed angiotensin converting enzyme-inhibitors (ACE-I). However, significantly fewer women were prescribed ACE-I when compared to men (56% vs. 82%). Furthermore, only 47% of women were prescribed Beta-blockers as compared with 76% of men. Whites and non-Whites had similar distributions of ACE-Is, however, significantly more Whites than non-Whites were prescribed Beta-blockers (73% vs. 37%, respectively). Of the total sample, 35% took <6 medications per day and 65% took 6 or more medications per day.

Table 7: Gender and Racial Differences with Medication Usage

	TOTAL % (N)	**FEMALE % (n)**	**MALE % (n)**	***p***	**WHITES % (n)**	**NON-WHITES % (n)**	***p***
MEDICATION							
ACE-I	67 (42)	56 (20)	82 (22)	.03	68 (28)	64 (14)	NS
Beta-Blockers	60 (38)	47 (17)	78 (21)	.01	73 (30)	37 (8)	.004
Diuretics	79 (50)	81 (29)	78 (21)	NS	85 (35)	68 (15)	NS
Statins	27 (17)	20 (7)	37 (10)	NS	27 (11)	27 (6)	NS
Digoxin	31 (19)	27 (10)	33 (9)	NS	25 (10)	41 (9)	NS
<6 meds/day[a]	35 (22)	41 (11)	41 (11)	NS	34 (14)	36 (8)	NS
≥6 meds/day[a]	65 (41)	59 (16)	69 (25)	NS	66 (27)	64 (14)	NS

Note. ACE-I=Angiotensin Converting Enzyme Inhibitor; NS= not significant

[a]Total number of medications taken per day (n=63), range=2-16; mean=6.76, SD=2.66

Psychosocial Factors

Several psychosocial factors were studied including health perception, self-efficacy, social support, and depressive symptoms. These measurements were used to answer the aims of this study. A list of the instruments used, including the number of items and range of possible scores were described in Appendix C. These variables were recoded as dichotomous variables and were also examined for relationships to the outcome variable self-management behaviors using logistic regression which will be discussed in detail later.

Health perception

Health perception was assessed by asking subjects to respond to the question, "For your age, in general, would you say your health is excellent, good, fair, poor, or bad?". Of the total sample, only 18% had "good health perception" which means the subjects rated their health as either excellent or good. Eighty two percent of subjects had "poor health perception" whereby subjects rated their health as fair to bad. When comparing gender and racial differences, more men than women (97% vs. 69%, p=.008, respectively) stated they had poor health perception and more non-Whites than Whites had poor health perception (83% vs. 81%, p=NS, respectively). Non-White males appeared to have worse health perception scores (Tables 8 and 9).

Table 8: Gender and Racial Differences in Health Perception

	TOTAL % (N=65)	FEMALES* % (n=36)	MALES* % (n=29)	WHITES** % (n=42)	NON-WHITES** % (n=23)
Good Health Perception (Excellent-Good)	18 (12)	31 (11)	3 (1)	19 (8)	17 (4)
Poor Health Perception (Fair-Bad)	82 (53)	69 (25)	97 (28)	81 (34)	83 (19)

Note. *p=.008; ** p=NS

Table 9: Frequency of Health Perception Categories by Gender and Race

	TOTAL % (N=65)	FEMALE % (n=36)	MALE % (n=29)	WHITES % (n=42)	NON-WHITES % (n=23)
Excellent	2 (1)	3 (1)	0	2 (1)	0
Good	17 (11)	28 (10)	3.4 (1)	17 (7)	17 (4)
Fair	45 (29)	42 (15)	48 (14)	36 (15)	61 (14)
Poor	19 (12)	17 (6)	21 (6)	19 (8)	17 (4)
Bad	19 (12)	11 (4)	28 (8)	26 (11)	4 (1)

Self-Efficacy

Self-efficacy was assessed to determine how confident subjects were in performing certain HF self-management behaviors. In general, subjects felt totally confident (score of 10 in SE range 1-10) in getting information about their HF (45%), recognizing if they've had a change in their weight (48%), breathing (55%), or swelling (59%), taking their medications as prescribed (69%), or asking their provider about things that concern them (59%). Interestingly, 46% of the total sample also felt totally confident about weighing themselves daily despite the low percentages of those who actually performed the behavior of weighing themselves daily (43%). Subjects were less confident in adhering to a low salt diet (37%), exercising at least 3 times a week (26%), exercising without making their symptoms worse (13%), and managing their condition on a regular basis (29%). Women (8%) were less likely to be confident about managing their HF compared to men (0%). Mean scores for each self-efficacy items were also obtained and delineated in Table 10. Self-efficacy to take medications as prescribed had the highest mean (SD) score of 9.16(±1.56). The lowest self-efficacy scores were those that pertained to self-efficacy to exercise at least 3 times per week and self-efficacy to exercise without making their symptoms worse (mean (SD) 5.94(± 3.43) and 5.61(±3.23), respectively). Subjects also reported high self-efficacy in performing HF self-management behaviors such as weighing themselves daily and keeping a low sodium diet (mean (SD) 7.32(±3.19) and mean 7.03(±3.04), respectively).

The instrument also has three subscales: (1) SE to get information about disease, (2) SE to manage signs and symptoms, and (3) SE to manage disease in general. Mean scores for each subscale were obtained by summing the numerical responses and dividing

the total by the number of items contained in each respective scale. A total mean score was then generated by summing up the subscale scores and dividing it by three. Scores for each subscale are shown in Tables 12. The overall total scores for self-efficacy showed a range of 1.49-10, with a mean of 7.78(± 1.79).

Table 10: Means and Standard Deviations on Heart Failure Management Self-Efficacy items

	Mean	SD	Range
SE to get information	7.80	2.75	1-10
SE to recognize a change in weight	7.75	2.80	1-10
SE to recognize a change in breathing or fatigue	8.45	2.42	1-10
SE to recognize swelling	8.57	2.29	1-10
SE to manage HF	6.58	2.35	1-10
SE to talk to MD	8.09	2.35	1-10
SE to ask provider about concerns	8.77	2.08	2-10
SE to take meds as prescribed	9.16	1.56	4-10
SE to weigh self daily	7.32	3.19	1-10
SE to keep a low sodium diet	7.03	3.04	1-10
SE to exercise 3x/week	5.94	3.43	1-10
SE to exercise w/out making sxs worse	5.61	3.23	1-10

Note. SE=Self-efficacy, HF=heart failure; sxs=symptoms; SD=standard deviation

Table 11: Means (SD) for Self-Efficacy Subscale Scores

	Mean	SD	Range
SE to get information about disease	7.80	2.75	1-10
SE to manage signs & Symptoms	8.25	2.11	1.33-10
SE to manage disease in general	7.29	1.72	2.13-10
Self-efficacy total Scores	7.78	1.79	1.49-10

Note. SE=Self-efficacy

To categorize subjects who felt "high self-efficacy" versus "low self-efficacy", a cut point of ≥70% self-efficacy was used to determine if the subject had "high self-efficacy". This cut point was based on previous research (Lorig, Chastain, Ung, Shoor, & Holman, 1989). An analysis of gender and racial differences in those who had high self-efficacy are described in Table 12. Of the total sample, 70% had high self-efficacy with more men than women (71% vs. 69%, respectively). More Whites had high self-efficacy when compared to non-Whites (71% vs. 70%, respectively).

Table 12: Gender and Racial Differences in High and Low Self-Efficacy[a]

	TOTAL % (n)	FEMALE % (n)	MALE % (n)	WHITES % (n)	NON-WHITES % (n)
High Self-Efficacy	70 (45)	69 (25)	71 (20)	71 (29)	70 (16)
Low Self-Efficacy	30 (19)	31 (11)	29 (8)	29 (12)	30 (7)

[a] Based on total scores of ≥70%

Additionally, frequencies on subscale scores ≥70% are also reported in Table 13. Subjects felt more confident in managing their signs and symptoms (82%) than getting information about HF (71%). Furthermore, even lower self-efficacy scores were noted on the subscale "SE to manage disease in general" with only 56% of subjects being classified as having high self-efficacy.

Table 13: Gender and Racial Differences on the Frequency of Self-Efficacy Subscale Scores >70%

	TOTAL % (n)	FEMALE % (n)	MALE % (n)	WHITES % (n)	NON-WHITES % (n)
SE to get information about disease	71 (46)	69 (25)*	72 (21)*	71 (30)	70 (16)
SE to manage signs & symptoms	82 (53)	81 (29)	83 (24)	83 (35)**	78 (18)**
SE to manage disease in general‡	56 (36)	58 (21)	54 (15)	56 (23)	57 (13)
Self-efficacy total scores‡	70 (45)	69 (25)	71 (20)	71 (29)	70 (16)

Note. ‡=Data for N=64; * p=.05; **: p=.01

Social Support

Social support was measured using the ENRICHD Social Support Inventory (ESSI). Social support total scores were based on previous research done with the ESSI that state scores of ≤18 represent low social support (The ENRICHD Investigators, 2001). The mean ESSI score for this sample was 19.7 ± 4.6 (range 6-25) with data available from 64 subjects. As stated previously, 56% were not married or living with a partner. More women (69%) compared to men (39%) were either single, divorced, or widowed. Furthermore, there were no significant differences in Whites and non-Whites who were not married or living with a partner (57% vs. 55%, respectively).Of the total

sample, 83% of subjects were classified as having high social support with no significant differences by gender and race (Table 14).

Table 14: Gender and Racial Differences in Social Support Groups

	TOTAL % (N)	FEMALE % (n)	MALE % (n)	WHITES % (n)	NON-WHITES % (n)
High Social Support	83 (53)	81 (29)	86 (24)	83 (35)	82 (18)
Low Social Support	17 (11)	19 (7)	14 (4)	17 (7)	18 (4)

Depressive Symptoms

Depressive symptoms were measured using the Center for Epidemiologic Studies Depression (CES-D) scale. Subjects rated how often they experienced certain moods and/or behaviors within the last week. Data on 64 subjects are listed on Table 15 including gender and racial differences in scores. Data is also listed based on numbers of subjects who rated a particular mood or behavior occurring most or all of the time (5-7 days).

