Exploring Self-care Among Low Socioeconomic Status Heart Failure Patients:

A Mixed Methods Study

BY

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THESIS

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This thesis is dedicated to my parents, Warren and Nancy DeKraay, and my family, Chloe, Helena and Brian who have given me the encouragement to succeed. I would also like to dedicate this dissertation to those amazingly, dedicated, hopeful, individuals who reminded me, every step of the way, that this was possible.
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<td>AUDIT</td>
<td>Alcohol Use Disorders Identification Test</td>
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<td>Bi-V</td>
<td>Biventricular</td>
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<td>CAD</td>
<td>Coronary Artery Disease</td>
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<td>CI</td>
<td>Confidence Interval</td>
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<td>CMS</td>
<td>Centers for Medicare and Medicaid Services</td>
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<td>DBS</td>
<td>Dried Blood Spot Test</td>
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<td>ED</td>
<td>Emergency Department</td>
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<td>EP</td>
<td>Electrophysiology</td>
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<td>HF</td>
<td>Heart Failure</td>
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<td>HFpEF</td>
<td>Heart Failure with Preserved Ejection Fraction</td>
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<td>ICD</td>
<td>Implantable Cardioverter-Defibrillator</td>
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<td>ICD-9-CM</td>
<td>International Classification of Disease, Ninth Revision Clinical Modification</td>
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<td>IRR</td>
<td>Crude Incidence Rate Ratio</td>
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<td>ISES</td>
<td>Individual-level Socioeconomic Status</td>
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<td>Neighborhood Socioeconomic Status</td>
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<td>Self-Care Heart Failure Index</td>
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<td>SES</td>
<td>Socioeconomic Status</td>
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<td>SPSS</td>
<td>Statistical Package of Social Sciences Software</td>
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<td>UHR</td>
<td>Unplanned Hospital Readmissions</td>
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<td>USDTL</td>
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SUMMARY

Heart failure costs the U.S. health care system $20.9 billion annually and is a serious public health burden to society.\(^1\) Eighty percent of heart failure (HF) costs are related to hospitalizations and unplanned hospital readmissions (UHR).\(^2\) Self-care has been identified as a foundation of HF management, and poor self-care has been identified as one reason for UHRs. Another factor influencing UHRs is socioeconomic status (SES); researchers have identified that patients with low SES have more UHRs than patients who have high SES. In recent years, researchers have examined the impact self-care has upon UHRs in patients with HF. However, the factors influencing self-care among low SES patients with HF experiencing a UHR has not been examined.

A mixed methods study using an embedded concurrent design was used to understand how family dynamics and individual factors influence self-care among low-SES patients who have HF. Qualitative data and quantitative data were collected from subjects \((n = 35)\) during a one-time interview during an inpatient stay at two publicly funded hospitals in Chicago. Inclusion was based on age \((> 18)\), language spoken (English), lack of a cognitive deficit, and whether the subject had experienced a HF UHR 180 days prior to the recruitment visit. The data were gathered using a semistructured interview, a blood test measuring alcohol use, a demographic survey, and survey tools measuring self-care, perceived stress, and alcohol use.

There are several novel findings from this study. (1) The majority of subjects performed inadequate self-care. (2) For many subjects, negative family dynamics and life circumstances (i.e., multiple family deaths) were related to inadequate HF self-care management and increased UHRs. (3) Subjects who experienced multiple poor interactions with health care systems, lived in high-crime geographic areas and experienced fragmented care (i.e., visit multiple hospitals)
demonstrated a high level of apathy and low motivation to engage with the health care system and pro-actively manage their HF. (4) Subjects with the highest number of UHRs were more likely to have a history of addiction or be current substance abusers.

The results of this study show the unique challenges experienced by HF patients with low SES. These life circumstances and individual factors play a critical role in HF self-care and HF UHRs. Further research is needed to develop strategies to identify these factors and design interventions to support self-care among this patient population.
I. INTRODUCTION

Heart failure (HF) costs the U.S. health care system $20.9 billion annually and is a serious public health burden to society.¹ Eighty percent of HF costs are related to hospitalizations and unplanned hospital readmissions (UHR).² HF is the number one reason elderly patients are admitted to the hospital and the number one reason patients are readmitted within 30 days of discharge.³,⁴ These data are not surprising because more than 5.1 million adults have HF, and HF is the leading discharge diagnosis for those greater than 65 years of age.³,⁴ Because life-prolonging therapies have been developed for HF patients and the population is aging, it is estimated that the number of patients with HF will increase by 23% between now and 2030.¹ This growth is faster than that of any other cardiovascular disease.¹ As a result, HF admissions and HF UHRs will continue to be significant burdens on society.

Reducing 30-day UHR for patients with HF has become a national priority.⁵ Hospitals that have excess UHRs are being financially penalized by the Centers for Medicare and Medicaid Services (CMS). Unplanned HF readmissions as well as excessive and inappropriate use of acute care services (e.g., emergency or urgent care settings) are the most costly medical expenses for a patient and the health care system.²,⁶ Nearly 24% of Medicare patients and 30% of Medicaid patients with HF return to the hospital within 30 days of discharge.⁷ In addition, UHR rates are higher among hospitals serving a disproportionate number of HF patients classified as having low socioeconomic status (SES) and who may be disproportionately affected by social determinants of health.
Knowing the importance of social determinants of health on the inequities of cardiovascular disease, professional organizations have published scientific statements and policy papers about the impact of social determinants of health on cardiovascular disease.9 Identifying the life circumstances and family dynamics among low SES HF patients experiencing a UHR could improve care for these patients and lower health care costs. Current risk models and clinical strategies to reduce readmission are inadequate to repair this problem.5,10-12 New research is needed to determine the causes of UHR among low SES HF patients so that new risk models and clinical strategies can be developed. There may be multiple reasons for high UHR among low SES HF patients; however, UHR among HF patients is often linked to some aspect of poor or failed self-care.13

Self-care is an “active cognitive process that persons engage in for the purpose of maintaining their health or managing their disease and illness.”14,15 Self-care can be impacted by patient characteristics such as race, income, multiple comorbidities, and health literacy.13,16,17 Heart failure self-care includes behaviors that maintain physiological stability (maintenance) and behaviors in response to symptoms when they occur (self-management). Self-care strategies include monitoring of symptoms, adhering to medications, exercising, maintaining diet, and contacting health care providers when symptoms worsen.18 Inadequate HF self-care has been identified as the most common cause of rehospitalization.11 However, results have been equivocal in self-care interventions to reduce HF UHR as have other strategies, such as arranging follow-up clinic appointments post-discharge.5 The results of a recent integrated review examining interventions associated with reducing 30-day HF UHR rates concluded that “knowledge of factors that affect readmissions remains in an early phase of research.”5
Therefore, studies using mixed methods approaches are needed to understand how other factors, both patient and environmental, may affect self-care and subsequently readmission.5

**Purpose**

The purpose of this mixed methods study was to explore individual factors and life circumstances and how they contributed to self-care and influenced UHR among HF patients with low SES.

**Specific Aims**

The specific aims were: 1. Describe the self-care practices among HF patients with low SES who experienced a UHR. 2. Characterize the contribution of individual factors and life circumstances to self-care among low SES patients who experience UHR. An exploratory aim of this study was to explore whether there are differences among the individual factors and life circumstances between HF patients with frequent UHRs and those with only one UHR.

To accomplish the specific aims, the following questions guided the research: What are the individual factors and life circumstances among HF patients with low SES and UHR and how do these individual factors and life circumstances affect self-care and UHR? Do individual factors and life circumstances differ across two groups of patients who are readmitted within 180 days ($\leq 4x$ and $\geq 5x$) among HF patients with low SES and a history of UHR?

**Theoretical Perspectives Guiding the Study**

The theoretical framework that guided this study was the Social Ecological Model (SEM).19 The fundamental principle of the SEM is that health and behavior and each of their determinants are interrelated. This model incorporates the important relationships among individual factors, life circumstances, and environment (or context), and recognizes their influence on an individual’s behavior.
The SEM provides a framework for understanding how individual health behaviors, such as self-care, are linked to a patient’s environment (in our case, among HF patients with low SES). The SEM describes five levels that are interrelated: intrapersonal factors, interpersonal factors, organizational, community, and public policy (Figure 1-1). Information about the five levels proposed by the SEM are from the patient’s perspective. It is proposed that these five levels in turn influence an individual’s self-care and UHR. In this study, semi-structured interviews were conducted to obtain a comprehensive description of the patient’s life circumstances and individual factors that may have impacted their self-care and UHR. Some of the quantitative and qualitative data was collected with both surveys and interviews. Quantitative tools, such as surveys, were used to measure patients’ perceived stress, alcohol use, and self-care. Patients were asked standardized questions about the number of comorbidities, number of people living in the home, type of insurance, and transportation methods to the hospital. The interview guide was designed to explore the patient’s experience prior to his/her UHR and identify factors impacting the patient’s ability to perform self-care. Open-ended questions were used to assess intrapersonal factors, such as stress, substance abuse, and self-care behaviors. Open-ended questions were also used to assess interpersonal factors related to life circumstances, such as family dynamics and social support. Questions were created to assess community factors and social stressors, such as exposure to crime and violence. Organizational factors were explored in questions related to patients' access to health care. Public policy factors were assessed with questions related to the patient’s perception of their publicly funded health insurance and crime in their community.
In summary, a concurrent embedded mixed methods study was employed with simultaneous data collection using both qualitative and quantitative sources. Semi-structured interviews and standardized instruments explored the multifaceted relationships among individual factors and life circumstances and self-care among HF patients with low SES who experienced UHR. Interpretation of the integrated data was intended to provide answers to questions that have evaded quantitative and qualitative researchers when those research methods were used alone. This study contributed to existing research by focusing on HF patients with low SES and UHR. This study focused on this patient population and their perspective of their self-care and reasons for UHR, whereas previous mixed methods research has been among low SES patients but was not disease-specific. Results from this mixed methods study will provide information that can be used to develop and test new risk models and innovative interventions.

Table I below lists definitions of terms used frequently in this study.
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<td>Acute care services</td>
<td>Health care services associated with the hospital or emergency department.</td>
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<td>Health care access</td>
<td>An individual’s ability to contact a health care provider (physically or remotely).</td>
</tr>
<tr>
<td>Health care utilization</td>
<td>An individual’s use of resources, such as the hospital, emergency department, or outpatient services.</td>
</tr>
<tr>
<td>Individual/Interpersonal factors</td>
<td>Alcohol abuse and stress</td>
</tr>
<tr>
<td>Interpersonal factors</td>
<td>Variables related to social support systems. Examples include social support and family dynamics.</td>
</tr>
<tr>
<td>Life circumstances</td>
<td>Family dynamics, economic issues, social support, living situation.21</td>
</tr>
<tr>
<td>Phosphatidylethanol (PEth)</td>
<td>Novel biomarker found in the blood to corroborate alcohol intake in the past 6 weeks.</td>
</tr>
<tr>
<td>Recruitment visit</td>
<td>Unplanned HF readmission during which patient was enrolled in this study.</td>
</tr>
<tr>
<td>Self-care</td>
<td>An active, cognitive process in which persons engage for the purpose of maintaining their health or managing their disease and illness.14</td>
</tr>
<tr>
<td>Sociodemographic factors</td>
<td>Variables related to an individual’s socioeconomic status and demographics.</td>
</tr>
<tr>
<td>Socioeconomic status</td>
<td>Traditionally conceptualized as the social standing of an individual or group.22</td>
</tr>
<tr>
<td>Social determinants of health</td>
<td>The social factors and physical conditions of the environment where people are born, live, learn, play work, and age.</td>
</tr>
<tr>
<td>Unplanned hospital readmission</td>
<td>An unplanned hospital readmission</td>
</tr>
</tbody>
</table>
II. LITERATURE REVIEW

Factors Associated with Unplanned Hospital Readmissions Among Patients with Low Socioeconomic Status

SES is conceptualized as one’s position in the social structure and encompasses lifetime access to knowledge, resources, and opportunities. Patients with low SES are 43% more likely to be readmitted than patients with high SES. For example, studies using census tract data as a proxy for SES have demonstrated that patients who live in a census tract with a poverty level in the lowest quintile had an increased 30-day readmission rate compared with patients living in the highest quintile. Using patient medical record data (N = 6832) obtained from a single medical site and controlling for patient demographics and medical conditions, patients living in high poverty, low education, and low household incomes were found to be at greater risk of readmission (odds ratio [OR] 1.32, 95% confidence interval [CI] 1.07-1.64). Using employment status or occupation as a proxy for SES, low SES was also found to be an independent predictor of readmission even after controlling for confounding factors such as comorbidities and age. In addition to being recognized as an important contributor to readmission in the general patient population, low SES is also associated with higher UHRs among HF patients.

There are data supporting a relationship between SES and UHR among HF patients. Tsuchihashi et al. examined variables that predicted the risk of readmission among HF patients (n = 236). Within one year after discharge, 35% were readmitted and “no occupation” was identified as a significant predictor of readmission ([OR] 2.6, 95% [CI] 1.2-5.5). Bikdeli et al.
examined the association between a composite measure of SES (i.e., income, education, and occupation) and six-month UHR among HF patients ($N = 1557$). After adjusting for New York Heart Association (NYHA) class, comorbidities, and laboratory test results (e.g., creatinine and troponins), patients in a low-SES neighborhood were more likely to have a UHR within six months than those living in high-SES neighborhoods (51.9% vs. 44.7%; OR 1.35, 95% CI 1.01-1.82; $P = 0.042$). Despite the data establishing an association between low SES and readmission among HF patients, the exact factors of SES and how they impact a patient’s readmission remain unknown. So far, the difficulty in identifying the factors has been partially explained by the lack of clinically reliable data from retrospective chart reviews and the lack of a standardized measurement of SES.