The scores were calculated based on previous research utilizing a cut point of a score > 16 was considered having depressive symptoms. Of the total sample, the mean CES-D score was 25.2 (± 12.8), range 0-54. The CES-D scores were reported as the proportion below or above a score of 16. Overall, 70% were depressed, men having more depressive symptoms than women (75% vs. 67%, respectively). In addition, non-Whites were found to also have more depressive symptoms when compared to Whites (77% vs. 67%, respectively).

Table 15: Gender and Racial Differences on the Frequency of CES-D Items[a]

	TOTAL N=65 % (N)	FEMALE n=36 % (n)	MALE n=29 % (n)	WHITES % (n)	NON-WHITES % (n)
Bothered by things	34.4 (22)	33 (12)	36 (10)	36 (15)	32 (7)
Did not feel like eating	23 (15)	31 (11)*	14 (4)*	24 (10)	23 (5)
Could not shake off the blues	27 (17)	31 (11)	21 (6)	21 (9)	38 (8)
Just as good as other people	53 (34)	56 (20)	50 (14)	48 (20)	64 (14)
Had trouble keeping mind on what I was doing	23 (15)	28 (10)	18 (5)	24 (10)	23 (5)
Felt depressed	31 (20)	36 (13)	25 (7)	26 (11)	41 (9)
Felt everything was an effort	42 (27)	50 (18)	33 (9)	44 (18)	41 (9)
Felt hopeful about the future	31 (20)	36 (13)	26 (7)	29 (12)	36 (8)
Thought life had been a failure	11 (7)	11 (4)	11 (3)	12 (5)	9 (2)
Felt tearful	22 (14)	31 (11)	11 (3)	17 (7)	32 (7)
Sleep was restless	38 (24)	36 (13)	39 (11)	43 (18)	27 (6)
Was happy	34 (22)	39 (14)**	29 (8)**	36 (15)	32 (7)
Talked less than usual	17 (11)	19 (7)	14 (4)	12(5)	27 (6)
Felt lonely	30 (19)	36 (13)	21 (6)	26 (11)	36 (8)
People were unfriendly	2 (1)	3 (1)	0	2 (1)	0
Enjoyed life	44 (28)	44 (16)	43 (12)	43 (18)	46 (10)
Had crying spells	16 (10)	25 (9)**	4 (1)	12 (5)	23 (5)
Felt sad	25 (16)	36 (13) *	11 (3)*	19 (8)	36 (8)
Felt that people disliked me	6 (4)	11 (4)	0	19 (8)	36 (8)
Could not get going	34 (22)	39 (14)	29 (8)	33 (14)	36 (8)

Note. [a] Percentages on subjects who experienced certain moods and behaviors most or all of the time (5-7 days);

* p=.04; ** p=.05

Gender differences were also reviewed by item level analysis. Significant differences were found between women and men. Women were more likely to not feel like eating (31% vs. 14%, p=.04), have crying spells (25% vs. 4%, p=.05), and feel sad (36% vs. 11%, p=.04), respectively. Women were also found to be happier (39% vs. 29%, p=.05), respectively. Women were more likely to (1) not shake off the blues (31% vs. 21%); (2) have trouble keeping their mind on what they were doing (28% vs. 18%); (3) feel depressed (36% vs. 25%); (4) feel that everything was an effort (53% vs. 29%); (5) feel lonely (36% vs. 21%); and (6) feel they could not get going (39% vs. 29%), respectively, although not significant. Despite women having more depressive symptoms, they also felt more hopeful about the future than men (33% vs. 29%), respectively.

Health Care Utilization

Information on prior emergency department (ED) visits and hospitalizations were also obtained (Table 16). Overall, 63% of the total sample had ≤2 visits to the ED in the prior 12 months, and 37% with more than 2 visits. Three percent of those had more than 10 visits. Of those, more men and Whites (41% vs. 38%, respectively) had > 2 visits to the ED. Of the total sample, 75% had ≤2 hospital admissions in the prior 12 months and 25% had more than 2 visits. More men and non- Whites were hospitalized more frequently (31% and 26%, respectively). Additionally, when subjects were asked who they saw when they had symptoms, 59% of them stated they visited the ED initially.

Table 16: Gender and Racial Differences in Health Care Utilization

	TOTAL % (N) 100 (65)	**FEMALE % (n) 55 (36)**	**MALE % (n) 45 (29)**	**WHITES % (n) 65 (42)**	**NON-WHITES % (n) 35 (23)**
Who do pts. see when they have symptoms?					
PCP	22 (14)	20 (7)	24 (7)	24 (10)	18 (4)
Cardiologist	14 (9)	9 (3)	21 (6)	14 (6)	14 (3)
ED	59 (38)	66 (23)	52 (15)	57 (24)	64 (14)
Other providers	5 (3)	6 (2)	3 (1)	5 (2)	5 (1)
ED Visits					
≤2 visits in the last 12 months	63 (41)	67 (24)	59 (17)	62 (26)	65 (15)
> 2 visits	37 (24)	33 (12)	41 (12)	38 (16)	35 (8)
Hospitalizations					
≤ 2 admissions in the last 12 months	75 (49)	81 (29)	69 (20)	76 (32)	74 (17)
>2 visits	25 (16)	19 (7)	31 (9)	24 (10)	26 (6)

Note. PCP=Primary care provider; ED=Emergency Department

Heart Failure Self-Management Behaviors

Heart failure self-management behaviors were assessed using the revised Self-Management of Heart Failure Questionnaire (SMHF). Subjects were asked how often they performed essential routine behaviors such as monitoring daily weights and adhering to a low salt diet, exercise, and medication regimens (self-care maintenance). Subjects were also asked how worried they would be if they experienced certain HF symptoms (symptom evaluation). Subjects were also asked if they had experienced trouble breathing in the last three months. If subjects did experience trouble breathing, a very common

complaint among HF patients, they were asked what action they performed to alleviate the symptoms and whether or not it helped (treatment implementation).

There were four subscales that incorporated the questions listed above: (1) Self-Care Maintenance; (2) Symptom Evaluation; (3) Treatment Implementation; (4) Treatment evaluation. Responses to the self-care maintenance and symptom evaluation subscales used a 4-point Likert scale. A mean score for each subscale was calculated and then summed for a total self-management behaviors score. Due to the lack of scoring information available for this instrument in its modified version, a cut point ≥14 was used to denote "good self-management" which is the median of the total scores obtained.

The mean for the total self-management behavior score was 12.8 ± 4.17 SD (range 5.29-19). Of the total sample, 46% had good self-management behaviors and 54% had poor self-management. There were no significant differences in gender. However, more Whites performed good self-management when compared to non-Whites (52% vs. 35%, respectively) (Table 17).

Table 17: Gender and Racial Differences in Self-Management Groups

	TOTAL % (N)	**FEMALE % (n)**	**MALE % (n)**	**WHITES % (n)**	**NON-WHITES % (n)**
Good SM	46 (30)	57 (17)	43 (13)	73 (22)	27 (8)
Poor SM	54 (35)	54 (19)	46 (16)	57 (20)	43 (15)

Note. SM=self-management

The dichotomous variables (age, race, marital status, education, insurance, ER visits, hospitalizations, NYHA, diabetes, HTN MI, hyperlipidemia, duration of HF, EF, health perception, self-efficacy, social support, and depression) were used with "good

self-management" and "poor self-management" in 2x2 contingency tables to describe the relationships these variables have on self-management (Appendix H). Surprisingly, the data showed that more subjects who were older (≥65 years) had good self-management compared to younger subjects (<65 years) (61% vs. 40%, respectively). Other findings that were surprising were: (1) those subjects with less education had good self-management behaviors compared to those with greater than a high school education (57% vs. 32%, respectively)); (2) those who had HF ≤ 2 years performed good self-management than those who have had HF for a longer period of time (>2 years) (57% vs. 44%); (3) those with lower EFs (<20%) had good self-management behaviors (56% vs. 44%), (4) those with low social support had better self-management compared to those with high social support (55% vs. 45%, respectively), and (5) those with poor health perception had good self-management compared to those with good health perception (49% vs. 33%). Findings that were more consistent with previous research included: (1) Whites performed good self- management compared to non-Whites (52% vs. 35%); (2) Those that were married had good self-management (46%); (3) those who had less functional disability (NYHA I-II) (58%) had better self-management; (4) those who had high self-efficacy (47%) also had good self-management; and (5) those who were not depressed (58%) had good self-management.

HF self-management behaviors on the Self-Care Maintenance Scale (items 1-7) are described on Table 18. Overall, 43% weighed themselves on a daily basis, 75% adhered to a low salt diet consisting of 2-3 grams per day, 51% of the subjects performed any exercise, and 57% received flu shots each year. Almost all patients reported taking

their medications as prescribed. No significant differences were found with gender and race.

When asked how worried or troubled they would be if they had certain symptoms, 68% said they would be "very worried" if they had trouble breathing, 65% said they would be "very worried" if they had dizziness, and 55% said they would be "very worried" if they had trouble sleeping because of trouble breathing. Only 20% felt very worried if they just didn't feel well. Women were more likely than men to be worried if they had sudden weight gain (42% vs. 28%) and were tired or fatigued (33% vs. 24%) respectively.

Table 18: Gender and racial Differences on the Frequency of HF Self-Management Behaviors

	TOTAL % (N)	**FEMALE % (n)**	**MALE % (n)**	**WHITES % (n)**	**NON-WHITES % (n)**
Weigh Daily	43 (28)	53 (19)	31 (9)	43 (18)	44 (10)
Limit Salt	75 (48)	71 (25)	79 (23)	81 (34)	64 (14)
Exercise	51 (33)	53 (19)	48 (14)	52 (22)	48 (11)
Take Meds	99 (64)	97 (35)	100 (29)	100 (42)	96 (22)
Keep Ideal Weight	48 (31)	56 (20)	39 (11)	50 (21)	46 (10)
Talk to doctors	85 (55)	89 (32)	79 (23)	88 937)	78 (18)
Get Vaccinations	57 (37)	58 (21)	55 (16)	64 (27)	44 (10)

Of the total sample, 71% had trouble breathing in the last three months. Of those who reported they had trouble breathing, there were more women than men (72% vs. 69%, respectively) and more non-Whites compared to Whites (74% vs. 69%, respectively). Of those who had trouble breathing, only 28% immediately recognized it as

a symptom of HF. When asked what actions they performed to alleviate their trouble breathing, only 22% said they reduced their salt intake, 24% reduced their fluid intake, 20% took an extra water pill, and 72% did not do anything. Of those that performed any treatment to alleviate breathing problem, only 20% said it helped them feel better.

A summary of all the psychosocial variables are presented in Table 19. In addition, a summary of how variables were divided are presented in Appendix I.

Table 19: Summary of the Gender and Racial Differences for Psychosocial Variables

	TOTAL % (N) 100 (65)	**FEMALE % (n) 56 (36)**	**MALE % (n) 44 (28)**	**WHITES % (n) 65 (42)**	**NON-WHITES % (n) 35 (23)**
Good Health Perception (Excellent-Fair)	18(12)	31 (11)	3 (1)	19 (8)	17 (4)
Poor Health Perception (Poor-Bad)	82 (53)	69 (25)	97 (28)	81 (34)	83 (19)
High Self-Efficacy (SE)‡	70 (45)	69 (25)	71(20)	71 (29)	70 (16)
Low Self-Efficacy	30 (19)	31 (11)	29(8)	29 (12)	30 (7)
High Social Support‡	83 (53)	81 (29)	86 (24)	83 (35)	82 (18)
Low Social Support	17 (11)	19 (7)	14 (4)	17 (7)	18 (4)
Non-Depressed‡	30 (19)	33 (12)	25 (7)	33(14)	23 (5)
Depressed	70 (45)	67 (24)	75 (21)	67 (28)	77 (17)
Good SM	46 (30)	47 (17)	45 (13)	52 (22)	35 (8)
Poor SM	54 (35)	53 (19)	55 (16)	48 (20)	65 (15)

Note. ‡Data not reported for 1 (n=64); SM=Self-management

Analysis to Aim 2

Barriers and challenges to self-management

A qualitative component was included in the data collection to *describe the challenges, difficulties, and/or barriers subjects' face in performing HF self-management behaviors.* Qualitative data was collected by asking 3 questions: (1) What are the major concerns about your disease? (2) What gets in the way of taking care of yourself? (3) What part(s) of your treatment makes you feel better? These questions were asked during the structured interview and responses were recorded verbatim.

The data was "cleaned" by deleting filler words such as "er", "um,", and "you know". Data was transcribed and searched for themes. The transcribed interviews were analyzed using content analysis methods. Data was put into categories and was placed on a coding sheet. A tallying procedure was used to record the actual number of times a theme occurred across all cases.

Major concerns about the disease

The most common categories that represented the major concerns about HF in this sample included having more heart problems (10/65), i.e. heart attacks, heart failing, breathing difficulties (8/65), getting better (7/65), wanting to live longer (7/65), and death (6/65). Seven subjects commented they did not know what concerns them. Five subjects said "nothing", "not much", concerned them. Medicines were a concern in only 3 subjects.

Barriers to taking care of themselves

Symptoms i.e. fatigue, shortness of breath, hip/back pain (15/65) and living alone/inability to take care of self (6/65) were the most common barriers to taking care of

oneself. Several subjects (5/65) also reported financial challenges like "not having enough money for medications" and "not having the right insurance". Six subjects said "nothing" or "don't know".

Part of treatment that makes them feel better

When asked about treatments that helped them feel better, a majority stated that medications (6/65), including oxygen and nebulizer/breathing treatments (10/65) made the most difference allowing them to breathe better. Additionally, talking to their physicians, getting information about their condition, as well as being in the hospital were the other responses.

Analysis to Answer Aim 3

Relationships between demographic, clinical, and psychosocial variables and HF self-management behaviors

The third aim of this study was to *examine the relationships among the variables described above and to determine whether demographic, clinical, psychosocial factors, and health care utilization predicts self-management behaviors.* Logistic regression was used to estimate the odds that one would perform good self-management behaviors. Certain predictor variables that have been studied in previous research were also used to examine any relationships that may exist between the predictor variables and self-management behaviors in this sample. A total of 19 variables were identified as potential predictor variables (Table 20). These variables were recoded to make them dichotomous variables for analyses. An analysis using 2x2 crosstabs were initially used to identify if each variable was significant. These results were listed in Appendix J. Due to the fact that very few of the potential predictor variables were statistically significant with a $p<.05$,

the criteria for using it as a predictor variable was decreased to a $p<.30$. This allowed for an analysis using 5 predictor variables for the logistic regression model: race, age, education, NYHA classification, and depression (Table 21).

Table 20: Potential Predictor Dependent Variables

Predictor variables entered	Odds Ratio (OR)	95% Confidence Interval (CI)
Race	.48	.17, 1.38
Age	2.31	.76, 7.04
Marital Status	.91	.32, 2.59
Education	2.77	.99, 7.72
Income	.80	.29, 2.15
Insurance	.84	.31, 2.23
ED visits	.75	.27, 2.07
Hospitalizations	.62	.19, 1.98
NYHA	.45	.16, 1.25
Diabetes	.75	.28, 1.99
HTN	.72	.22, 2.33
MI	1.21	.45, 3.21
Lipid	.97	.30, 3.09
HF duration	.58	.17, 1.95
Ejection Fraction	1.61	.39, 6.67
Health perception	.75	.27, 2.07
Self-efficacy	.44	.08, 2.48
Social Support	1.45	.39, 5.34
Depression	.53	.17, 1.57

Note. ED=emergency department; NYHA=Hew York Heart Association; HTN=hypertension; MI=myocardial infarction; HF heart failure

Table 21: Predictor Variables Used in the Logistic Regression[a]

Predictor variables entered	Odds Ratio (OR)	95% Confidence Interval (CI)	*P* value
Race	.48	.17, 1.38	.17
Age	2.31	.76, 7.04	.13
Education	2.77	.99, 7.72	.05
NYHA	.45	.16, 1.25	.13
Depression	.53	.17, 1.57	.25

Note. NYHA=New York Heart Association

[a] Predictor variables used for the logistic regression model were based on $p<.30$ criteria.

The first regression analysis was performed with a sample of 65. As shown in Table 22, the overall predictive model was statistically significant (model $\chi^2 = 12.11$, $p=.03$). However, only one variable, NYHA class, was found to be a significant predictor of performing self-management behaviors, after controlling for race, age, education, and depressive symptoms. Thus, those who were NYHA I-II (fewer symptoms) had the greatest likelihood of performing good self-management. Furthermore, the OR=3.36, CI=.092, 12.37 of the subjects who were older (≥65 year old) were three times more likely to perform good self-management behaviors compared to a younger population. And, those who had less education (< high school education) were almost two and a half times more likely to perform good self-management behaviors (OR=2.474, CI=0.80, 7.60). The overall rate of correct classification was 70.3% in this sample.

Table 22: Logistic Regressions results 1.0: Prediction of the likelihood of good self-management behaviors (N=65)[a]

Predictor Variables	OR	95% CI	*P* value
Race	.58	.18, 1.84	.35
Age	3.37	.92, 12.37	.06
Education	2.47	.80, 7.60	.11
NYHA	.25	.07, .86	.02
Depression	.61	.18, 2.00	.41

Note. OR=Odds Ratio; CI= Confidence Interval

[a]-2 Log Likelihood=76.366; Model Chi-square (df = 5)=12.107; p=.03; Overall rate of correct classification=70.3%

A second regression analysis was done to further determine if it would create a better model for predicting self-management behaviors. This predictive model was also statistically significant (model χ^2 =10.53, p=.01). After controlling for age and education only, NYHA was still the only variable that significantly predicted good self-management behaviors (p=.03). However, age and education were closer to being statistically significant (p=.06 and p=.06, respectively). Additionally, although the model was significant, the classification results indicate only modest success, with an overall correct classification of 67.7% in the analysis sample (Table 23).

Table 23: Logistic Regression Results 2.0: Prediction of the likelihood of good self-management behaviors (n=65)[a]

Predictor Variables	**OR**	**95% CI**	***P* value**
Age	3.41	.94, 12.24	.06
Education	2.89	.97, 8.62	.06
NYHA	.27	.08, .90	.03

Note. OR=Odds ratio; CI=Confidence interval

[a] -2 Log Likelihood=79.194; Model Chi-square ($df = 3$)= 10.530; p=0.02; Overall rate of correct classification= 67.7%.

CHAPTER V: DISCUSSION

This chapter discusses the findings of this study, recommendations for future research, and implications for nursing practice. This descriptive study of a convenience sample of 65 women and men with heart failure described the demographic profile, clinical and psychosocial factors, health care utilization, and the self-management behaviors, as well as the challenges experienced in performing self-management behaviors of this predominantly indigent sample.

Previous work on self management behaviors have been done on mostly elderly, white males, with few studies representing minority and indigent groups. In this study sample, there were younger subjects (mean age 59±14 SD), and more women than men (55% vs. 45%, respectively). Additionally, over half of the sample had less than a high school education, were unemployed, and had annual incomes of <$10,000. Furthermore, a majority of the patients were uninsured. These factors have all been associated with poorer outcomes, including overall mortality (Philbin & DiSalvo, 1998).

Furthermore, consistent with the literature on HF patients, this sample had high co-morbidity rates with more women and non-Whites having diabetes (64% and 48%, respectively) and hypertension (75% and 83%, respectively) which are major risk factors for heart failure. Several studies have suggested that hypertension is associated with a two-to four-fold increase in the incidence of HF (Levy, Larson, Vasan, & Kannel, 1996). Additionally, more recent Framingham data have confirmed that younger women with diabetes have an 8-fold increase in HF incidence (Ho, Pinsky, Kannel, & Levy, 1993).

Ischemic heart disease is the most common cause of HF, especially in males and older women (Adams et al., 1996; Ho, Anderson, Kannel, Grossman, & Levy, 1993). In

this sample, 45% had ischemia as the etiology for their HF with more men and Whites (52% and 57%, respectively). More women (61%) had non-ischemic heart disease which may be related to the fact that this sample tended to be younger than in other studies. Despite a majority of the study sample having a ischemic disease as the etiology of their HF, only 33% of the total sample had a revascularization procedure to improve ischemia. Interestingly, in this sample, more women and Whites received revascularization procedures than men and non-Whites. This differs from other studies that found almost all invasive cardiac procedures, most commonly catheterization, were done twice as often in men (7%) than in women (4%) during hospitalizations for HF (Fisher et al., 1982; Kelsey et al., 1993; O' Connor et al., 1993; Loop et al., 1983). However, more men than women received cardiac surgery. Kelsey et al. (1993) reported higher mortality rates in women who underwent a procedure and O' Connor et al., (1993) reported increased risk of death in women who underwent coronary artery bypass grafting. It is also interesting that, in this sample, so few had any other type of procedures such as pacemaker/defibrillator implantation and electrophysiological testing (EPS). Previous research showed more Whites and males had invasive cardiac services (Philbin & DiSalvo, 1998; McMurray J., McDonagh, T, Morrison CE, Dargie, HJ, 1993; Burns, RB., McCarthy, EP, Moskowitz, MA, Ash, A, Kane, RL, Finch, M., 1997). However, these gender differences have been noted only between White men and women and seem to be age-related.