Theoretically, SES has been defined by incorporating three variables: income, education, and occupation. These variables are overlapping, but not identical. In addition, researchers have often used only one variable to capture and categorize a patient’s SES, but often not all three, which has made it impossible to make direct comparisons across SES studies. Comparisons of education and patient self-reported income suggest that self-reported income has a stronger relationship with health outcomes than area level indicators of income. Sheybogun et al. examined the relationship among the poverty-income ratio, education, and all-cause mortality among adults ($n = 15,646$) who participated in the third National Health and Nutrition Examination Survey (NHANES). The authors found self-reported income was a more robust predictor of mortality than education (OR 11 95%, CI 1.52-2.95).

Other SES variables used in large clinical trials have been insurance type (Medicaid vs. commercial) or census tract data identified from a patient’s zip code. Impoverished neighborhoods suffer from a lack of transportation, lack of access to health care, or lack of full
service grocery stores. Yet a review of the literature of measures of SES has determined census tract data from a patient’s zip code as the most frequently used SES variable in research studies. The ultimate goal of researchers and policy makers alike would be to find a measure of SES that can be collected easily, reliably, and consistently in this patient population. Unfortunately, there is no single SES variable that can be measured across generations, ethnicities, and geographic variations. For example, an income of $30,000 for a family of four living in Chicago is different from an income of $30,000 for a family of four living in rural Iowa. The accuracy of income as an indicator of SES is also questionable (i.e., elderly patients who own their home are insured by Medicare). Regardless of which tool is used to measure a person’s SES, multiple studies have established the relationship between low SES and increased rates of chronic disease, lack of preventive care, and shorter life expectancy.

Realizing that more data were needed to clarify “why” SES patients experience high UHR rates, several studies have been performed examining the impact SES has on patients with chronic diseases. These studies describe the unique challenges low-SES patients experience during their hospitalization and after discharge. Patients with low SES experience the transition (i.e., home to hospital after discharge) differently from patients with high SES. To examine the effects that low SES has on a patient UHR, Kangovi et al. surveyed patients (N = 1084) readmitted (patient diagnosis not indicated) about their transition experience post-discharge and compared these experiences across SES levels. Post-discharge, low-SES patients were more likely than high-SES patients to: 1) describe difficulty understanding and executing post-discharge instructions; 2) describe difficulty adhering to medications; 3) have higher rates of substance abuse, and 4) experience stress or depression.
Several qualitative studies have been conducted to elucidate the reasons for UHR among low-SES patients. Kangovi et al. interviewed 65 low-SES patients or their caregivers to explicate reasons for UHR. Patients believed discharge plans were misaligned with patient realities because many patients were concentrating on other socioeconomic challenges. In a different study, researchers conducted 21 semi-structured interviews with inner-city minority low-income patients readmitted within 6 months prior to enrollment into the study. Lack of understanding was not the cause of patients' UHR, but the UHR was influenced by variables such as distress, depression, illicit substance use, and lack of transportation to clinic appointments. The lack of transportation influenced patients' UHR in two ways: (1) hindered the patient’s ability to attend his/her clinic appointments and (2) because the patient did not have a car, patients’ family members who were working were only able to take the patient to the emergency department (ED) in evening hours.

Another qualitative study was performed to elucidate the factors associated with UHR among HF patients. Retrum et al. interviewed 28 patients who were readmitted within 180 days of an index HF admission. Based on patient experiences from the interviews, five themes were identified as reasons for readmission: distressing symptoms, psychosocial factors, adherence to self-care instructions, unavoidable progression of illness, and health system failures. Self-care issues were commonly cited and were usually diet, but in this study, patients did not feel lack of adherence to self-care instructions was the primary cause of readmission. Retrum et al. did not measure SES, and 13 of the readmissions were for a non-HF diagnosis. Despite SES not being measured in this study, six patients cited economic issues as occasionally preventing them from purchasing medications. The findings emphasized that causes of readmission are multifaceted and heterogeneous among this primarily Caucasian HF population. Therefore, these factors
should be more fully examined in a different HF population. The current study focused on further exploring the influences of individual factors on HF self-care and UHR in a low-SES patient population.

The above confirm the concept that patients with low SES experience the discharge and transition of care differently from patients with high SES. However, the gap in the literature resides in whether HF patients with low SES experience the same challenges and whether these factors influence a HF patient’s self-care. Self-care is vitally important among HF patients, and inadequate self-care is associated with UHR. Furthermore, no published data exist about whether HF patients with low SES have difficulty performing self-care, which therefore influences their UHR. Additional work is needed to identify the individual factors that influence self-care and UHR among HF patients with low SES.

**Self-Care in Heart Failure Patients**

While self-care was not noted explicitly in the aforementioned studies, individual factors such as attitudes and beliefs have been recognized as a possible influence on self-care behaviors of HF patients. Self-care is a process of attentiveness and action in response to alterations in a patient’s status, and self-care encompasses both maintenance and management. Maintenance involves strategies such as weight monitoring, following a strict medication regimen, and ingesting a low sodium diet. Self-care management refers to symptom identification, action in response to symptom (e.g., calling health care provider), and evaluation of treatment effectiveness.

Adequate self-care is the cornerstone of HF management and has been linked to HF knowledge, absence of depression or anxiety, adequate social support, and good cognitive function. Prospective studies examining self-care interventions and their relationship to
outcomes among HF patients are many, but the results have been inconclusive. DeWalt and colleagues performed a randomized controlled trial evaluating the effect of a self-management program on acute care service utilization among HF patients. Patients randomized to the intervention arm received self-care materials written for individuals with low health literacy. The materials emphasized daily weight measurement, diuretic dosing, symptom recognition, and appropriate response. Of the 123 patients enrolled (64 control, 59 intervention), patients in the intervention group had a lower rate of hospitalization or death (crude incidence rate ratio [IRR] = 0.69; CI 0.4, 1.2; adjusted IRR = 0.53; CI 0.32, 0.89). In an integrative review by Barnason et al., researchers examined interventions encouraging self-care in patients with HF. Studies frequently examined HF knowledge as the outcome of the intervention, and most of those studies reported significantly higher levels of knowledge in the intervention groups. However, discrepant findings were reported in studies examining self-care interventions to successfully decrease UHRs. Four studies reported successful self-care interventions decreasing UHRs, yet three studies found no difference in UHRs between intervention groups and control groups. Further research is needed to identify why self-care management strategies for HF patients have not been consistent in reducing UHRs.

Research is available examining self-care in other chronic diseases besides HF. Among low-SES patients with chronic diseases such as diabetes, hypertension, and chronic kidney disease, self-care is a significant issue. Among people with diabetes, poor self-care has been linked to diabetes complications and may explain health disparities in diabetes outcomes. Gordon et al. explored kidney transplant recipients' (N = 82) self-care strategies post-kidney transplant. Self-care practices in this patient population include adequate hydration, moderate physical activity, and maintaining a low-salt, low-cholesterol diet. The qualitative study revealed
that most patients were non-adherent to fluid requirements, and only 22% were engaging in regular physical activity. Common barriers included difficulty remembering to practice self-care, unavailability of funds to purchase fluids (kidney patients require increased fluid intake) or join a gym, and inaccessibility of low-salt or low-cholesterol foods.52

Although self-care in HF patients is a well-examined concept, an important gap in the literature is the lack of information about self-care among HF patients with low SES. In a mixed methods study examining the self-care behaviors among a low-SES HF patient population, Macabasco-O’Connell and colleagues explored the self-care behaviors of 65 low-income HF outpatients.53 For the qualitative arm, participants were asked three open-ended questions: “What are the major concerns about your disease? What gets in the way of taking care of yourself? What part of your treatment makes you feel better?” The Self-Care of Heart Failure Index (SCHFI) tool was used to measure self-care, and patients were conveniently sampled from an outpatient clinic visit. The investigators reported a high incidence of poor self-care among patients with an income < $10,000 and lower than a high school education (54%).53 The themes identified were worsening symptoms, concerns about finances, lack of access to care, and progressing heart problems. This sample was younger than the general HF patient population reported in other studies, had a higher incidence of non-ischemic HF, and employed a convenience sampling strategy to recruit patients from an outpatient clinic.53 The current study included a low-SES HF patient population, so the results can be used by others who are exploring self-care practices among HF patients with low SES and UHRs.

Individual Factors and Life Circumstances Associated with Self-Care

The present study examined individual factors, such as alcohol abuse, stress, and life circumstances, such as family dynamics and social stressors, that adversely impact a patient’s
ability to perform self-care, thereby leading to frequent UHRs. While the presence of certain types of life circumstances, such as social support, has been well examined in HF research, there is a lack of information about additional life circumstances, such as family dynamics and social stressors and their impact on self-care and UHR. Individual factors, such as alcohol abuse, have been examined in patient populations other than HF, and one of the few comprehensive studies examining alcohol use and readmissions found that, among surgical patients with alcohol use disorders, individuals experiencing alcohol abuse or alcoholism had an increased risk of UHR.54 The lack of data regarding the impact of certain individual factors and life circumstances on self-care and UHR among HF patients with low SES is surprising because intuitively these variables would have a relationship with self-care and UHRs.

**Alcohol Abuse**

Problem drinking, referring to the type of drinking of alcohol that causes difficulties in a person’s life, has been associated with increased health care service utilization.55 Alexandre et al. examined 253 problem drinkers and 1,225 non-problem drinkers and found that problem drinkers (i.e., those with a score > 4 on the Short Michigan Alcohol Screening Test) had a significantly greater number of outpatient visits, emergency room visits, and admissions to a hospital than non-problem drinkers (p < 0.05).55 In addition, others such as Lin et al. have shown in the setting of other chronic illnesses, such as schizophrenia, that those with alcohol use disorders had significantly higher 30-day readmission rates compared with those without alcohol use disorders.56 However, there is limited data in the area of HF and the impact of alcohol use disorders on 30-day UHRs in HF patients. Only one study could be found that examined the relationship between alcohol use and multiple readmissions among HF patients.57 In a retrospective chart review of veterans discharged from a VA hospital (N = 753), 220 patients had
a UHR with HF. Using multivariate analysis, alcohol use after the index admission was a significant predictor of a readmission (OR 5.92, 95% CI 3.83-9.13).

In the aforementioned studies, the reason alcohol use disorders lead to an increase in UHR for HF patients is unknown. It has been proposed that UHR in HF patients may be associated with poor self-care behaviors. For example, in patients with alcohol use disorders, patients may not have the ability to properly conduct weight monitoring or correctly respond to worsening symptoms. On the other hand, excessive alcohol use may lead to UHR because excessive alcohol use can lead to left ventricular dysfunction and decreased contractility. Both of the latter mechanisms can lead to decreased cardiac output and cause an increased HF exacerbation UHR. In the United States, about 67% of adult men and about 50% of adult women drink alcoholic beverages occasionally,\(^58\) and nearly half of the HF patients enrolled in the Studies on Left Ventricular Function described drinking 1 to 14 alcoholic drinks per week.\(^58\) It is important to note that 40% of patients with idiopathic dilated cardiomyopathy (a leading cause of HF) reported a history of excessive alcohol consumption.\(^59, 60\)

**Illicit Drug Use**

In the present study, in addition to screening the subject for alcohol use, the PI asked the subject open-ended questions about illicit drug use, such as heroin and cocaine. This is because, in some patient populations, the co-use of excessive alcohol and illicit drugs is prevalent. Similar to alcohol, these drugs may have adverse cardiovascular effects that lead to acute decompensated HF. In addition, there is evidence that use of illicit drugs is associated with increased use of acute care services, such as the emergency room.\(^61\) However, the exact prevalence of illicit drug use among HF patients is unknown.
There are several reasons the incidence of illicit drug use among HF patients is unknown. This in part might relate to either a lack of an established definition of illicit drugs or a lack of a standardized screening method for drug use or both. The definition of illicit drugs has changed over the years, and with recent updates regarding the legalization of marijuana, the definition will continue to change. Currently, there are nine major illicit drug classes: marijuana, inhalants, hallucinogens, cocaine, stimulants, heroin, sedatives, prescription opioids, and tranquilizers. However, there is no screening tool for all nine drugs.

There are no data on the relationship between HF UHRs and patients who use cocaine, yet there are data in the literature about cocaine use and its relationship to heart attacks and the development of incident HF. The incidence of cocaine cardiomyopathy is undetermined and probably underreported; however, animal experiments imply that cocaine-induced oxidative stress may induce the development of cardiomyopathy. Per the 2012 National Survey on Drug Use and Health, cocaine is the second most frequently used illicit drug in the U.S. and over a one-month period, 1.6% of the population used cocaine.

Due to the lack of a standardized screening method, identifying the prevalence of illicit drug use in hospitalized patients has been difficult. Yet, data do support an increase in use of acute health care services by patients who use illicit drugs. Wu et al. examined illicit drug use and alcohol abuse from the National Survey on Drug Use and Health using a computer-assisted self-interviewing method. They compared subjects who used the emergency department and those who did not. Those who used the emergency department had a higher incidence of illicit drug and alcohol use than patients who were not emergency department users (15.2% vs. 12.1%).
The data supporting associations between SES and increased use of illicit drugs and alcohol have been mixed.\textsuperscript{64} In a study examining the relationship between neighborhood SES and substance use among U.S. adults, there was increased illicit drug use among those adults who had a low income < $10,000 (OR 1.29, CI 0.62-2.68).\textsuperscript{65} In a literature review examining substance use by neighborhood SES, the authors found that most studies supported the hypothesis that a neighborhood considered low-SES is associated with both excessive alcohol and illicit drug use.\textsuperscript{34} However, three studies supported the opposite: neighborhood affluence and high-SES neighborhoods were associated with increased substance use.\textsuperscript{34} One reason the authors hypothesized for the conflicting results was because of the different defined outcomes or the definition of SES among the studies.\textsuperscript{34}

**Stress**

Perceived stress is a “measure of the degree to which situations in one’s life are appraised as disturbing.”\textsuperscript{66, p. 381} Stress has been associated with a multitude of negative health outcomes.\textsuperscript{67} However, the exact connection between stress and CAD remains unknown. Proposed physiologic models include potential mechanisms such as: increased sympathetic response and corresponding plasma norepinephrine levels related to anxiety and stress. In fact, increased norepinephrine levels are correlated with higher mortality rates in patients with HF.\textsuperscript{68} Others hypothesize that the relationship between stress and CAD may be related to coping methods people use in response to stress such as smoking, use of illicit drugs or alcohol, and failing to adhere to therapy.\textsuperscript{69} Poor coping methods can also affect a person’s self-care ability, leading to medication non-adherence, lack of symptom management, and dietary non-adherence.\textsuperscript{70} However, the data supporting the association between stress and negative health outcomes has primarily been derived from CAD patients or patients with other chronic diseases and not HF.
In addition, stress has been recognized as a risk factor for UHR in patients with CAD. Edmondson et al. examined 342 hospitalized acute coronary syndrome patients and the amount of stress they felt prior to index admission. High stress was associated with increased risk for UHR in both unadjusted (HR = 2.29, 95% CI 0.90-5.86) and fully adjusted models (HR = 3.21, 95% CI 1.13-9.10). Because CAD is a significant risk factor for the development of HF, these data would suggest that stress may play a role in UHR among HF patients.