Overall, in this sample, more subjects were found to have higher EFs. More men and non-Whites, however, had worse EFs (EF<20%) than women and Whites. Interestingly, despite this sample having higher EFs overall, they also appeared to be

more symptomatic with 60% being classified as Class III-IV with more women than men in this classification (64% vs. 56%, respectively). According to the Multicenter Investigation of Limitation of Infarct Size (MILIS), EF was significantly higher in women than in men (49% vs. 45%; p=<.05) (Toffler et al., 1987). Several other studies have noted that women tended to be more symptomatic than men, especially with dyspnea and fatigue (Bennett, Baker, & Huster, 1998; Reidinger, Dracup, & Brecht, M., 2000; Reidinger, Dracup, Brecht, Padilla, Sarna, & Ganz, 2001). Chin and Goldman (1998) also found that women with HF had lower physical functioning than men, and after the 1-year follow-up, the differences were even greater. However, Burns and colleagues (1997) found no difference between men and women. The difference in results could be that Burns et al. (1997) used more direct measures of functional status as opposed to other studies including the present study. Gender differences need to be further explored, especially in the context of symptoms, function, and ultimately, quality of life.

Other important risk factors that were consistent with previous research are the low numbers of subjects that adhered to a low sodium diet and exercise regimen. Of the total sample, only 18% of subjects maintained a low sodium diet. One explanation for this may be that subjects have not had any education on lifestyle changes necessary in patients with HF since only one woman in this sample and none of the men had received any formal cardiac rehabilitation services. This would also explain the low numbers of subjects who performed any exercise. Patients with HF often are very symptomatic with complaints of fatigue and dyspnea. As a results, most patients who don't know they should exercise and to what extent may be apprehensive in doing so. This lack of

knowledge is important because a number of trials evaluating exercise in HF patients have shown that exercise significantly improves quality of life (Tyni-Menne, Gordon, & Sylven, 1996; Kavanagh, Myers, Baigrie, & Mertens, 1996; Tyni-Lenne, Gordon, Jannson, Bermann, & Sylne, 1997; Wielinga, Erdman, & Huisveld, 1998; Willenheimer, Erhardt, Cline, Rydberg, & Israelsson, 1998; Belardinella, Georgiou, Giani, & Purcaro, 1999; Quittan, Sturm, Weisinger, Pacher, & Fialka-Moser, 1999) and decreases anxiety and depression (Kostis, Rose, Cosgrove, Shindler, & Wilson, 1994). Furthermore, there have been studies that have shown that women were less frequently referred to cardiac rehabilitation programs (Halm, Penque, Doll, & Beahrs, 1999). Since exercise seems to be very beneficial in HF patients, it is important that patients be referred to cardiac rehabilitation programs.

Medication Usage

Women and other ethnic groups are greatly underrepresented in the major clinical pharmaceutical trials. In fact, Stromberg et al., (2003) reported only 30% or less of the subjects in pharmaceutical trials were women. Data from previous studies suggests that medications that have been shown to improve survival in HF are underutilized in both women and those of lower SES. If the appropriate medications are prescribed, it was found that they are prescribed at suboptimal doses.

The findings in this study are similar to what has previously been reported regarding medications and gender- and ethnic-related differences. Significantly fewer women were prescribed ACE-I and beta-blockers as compared to men. Only 56% of women compared to 82% of men were prescribed ACE-I and only 47% of women compared to 78% of men were prescribed beta-blockers. It is unclear why there is such a

large discrepancy in the utilization of these drugs except for the fact that some research have reported than women had more adversely effects from ACE-I than men (The SOLVD Investigators, 1996). Furthermore, it has also been noted, in prior research, that women did not benefit from these drugs as much as in men (CONSENSUS trial study group, 1987; The SOLVD Investigators, 1991). However, Garg and colleagues (1995) found that in their meta-analysis of 30 ACE-Inhibitor trials, the reduction in mortality and morbidity was similar in both sexes. Authors from the large beta-blocker trials also noted similar reduction in mortality in women and men (Packer et al., 1996; Hjalmarson, Goldstein, & Fagerberg, 2000). Thus, there is similar benefit for women and men from these medications.

Psychosocial Variables

Psychosocial variables such as anxiety and depression have been associated with morbidity and mortality in patients with cardiovascular disease. Several studies have described depressive symptomatology, lack of knowledge and/or self-management behaviors, lack of social support, and non-adherence with HF treatments put patients at risk for complications and subsequent hospital readmission (Ghali et al., 1988; Vinson et al., 1990; Dracup, Walden, Stevenson, & Brecht, 1992; Hawthorne & Hixon, 1994; Opasich et al., 1996; Chin & Goldman, 1997; Murberg, Bru, Aarsland, & Svebak, 1998; Havranek, Ware, & Lowes, 1999; Williams et al., 2002). However, the results of these studies have been inconsistent. In the present study we attempted to describe the psychosocial factors associated with HF in this indigent sample.

Health Perception

Because HF patients frequently have more symptoms and functional impairment, their quality of life is typically compromised. In a study done by Havranek and colleagues (2001), they found that health perception was a strong predictor of subsequent occurrence of clinical events in patients with HF. In our sample, more patients (82%) rated their health as "fair to bad" or "poor health perception" with a higher proportion of men than women with "poor health perception" (97% vs. 69%, respectively).This is interesting to note, since a majority in this sample also had high physical symptom impact. However, there have been studies that have reported subjects having worse physical health but better mental health, especially in women (Juenger et al, 2002; Bennett, Baker, & Huster, 1998). On the contrary, Burns et al.(1997) reported 50% to 70% of the study sample reported their perceived health as fair or poor.

Self-Efficacy

Self-efficacy in this sample was assessed because several studies support that self-efficacy is a strong predictor of self-management behaviors (Crabtree, 1986; Godding & Glasgow, 1985; Lorig, Chastain, Ung, Shoor & Holman, 1989; Dilorio, Faherty & Manteuffel, 1992). Of the total sample 70% of the subjects rated themselves as having high confidence levels in general. In addition, it was found that Whites had slightly higher levels of self-efficacy than non-Whites (71% vs. 70%). Subjects reported high self-efficacy in performing self-management behaviors such as taking medications, weighing themselves daily, and maintaining a low salt diet with lower scores with self-efficacy to exercise at least 3 times per week and self-efficacy to exercise without making their symptoms worse. It is of interest that subjects felt very confident they could do these

skills, yet only 43% weighed themselves and 75% adhered to a low salt diet. Almost all patients, however, stated they take their medications as prescribed. Lack of patient education in this sample may be the reason for lower numbers in performing self-management behaviors. These patients take their medications because someone has told them to do so. Perhaps, if these patients were educated on the importance in performing these skills as a way to keep themselves healthy, these numbers may increase.

Social Support

Social support has been found to also be an important predictor of morbidity and mortality in patients with coronary heart disease (Berkman, Leo-Summers & Horwitz, 1992; Case, Moss, Case, McDermott, & Eberly, 1992), although still little is known in patient with HF. Some studies have found that there is greater patient adherence to medical therapy and lifestyle changes in patient with emotional support (Krumholz, 1998). Also, previous research has reported that women who did not have emotional support had more depression and lower quality of life (Friedman & King, 1994; Friedman, 1997; Martensson, Karlsson, & Fridlund, 1998).

The results of this study showed that despite the fact that 56% were not married or currently not living with a partner and that significantly more women compared to men (69% vs. 39%) were either single, divorced, or widowed, the overall total sample had high levels of social support score with no differences found with gender and race. This is interesting since this sample also had higher levels of health perception.

Depressive Symptoms

Depression has been found to be related to patient non-adherence and worse outcomes (De Geest et al., 2003; Williams, Kasl, Heiat, Abramson, Krumholz, &

Vaccarino, 2002; Havranek, Ware, & Lowes, 1999; Hawthorne & Hixon, 1994; Dracup, Waldern, Stevenson, & Brecht, 1992). Other researchers have also found depression to be related to gender and low socioeconomic status (Weissman & Klerman, 1992; Freedland, Carney, Rich, Caracciolo, Krotenberg, Smith & Sperry, 1991; Murberg, Bru, Aarsland, & Svebak, 1998). Depressive symptomatology has also been described as a major risk factor for non-adherence in patient populations with chronic diseases (DiMatteo, Lepper, & Croghan, 2000).

In this study, depression was measured by the CES-D. Results of this study showed the mean CES-D scores 25.2(± 12.8). This score reveals that this population is "clinically depressed". Previous work using the CES-D, used the cut point of ≥21 denoting "clinical depression" (Williams, Kasl, Heiat, Abramson, Krumholz, & Vaccarino, 2002). This score was also found to be a significant risk factor for incident HF and subjects were more likely to be hospitalized with HF in the population-based study (Williams, Kasl, Heiat, Abramson, Krumholz, & Vaccarino, 2002).

The sample in the present study was similar to those found in earlier studies where depressed patients were less likely to be married and had fewer years of education (Williams, Kasl, Heiat, Abramson, Krumholz, & Vaccarino, 2002; Havranek, Ware, & Lowes, 1999). Additionally, in the present study, there were more women found to be depressed than men (37% vs. 33%, and more non-Whites compared to Whites (77% vs. 67%). Women also exhibited more depressive symptoms like loss of appetite, crying spells, and feeling sad. Other studies have also noted women having higher rates of depression than men (Weissman & Klerman, 1977; Nolen-Hoeksema, 1990). Weissman

& Klerman (1992) have shown rates of major depression for women to be nearly double that of men.

It is intriguing that this sample would have such high CES-D scores given a majority of subjects also reported high levels of self-efficacy and high social support. Social support has been considered as a buffer for depression and psychological well-being, especially in women (Krumholz et al., 1998; Friedman & King, 1994; Friedman, 1997; Martensson, Karlsson, & Fridlund, 1998). However, despite high social support in these subjects, they experienced significant symptoms of depression.

It is also of note that this sample had multiple comorbidities, as well as very low income levels and were uninsured. Socioeconomic status (SES) has been shown to be related to depression (Brown & Harris, 1978) and hospital readmissions (Tsuchihashi et al., 2001). There are very few studies that have addressed SES in HF and a cross-sectional study does not allow for an assessment of whether the degree to which SES affects depressive states remains unclear. Perhaps, a lot of their depressive symptoms come from other areas of their life other than their heart failure, or are pre-existed because of finances and health care access. This is an area that requires further research using a prospective, longitudinal study design. Results from this study indicate that having high social support and good health perception may not be related to having less depressive symptoms if there are other reasons for depression like problems associated with low SES. Findings from a study by Riegel and Carlson (2002) also described a similar phenomenon in that "many were preoccupied with major life stresses that sapped their coping resources" and that "life stresses decrease motivation for self-care..." (p. 294).

Health Care Utilization

Gender and race have often been noted as important determinants of ED visits, hospital admissions, and increased lengths of stay (Philbin & DiSalvo, 1998.) In this sample, more males and non-Whites were hospitalized and more males and Whites visited the ED. Research in this area has been inconsistent. For example, in some studies, men had shorter hospital stays and lower hospital costs when compared to women (Philbin & DiSalvo, 1998; McMurray, McDonagh, Morrison, & Dargie, 1993). However, in the SOLVD studies, women had higher annual admission rates than men (Bourassa et al., 1993) whereas Opasich et al.(2000) found no differences between women and men in frequency of hospital admissions.

Moreover, racial differences have been noted and implies a race gender interaction. In a study by Alexander et al. (1999), they found that black men and women had higher rates of hospitalizations than white men and women. In fact, in the state of California, Alexander et al. (1999), found that the rate of hospitalization for black men were 2.2 times higher than for white men. A larger sample would be needed to allow for the testing of a race gender interaction.

Self-Management Behaviors

Self-management behaviors were assessed to learn more about the frequency of behaviors in this sample. Given that these patients, presumably, have had no previous formal, structured education on HF, it was interesting to note these occurrences. As expected, most of the patients had "poor self-management" with fewer patients who weighed themselves and who exercised. However, a majority of patients did report taking their medications as prescribed. This is consistent with the findings from Artinian,

Magnan, Sloan and Lange (2002) and Ni and colleagues (1999). They also found that patients took their medications "most of the time", contrary to what other researchers have reported (Monane, Bohn, Gurwitz, Glynn & Avorn, 1994; Bushnell, 1992). Similar to the studies of Artinian and colleagues (2002), and Ni and colleagues (1999), it is important to note that the present study did measure medication compliance through subjective means as well. It is also interesting that Artinian's study was done at a Veterans Affairs Medical Center which may have provided patients with better access to medications. In the present study, however, most patients were of low SES with no additional money for meds or insurance that assisted with a prescription plan.

Weight was monitored infrequently in this sample. Only 43% weighed themselves on a daily basis. This was congruent with findings of several other researchers. Artinian and colleagues (2002) found that patients rarely weighed themselves. Ni and colleagues (1999) also found similar results. They reported only 40% of their sample (N=113) weighed themselves daily, and Bushnell (1992) reported only 30% of patients weighed themselves daily. In a study done by Jaarsma and colleagues (2000), they noted 43% of their sample did not weight themselves because "they did not find it useful". Effective self-management entails daily monitoring for signs and symptoms of HF. Performing daily weighting can provide patients with a mechanism to evaluate how much fluid retention they have by noting even modest weight gain so that interventions can occur immediately. These interventions can be as simple as asking patients about their diet and asking them to decrease their sodium intake, or perhaps, making medication adjustments. In any case, these interventions may assist the patient in preventing ED visits and hospital

admissions for HF because for some patients, weight gain may be the first sign of impending heart failure.

When symptoms were assessed, a majority of the subjects (71%) reported trouble breathing in the last 3 months. Of those who reported breathing difficulties, it was disheartening to find that 72% failed to recognize it as a symptom of HF. In addition, of those who had trouble breathing, less than one fourth of subjects performed any treatments to alleviate their symptom, and of those who did perform a treatment, only 20% stated it helped them feel better. In a recent study done by Riegel et al. (2004), they found almost 80% of the sample was symptomatic with shortness of breath and, of those, 49% failed to recognize it as a symptom of HF. Additionally, less than half of the symptomatic patients implemented any kind of treatment and 58% of them were able to evaluate the effectiveness of their actions. These findings confirm that patients have lots of difficulty recognizing their symptoms of HF. This may be complicated by the fact that these patients also have multiple other comorbidities that may mimic symptoms of HF. This validates what other investigators have reported in that patient education is very important in teaching patients how to recognize symptoms of HF and it is essential to provide patients with strategies for alleviating or preventing symptoms.

Barriers and Challenges to Self-Management Behaviors

The major concerns about HF, barriers to performing self-care, and what treatment gives them relief were explored in this qualitative component. The present study confirms the results to previous research. The major concerns that were most commonly shared were having more heart problems, breathing difficulties, living longer, and dying. Symptoms and the need for information were found to be common barriers in

this sample. Additionally, patients reported that having breathing treatments, talking to their physicians and getting information about their condition made them feel better.

The major concerns in this sample of HF patients were having further heart problems, breathing difficulties and death are certainly factors that many other patients experience. It is unclear, however, by asking the questions, how much information about HF they actually understood. They may all have the misconception that having HF causes death and that there is nothing one can do to prevent the condition from progressing. One suggestion may be that when subjects had trouble breathing, 72% did not do anything to alleviate it. This may all be related to the lack of knowledge about HF and self-care management.

In a study done by Riegel and Carlson (2002), lack of knowledge and symptom burden were also reported. Additionally, they also reported that most patients were having major concurrent comorbid conditions as a barrier to self-care because it adds complexity to the self-care regimen. The majority of the subjects had numerous comorbid conditions including diabetes and hypertension further complicating the self care issues in terms of presenting an even greater challenge.

Symptoms of fatigue and shortness of breath seem to be a major barrier to performing self-care. It is evident that these subjects had difficulty interpreting these symptoms and lacked knowledge about treatment options. Again, by providing these patients with the necessary tools and education to assist them with performing self-management behaviors, they may be able to learn how to prevent these symptoms.

Other barriers to self-care were living alone and having limited or insufficient financial resources. Findings from this study, reported previously, were that subjects felt

they had high social support. However, when asked about barriers, this was a common theme. There is some incongruency in the concept of support and since this study did not separate support from family and friends with other support from health care providers, it is difficult to make an accurate interpretation about how support relates to self-management in this sample. Further research is needed to identify if increasing access to other health care providers will facilitate self-management behaviors.

Financial challenges are always of concern in a sample of low SES. These patients have no insurance and no money for care and medications. Furthermore, because they have no insurance, they are often excluded in getting referred to patient education programs and cardiac rehabilitation. Perhaps referring these patients to social workers and counselors who can help them with additional resources and services may decrease this barrier.

When asked about treatments that make the subject feel better, a common theme was information from the doctor. Riegel and Carlson (2002) also reported that support and getting information from the physicians held special meaning to these patients. While others have noted that social support helps patients deal with HF (Happ, Naylor & Roe-Prior, 1997; Bushnell, 1997; Martensson, Karlsson & Fridlund, 1997; Koenig, 1998), subjects in Riegel and Carlson's study reported that support from various health care providers facilitated their ability to deal with the diagnosis.

Relationships between demographic, clinical, psychosocial, and health care utilization variables

Multiple logistic regression analyses were done to identify independent predictors of self-management behaviors. Three predictors of self-management were identified in

this descriptive study: age, education, and symptom severity as measured by the NYHA classification system. However, only one variable, symptom severity or NYHA, was statistically significant (p=.03).

Symptom severity has been described as a predictor of self-care in the study by Rockwell & Riegel (2001). The results of the present study were incongruent with those found by Rockwell and Riegel (2001) whereby those who experienced less symptoms had higher self-care scores. Rockwell and Riegel stated that one explanation for their study could be that patients who are more symptomatic may be more knowledgeable about the symptoms, thus, necessitating higher self-care skills. They also state that symptom severity could be a proxy for duration of illness. The findings in this study, however, suggest that those who are less symptomatic have a greater likelihood to perform self-management behaviors than those who are more symptomatic. Furthermore, it was also found in this study that those who were recently diagnosed with HF had better self-management than those who have had HF for a longer period of time. Although it is likely that those with advanced disease may have more experience with disease-related symptoms and its management, those who have had the disease longer may also become more complacent with treatment.

In this study, education was also a predictor (p=0.06) of good self-management. . In fact, the results of this study revealed that those who were less educated (less than high school education) were almost three times more likely to perform good self-management.behaviors. This is contradictory to findings of previous research found that better educated persons were more likely to perform self-management than those who are poorly educated (Rockwell & Riegel, 2001; Burke & Dunbar-Jacob, 1997; Given, Given

& Coyle, 1984). One explanation for this finding may be that those who have more education are busy working, thus have problems with managing their disease. Education is sometimes associated with higher socioeconomic status and may be associated with higher income levels. These factors may also help facilitate the performance of self-management behaviors, however, SES was not found to be a significant predictor of self-management in the present study. Further research is necessary to evaluate the influence of education in the indigent population.

Age was another variable that may predict self-management. However, it was not found to be statistically significant (p=.06). It is interesting to note that those who were older (≥65 years old) tended to perform good self-management when compared to those who were younger. In fact, those who were older were three times more likely to perform good self-management. This may contribute to the idea that was presented previously in that the patients who were older may have been dealing with HF longer or have more time to care for themselves; thus, perform better self-management.

Significance

The results of this study demonstrate the difficulties that this sample of HF patients have in performing self-management behaviors. The challenges these patients face are multi-dimensional. These patients are affected by multiple comorbid conditions that impact their self-management. In fact, one in five Americans has a chronic condition (Wu & Green, 2000). This rate also continues to grow as the population gets older (Wu & Green, 2000). Furthermore, these patients not only have the stress of having to deal with a chronic, debilitating condition, but they also have to deal with extreme life and financial stress as well. Approximately one third of non-Whites are without any form of health

insurance (Eberhardt et al., 2001). Although these patients seem to have family support and self-confidence to handle their disease, it is clear that they also lack the knowledge and health care support to monitor their signs and symptoms appropriately. These results suggest an important and urgent need for creative approaches to providing adequate information to patients with HF to improve self-management behaviors.