Stress has been examined in the setting of SES and has been recognized as a factor in the association between low SES and the development of CAD. In a prospective longitudinal study of 24,443 participants without CAD at baseline, those individuals reporting the highest levels of stress had a higher possibility for incident CAD if they reported low income (sociodemographic-adjusted HR 1.36, 95% CI: 1.04-1.78) but not high income (sociodemographic-adjusted HR .82, 95% CI: 0.57-1.16).

High amounts of stress and its relationship to low SES can be characterized by a multitude of factors, including exposure to violence and crime, lack of financial resources, and many other obstacles and inconveniences people have living in poor communities. Other theories explaining the relationship between high stress and low SES suggest that stress is the result of the lack of “perceived control” those with low SES have over their life circumstances. Minorities experience racism and discrimination, which is also related to stress. However, most of the studies referenced have been cross-sectional and have not isolated the exact variables and their relationship between stress and SES. Therefore, stress was reflected in this study as a general construct that is known to affect health and well-being.

Stress management programs and interventions have shown that managing stress is an important component of successful self-care. Lynch and colleagues conducted a qualitative study
to examine the relationship between stress and diabetes self-care strategies among low-SES patients enrolled from two large urban hospitals. Low-SES African American and Mexican American diabetic subjects (N = 84) participated and were organized into 12 focus groups. Low-SES Mexican American patients were more likely to describe controlling stress as a method to manage their diabetes than African Americans. This study substantiated the importance in examining the relationship between stress and HF among low-SES patients.

While most current research examining the relationship between stress and the development of CAD found statistically significant relationships, the same association has not been identified between stress and HF. The causes of the development of HF have primarily been studied in physiological models but not in psychosocial models, leaving a gap in the literature regarding how psychological stress relates to HF. Results from this study will add to the body of literature understanding the relationships among low SES, HF, stress, and self-care.

**Family Dynamics**

For people with HF, several studies have examined the influence of social support on an individual’s self-care. Among HF patients, adequate self-care is linked to social support from family and friends, and marital support is linked to increased medication adherence. Despite the reported positive benefits of family support on HF self-care, negative family dynamics have also been reported in the social support literature. For example, family criticism is associated with negative health behaviors in patients with diabetes. Likewise, better family functioning has been associated with better self-care behaviors, but discordance between patient and family members is associated with an over-emphasis on symptoms like pain intensity and higher levels of fatigue and anger. In addition, among HF patients, negative family dynamics and personal struggles are associated with negative self-care behaviors. Riegel and Carlson examined the
barriers to self-care in 26 individuals with HF and identified personal struggles with family members as a barrier to self-care. Most research supports the critical role family support plays in adequate self-care, yet thus far, no published studies have examined the role negative family dynamics has on self-care among HF patients with low SES.

**Programmatic Approaches to Reduce UHRs**

Recognizing the high utilization of hospital services among patients with complex physical, behavioral, and social needs, several hospitals across the United States have implemented intensive outpatient care management programs targeting this specific population. Preliminary data suggest that these programs are effective at reducing the cycle of ED and hospital utilization among this patient population. However, successful interventions to prevent 30-day UHRs among HF patients with low SES have not been developed.

Contemporary interventions to prevent HF UHRs have mostly focused on improving coordination of care strategies. Strategies include intense inpatient education, medication reconciliation prior to discharge, follow-up appointments scheduled within seven days, and follow-up phone calls within 72 hours of discharge. However, care coordination has only been shown to minimally impact 30-day re-admission rates. A survey of hospitals enrolled in the Hospital to Home program (H2H), a novel and data-based intervention program, showed that less than 7% of hospitals implemented all the requisite strategies to reduce UHRs, and those that did not had only modest (0.14%) reductions in 30-day readmission rates.

Risk factors associated with HF UHRs have been identified and implemented in statistical and algorithmic models to predict whether a patient is at risk for readmission. However, these statistical models have shown little to no predictive value for readmission. The HF risk prediction model used by CMS controls for disease severity (i.e., ejection fraction,
clinical biomarkers, comorbidity, age and gender), but not sociodemographic variables. The lack of sociodemographic variables has been hypothesized as the reason that risk prediction models perform poorly. Results from several studies in a review have implicated sociodemographic variables as increasing the risk for UHRs in HF patients, but the studies did not assess the social factors with valid and reliable instruments or analyze the data with sophisticated multivariate techniques.

**Heart Failure Clinical Guidelines to Improve Outcomes**

In the most recent consensus practice guidelines, the authors recommend that health care providers identify factors that increase risk of readmission. In addition to clinical features, the authors mention behavioral, psychological, and social factors that can impact the ability to care for one-self and ultimately increase readmission rate. However, the guidelines do little to assist the clinician in measuring or assessing the relative importance of these features at a patient level. On a policy level, the guidelines do not make any accommodation for practices/centers that care for a disproportionate percentage of patients with these challenges.

**Summary and Gaps in the Literature**

Patients with low SES are readmitted more frequently than patients who have high SES, and several studies have examined the perspectives of low-SES patients for their reasons for readmission. Among HF patients with low SES, large epidemiological studies have also shown an association between low SES and readmission. However, among HF patients with low SES, no studies have explored the influence of individual factors and life circumstance on self-care from the perspective of readmitted patients. It is critical to understand why HF patients with low SES are readmitted to develop effective interventions to decrease unnecessary spending and improve outcomes in this vulnerable patient population.
This study is important for several reasons. First, exploring the patient perspective (qualitative component) as to which factors contribute to self-care may reveal new insights as to why HF patients with low SES experience unplanned hospital readmissions. Second, a prospective mixed methods study has not been performed in this patient population and will contribute to the knowledge base of HF readmissions by using a different type of research methodology. Finally, understanding the problem from the patient’s viewpoint will aid in developing strategies to assist this population to use alternative yet effective health care services.

Gaps in the literature include:

- It is unknown what roles life circumstances and individual factors play in HF self-care among low-SES patients.
- Mixed methods designs to examine life circumstances and individual factors influencing self-care have not been used in HF patients with low SES and may provide new insight.
- It is unknown the impact of alcohol abuse and stress in HF patients with low SES in relationship to self-care.
III. METHOD

This chapter details the study design, setting, and sample; data collection methods; and statistical analysis. Also reviewed are tools and questionnaires to measure SES, self-care, alcohol abuse, and stress. An embedded concurrent design was used, in which quantitative data were embedded within a qualitative study. Although multiple variables influence a patient’s interaction with the health care system, this research focused on variables not frequently studied in HF research. The qualitative and quantitative data were integrated during the analysis phase, and the quantitative data were used to elaborate on the findings of this predominantly qualitative study.

Design, Setting, and Sample

This mixed methods study used an embedded concurrent design, in which one data set provided a supportive, secondary role (quan) to the primary data set (QUAL). A visual model of the design is provided in Figure 3-1.89
Qualitative data and quantitative data were collected during the one-time interview using semi-structured interviews and standardized instruments. The qualitative data were the dominant data set, and the quantitative data were used to supplement the qualitative findings.

Subjects were enrolled from two urban academic hospitals located in Illinois (University of Illinois Hospital [UIH] and Stroger Hospital of Cook County [Stroger]). Both hospitals serve low-SES minority patient populations who are publicly insured or uninsured. Approximately 259 patients are discharged per year from the UIH inpatient service with HF as the primary diagnosis. In 2012, the UIH HF 30-day patient readmission rate was 24% (all-cause). UIH’s HF population is 70% African American, 15% Hispanic, and 8% Caucasian. Approximately 450 patients are discharged every year from Stroger with HF as the primary diagnosis. In 2012, the Stroger’s HF 30-day patient readmission was 25.5% (all cause).
A purposive sampling method was used to recruit hospitalized patients with HF and low SES who were readmitted with a HF exacerbation. Similar to other mixed methods studies, the target enrollment was 35 HF patients. The number of subjects in a mixed methods study is small to allow for in-depth information about the qualitative concept being explored. Data saturation for this study was met with a sample size of 35 subjects. The list below details the study inclusion and exclusion criteria.90 91

**Inclusion Criteria**

- Currently hospitalized with the diagnosis of HF (HF with reduced ejection fraction or HF with preserved ejection fraction) and hospitalized for HF in the previous 180 days
- Age 21 years or older
- Able to read and understand English and give informed consent
- Low SES by one of the following categories:
  - Subject living in a census block where 30% of the individuals were living below the poverty level
  - Family income < $35,000

**Exclusion Criteria**

- Documented neurological disease

**Recruitment Procedures**

**Identification of Eligible Subjects**

The PI screened potential subjects through daily rounds of HF inpatients at UIH and Stroger. The PI reviewed medical records of the subject to identify whether the subject met eligibility criteria. If eligible, the PI approached the patient, and the procedures and risks of the study were explained to the patient. Interested and eligible patients were invited to participate in
the study, and informed consent was obtained. After consent, the subjects completed questionnaires, and the PI conducted a semi-structured interview; lastly, PEth data were collected. All subjects were compensated ($20) for their participation.

**Qualitative Data Collection**

Semi-structured interviews were conducted that focused on life circumstances and individual factors and how they influenced the subject’s self-care and UHR. Topics covered in the interview included: stressors associated with patients’ living circumstances, strategies patients used to foster self-care, family dynamics, alcohol and illicit drug use, and coping strategies patients used to decrease stress. Subjects were encouraged to fully describe their life circumstances and how circumstances influenced their self-care (Appendix F). To assess individual factors influencing the subject’s self-care, subjects were asked a series of open-ended questions. To promote additional explanation by the subject, the researcher used two styles of probes: thoughtful silence and clarifying questions. Clarifying questions included phrases such as “What do you mean by that?” and “Tell me more about a time that happened.” Questions used in the interview were developed from a literature review, the PI’s clinical experience, and early data analysis after pilot testing the interview on two HF patients. The interviews were conducted in the patient’s private hospital room, or, if the patient was sharing a room, the interview was conducted in a private office located in the hospital. During the interview, the PI recorded the interview using two tape recorders.

**Quantitative Data Collection**

**Medical Record Review**

Data on gender, race, age, duration/etiology of HF, medications, comorbid conditions, and NYHA class on admission were extracted from the medical record (Appendix A).


**Sociodemographic Data**

Data were self-reported by the subject (Appendix B).

**Measures**

**Unplanned Hospital Readmission**

As noted in Table I, UHRs were defined as any readmission within the previous 180 days of the recruitment visit. Several qualitative studies examining reasons for UHRs in low-SES patients have used 180 days as a readmission cut off to capture a range of patient experiences. UHRs were collected from self-report and the medical record. UHRs were further defined as *all-cause UHRs* for those readmissions that were for any other diagnosis besides HF and *HF UHRs* for those where HF was the primary admission reason.

**Socioeconomic Status**

SES is traditionally defined by a person’s education, income, and occupation. SES is usually measured with one variable: income. Previous research has suggested that income may be the strongest predictor of health, but emerging research suggests geographic-level SES indicators may also be good indicators. Due to the lack of a consensus in the literature of a standardized SES tool, we measured SES at the individual level (ISES) and neighborhood level (NSES). If the patient had either low NSES or low ISES, the patient was considered “low SES.”

**Neighborhood-SES (NSES).** NSES was measured with zip code (census tract). Participants living in a census block characterized by more than 30% of residents living below the federal poverty level were classified as low NSES. Census tract data were extracted from the 2010 U.S. Decennial Census Data and the results from the 2015 American Community Survey. Bikdeli et al. studied both area levels of SES and individual SES (income) and their relationship to outcomes for 1,557 patients with HF. Among patients with HF, low NSES was
significantly associated with 6-month all-cause readmission (OR 1.49; 95% CI, 1.04-2.13). Additional studies have established the predictive validity of this method using mortality or urgent readmission as an outcome.\textsuperscript{93, 94}

**Individual-level SES (ISES).** ISES was a self-reported measure and was based on income. Previous research using ISES as an indicator of low SES has established a relationship with poor outcomes, such as mortality.\textsuperscript{32, 36} Powell and others recruited patients from Stroger hospital (and two other metropolitan Chicago hospitals) to evaluate the effectiveness of a self-management program in 902 patients with HF.\textsuperscript{95} Subjects reporting an annual household income below the $30,000 were considered low SES. The results of the trial showed significant interaction between the treatment groups and their self-reported income, suggesting that self-management counseling is beneficial for low-income patients.\textsuperscript{95} Since this study recruited patients from October 2001 through October 2004, we increased the cut-off in our study to $35,000 to reflect inflation.

**Heart Failure Self-Care**

The Self-Care of HF Index (SCHFI) has been used frequently in HF research to measure an individual’s self-care practices and beliefs. The SCHFI is a reliable and valid instrument with 22 items measured on a 4-point Likert scale.\textsuperscript{96} The items form three different subscales: self-care maintenance, management, and confidence. Self-care maintenance has 10 items measuring symptom monitoring and compliance behaviors that prevent HF exacerbation. The self-care management scale has 6 items measuring the patient’s ability to recognize symptoms and implement treatment. The self-care confidence scale has 6 items to measure the patient’s perceived ability to manage their HF. Scores on each of the SCHFI scales are standardized to 100, with higher scores indicating better self-care.\textsuperscript{97} A cut point of 70 or greater on each of the
SCHFI scales was established by Riegel et al. (2009) as indicating adequate self-care.¹³ Construct validity was established by Dickson et al.¹⁷ In a mixed methods study of an ethnic minority black population with HF (N = 30) Dickson et al. used the SCHFI to measure self-care.¹⁷ Construct and discriminant validity have been demonstrated by factor analysis with lower than desired reliability coefficients for self-care management (0.59) and self-care maintenance (0.59) and adequate for self-care confidence (0.84).⁹⁷ In this study, we used the SCHFI tool to determine subject’s self-care ability and whether it related to the subject’s individual factors and life circumstances (Appendix C).

**Stress**

The Perceived Stress Scale (PSS-10) was developed by Cohen to evaluate an individual’s perception of stressful events. The PSS-10 items were designed to assess the extent to which subjects find their lives unpredictable, uncontrollable, and overloaded. The PSS assesses an individual’s perception of global life stress over the last month rather than specific stressful events or situations and has correlated with health and health-related outcomes. The PSS-10 is a 10-item multiple-choice test that takes 2-3 minutes to administer and has been used in several studies examining health outcomes related to stress. Respondents answer using a 5-point Likert scale including never, almost never, sometimes, fairly often, and very often. The scale produces a single score, with high scores indicating higher levels of stress. Total scores range 0-40. Cohen et al. reported concurrent and predictive validity of the PSS-10 and test-retest reliability of 0.85.⁹⁸ Further work by Schwarz et al. found Cronbach's alpha of 0.86.⁹⁹ In a study examining the association of perceived stress with incident coronary artery disease (CAD), researchers prospectively enrolled 24,443 participants without CAD at baseline. Results were stratified by income (representing low SES) and stress. Participants who reported high stress were more likely
to be female and African American. High stress was associated with greater risk of incident CAD and death for individuals with low income (HR 1.55, 95% CI 1.31, 1.82) but not high income (HR 1.13, 95% CI: 0.88, 1.46). The PSS-10 is also part of the NIH Toolbox for the evaluation of neurological and behavioral function. In this study, we used the PSS-10 to determine subjects' perceived amount of stress related to their self-care and hospital admission (Appendix D).

**Comorbid Conditions**

The number of comorbid conditions was calculated using the International Classification of Disease, Ninth Revision Clinical Modification (ICD-9-CM). These data were gathered from the medical record, and all diagnoses in the medical records were documented. To address issues of poor documentation by health care providers related to psychiatric illnesses, the subject was considered to have a psychiatric illness if they were on a psychiatric medication. The comorbid conditions measured are listed in Appendix A.

**Alcohol Abuse**

Alcohol abuse was measured using the Alcohol Use Disorders Identification Test (AUDIT), a 10-item scale assessing three domains of alcohol use and abuse. The three subscales are: dependence symptoms, hazardous alcohol use and abuse, and harmful alcohol use. The AUDIT total score ranges 0-40. Among adults (≥18 years), a score of 8 or more indicates hazardous drinking or “problem drinking,” whereas greater than a 13 indicates alcohol abuse. The AUDIT is a validated scale used worldwide to identify individuals with hazardous alcohol use patterns and is used to identify individuals at risk of alcohol use disorder (Appendix E).
**Phosphatidylethanol (PEth)**

PEth levels were measured using a dried blood spot test (DBS). The DBS method allows for noninvasive and cost-effective approaches for the measurement of biomarkers in clinical and population studies. A fingerpick is required for 5 blood drops onto a DBS card. The DBS card is sent within 24 hours of collection to United States Drug Testing Laboratories, Inc. (USDTL, Des Plaines, IL) for analysis. The limit of quantification for DBS PEth is 8 ng/mg.

**Data Analysis**

**Qualitative Data Analysis**

Content analysis was used to analyze qualitative data. Qualitative data analysis began after data collection and occurred with several steps. To prepare the data, the interviews were electronically recorded and transcribed by a professional transcription service into Word files. Once in a Word document, the transcriptions were checked for accuracy and compared to handwritten notes taken during the interview. The Word document was entered into the ATLAS.ti program.

The ATLAS.ti program allows large amounts of data to be consolidated into one program and systematically analyzes text to identify a phenomenon. It also provides analytical and visual tools to organize the data. There are two essential level for analyzing data with ATLAS.ti. (1) textual and (2) conceptual. The textual level includes coding text, writing text, and including memos. The conceptual level focuses on model building, forming thematic networks, and linking codes in diagrams.

A codebook was developed during data analysis through an iterative process of coding and then identifying emerging themes. Emerging themes both within case and across coding categories were incorporated into the codebook. To identify common themes among subjects, the
PI performed within-case analysis and across-case analysis (Table II). During within-case analysis, the PI analyzed the qualitative data by becoming immersed in the individual interview. The PI performed line-by-line analysis of the transcript to identify codes, and also identified re-occurring themes within case interviews (Appendix G). Initially within-case analysis grouped the codes within categories of the social ecological model and the domains of the SCHFI model (self-care confidence, self-care management, and self-care maintenance). Secondly, the PI performed across-case analysis and identified similar codes common to all participants (Appendix H). The PI reconnected any within-case significant statements or themes with the general themes identified from across-case analysis. Coding categories were revised when emerging themes were identified and verified by a second person who had experience with qualitative data analysis.

| TABLE II |
|---|---|
| WITHIN- AND ACROSS-CASE ANALYSES STRATEGIES | |
| **Strategy** | **Data Analysis** |
| Line by line review | Within-case analysis |
| Identifying codes | Within-case analysis |
| Re-occurring themes | Within-case analysis |
| Comparison of significant statements | Across-case analysis |
| Comparison of themes | Across-case analysis |
| Re-connection of significant statements and individual themes and general themes | Within and across-all cases |
Quantitative Data Analysis

Analysis of the quantitative data occurred at the completion of the study. Because this was an embedded study with QUAL being the primary design and the number of subjects was small (35 subjects), the type of statistical analysis was limited. Demographic and health information was analyzed using descriptive statistics. Medians and ranges were calculated and used to supplement means and standard deviations whenever it was appropriate. All statistical analyses were performed with Statistical Package of Social Sciences Software (SPSS) version 22.

Integrated Data Analysis

The qualitative and quantitative data were integrated during the analysis phase following the completion of the study. Interpretation of the results involved removing oneself from the detailed results and taking a larger view of the findings. The narratives of the perceptions of factors influencing the patient’s self-care management and UHR and the quantitative scores of the number of UHRs within 180 days served as the anchor for the analysis of the integrated data (QUAL+quan).

During the final analysis phase, data were integrated rather than maintaining independence of the qualitative and quantitative results (Appendix I). Using triangulation methods, the PI analyzed the secondary data results (the quantitative findings of the self-care management results) to similar qualitative themes.\(^9\) This was completed with each individual subject and then as a group. Divergence and convergence of the quantitative and qualitative results were examined between the two data sets. Divergent findings were examined, documented, and accounted for during interpretation.
Methodological Rigor

Maintaining methodological rigor was necessary to ensure the validity of the data, results, and their interpretation. Reliability and validity are two methods to establish credibility. In the (QUAL+quan) embedded mixed methods design, reliability and validity are primarily related to the qualitative data. In qualitative research, there is more of a focus on validity than reliability to determine whether the account provided by the subject is credible. In this study, validity was established with triangulation and peer debriefing. Triangulation is when two or more methods of data collection are used to confirm results. The data collected from the quantitative tools were used to support the data collected from the interviews. A second method to establish validity was peer debriefing. Peer debriefing included a review of the preliminary qualitative data with Advanced Practice Nursing HF experts. Peer debriefing was implemented periodically throughout data collection. Peer debriefing occurred with another HF nurse practitioner and a HF nurse expert. The truthfulness of the qualitative data was enhanced by the approval of the interpretation by these heart failure clinicians who have extensive experience in working with the patient population defined. Peer debriefing occurred periodically and included a review of the preliminary qualitative data.

To increase the trustworthiness and validity of the data, the PI and another doctoral student coded a subset of transcripts using the codes from the codebook. The doctoral student had extensive experiencing in coding and interpreting qualitative data. The PI and doctoral student discussed each code line by line, and if there was a discrepancy in a code, it was discussed whether the code should be adapted or changed. This process occurred more frequently in the earlier stages of analysis and tapered off as coding became more consistent over time.
Ethical Considerations

Potential Risks

The risks of this study were primarily associated with the stress patients could experience when responding to interview questions. Talking about issues related to social issues could have made patients feel uncomfortable, and the researcher looked for signals indicating the patient was experiencing stress. The researcher recognized the potential for further questions about stressors and was prepared to refer patients to an inpatient social worker for further available resources.

Human Subject Protection and Informed Consent

Participants were informed prior to the interview that they had the right to refuse to participate at any time without consequence. Confidentiality was maintained through the use of participant codes on the interview transcripts and demographic data forms.

Potential Problems and Limitations

A limitation of the mixed methods design is that the purposive sampling strategy was driven by the qualitative approach. All patients who met inclusion criteria were potential subjects, but due to the researcher not being available at all times, this limited the ability to recruit subjects to those who were available on the days of data collection. While the study was not sufficiently powered to conduct multivariate analyses of individual and life circumstance, the quantitative data allowed for integration of data.
IV. RESULTS

This chapter presents the results of this mixed methods study. The first section describes the demographic and HF characteristics of the patient sample; subsequent sections present results from the SCHFI, PSS-10, and AUDIT instruments. The PEth results are then presented. The results from qualitative analysis are described after that, followed by presentation of the results from the integrated analysis.

**Demographic Characteristics**

The majority of subjects \( n = 35 \) were African American, and ages ranged from 36 to 89 years (Table III). Many of the subjects had a nonischemic HF etiology, whereas 25.7% had an ischemic etiology. A majority of subjects had HF with reduced ejection fraction (HFrEF; 54%) and the remainder had an HF with preserved ejection fraction (HFpEF; 43%). The number of comorbidities ranged from 0 to 10 with the majority of participants having hypertension (88%), hyperlipidemia (60%) and an atrial arrhythmia (51%). The mean length of HF duration was 4.8 years \( \pm 4.6 \) (range 6 months to 20 years) with 40% of subjects having HF for two years or less.

The majority of the subjects did not graduate from high school (63%) and only 8.6% reported having a college education (Table III). Eleven percent of subjects were homeless. The majority of subjects reported living in Chicago communities that were experiencing large amounts of violence as reflected in high 2015 homicide rates for these geographic areas\(^{106}\) (Appendices J and K).
### TABLE III
DEMOGRAPHICS ($n = 35$)

<table>
<thead>
<tr>
<th></th>
<th>Mean ± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Yrs)</td>
<td>60 ± 12.76</td>
</tr>
<tr>
<td>Years with HF</td>
<td>4.8 ± 4.6</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>18 (51.4)</td>
</tr>
<tr>
<td>Female</td>
<td>17 (48.6)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>AA</td>
<td>32 (91.4)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 (5.7)</td>
</tr>
<tr>
<td>White</td>
<td>1 (2.9)</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;8th grade</td>
<td>3 (8.6)</td>
</tr>
<tr>
<td>Did not graduate high school</td>
<td>19 (54.3)</td>
</tr>
<tr>
<td>High school graduate</td>
<td>5 (14.3)</td>
</tr>
<tr>
<td>Few years of college</td>
<td>5 (14.3)</td>
</tr>
<tr>
<td>College</td>
<td>3 (8.6)</td>
</tr>
<tr>
<td><strong>Annual household Income</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;30,000</td>
<td>33 (94.3)</td>
</tr>
<tr>
<td>&gt;30,000</td>
<td>2 (5.7)</td>
</tr>
<tr>
<td><strong>Low SES neighborhood</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>28 (80)</td>
</tr>
<tr>
<td>No</td>
<td>3 (8.6)</td>
</tr>
<tr>
<td><strong>Homeless</strong></td>
<td></td>
</tr>
<tr>
<td>Homeless</td>
<td>4 (11.4)</td>
</tr>
<tr>
<td><strong>Hospital</strong></td>
<td></td>
</tr>
<tr>
<td>UIC</td>
<td>17 (48.5)</td>
</tr>
<tr>
<td>Stroger</td>
<td>18 (51.4)</td>
</tr>
<tr>
<td><strong>Ejection Fraction</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;20%</td>
<td>11 (31.4)</td>
</tr>
<tr>
<td>21-30%</td>
<td>5 (14.2)</td>
</tr>
<tr>
<td>31-40%</td>
<td>3 (8.5)</td>
</tr>
<tr>
<td>41-50%</td>
<td>2 (5.7)</td>
</tr>
<tr>
<td>&gt;51%</td>
<td>13 (37.1)</td>
</tr>
<tr>
<td><strong>EP Devices</strong></td>
<td></td>
</tr>
<tr>
<td>Bi-V or ICD</td>
<td>6 (17.1)</td>
</tr>
</tbody>
</table>

Abbreviations: Bi-V, biventricular; EP, electrophysiology; ICD, Implantable cardioverter-defibrillator
Health Care Organization Follow-Up

Only one subject did not have insurance, but this subject was receiving assistance to apply for insurance during their hospitalization. Eighty-five percent (N = 30) of the patients had a follow-up clinic appointment after their last admission; however, 16 of the participants who had a follow-up appointment did not make their appointment. Only two individuals drove themselves to their clinic appointments, while 49% had someone else drive them to their clinic appointments. 26% of individuals relied on public transportation to their clinic appointments, while 20% arranged transportation through public aid or the hospitals’ assistance.