There is a growing interest in the public health arena and across disciplines in interventions that can be applied across chronic diseases. In light of health disparities and the increasing numbers of those with chronic conditions, there is a great need for specific interventions that can improve health behaviors and health status in the indigent populations. Thus, the concept of disease self-management is not new. During the past decade, chronic disease self-management programs have demonstrated the positive impact on health behaviors, health status, and health care utilization (Brown et al., 2000; Lorig, Gonzalez & Ritter, 1999; Lorig et al., 1999; Clark et al., 1992; Glasgow et al., 1997; Lorig et al., 2001). Many of these interventions, however, were developed in one chronic disease population and not adequately tested in other chronic disease populations. Additionally, many of the interventions studied were not representative of populations of non-Whites and of those who have no insurance and/or access to appropriate health care.

There are on-going programs throughout the world that are assisting HF patients learn more about their condition, provide frequent monitoring and support, as well, as provide care that adheres to the national HF guidelines. But uninsured, indigent patient may not have access to these programs. This study gives further evidence that these patients may also require other types of assistance including social work and counseling to combat the financial challenges and depressive symptoms. Teaching patients how to

take care of themselves and providing them with strategies for keeping themselves well may not be enough. Programs need to be developed and implemented to serve this underserved HF population. The program should include multidisciplinary care models incorporating components described by the AHA consensus paper. These models should include: comprehensive and intensive patient education, counseling, and skill-building; (2) interventions targeting adherence; and (3) frequent follow-up and increased access to health care providers (Grady et al., 2000). As clinicians, we must look at the entire social context of what these patients need and incorporate that into our clinical practice, as well as attempt to decrease health disparities.

Limitations

There are several limitations to this study. First, the study was limited by the use of a convenience rather than a random sample. A cross-sectional study design precludes conclusive testing of a causal relationship. The study sample was small and limited to individuals who could speak and read English. This restricts the generalizability of the findings. In addition, a sample of 65 subjects may have resulted in a type II error. Most of the information provided for this study was also obtained through self-report via structured interview and medical record abstraction which assumed complete and accurate recording and documentation. Techniques that were utilized to minimize possible errors included verification of data with other health care providers and family members, if they were present. Furthermore, the measure used for assessing symptom severity, which turned out to be the only variable that truly predicted self-management behaviors were based on subjective measures of the patient's symptoms. Perhaps, a more direct measure of function such as the 6-minute walk test was necessary. However,

numerous studies have used this subjective measure as a proxy measure for symptom severity with much accuracy.

Due to the paucity of reliable measures of self-management in the initial phases of this study, as well as to date, the method of measuring the dependent variable, self-management behaviors, may not have been done as accurately as one would like. The instrument continues to be revised and perfected. It is the belief of the researcher that the instrument used was the best instrument to date.

Implications for nursing

The role of nurses in the care of chronic disease management has evolved in the last few years. More nurses and/or nurse practitioners are assuming roles that provide patients with education and intensive case management. It is important for nurses in this position to be aware of the needs of indigent patients with HF, as well as gender and racial differences. Findings of this study have described the need for intensive education and support to increase knowledge and care for indigent patients. Additionally, depression was also noted in a majority of subjects. This may not be unique to this sample, but may also be prevalent in the overall population of those with chronic diseases. This suggests the need for on-going clinical assessments for depression so that nurses can intervene or refer the patient to a mental health professional.

Future Research

Further research is required to examine the importance and explain the differences in demographic, clinical, and psychosocial factors between women and men and between Whites and non-Whites, indigent and non-indigent. Before heart failure interventions can

be successful, we must have a better understanding of the variations by gender, race, and SES so that we may tailor our interventions accordingly.

Contrary to previous findings, this study shows that patients with lower educational achievement can also perform good self-management. Future research should be done to further explore this in larger samples. Future research should also test whether education in patients who have less education get similar benefits as those with higher levels of education.

Another area for future research should concentrate on examining different strategies to manage patients with depression. Depression seems to be prevalent not only in this sample, but also in patients with chronic diseases in general. Early identification and intervention may promote better self-management behaviors and ultimately better outcomes.

Finally, further research must be done on the methods used to measure self-management behaviors. Future research should incorporate psychometric testing of various instruments evaluating self-management behaviors so that researchers can utilize the one that can measure this concept most accurately. In addition, instruments that are culturally sensitive, in different languages, and of appropriate readability levels need to be developed. Furthermore, future studies are also needed to identify other predictors of heart failure self-management behaviors. Replication of this study in larger samples would give additional support to the findings and is needed to help design HF interventions in more diverse groups.

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Appendix A: Consent Form

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO BE A RESEARCH SUBJECT
Heart Failure Self-Management Behaviors in an Indigent Population

A. PURPOSE AND BACKGROUND

Dr. Erika S. Froelicher PhD, RN and Aurelia M. O' Connell MSN, ACNP in the Department of Physiological Nursing are conducting a research study to help understand how men and women with heart failure take care of themselves and manage their disease (self-management behaviors). You are being asked to participate in this study because you have heart failure.

B. PROCEDURES

If you agree to be in the study, the following will happen:

a. You will be asked to schedule an appointment to respond to several questionnaires asking about how you take care of yourself and your heart failure (self-management behaviors), social support, depressive symptoms, self-efficacy or your confidence level in doing certain heart failure behaviors, and general health perception. It should take approximately 1 to 1½ hours to complete the questionnaires.

b. These procedures will be done at University Medical Center in Fresno, 445 South Cedar Avenue, Fresno, CA 93702.

C. RISKS/DISCOMFORTS

a. Participation in this study does not pose any severe risks or discomfort. You may become fatigued or stressed during the time you are filling out the questionnaires. If this occurs, you may stop and rest, and then resume filling out the questionnaires when you are ready.

b. Some of the questions on the questionnaires may make you uncomfortable or upset, but you are free to decline to answer any questions you do not wish to answer at any time.

c. Confidentiality: Participation in research may involve a loss of privacy; however, your records will be handled as confidentially as possible as permitted by law. In the event of an audit, your records may be reviewed by the staff of the Community Medical Center's Institutional Review Board (IRB) or the UCSF Committee on Human Research. These are committees charged with the protection of human subjects in research. The research team will continue to protect your personally identifiable

health information as described in this consent form. Only Dr. Erika S. Froelicher and Aurelia M. O' Connell will have access to your study records. Once the study is completed, the study records will be destroyed. No individual identities will be used in any reports or publications that may result from this study.

D. BENEFITS

There will be no direct benefit to you from participating in the study. However, the information that you provide may help health professionals better understand behaviors of self-management in patients with heart failure.

E. ALTERNATIVES

You may choose not to participate in this study.

F. COSTS

There will be no costs to you as a result of taking part in this study.

G. PAYMENT

There is no reimbursement offered to the subjects. The researchers will not be financially reimbursed for enrollment of subjects.

H. QUESTIONS

You have talked to Dr. Erika S. Froelicher, Aurelia M. O' Connell, or the person who signed below about this study and have had your questions answered. If you have further questions, you may call him/her at (559) 312-5584.

If you have any comments or concerns about participation in this study, you should first talk with the researcher. If for some reason you do not wish to do this, you may contact the Community Medical Center's IRB, which is concerned with the protection of volunteers in research projects. You may reach the IRB office between 8:00 and 5:00, Monday through Friday, by calling (559) 459-4773.

I. STATEMENT OF RESEARCH RELATED INJURY

In the event of a research related injury, medical care will be available. However, the cost of the care will be charged to you or your insurance company. By signing this consent form, you will not be waiving any of the legal rights to which you would otherwise be entitled.

CONSENT

You will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point. Your decision as to whether or not to participate in this study will have no influence on your present or future status as a patient.

You will be asked to sign a separate form authorizing access, use, creation, or disclosure of health information about you.

If you wish to participate in this study, you should sign below.

Date	Signature of Study Participant
Date	Signature of Investigator
Date	Witness
Date	Signature of Person Obtaining Consent

Appendix B: Medical Abstraction Form

PATIENT DEMOGRAPHICS

PATIENT ID_____ **DOB:**_____
SITE ID_____

GENDER: ☐ Male ☐ Female

RACE

☐ White ☐ Native Hawaiian or Other Pacific Islander ☐ American-Indian or Alaska Native
☐ Asian ☐ Black or African- American

ETHNICITY: ☐ Hispanic or Latino ☐ Non-Hispanic or Latino

EDUCATION

Secondary School (highest grade completed): ☐ 8th ☐ 9th ☐ 10th ☐ 11th ☐ 12th
College: ☐ 1 yr ☐ 2 yr ☐ 3 yr ☐ 4 yr ☐ Other (Specify)_____

SOCIAL/FAMILY HISTORY

☐ Married ☐ Single ☐ Divorced

Working: ☐ No ☐ Yes Occupation: _____

Insurance: ☐ Medicare ☐ Medicaid ☐ UNM Care ☐ Self-Pay ☐ Other_____

Income level: ☐ $0-5,000 ☐ $5-10,000 ☐ $10-15,000 ☐ $15-20,000 ☐ $20-25,000 ☐>$25,000

How many adults and how many children does the family income need to support?
Adults _____ Children _____

☐ Alcohol (type/frequency) _____ ☐ Tobacco (indicates pack years)_____
☐ Illicit drugs (Specify)_____ ☐ Diet(Specify)_____
☐ Exercise(Type/duration/frequency)_____
☐ Cardiac Rehab

MEDICAL/SURGICAL HISTORY (Check All That Apply)

☐ Diabetes ☐ Hypertension ☐ Asthma ☐ COPD ☐ MI ☐ Angina ☐ Hyperlipidemia

☐ PVD ☐ Renal disease ☐ Thyroid disease ☐ Valvular Disease ☐Other_____

☐ PTCA/Stent ☐ CABG ☐ Pacemaker ☐ AICD ☐ Post-transplant

HEART FAILURE HISTORY/ ETIOLOGY

Duration of HF: ☐ 0-6 mo ☐ 6-12 mo ☐ 1-2 yr ☐ >2 yr ☐ Other_____

Etiology: ☐ CAD ☐ Valvular ☐ HTN ☐ Idiopathic ☐ Diastolic ☐ Other_____

Ejection Fraction (%): ☐ <10 ☐ 11-20 ☐ 21-30 ☐ 31-40 ☐ >40

NYHA Functional Class (see Table___): ☐ I ☐ II ☐ III ☐ IV
Do you attend a HF program? ☐ No ☐ Yes How long? _____

Who do you call or see when you have symptoms of HF? ☐ Primary care provider ☐ Cardiologist
☐ HF program ☐ Emergency room ☐ Other_____

UTILIZATION HISTORY

# of ER visits in the last 6 months: _____
Dates:_____

# of Hospitalizations: _____
Dates:_____

MEDICATION HISTORY

ACE-I ☐ No ☐ Yes Drug_____ Dosage:_____
ARB ☐ No ☐ Yes Drug_____ Dosage_____
Beta-Blocker ☐ No ☐ Yes Drug_____ Dosage_____
Diuretics ☐ No ☐ Yes Drug_____ Dosage_____
Potassium supplements ☐ No ☐ Yes Drug_____ Dosage_____

OTHER MEDICATIONS:

_____
_____
_____
_____
_____

OTHER:

1) What are the major concerns about your disease?