Unplanned Hospital Readmissions (UHR)

During the 180 days prior to the recruitment visit, all-cause UHR averaged nearly 4 UHRs per patient (range 2 to 12). For 23% of patients, the Recruitment Visit occurred within 2 weeks of a prior hospitalization (Table IV). The average length of stay for the most recent HF UHR prior to the Recruitment Visit was 4 days (range of 2-8 days). The most frequently cited symptom during the Recruitment Visit was shortness of breath (94.3%).

<table>
<thead>
<tr>
<th>TABLE IV</th>
<th>UNPLANNED HOSPITAL READMISSIONS DURING 180 DAYS PRIOR TO THE RECRUITMENT VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Unplanned Hospital Readmissions</td>
<td>Mean ± Std Dev</td>
</tr>
<tr>
<td>All-cause (HF + other diagnosis)</td>
<td>3.91 ± 1.9</td>
</tr>
<tr>
<td>HF-related</td>
<td>3.09 ± 1.34</td>
</tr>
<tr>
<td>Length of time between Recruitment Visit and previous HF hospitalization</td>
<td>N (%)</td>
</tr>
<tr>
<td>1 week</td>
<td>5 (14.3)</td>
</tr>
<tr>
<td>2 week</td>
<td>3 (8.6)</td>
</tr>
<tr>
<td>1 month</td>
<td>8 (22.9)</td>
</tr>
<tr>
<td>2 month</td>
<td>5 (14.3)</td>
</tr>
<tr>
<td>3 month</td>
<td>5 (14.3)</td>
</tr>
<tr>
<td>4 month</td>
<td>4 (11.4)</td>
</tr>
<tr>
<td>5 month</td>
<td>4 (11.4)</td>
</tr>
<tr>
<td>6 month</td>
<td>1 (2.9)</td>
</tr>
</tbody>
</table>
Social Support and Housing

Most subjects were living with another person or group of people (69%). Thirty-four percent reported living with a significant other or family member, and 23% were living with 3 or more individuals. Four individuals were homeless.

Self-Care Heart Failure Index (SCHFI)

A score $\geq 70$ on each of the SCHFI subscales indicates adequate self-care (Table V). A low percentage of subjects had adequate self-care management (8.5%) and adequate self-care maintenance (17%; Table V). The highest scores were found with the self-care confidence scale, for which 23% were found to have adequate self-care confidence.

<table>
<thead>
<tr>
<th>SCHFI</th>
<th>Mean ± SD</th>
<th>(Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care Management Scale</td>
<td>46 ± 17</td>
<td>(5-75)</td>
</tr>
<tr>
<td>Self-Care Maintenance Scale</td>
<td>52 ± 19</td>
<td>(13-86)</td>
</tr>
<tr>
<td>Self-Care Confidence Scale</td>
<td>56 ± 17</td>
<td>(22-88)</td>
</tr>
</tbody>
</table>

Percent with cut-off score of $\geq 70$

<table>
<thead>
<tr>
<th>SCHFI</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care Management</td>
<td>8.5%</td>
</tr>
<tr>
<td>Self-Care Maintenance</td>
<td>17%</td>
</tr>
<tr>
<td>Self-Care Confidence</td>
<td>23%</td>
</tr>
</tbody>
</table>

Perceived Stress Scale (PSS-10)

The mean PSS-10 score was 15 ± 8 (SD), and values ranged 0-30. Scores greater than 20 indicate high perceived stress, and 34% of subjects had PSS-10 scores greater than 20.
Alcohol Use Disorders Identification Test (AUDIT)

Sixty percent of the subjects \((n = 21)\) reported that they never drank alcohol. The mean AUDIT score was \(1.4 \pm 5\). Scores greater than 8 indicate “hazardous” or “problem drinking” whereas greater than a 13 indicates alcohol abuse. Only one subject scored above “problem drinking” cut point (AUDIT score = 26).

Phosphatidylethanol (PEth)

Among the 35 subjects in this study, three tested positive (mean 118 +/- 82 ng/mL). The cutoff level for a positive PEth test was 8 ng/mL. Of note, none of these patients had an abnormal AUDIT score.

Qualitative Analysis

Three overarching themes emerged from the qualitative analysis: (a) diminished health care autonomy, (b) resignation to fate, and (c) life circumstances and family dynamics overwhelmed the subject’s ability to perform adequate self-care (Table VI). Next, the emergent sub-themes were summarized and presented in eight categories: (a) life circumstances and family dynamics, (b) experiences with death, (c) self-care management practices, (d) dietary practices, (e) attitudes toward health care system, (f) social support, (g) stress, and (h) intrapersonal feelings. A biography of each subject is listed in Appendix L.

Overarching Themes

Overarching themes are shown in Table VI.
TABLE VI
OVERARCHING THEMES

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diminished health care autonomy</td>
<td>The subjects do not activate the health care system on their own. This is either because he or she is dependent on others for transportation or dependent on atypical social support. Also, past experiences in which the subject was unable to contact a health care provider by phone, or negative events the subject experienced at other hospitals, diminished the subject’s motivation to engage the health care system.</td>
</tr>
<tr>
<td>Resignation to fate</td>
<td>Subject believes in God, but subject is resigned to their fate. They believe they do not have control of their life circumstances.</td>
</tr>
<tr>
<td>Life circumstances and family dynamics overwhelm subject’s ability to perform adequate self-care</td>
<td>Subject has negative life circumstances and negative family dynamics that impact his/her ability to monitor or intervene in his/her own self-care.</td>
</tr>
</tbody>
</table>

Diminished Health Care Autonomy

Subjects described how they experienced *diminished health care autonomy* throughout the passages that described self-care and life circumstances and family dynamics. Diminished health care autonomy occurs when a subject is unable to activate his/her own health care. The theme *diminished health care autonomy* was developed from the subjects' descriptions of past experiences. Past experiences included negative interactions with the health care system, which diminished motivation to seek health care. Subjects other negative past experiences or lack of access to the health care system led the subject not to engage in self-care. These past experiences shaped the subject’s feelings of failure to perform adequate self-care. The following is an example.
One 66-year-old subject, Mr. H, had HF for three years and had been readmitted five times in the last 180 days. He lived at home with his girlfriend of three years. His wife died 4 years earlier from cancer. His 9-year-old granddaughter also lived in the home. He was a recovered alcoholic and retired from being a janitor for 35 years. He was admitted to the hospital after not filling his prescriptions the week before and becoming fluid overloaded. He stated that he did not feel it was very important to get his medications refilled. Because of his past experience of not being able to contact health care providers by phone, he thought he could wait to talk to his health care provider about his prescription at his next clinic appointment. He did not try contacting his health care provider and did not have transportation to the clinic. His girlfriend was “fussing” at him to go to the doctor to evaluate his swollen legs and increased shortness of breath, but he wanted to wait until his previously scheduled clinic visit. In the past, he had difficulty arranging transportation and did not want to call an ambulance because the ambulance would take him to a different hospital from the one he preferred. When asked why he was admitted, his response was:

“I don’t know. I guess I wasn’t eating right, eating too much salt; it sounds like that.”

Mr. L was a patient who had an extensive history of crack cocaine abuse. He had tried to arrange transportation in the past, but was unable to pay the $3 co-pay, so he never made any of his clinic appointments. He had run out of medicine one week prior to his admission and had not tried to contact his health care provider for more medicines. He walked to the emergency department when he was short of breath and could only walk 10 steps at a time.

(#16) I just wake up and get by
Resignation to Fate

Subjects were categorized as having *resignation to fate* when they were accepting of whatever happened to them as something they could not control—whether it was positive or negative. Most subjects would invoke this theme after they had explained a series of negative events—including their HF getting worse and how they knew something from a higher power had something better in store for them.

Mr. J was a 36-year-old who recently experienced several negative life experiences and did not have any social support. Mr. J had recently become homeless after living in an apartment without heat during the winter, he had been robbed several times, and his HF was getting progressively worse. He also expressed grief regarding his mother’s death three years earlier.

(13) “So I just kinda just deal with it, you know, without being resentful and being mad about it. I just accept it until I can see the rainbow at the end; I mean the pot of gold at the end of the rainbow.”

Throughout the passages of subjects describing their life experiences, subjects acknowledged their belief in God and how their spiritual faith assisted their acceptance of their health, lives, and communities. *Resignation to fate* was often expressed when an individual was discussing multiple events that would be considered stressful to most. The example below illustrates *resignation to fate*.

Mr. J was a 36-year-old male who was readmitted within 3 weeks of his first HF exacerbation. He was recently out of prison and unemployed and trying to become a rapper. He did not have a permanent home and was living with various friends. Mr. J explained how several of his family members had died and also discussed his son’s death.
from a medication error at a hospital. He explained how his belief in God made it easier to accept these events.

(#22) “God got something for me. And He already knows what I’m in store for, so I’m just getting myself right for it.”

Mr. K was a 59-year-old who had been readmitted three times to three different Chicago area hospitals in the last 180 days. He had five comorbidities, including a stroke that caused him to be disabled. He discussed his penchant for eating high-sodium foods and recognized that these poor dietary choices may have played a role in his admission. He had been experiencing symptoms of shortness of breath for 1 week prior to admission; however, he waited until his doctor appointment to address his symptoms with a health care provider. His symptoms were severe several days prior to his admission, and he could not walk without becoming extremely short of breath and was sleeping sitting up at the kitchen table.

(#35) It (my illness) don’t stress me out. It don’t even bother me. I leave it in God’s hands.

**Life Circumstances and Family Dynamics and Overwhelm Subject’s Ability to Perform Adequate Self-Care**

Many subjects were more focused on dealing with family dynamics or life circumstances rather than on their own self-care. Subjects frequently described life circumstances that were incompatible with adequate self-care, and some recognized these circumstances as impacting their ability to perform adequate self-care, while others did not.

Mr. M was a 62-year-old subject whose daughter died two weeks prior to his current admission; she had been preparing his low sodium meals. Besides dealing with the grief
regarding his daughter’s sudden death, he was in the process of obtaining custody of her 9-year-old son. He found the idea of learning how to cook healthy meals overwhelming.

(#14) I gotta learn how to cook and try to make balanced meals. It seems like an impossible job.

Mr. J was a 36-year-old who ate high-sodium foods, was not adherent to his medication regimen, and had not made it to his clinic appointments scheduled after his last admission. He acknowledged that his current homeless situation impacted his ability to perform adequate self-care and caused him to be readmitted. When he was asked about how the health care organization could help him from being readmitted, his response was the following.

(#13) “It wasn’t anything that the hospital situation (could do). It’s outside of the hospital.”

Subthemes

In this section, the emergent sub-themes (Table VII) are summarized and presented in eight categories: (a) life circumstances and family dynamics, (b) experiences with death, (c) self-care management practices, (d) dietary practices, (e) attitudes toward health care system, (f) social support, (g) stress, and (h) intrapersonal feelings.


### TABLE VII

**SUB-THEMES**

<table>
<thead>
<tr>
<th>Overarching Theme</th>
<th>Diminished health care autonomy</th>
<th>Resignation to fate</th>
<th>Life circumstance and family dynamics overwhelm subject’s ability to perform adequate self-care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sub-themes</strong></td>
<td>Experiences with death</td>
<td>Experiences with death*</td>
<td>Life circumstances and family dynamics*</td>
</tr>
<tr>
<td></td>
<td>Life circumstances and family dynamics</td>
<td></td>
<td></td>
</tr>
<tr>
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<td>Self-care management practices</td>
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*primary theme

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**Life Circumstances and Family Dynamics**

Through a series of open-ended questions, subjects described their current life circumstances and family dynamics. Life circumstances included housing instability, living with multiple family members, public transportation, substance abuse, disability, unskilled labor, and economic challenges.

Several subjects discussed their *housing instability*. Housing instability existed when the subjects had recently moved to a new location or the participant was homeless. The subjects who were homeless described their homelessness or being evicted from their home and searching for a new apartment within their budget. Four subjects were homeless and were either living in a shelter or in their cars. One subject described his becoming homeless as a process where he got evicted from his home, then lived in multiple hotel rooms, and then became homeless.

(*13*) *A week prior to the actual vacate date, I kinda went from bad to worse because the apartment that I was staying in had got vandalized a couple times, which made me pack*
up my stuff and put my stuff in storage. And since that time, I was renting hotel rooms with some savings that I had saved away. Upon doing that, I was like, I can’t keep doing this because I’m gonna run out of money. And with that being said, I was getting sicker and sicker.

Mr. B. was occasionally living in his car when he could not stay with his girlfriend. He had been diagnosed with HF 6 months before the current admission but was not taking his medications. He said he was concentrating on “other things” in his life and when he was not in the hospital, he did not think about his illness.

(#8) Once I can get away from it (his illness and the hospital), I stay away from it.

Twenty-one subjects were living with other family members and rarely with a significant other. Because most subjects were older individuals, those subjects living with other family members were living with grown children, siblings, and grandchildren or elderly parents. Several reasons were given by subjects to explain why they were living with other family members, but the most frequently reported reason was to reduce housing costs. Several subjects were temporarily living with another person while someone was recovering from an economic challenge. For older subjects, their disability or social security check assisted with housing costs and assisted in supporting family members.

(#29) I don’t pay rent. My daughter does, but I pay everything else, the lights, the gas, the cable, the phone.

Subjects frequently described themselves as caring for family members. These subjects described taking care of grandchildren while other family members were working. Several subjects described having custody of a grandchild or niece/nephew due to the parent having substance abuse issues or due to the death of a parent. Though the subject may have been the
grandchild’s custodial guardian, the grandchild was an adult so did not require the usual child care responsibilities. Subjects also described caring for other family members or friends as a form of community support to assist the other individual.

(#26) *My brother is a crack addict. I didn’t mention him, and I have taken care of his children since they were born basically.*

(#30) *DCFS has my grandkids, and he was in SS living. And when you turn 21, you have to leave there, and he didn’t have any place to go. He couldn’t get a job because he snatched a lady’s phone when he was 16 and that is following him, and that is one reason he can’t get a decent job. I don’t really want to see him out on the street, so I told him to come and live with me.*

Subjects described their use of public transportation as their main form of transportation to doctor appointments and the emergency department. Subjects used public transportation because they did not own a car or had lost their license due to their inability to pay their parking tickets or to pay for their car’s maintenance.

(#18) *No, the deal was Jesse White went along with Mayor Rahm Emanuel, and what they did was they would suspend your shit.*

(#20) *I was unable to pay for the license plate and insurance. I got 1996 Yukon and you gotta pay for those, yeah.*

Due to the importance of public transportation for social support and health care, two subjects described the loss of a bus card as a significant event in their life.

(#16) *I got mad when I lost my bus card. I was furious.*

(#30) *I had a bus pass, but somebody stole it, and I notified them it had been stolen and they sent me a letter saying it had been used every day and I was no longer eligible for it.*
The lack of transportation was especially restrictive to subjects in the winter when subjects had to stand in the cold. Public transportation was also challenging when the subject’s shortness of breath limited his or her ability to walk either to or from the bus/train stop. For the current admission, several subjects reported being too ill to take public transportation, so they had someone drive them to the hospital. The subjects described the importance of a ride to the emergency department because if they called an ambulance, the ambulance would not take them to the hospital of their choice. Only two subjects described calling the ambulance to bring them to the hospital for their current admission.

(#23) I live in the shelter on Harrison and California, and I have to walk down here.
Even though I know I can do it, but it will take me a long time and now that it is real cold I can’t do it...because I get short of breath.

Several subjects expressed their reason for visiting multiple hospitals. If they called the ambulance service, it would take them to the hospital nearest to their home. Several subjects stated this was the reason they had to wait for someone else to drive them to the clinic or emergency department.

(#16) But when you call, they (the ambulance service) don’t take you where you want to go, so I get there the best way I can.

Multiple subjects experienced substance abuse, either current or past. Though one subject described himself as a recovering heroin addict, the substance most likely abused by subjects was crack cocaine. Four subjects actively used drugs prior to the current admission, though they all expressed a desire to quit.

(#16) With the drug... I just need somebody to be with me and help me. I don’t like where I am at. I don’t like it at all.
Most subjects were unemployed and were supporting themselves by either disability or social security. Prior to receiving disability, several women were employed as home health care workers. However, they started receiving disability because they were unable to work. The physical demands of being a home health care worker combined with their shortness of breath limited them so that they could not perform the job.

(#30) When I was working, I kept up, because I was working three jobs and I could have the money to pay the bills. I didn’t have any type of security; the job that I worked, they didn’t have any pension, so I was living from check to check. Since they stopped me from working, I have been in hell. I want to go back to work, and I tried, but it put me back in the hospital. So I really can’t lift a lot of stuff, and mostly, they want you to be able to lift and I can’t do that.

There were several disabled subjects who were NOT receiving disability but who would be considered disabled. They either did not know how to navigate the social services system to receive disability or they had tried to apply and had been denied. One homeless subject described how he had applied for disability before he went to jail, but he was unable to continue the application after he got out because “the attorney had put a ‘hold’ on his application.”

(#23) He (my friend) gave me his lawyer to apply for disability, but I didn’t follow up with him. I was in jail because I got in trouble, and when I got out, I went back to re-file for disability and he (the attorney) put a freeze on my account that I have to see him first. So, I don’t know whether he (the attorney) got me approved or not, but either way I have to talk to him.

Only a few of the subjects were currently working, but two of them were performing community service jobs to reduce a prison sentence. Of the subjects working, one was a
substitute teacher, one drove a truck, and two were working “cash” jobs (i.e., fixing cars in the street and stocking boxes for a local corner store).

(#16) So I opened up my own little business working on cars (on the street). I stayed out in the cold for two years during the winter in below zero weather.

Most subjects experienced economic challenges; however, the manner in which the economic challenges impacted their life varied. Subjects frequently cited economic challenges affecting their housing, food choices, transportation, and stress. One homeless subject explained how he did not have $3 to afford the co-pay for transportation provided by Medicaid.

(#16) I am not able to pay ($3) for that.

Paying for medications and appointments was NOT cited as an economic challenge for many subjects; in fact, subjects stated that medications were free and this was considered a positive experience. The example below illustrates a common theme of subjects not having to pay for their medicines.

(#2) I never have to pay the whole thing because I couldn’t afford the whole thing, so I don’t have a problem getting my medicine because I have Medicare, Medicaid and (Inaudible 57:18) card.

Subjects frequently described their communities as being dangerous. Several subjects mentioned dangerous communities in a matter-of-fact manner and something that the subjects said that they lived with on a daily basis. One subject who was 36 years old and recently diagnosed with HF explained how young kids were getting killed in his neighborhood.

(#6) In my neighborhood right now a lot of little young kids like 14 (are) getting shot and killed.
Other subjects expressed a desire to no longer be living in their dangerous community or expressed how their dangerous community did not allow them to do simple things.

(#16) There is too much shooting up. I don’t want to be around that.

However, other subjects lived in the same communities who were not fearful, though they acknowledged that the neighborhood was dangerous. In fact, several subjects expressed a feeling of empowerment and commitment to improving their community. One 81-year-old subject described how she would get rid of drug dealers when they would congregate outside of her house.

(#5) If I see a certain young man or woman walking back and forth too many times, I will ask them, Do you live here? And they are always courteous and say, No, ma’am. I say, Are you looking for somebody? No, ma’am. I say, Okay. The next thing is I tell them who I am and I say; do you see the end of that white fence right there? And I say, including the lady’s house next door? I don’t want to see you over there in front of her house and not in front of the church. . . . Most of the time they will say, yes, ma’am, and move along.

**Experiences with Death**

*Experiences with death* emerged as a prevalent theme among the sample. Across the sample, subjects mentioned the deaths of people they had known or been related to. The deaths were typically related to illness but also included death as a result of violence; in one case, a subject’s child died after a medication error at a hospital. In almost all of the narratives, subjects described the death of a spouse, child, sibling, or nieces and nephews. Even if the deaths of family members had occurred several years prior to the interview, they were described in detail.
However, several subjects had recently experienced a family member’s death and were significantly affected by the event.

(#2) She (my granddaughter) got killed on Cicero and Lake. There were four of them in a car and all four girls died. And that same night she got killed, her mother brought us the baby; so she had told her mother also if anything happened to her, to bring the baby to us.

(#11) My sister died from a stroke. Then my mom was watching her kids, and then like three years later, my mom died. She had a massive heart attack at work. And my mom was watching my dad. He came back into my mom’s life. He fell down the stairs and had a stroke. He eventually died. They put a pacemaker in, but he had died at the hospital. He tried getting out of bed; fell on his head that was it.

(#14) And I’ve been feeling pretty good except for the last couple of weeks, I started going down because I had my only daughter died instantly.

(#14) Yeah, they all dead. My sister died a few years ago at the age of 59. She had something wrong with her pancreas. My brothers, two of them, they had substance abuse was one of the things, but heart failure was the other one. It’s like with my mother. She died with a heart attack. My baby brother, he died with one too, and he was 31.

(#22) Yeah. My son was on the news. My son died. I had twins. My daughter she lived, but my son died; they gave him the wrong medication so...

In one interview, the researcher asked the subject the following question: **How many funerals would you say you have been to in the last five years?**

#25: So many that I don’t know exactly.
Self-Care Management Practices

Subjects described poor self-care management strategies throughout the narratives and gave varying accounts of interventions for escalating symptoms. However, an emerging theme was going to the hospital as a self-care management action. Subjects viewed going to the hospital as an opportunity to learn more about self-care strategies and also considered it a positive experience.

(#18) When you’re in the hospital, it give you some kind of enforcement that you’re trying to do something to save your life. Yes, ma’am.

(#22) Well, in the hospital I learn more about how I gotta take care of myself. I love the hospital I run to it, ya know? Because I need to know.

(#33) No, I don’t let them treat me at home, because I know when to come into the hospital.

Although subjects viewed going to the hospital as an opportunity to learn more about self-care strategies and considered it a positive intervention, they would wait until their symptoms of shortness of breath and swelling escalated and/or until someone else decided that they needed to be admitted. The theme someone else decides emerged as a prevalent theme of the sample. Many subjects did not make the decision themselves to be admitted but were told by a family member or health care provider at a routine clinic appointment. Subjects were not making the independent decision to come to the emergency room, even though they had been experiencing symptoms several days to one month prior to admission. Subjects who were admitted from the clinic reported living with symptoms and were waiting until their clinic appointment to speak to their doctor.
I knew I was gonna have the appointment. I had the visit coming up. They sent me to a clinic then they sent me back here (hospital).

I had an appointment so I had transportation ready (so I waited until the appointment).

Conversely, subjects' family members frequently made the decision for a subject to be admitted. Subjects explained how they would have preferred to stay home and not go to the hospital because they did not feel their symptoms were severe enough to be admitted. One woman explained how she did not want to come to the hospital, but her husband made her.

But my husband came home and was like No, you're going to the hospital. I didn’t want to go.

Dietary Practices

Most subjects did not adhere to a low-salt diet, but they reported understanding that they were supposed to do so. Dietary knowledge and implementation conflict emerged as a prevalent theme on why subjects did not adhere to a low-salt diet. Several subjects acknowledged their dietary indiscretion as a reason for admission but also acknowledged they were not paying attention to what they were eating prior to admission. When asked, “What do you think caused your symptoms?” or “Why do you think you were readmitted?” subjects would state the cause of their symptoms or admission was the result of eating salt.

I don’t eat much food with a lot of salt, but apparently, I was eating food with salt.

What I might have did, what I might have did, I may have ate so much salt on the holiday. That may set it off.

I don’t know. I guess I wasn’t eating right, eating too much salt, it sounds like that.
The subjects' lack of adherence to a low-salt diet was the result of their lack of control over who prepared meals or purchased the groceries. Subjects described how they depended on family members or neighbors to do the grocery shopping or make their meals. Because of this dependence on others to make their food, subjects did not want to request a low-salt diet and be a burden to the individual who was assisting them. Several subjects revealed how their family members had brought them a high-salt item at the grocery store and the subjects knew they should not eat it, but they did anyway.

(#5) My neighbors send me food and I stopped trying to tell them what not to put on the plate.

(#29) I never eat salt, but because I didn’t feel good, I like potato chips. I usually buy salt-free but because I couldn’t get to the big store, my grandkids got a bag at the corner store and I was eating them. But other than that, I don’t eat salt.

Several subjects described their lack of knowledge of how to cook low-salt meals. For example, one subject acknowledged that he did not know how to make balanced meals or low-salt meals after his 29-year-old daughter died three weeks before his readmission. His wife and daughter had both cooked for him for the last 30 years, and when his wife and then his daughter died, he did not know how to shop or cook low-salt meals. He felt this was an overwhelming task.

(#14) I gotta learn how to cook and try to make balanced meals. It seems like an impossible job.

Attitudes Toward Health Care Systems

Subjects had different attitudes toward the health care systems. Some attitudes were positive in terms of satisfaction with their current health care and absence of co-pays for
medications or clinic visits. However, subjects also expressed negative attitudes toward different some hospitals because of substandard care, which was one of the reasons these patients were visiting multiple hospitals.

Subjects mentioned their satisfaction with the current medical care at the hospital facility where they were being interviewed. However, many subjects had visited multiple hospitals prior to this current hospital admission. One reason for this practice was because the subject considered that the hospital closest to his or her home provided substandard care. Several subjects discussed their perception of the negative care provided at an outside institution.

Ms. G was a 56-year-old African American woman who was readmitted 6 times in the last 180 days. She has been to 3 different hospitals in the last 6 months.

(#12) I had an opportunity to go to a hospital closer, but I don’t like Hospital A. I don’t like Hospital B. Hospital C, I probably would have went there. But the best one is here, so . . . I didn’t want to go Hospital D either.

Mr. C was a 63-year-old male who has been readmitted to three different hospitals in the last 180 days. He had visited multiple hospitals because of his negative experiences at other hospitals. He felt the care during his previous hospitalization at another hospital was substandard because they did not treat him with a sufficient amount of diuretics.

(#20) Hospital A didn’t do nothing. They got me down on record. They didn’t do nothing for me at Hospital A. Somebody said go to Hospital B. So there I came.

(#28) At first I didn’t have Hospital A. I was going to Hospital D until they messed me up, and then I changed to here.
Subjects made positive comments about their financially covered clinic visits or medicines. Prior to the Affordable Care Act, many subjects had a co-pay for medications and now, because they no longer had a co-pay, they were happy they could afford the medications.

(#4) No, the medicine, the county... I have no problem with the cost because it doesn’t cost me anything.

(#19) No. I don’t have to pay for medicine now. I don’t have a co-payment. Before I had a co: I had to pay.

(#20) Yeah. It helps me pay these bills. Ain’t gotta pay no co-pay. I’m glad to have what I got. Yep.

However, a conflicting attitude revealed subjects’ frustration toward their current health care system. Frustration was related to the lack of access to the health care provider by phone. Several participants felt that their admission could have been prevented if they had been able to contact their provider by phone to report their symptoms. Subjects also expressed frustration with their previous hospitalization because they felt that they had been discharged too early or that their health care provider had not provided adequate care to prevent the current hospitalization.

(#1) Sometimes they call back quick and sometimes they don’t, you know. So I just try to end up going to the emergency room.

(#6) I call and try to reschedule; they had me on hold for like the whole day.

(#11) It’s frustration, you know, not knowing what’s going to happen to you, if you’re gonna blow up again, if you’re gonna go home for two days.