2) What gets in the way of taking care of yourself?

3) What part(s) of your treatment helps make you feel better?

Legend: COPD= Chronic obstructive pulmonary disease; MI= myocardial infarction; PVD= peripheral vascular disease; PTCA=percutaneous transluminal coronary angioplasty; CABG=coronary artery bypass graft; AICD= automatic implantable cardiac defibrillator; CAD= coronary artery disease; HTN= hypertension; HF= heart failure; ACE-I= Angiotensin converting enzyme-inhibitor; ARB= angiotensin receptor blocker

VARIABLE	INSTRUMENT	DESCRIPTION	# OF ITEMS	ADMINISTRATION/ TIME	POSSIBLE SCORE RANGE
Self-management behaviors	Self-Management of Heart Failure (SMHF) - Revised	Developed to evaluate self-management behaviors of HF patients. Self management is measured with four subscales: recognition, evaluation of sign/symptom importance, action, and evaluation of treatment effectiveness.	18 items	Self-report; 20 minutes	A scoring algorithm was devised that 1) recognizes the ability to stay asymptomatic through self-management behaviors, and 2) weights all five self-management scores equally. Please see codebook for details. All patients are given up to 7 points for self-management maintenance. Those who are symptomatic get up to 20 points for self-management. Those who are asymptomatic get 12 points for effectively managing the diagnosis. An additional 4 points are available for symptom importance for a total of 20 points reflecting self-management ability. Please see scoring chart..
Social support	ENRICHD Social Support Inventory (ESSI)	Developed to measure perceived emotional support. Items were developed from scales and items from prior studies that were predictive of AMI	7 items; Likert scale	Self-report; 10 minutes	Response categories range from 1 (none of the time) to 5 (all of the time). A score of ≤ 3 on 2 or more items and a total score of ≤ 18 suggests low perceived social support
Depressive symptoms	Center for Epidemiologic Studies Depression (CES-D)	Identifies depressive symptoms. Items were selected from previously validated scales of depression. Items consist of 6 components: depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance.	20 items; Likert scale	Self-report; 30 minutes	Response categories range from 0 (rarely or none of the time) to 3 (most or all of the time). Four positive questions (questions 4, 8, 12, & 16) are worded positively to discourage a response set. The scores of these questions are reversed by subtracting the score from 3. The scores for the 20 items are then summed, resulting in a potential score ranging from 0 to 60. If more that 5 items on a scale are missing, a score is not

					calculated. If 1 to 5 items are missing, the scores on the completed items are summed and divided by the total # of items answered and then multiplied by 20. A score of ≥16 is considered depressed, with higher scores indicating higher levels of depression.
Self-efficacy	Self-Efficacy to Perform Self-Management Behaviors Questionnaire	This instrument was derived from the Chronic Disease Self-Management Study. It assesses how confident one is in doing certain self-management behaviors i.e. exercise, getting information about disease, obtaining help, communicating with provider, managing the disease, managing symptoms, managing shortness of breath, & managing depression.	12 items; multi-item Likert scale	Self-report; 15 minutes	Scoring is divided into scales as described previously. For each scale, the mean of the scores of the items are obtained. If more than two items are missing in each section, the value of the score for the scale is set to missing. Total scores for each scale range from 1 to 10, with higher scores indicating greater levels of self-efficacy.
Health perception	Health Perception Question	Health perception refers to personal beliefs and evaluations of general health status. It has been demonstrated to be a significant predictor of mortality and health care resource use.	1 item	Self-report; 2 minutes	Answers include excellent, good, fair, poor, or bad.

Appendix D: Health Perception Question

Please answer the following question and mark the answer with an "X":

For your age, in general, would you say your health is excellent, good, fair, poor, or bad?

____ excellent

____ good

____ fair

____ poor

____ bad

Self-Efficacy (SE) to Perform Self-Management Behaviors Questionnaire

We would like to know how confident you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

SE Get Information About Disease

Responses

1.	How confident are you that you can get information about your disease?	Not at all Confident	1	2	3	4	5	6	7	8	9	10 Totally confident

SE Manage Sign and Symptoms

How confident are you that you can …

1.	Judge or recognize when you have had a change in your weight?	Not at all Confident	1	2	3	4	5	6	7	8	9	10 Totally confident
2,	Judge or recognize when you have had a change in your breathing or fatigue?	Not at all Confident	1	2	3	4	5	6	7	8	9	10 Totally confident
3.	Judge or recognize when you have swelling?	Not at all Confident	1	2	3	4	5	6	7	8	9	10 Totally confident

SE to Manage Your Disease in General

1.	Having an illness often means doing different tasks and activities to manage your condition. How confident are you that you can do all the things necessary to manage your condition on a regular basis?	Not at all Confident	1	2	3	4	5	6	7	8	9	10 Totally confident

How confident are you that you can...

2.	Judge or recognize when the changes in your illness mean you should talk to or visit a doctor?	Not at all Confident	1	2	3	4	5	6	7	8	9	10	Totally confident
3.	Ask your provider things about your disease that concerns you?	Not at all Confident	1	2	3	4	5	6	7	8	9	10	Totally confident
4.	Take your medications as prescribed?	Not at all Confident	1	2	3	4	5	6	7	8	9	10	Totally confident
5.	Weigh yourself daily?	Not at all Confident	1	2	3	4	5	6	7	8	9	10	Totally confident
6.	Keep the salt in your diet lower than 2000-3000 mg (2-3 gm) each day?	Not at all Confident	1	2	3	4	5	6	7	8	9	10	Totally confident
7.	Exercise at least three (3) times each week?	Not at all Confident	1	2	3	4	5	6	7	8	9	10	Totally confident
8.	Exercise without making your symptoms worse?	Not at all Confident	1	2	3	4	5	6	7	8	9	10	Totally confident

Appendix F: ENRICHD Social Support Instrument (ESSI)

Please read the following questions and circle the response that most closely describes your current situation.

1. **Is there someone available to you whom you can count on to listen to you when you need to talk?**

None of the time	A little of the time	Some of the time	Most of the time	All of the time
1	2	3	4	5

2. **Is there someone available to give you good advice about a problem?**

None of the time	A little of the time	Some of the time	Most of the time	All of the time
1	2	3	4	5

3. **Is there someone available to you who shows you love and affection?**

None of the time	A little of the time	Some of the time	Most of the time	All of the time
1	2	3	4	5

4. **Is there someone available to help you with daily chores?**

None of the time	A little of the time	Some of the time	Most of the time	All of the time
1	2	3	4	5

5. **Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?**

None of the time	A little of the time	Some of the time	Most of the time	All of the time
1	2	3	4	5

6. **Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?**

None of the time	A little of the time	Some of the time	Most of the time	All of the time
1	2	3	4	5

7. **Are you currently married or living with a partner?**

Yes No

The criterion for low social support was based on the patient's score on 5 (items 1, 2, 3, 5, and 6) of 7 items on the instrument. Low perceived social support has a score of ≤ 2 on at least 2 of the 5 items, and a total score of ≤ 18.

Appendix G: CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION (CES-D) SCALE

Instructions for questions: Below is a list of the ways you might have felt or behaved. Please tell me know often you felt this way during the past week.

During the past week:	**Rarely or none of the time (less than 1 day)**	**Some or a little of the time (1-2 days)**	**Occasionally or a moderate amount of time (3-4 days)**	**Most or all of the time (5-7 days)**
1. I was bothered by things that usually don't bother me.	0	1	2	3
2. I did not feel like eating; my appetite was poor.	0	1	2	3
3. I felt that I could not shake off the blues even with help from my family or friends.	0	1	2	3
4. I felt that I was just as good as other people.	0	1	2	3
5. I had trouble keeping my mind on what I was doing.	0	1	2	3
6. I felt depressed.	0	1	2	3
7. I felt that everything I did was an effort.	0	1	2	3
8. I felt hopeful about the future.	0	1	2	3
9. I thought my life had been a failure.	0	1	2	3
10. I felt tearful.	0	1	2	3
11. My sleep was restless.	0	1	2	3
12. I was happy.	0	1	2	3
13. I talked less than usual.	0	1	2	3
14. I felt lonely.	0	1	2	3
15. People were unfriendly.	0	1	2	3
16. I enjoyed life.	0	1	2	3
17. I had crying spells.	0	1	2	3
18. I felt sad.	0	1	2	3
19. I felt that people disliked me.	0	1	2	3
20. I could not get going.	0	1	2	3

Scoring:

To determine a "depression score," add each of the numbers circled to get a sum. First, however, "reverse" the scale items for items 4, 8, 12, and 16 so the 0=3, 1=2, 2=1, and 3=0. These four items reflect positive experiences rather than negative ones. Now add the 20 numbers; the score will be in the range of 0 to 60. *If four or more items are missing, do not score the CES-D.*

Item weights	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	All of the time (5-7 days)
Items 4, 8, 12, and 16	3	2	1	0
All other items:	0	1	2	3

Score is the sum of the 20 item weights. Possible range is 0 to 60. If more than four questions are missing answers, do not score the CES-D. A score of 16 or more is considered depressed.

Appendix H: Self-Management of Heart Failure Questionnaire - Revised (SMHF-Rev)

SECTION A: How often do you do the following?