(#8) The first time they didn’t pull the fluid off, so they sent me home and I still had the fluid. So I guess it just got worse.
Social Support

An important theme that emerged in the qualitative analysis was atypical social support. Atypical social support is a variation of social support that is provided by family or friends. Atypical social support is not emotionally supportive to the subject but does provide tangible support such as transportation. Although subjects lived with family members, significant others, or friends, often these individuals were often not invested in the subject’s health. By virtue of their familial or other close relationship to the subjects, the family members or friends appeared as if they were invested, but in reality, they were not. These individuals could only offer inconsistent social support, and subjects often had to rely on this atypical support network. This atypical social support network merely provided sporadic tangible support to the subject, such as occasional transportation or cooking meals, but it was not available if the person providing it was not available. For example, transportation was only available to subjects when their family members were home, and this was frequently not during clinic hours. In addition, if the family member took the subject to the emergency room, the family member would frequently need to return to work and nobody would be available to accompany the subject through their admission.

The following statements were representative of this theme.

(#14) Yes. I came through the emergency department, but I got a friend dropped me off.
(#28) Yes because if they don’t come and get me, sometimes my daughter, she works, but she has a car, so sometimes she will have to take off. My son works and he will have to take off to take me to the doctor.

Sometimes the subject was unwilling to give his or her family or friends the opportunity to assist them and provide emotional support. Subjects would not tell their family members or neighbors about their dietary restrictions or their diagnosis of HF because subjects did not want
to worry family members or be viewed as “ill” or weak. Several subjects mentioned that they did not want to be a “burden” to their families, so they wouldn’t tell family members about their health needs or appointments.

(#20) And sometimes I don’t be feeling the best, but I don’t want to let them know.

(#12) I haven’t told her about it. I haven’t told her that I had been back two times.

Another type of atypical social support was subjects’ definition of social support. Several subjects considered a positive social support network as those individuals who would let the subject do what they wanted, especially in terms of eating a high-salt diet. For example, the following 67-year-old male subject, who lives alone and has been readmitted four times in the last 180 days, described his positive social support network as the following.

(#9) Well, you know one thing I like about them is they let me do what I do.

Problems with atypical social support were evident by the lack of investment by family members in the subject’s health. In fact, several subjects were providing emotional and tangible support to their own family members but not receiving it. The subjects considered family members as having more pressing emotional support needs than the subjects themselves. During the interview, subjects discussed their family members' social issues such as loss of income, unskilled jobs, or illness.

Ms. C is a 55-year-old woman who lives across the street from her 80-year-old mother who is also in poor health. Ms. C’s brother, who has substance abuse issues, lives close by, and Ms. C’s aunt also lives in the neighborhood. Ms. C’s aunt recently received custody of another family member's children because the parents had died. The children were causing stress in her aunt’s life, and Ms. C was trying to assist her emotionally and financially. Ms. C also emotionally supported her brother with his substance abuse issues
and provided tangible support such as grocery shopping and transportation to her mother.

Ms. C had been admitted to the hospital five times in six months.

(#19) Yeah. I don’t think about myself. I think about others before (me).

**Stress**

Stress encompassed several different themes and varied among the sample. Stress themes were (a) *realized stress*, (b) *desensitized to stress*, and (b) *realized stress with positive coping strategies*. *Realized stress* was when the subject discussed the varying events in his or her life and acknowledged them as stressful. Several subjects expressed the stress associated with living in a neighborhood where drive-by shootings were considered common. The following subject expressed concerns about sitting outside during the summer.

(#20) You can’t even sit on your porch. Someone might shooting and all that.

Mr. M, a 36-year-old male who was recently diagnosed with HF, released from prison, and currently performing community service, expressed his *realized stress*. Mr. M stated he “had a lot of things on his mind” and was under a large amount of stress. He was fighting with his girlfriend, who was recently diagnosed with cancer, and was worried that she was going to die like his aunt did one year prior. He also expressed stress related to his three children. He worried about his teenaged son getting killed, because the kids his son grew up with were getting murdered or involved with gangs.

(#6) Little boys be getting killed. The ones I saw come to his birthday parties and I’m like, Stay away from them!

As a result of the stress within his family relationships, his recent prison release, and his worry about the violence in his community affecting his children, Mr. M was under a large amount of stress and it was impacting his health care.
(#6) Sometimes you get so stressed out, sometimes I just, to tell you the truth, I stop caring (about my health).

Several subjects stated that they were not experiencing stress, yet the subject would discuss life events and family experiences that most individuals would consider stressful. This was labeled desensitization to stress.

Ms. G was a 54-year-old female who had recently experienced several family deaths. One death was a gang-related murder; another death was her sister recently died from an aneurysm; and another death was a nephew who recently had a car accident and died. Ms. G’s son was released from prison and was living with her, and she mentioned that he might get involved with the neighborhood gang. She was on medical leave from her job as a home health care worker because of her HF. Ms. G was not receiving disability because she kept missing her disability appointments due to lack of transportation. She did not have any source of income.

(#12) I don’t have no stress. I have no problems with stress. I hear ‘em and I don’t hear ‘em; I feel it and I don’t feel it.

Some subjects experienced realized stress yet they discussed positive coping strategies. Subjects mentioned prayer or listening to faith-based recordings to help them resolve their stress.

Mr. M. was a 60-year-old male whose wife had died three years earlier from a heart attack. All five of his siblings had died from heart attacks or substance abuse. The subject’s daughter had died two weeks prior to the current admission from a brain aneurysm, and he was applying for custody of his nine-year-old grandson. When asked how he coped with stress, he answered:

(#14) I pray a lot. That’s exactly how I do, I pray. I pray and I meditate.
Intrapersonal Feelings

The subjects were asked a set of open-ended questions about their life experiences; the questions were designed to elicit evaluative attitudes toward their life situation. Due to their life experiences, subjects often expressed themselves as surviving. Subjects would describe their current life experiences or past situations as “challenging.” They frequently described themselves as someone who was “surviving” or who was going to survive.

(#14) That’s what gives me the strength to continue to go on and keep my right mind able to help other folks when they go through and let them know you can make it. You can make it. I’m making it right now.

(#16) I just wake up and get by.

Other subjects also expressed hopelessness over their social environment or illness. Subjects described a series of life experiences and personal challenges that had overwhelmed the participants psychologically over time. Subjects developed an attitude of hopelessness toward health care and life in general. They felt they had reached a personal situation where it “couldn’t get worse,” and they appeared resigned to their current situation.

One subject who was 49 years old, homeless, recently blind, and diagnosed with HF during his previous admission described his current life situation:


Another male subject who was 36 years old, homeless following his mother’s death three years earlier, described his feelings of hopelessness to change the trajectory of his life and health.

(#13) I didn’t think that it would ever get this bad with even in the worstest of situations,
Mr. C was a 63-year-old subject whose health had been progressively getting worse over the previous 6 years. He felt that he had fought hard to get better but could not control his illness trajectory because it was related to his age and health.

(#20) I wish I could get well. I wish I could. Fighting no more, but I know I ain’t gonna be able to (get better). Getting older now. It’s gonna be there.

Integrated Analysis

The final step in the data analysis was to integrate the qualitative and quantitative data. The goal was twofold: (1) gain insight into self-care management strategies of the subjects and (2) explore differences between groups of subjects who were readmitted ≥ 5 times with groups of subjects who were readmitted ≤ 4 times.

Self-Care Management Scores

In this section, the self-care management scores were used to anchor the family dynamics and life circumstances themes. There were many common themes described by the subjects who scored “inadequate” on their self-care management scores. The themes that emerged were congruent with inadequate self-care management. However, the number of subjects who scored “adequate” on self-care management was small (n = 3); therefore, it was difficult to find common themes. Two common themes among the group who scored adequately were desensitized to stress and made own decision to be admitted to the hospital.

Common Themes among Subjects Who Scored “Adequate” on Self-care Management

Common themes among subjects who scored “adequate” on self-care management are shown in Table VIII.
### TABLE VIII
ADEQUATE SCHFI SCORES AND COMMON THEMES

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<th>Made own decision to be admitted to the hospital</th>
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<tr>
<td>Desensitized to stress</td>
<td>Desensitized to stress</td>
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<td><em>(CD) So you decided yourself? (#33) Yes.</em></td>
<td><em>(CD) So you decided yourself? (#33) Yes.</em></td>
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<tr>
<td><em>(#20) Yeah, I keep (stress) to myself</em></td>
<td><em>(#20) Yeah, I keep (stress) to myself</em></td>
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**Common Themes among Subjects Who Scored Inadequate Self-Care Management**

There was concordance between inadequate self-care management scores and narrative accounts of self-care management. When the data were integrated, the qualitative data provided an explanation of why self-care was inadequate among most subjects. The definition of self-care management includes symptom evaluation, treatment implementation, and treatment evaluation. Subjects experienced multiple barriers that limited their self-care management, such as lack of access to their health care provider by phone, lack of trust of health care organizations, and family dynamics or life circumstances that subjects judged to be more pressing than their own self-care.

The following themes are covered in this section with relation to the inadequate SCHFI management scores.

- Negative sociodemographic factors impacting self-care management
- Low standard of adequate self-care management
- Lack of trust of health care institutions
- Coming to the emergency department as a management strategy
- Waiting and watching
- Letting someone else decide to act on symptoms
Sociodemographic barriers that limited subjects' self-care management were homelessness, substance abuse, and lack of economic resources. These factors limited subjects' ability to intervene on their accelerating symptoms, especially in the domains of calling the doctor or nurse for guidance. Several subjects acknowledged these factors limited their self-care management and recognized the impact of these barriers on their health.

Mr. H was a 61-year-old male who was homeless for the six months prior to his admission. He was recently diagnosed with HF, and this was his second admission. He did not have a job or social support and had been dismissed from the homeless shelter and was living on the streets. He had a 25-year history of crack cocaine abuse and used drugs three days prior to admission. He acknowledged that his substance abuse was the source of his economic challenges and lack of positive relationships with his family. He had lost his medications two weeks prior to his admission and had gone to the pharmacy to get them refilled; however, the pharmacy would not refill them unless his health care provider called to cover lost medications. Instead of following through, Mr. H continued to use drugs the following week-and-a-half and acknowledged his drug use was a cause of his inability to care for him or act on his symptoms.

(#4) All the things we go through send us down certain roads. You know, a lot of this stuff, the bottom of it is, it goes back to the drug use. It all goes back to the drug use.

However, most subjects did not recognize that the socioeconomic barriers they experienced were influencing their ability to acknowledge their accelerating symptoms as a symptom of heart failure. When asked how well they felt they were taking care of themselves, subjects frequently stated that they were taking “great” or “good” care of themselves. However, many subjects were unable to describe how they managed accelerating symptoms of shortness of
breath and lower extremity swelling. The subjects in this study did not try the remedies listed in the SCHFI management domain. In fact, many subjects described good self-care as performing the basic activities of daily living and did not address remedies they might try to intervene on their symptoms.

Ms. H was a 59-year-old female who had been readmitted 12 times in the last 180 days. She was recovering from a crack addiction that she had quit the year before. She had some help with housekeeping because her nephew, who had recently moved in with her, could help her with laundry and clean the house; however, he did not provide emotional support or assistance with her medications. She used public transportation to come to the hospital. Despite being readmitted multiple times, Ms. H expressed confidence in her ability to take care of herself, and when asked how well she took care of herself, her response:

(#33) As far as hygiene, dressing, keeping myself clean, I do a very good job. I take my medicine on time. I just can’t do the things I used to do. I can’t get out and walk around like I used to, but as far as taking care of myself, I do a good job at that.

Another reason of inadequate self-care management was the lack of trust in health care systems, be it hospitals or health insurance companies. The barrier theme of lack of trust was emphasized by subjects’ descriptions of feeling that they received substandard care at different Chicago area hospitals. In addition, the feeling of lack of trust was emphasized by several subjects explaining how their insurance was changed or cancelled without them being informed, or how new fees were added on to their plan without them being informed. These feelings of lack of trust in health care made it difficult for subjects to adhere to prescribed self-care regimens or intervene on their symptoms of heart failure.
Mrs. R was a 67-year-old female who had been readmitted four times to two different hospitals in the last 180 days. She had multiple comorbidities and was living on a limited income with her husband. She had doctors at several different clinics and expressed her distrust with insurance companies because they kept adding on fees without telling her. (31) Medicare changed and signed you to another company that you don’t know anything about, so when you get to the medical center, they just say you are not qualified for this anymore; you have to pay this amount.

Most subjects did not discuss monitoring their HF symptoms as a strategy of self-care; in fact, many subjects described their self-care management strategy as coming to the emergency room. Many felt that coming to the hospital was the appropriate action to take when they noticed that their symptoms were worsening. This type of self-care management strategy was preferred because of the perceived high quality of care provided by hospitals rather than the outpatient clinics.

Mr. R had been readmitted seven times in the 180 days prior to his current admission. He lived alone and had no social support. He ate a high-salt diet despite knowing that he should not. When asked why he came to the hospital, his response was: (18) When you’re in the hospital, it give you some kind of enforcement that you’re trying to do something to save your life. Yes ma’am.

Another barrier to adequate self-care management that was expressed by many subjects was waiting and watching until their next clinic appointment. Waiting and watching was a barrier to self-care management because they would wait until their symptoms were so severe that by the time they decided to intervene it was too late and they had to be admitted. One reason for waiting and watching described by subjects was that they were unable to arrange
transportation to the clinic or they were unable to contact their health care provider—either because they did not have a phone number or the provider did not return their phone message. While this strategy of waiting and watching did not prove effective in preventing Ms. C’s current admission, it had worked for her in the past.

Ms. C was a 63-year-old woman who had recently moved to a bedbug-infested apartment in a dangerous community. She did not have a phone number to contact her health care provider after she ran out of refills for her medications. Eight days prior to her admission, she noticed her symptoms getting worse; however, she opted to wait for her previously scheduled clinic appointment because in the past her symptoms had sometimes improved. By the time she was seen by her clinic physician, her symptoms were so severe that she was immediately admitted.