	Never or rarely	Sometimes	Frequently	Always
1. Weigh yourself daily?	1	2	3	4
2. Keep the salt in your diet lower than 2000 – 3000 mg (2-3 Gm) each day?	1	2	3	4
3. Exercise at least 3 times each week?	1	2	3	4
4. Take medications as prescribed?	1	2	3	4
5. Keep your weight within 10% of your ideal weight?	1	2	3	4
6. Talk to your doctor whenever you need guidance?	1	2	3	4
7. Get immunizations (like a flu shot) every year?	1	2	3	4

SECTION B:

Listed below are symptoms that people with heart failure may have. If you had a change in any of these symptoms, how worrisome or troubling would it be?

(circle one number for each symptom)

	Not worrisome	Somewhat worrisome	Worrisome	Very worrisome
4. Trouble breathing	1	2	3	4
5. Tired or fatigued	1	2	3	4
10. Sudden weight gain	1	2	3	4
11. Swelling	1	2	3	4
12. Dizziness, loss of balance, or passing out	1	2	3	4
13. Trouble sleeping because of trouble breathing	1	2	3	4
14. Just didn't feel well	1	2	3	4

Self-Management of Heart Failure Questionnaire - Revised (SMHF-Rev)

Many patients have symptoms due to their heart failure. ***Trouble breathing*** *is the most common symptom of heart failure.*

15. In the past three months, have you had trouble breathing? Circle one.

1) No
2) Yes

SECTION C:

If you have NOT had trouble breathing in the last 3 months, SKIP THIS SECTION (16-18).

16. The LAST TIME you had trouble breathing, how quickly or easily did you recognize it as a symptom of heart failure? Circle one.

1) I didn't
2) It took me a while
3) Fairly quickly
4) Immediately

17. The **LAST FEW TIMES** you had trouble breathing, what did you do to relieve it?
Circle ALL that apply.

1) Reduced the sodium (salt) in your diet
2) Reduced your fluid intake
3) Took an extra water pill
4) None of the above

18. **IF YOU TRIED** reducing salt in your diet, reducing your fluid intake, or taking an extra water pill, did any of these things help relieve your trouble breathing? Circle one.

1) No, it did not help
2) Yes, it helped
3) I'm not sure if anything helped

Please fill in the date you completed this survey _____

Did someone help you complete this survey? ☐ ☐

Appendix I: Summary or Recoded Variables[a]

Recoded Variables:	0=not at risk	1=At risk
Race	0=whites	1=Non-Whites
Age	0=≤65	1=>65
Marital	0=married	1=not married
Education	0=>high school	1=< high school
Income	0=>$10,000	1=<$10,000
Insurance	0=medicare/private	1=Medicaid/uninsured
ER visits	0=≤2/yr	1=>2/yr
Hospitalizations	0=≤2/yr	1=>2/yr
NYHA	0=class I-II	1=Class III-IV
ACE-I	0=yes	1=no
B-BL	0=yes	1=no
Diuretics	0=yes	1=no
Duration	0=<6 months	1=>6 months
EF	0=>20%	1=≤20%
Health perception	0=Excellent/good (Good health perception) 1=fair-bad (poor health perception)	
Self-efficacy	0=>70% (high Self-efficacy) 1=<70% (Low self-Efficacy)	
Social Support	0=score >18 (High social support) 1=score<18 (low social support)	
Depressive symptoms	0=score <16 (not depressed) 1=score>16 (depressed)	
Self-management	0=score>14 (good self-management) 1=score<14 (poor self-management)	

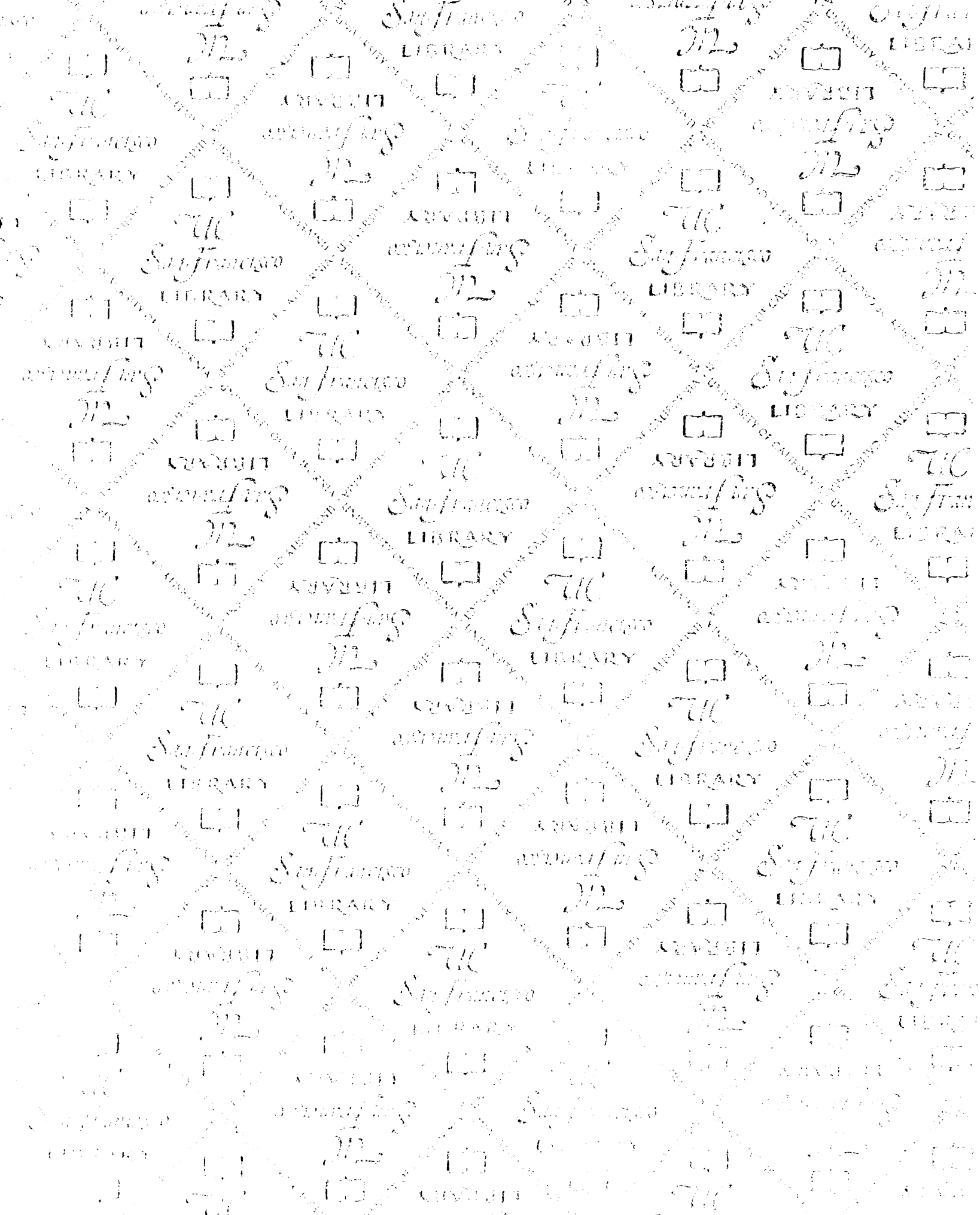
Note. [a] Representation of how demographic, clinical, and psychosocial variables were recoded as dichotomous variables.

Appendix J: Contingency Table for Self-Management Behaviors and Predictor Variables

Predictor Variables	**Self-Management Behaviors**	
	Good Self-Management % (n)	Poor Self-Management % (n)
Age < 65 y.o.	40% (19)	60% (28)
Age ≥65 y.o.	61% (11)	39% (7)
Total % (N)	46% (30)	54% (35)
Whites	52% (22)	48% (20)
Non-Whites	35% (8)	65% (15)
Total % (N)	46% (30)	54% (35)
Married	48% (10)	52% (11)
Not Married	46% (20)	55% (24)
Total % (N)	46% (30)	54% (35)
< high school education	57% (21)	43% (19)
>high school education	32% (9)	68% (19)
Total % (N)	46% (30)	54% (35)
Income <$10,000	44% (16)	56% (20)
Income >$10,000	50% (14)	50% (14)
Total % (N)	47% (30)	53% (34)
Insured	48% (15)	52% (16)
Uninsured	44% (15)	56% (19)
Total % (N)	46% (30)	54% (35)
<2 ED visits	48% (20)	51% (21)
>2 ED visits	42% (10)	58% (14)
Total % (N)	46% (30)	54% (35)
<2 hospital admissions	49% (24)	51% (25)
>2 hospital admissions	38% (6)	63% (10)
Total % (N)	46% (30)	54% (35)
NYHA class I-II	58% (15)	42% (11)
NYHA class III-IV	39% (15)	62% (24)
Total % (N)	46% (30)	54% (35)

Has diabetes	43% (15)	57% (20)
No diabetes	50% (15)	50% (15)
Total % (N)	46% (30)	54% (35)
Has HTN	40% (6)	60% (9)
No HTN	48% (24)	52% (26)
Total % (N)	46% (30)	54% (35)
Hx of MI	49% (16)	52% (17)
No hx of MI	44% (14)	56% (19)
Total % (N)	46% (30)	54% (35)
Has hyperlipidemia	46% (23)	54% (27)
No hyperlipidemia	47% (7)	53% (8)
Total % (N)	46% (30)	54% (35)
HF <2years	57% (8)	43% (6)
HF >2 years	44% (22)	56% (28)
Total % (N)*	47% (30)	53% (34)
EF<20%	56% (5)	44% (4)
EF>20%	44% (24)	56% (31)
Total % (N)*	45% (29)	55% (35)
Good health perception	33%(4)	68% (8)
Poor health perception	49%(26)	51% (27)
Total % (N)	46% (30)	54% (35)
High self-efficacy	47% (27)	53% (30)
Low self-efficacy	29% (2)	71% (5)
Total % (N)*	45% (29)	55% (35)
High social support	45% (24)	55% (29)
Low social support	55% (6)	46% (5)
Total % (N)*	47% (30)	53% (34)
Depressed	42% (19)	58% (26)
Not depressed	58% (11)	42% (8)
Total % (N)*	47% (30)	53% (34)

Note. * Data on total sample N=64.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