(#30) This time I came to the hospital because of shortness of breath and I was swollen, but I could have come earlier, but I had an appointment with my doctor, so I put it off until I came to see him, but I still didn’t get a chance to see him (because the nurse admitted her at the clinic before the physician was able to see the Ms. C).

Many of the subjects were referred by someone else to the emergency department, perhaps their family member or health care provider. This was labeled as letting someone else decide, and many subjects whose strategy was waiting and watching also experienced this. Subjects who were waiting and watching had many reasons for letting someone else decide and not making their own decision to go to the hospital. One reason subjects cited for letting someone else decide was that subjects were dependent on their family for transportation and their health care, and they waited for their family to decide. Another reason subjects reported going to
the hospital was because their health care provider had told the subject to come to the Emergency Department if their symptoms worsened.

Ms. C was a 45-year-old female who had end-stage HF. She had been admitted five times to three different hospitals in Chicago in the past 180 days. She stated that her family had become “panicked” the night she was admitted because she became short of breath. The more her family became upset with her shortness of breath, the more short of breath she became. The end result being that the family called an ambulance.

(#19) I couldn’t breathe. We were all in the washroom trying to get me to breathe. My husband was, like, call the ambulance. Yep.

Another example of letting someone else decide was when subjects described how they were told to go to the hospital by their health care provider would be Ms. G.

Ms. G was a 56-year-old female who had been admitted five times in the last 180 days. She was unable to contact her health care provider because she did not have his phone number. She felt the appropriate response to her shortness of breath was to go to the hospital. She felt that going to the emergency department was the appropriate decision because when she called her insurance company to ask what she should do about her symptoms, the person at her insurance company told her to do go to the emergency department.

(#12) I would have called him and told him the same thing, “I’m having trouble, what do I do?” But, see, Blue Cross Blue Shield, the choice I got, they tell me, go straight to the emergency room so… (I did)

Ms. C. is a third example of the theme letting someone else decide. Ms. C was an 80-year-old female and had been admitted four times in the last 180 days. She took her medicines as
prescribed but did not call her doctor when her symptoms worsened. Instead, she had her
granddaughter take her to the emergency department because the doctor from her previous
hospitalization told her to come to the emergency department when her symptoms got worse.

(#32) The doctor, when they released me before, they increased the pills, and they said if
it doesn’t take the fluid off, then come back to the emergency room.

Readmissions

Unplanned Hospital Readmissions were categorized into two groups: high (5 or more),
and moderate (4 or fewer). Differences in themes between the two are shown in Table IX.

<table>
<thead>
<tr>
<th>TABLE IX</th>
<th>DIFFERENCES BETWEEN THEMES OF HIGH UHRS VS. MODERATE UHRS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barrier Themes</strong></td>
<td><strong>High UHRS</strong></td>
</tr>
<tr>
<td></td>
<td><em>(n = 12)</em></td>
</tr>
<tr>
<td>Substance abuse (current or past)</td>
<td>60%</td>
</tr>
<tr>
<td>Visiting multiple hospitals</td>
<td>50%</td>
</tr>
<tr>
<td>Has emotional support but doesn’t ask for support</td>
<td>0</td>
</tr>
<tr>
<td>Desensitized to stress (has stressors but says they do not have stress)</td>
<td>75%</td>
</tr>
<tr>
<td>Does not want to be a burden</td>
<td>25%</td>
</tr>
<tr>
<td>Goes to hospital to get better</td>
<td>30%</td>
</tr>
<tr>
<td>Someone else decide for admission</td>
<td>30%</td>
</tr>
<tr>
<td>Unskilled labor/community service</td>
<td>0%</td>
</tr>
</tbody>
</table>

High Unplanned Hospital Readmissions

Subjects in the high-UHR group differed from subjects in the moderate-UHR group in
several important factors. Those in the high-UHR group were more likely to be experiencing
substance abuse or have a history of substance abuse. Subjects currently experiencing substance abuse acknowledged the role substance abuse played in their current admission.

Mr. M was a 57-year-old male who had been diagnosed with HF within the last year. He had been readmitted five times in the last 180 days, and his most recent admission was only five days following his previous discharge. He expressed distrust with his health care providers because he felt they did not manage his heart failure appropriately at his previous admission because his symptoms made him come back to the ED so quickly. He had an eight-year history of heroin abuse and quit one year prior to his admission. When asked why his HF appeared after he quit heroin, his response was:

(11) Then the last eight years when my mom died, that’s when I started doing heroin. So for eight years, I was getting high like that, and I didn’t know. Something was probably wrong with me then, but I didn’t know because I was high.

Another important difference between the two groups was the barrier theme of visiting multiple hospitals. Those subjects with high UHRs were more likely to describe visiting multiple hospitals than those subjects with moderate UHRs. Subjects with high UHRs described that their reason for visiting multiple hospitals was because of the quality of care at the other hospitals or the proximity of the different hospitals to their home.

Mr. R was a 57-year-old male who was living in a homeless shelter. He had been admitted to three different hospitals in the last 180 days, and each time he had walked into the emergency department. He chose the hospital that was closest to where he was at the time. He decided to go to the hospital and did not make an effort to go to the same hospital because he did not have money for transportation. When asked if he had a clinic appointment after his last admission, he responded:
Yes, but I have been having heart trouble, and I live in the shelter on Harrison and California and I have to walk down here. Even though I know I can do it, but it will take me a long time, and now that it is real cold, I can’t do it.

In the high-UHR group, there were more subjects who described being desensitized to stress than those subjects in the moderate-UHR group. The high-UHR group frequently stated they did not have stress, despite describing life circumstances and family dynamics most would consider stressful.

Ms. P was a 60-year-old who had been admitted five times in the last 180 days to three different hospitals in the Chicago area. This admission was within one week of her last discharge from a different hospital. She was taken by ambulance service in her previous admissions. Her granddaughter was murdered within the last six months and Ms. P was caring for her 2-year-old great-grandson. Her daughter was very sick, so her granddaughter had been living with Ms. P for three weeks prior to this admission. Ms. P reported that she does not sit near the windows for fear of being shot and killed from stray bullets during drive-by shootings.

I don’t really have any stress.

In the high-UHR group, there were more subjects who described going to the hospital to get better as a self-care management strategy. These subjects felt that going to the emergency department was a strategy that should be employed when a patient noticed that his or her symptoms were not improving.

Mr. R was a 61-year-old male who had been readmitted seven times in the last 180 days. He lived alone and did not have any social support. He had not taken his medications for several days prior to his admission because he ran out and had not yet contacted his
health care provider. When asked whether there was something the hospital could have done to prevent this admission, the subject’s response was the following.

(#18) When you get sick, nothing nobody can do. You come (to the hospital).

The high-UHR group had more subjects whose family made the decision to bring them to the hospital. This theme was a subtheme of someone else decide, yet in this subtheme, there were more in the high-UHR group whose family members, rather than health care providers, decided to bring the patient in.

Ms. P was a 79-year-old female who had been readmitted five times in the last 180 days. She lived alone, but her children frequently checked in on her by phone. Ms. P’s symptoms had been getting progressively worse until her son, who had been speaking with her by phone, insisted she go to the hospital because she sounded short of breath. The son arranged for his cousin to drive Ms. P to the hospital. When asked what made her decide to come to the hospital, Ms. P stated the following.

(#27) My son said, please go to the hospital.

**Moderate Unplanned Hospital Readmissions**

In the moderate-UHR group, there were more subjects who stated they had social support but did not ask for emotional support when they were under stress.

Ms. C is an 80-year-old woman who lived alone in the same apartment building, as her granddaughter. Her 57-year-old daughter had died from a heart attack the month before, and Ms. C was grieving. Her granddaughter was frequently traveling but regularly checked on Ms. C. Another granddaughter would take Ms. C to the grocery store on a weekly basis. Ms. C stated that she was very sad about her daughter recently dying. When asked who Ms. C looked to for support, Ms. C responded:
(#30) The one that lives here, she works away somewhere, but when she gets off, she will let me know that she can come and do certain things for me. Her daughter is going to be a professional basketball player and she goes to a lot of games and she goes out of town, so I try not to bother her.

These subjects frequently stated they did not want to be a burden to their family member or neighbors. Several stated that they did not want to have their family members take care of them.

Mr. C was a 63-year-old male who had been admitted to two different hospitals in the last 180 days. He lived alone but had very supportive sons who checked in on him regularly. He did not want to burden his children. He missed his last clinic appointment because he did not want to ask his family members for a ride. He was unable to drive his own car because his license plates were expired, and he was unable to pay for car insurance. He had trouble taking public transportation because of his shortness of breath, yet he did not like asking people to drive him to clinic.

(#20) I like to have my own way getting along. Be my own responsibility, you know, don’t depend on nobody.

In the moderate-UHR group, there were more subjects who described themselves as working or performing community service for a reduced prison sentence. The subjects who were doing community service did not have difficulty missing work to go to clinic appointments; however, the one subject who was employed by a trucking company expressed his inability to make clinic appointments because of his job not allowing him to take paid time off.

Mr. H was a 62-year-old male who had been married for 23 years. He worked as a truck driver in the city of Chicago, and his hours were 6am to 2pm. He and his wife worked
minimum wage jobs and were supporting four adult children and his siblings. If he missed work, he would not be paid and was concerned about paying his house and car payment. When asked if he made his HF appointment after his last admission, his response was:

(#21) the first one no (because it was in the morning).
V. DISCUSSION

Findings from this study reaffirm that low-SES HF patients experience frequent UHRs, with some experiencing more than five readmissions within 180 days of their recruitment visit. There are several novel findings from this study. (1) Most subjects performed inadequate self-care. (2) For many subjects, negative family dynamics and life circumstances (i.e., multiple family deaths) were related to inadequate HF self-care management and increased UHRs. (3) Subjects who experienced multiple poor interactions with health care systems lived in high-crime geographic areas, experienced fragmented care (i.e., visit multiple hospitals), and demonstrated a high level of apathy and low motivation to engage with the health care system and proactively manage their HF. (4) Subjects with the highest number of UHRs were more likely to have a history of addiction or be current substance abusers.

A unique characteristic of this sample is that most of the low-SES subjects were insured through the Affordable Care Act. It has been theorized that once patients had obtained insurance, they would not experience the limitations of accessing health care and would engage in self-care care management. The subjects in this study were assigned primary care physicians during a UHR before the Recruitment Visit, and the patients had scheduled clinic appointments between their UHRs. This programmatic strategy has been associated with the belief that better integration of care will decrease UHRs and improve self-care.\textsuperscript{107} Though the subjects in this study had economic assistance with their medication and had a medical home, their daily living (e.g., housing stability, food choices, and transportation, attendance at their clinic appointment) was still impacted by economic limitations and sociodemographic factors.
Low Standard of Adequate Self-Care

Findings from this study revealed that this population is challenged by their life circumstances and family dynamics that disallow adherence to current recommendations for HF self-care management. A preponderance of research has demonstrated the negative effects of low SES on patients' ability to care for themselves. In this study, subjects lived in some of the most high-crime and poverty-stricken neighborhoods in Chicago; subjects experienced multiple factors that impeded their ability to care for themselves. Many subjects acknowledged that socioeconomic issues, lack of transportation, and lack of finances for medications impacted their self-care; paradoxically, most subjects did not consider themselves to have deficits in self-care. Most subjects did not recognize that multiple hospitalizations might be associated with poor self-care. Subjects frequently described themselves as performing self-care because they performed basic hygiene and tried to take their medications consistently. Subjects misdefined adequate self-care management strategies because they occasionally missed their meds and appointments, sought treatment in the emergency room, and did not always follow a low-salt diet. These findings suggest that patients' standard of adequate self-care differs from the definitions commonly cited in the literature. This mismatch between clinician and patient definitions of self-care as well as multiple barriers to self-care management contributed to subjects' poor self-care. The combination of being unable to prioritize their health over their socioeconomic factors and having defined the self-care that they perform as good led subjects to continue their current inadequate self-care.

Eating a High-Salt Diet

Knowledge about HF self-care was not measured quantitatively in this study; however, many subjects described themselves as knowledgeable about a low-salt diet and how they were
not to “eat salt.” Yet, despite reporting they were knowledgeable about a low-salt diet, many subjects stated that their reason for admission was most likely related to eating a high-salt diet. This finding suggests that subjects either lacked a deep understanding of what “low-salt” actually meant or they were conflicted about their excessive salt intake. Most subjects in this study had had the diagnosis of HF for an extended period of time and had received education about low-salt diets. Yet there appeared to be a gap in knowledge, understanding, and implementation of a low-salt diet.

Previous studies have suggested that more in-depth dietary education would reduce this gap; however, there are other possibilities for the lack of implementation of a low-salt diet. The subjects' access to low-salt foods may have been limited because of economic issues, and (1) the subject did not want to tell the interviewer that they did not have enough money to afford “low-salt” food or 2) the subject's definition of a low-salt diet was incorrect.

**Lack of Action on Accelerating Symptoms**

Subjects’ lack of action on accelerating symptoms has been previously reported. However, in the low-SES patient population, this finding should be interpreted in light of four interacting themes: (1) desensitization to stress; (2) resignation to fate; (3) atypical social support; and (4) lack of trust in health care systems. These themes were developed over time by the life experiences and family dynamics unique to this patient population. The interaction among these categories left the patients with the inability to engage in their own health and effect a change in the outcome.

Previous research has identified stress as a risk factor for CV disease; however, the relationship between stress and HF outcomes is not as well defined. In this study, the integration of the data between the PSS-10 and the qualitative data revealed several unique findings.
Subjects frequently described themselves as not having stress or not thinking about stress, yet these subjects described life circumstances that most individuals would consider stressful. The subjects’ desensitization from stress may be because stressful events are common among the communities from which the patients were recruited and has become a social norm. Community violence, lack of financial resources, and death of family members have desensitized the subject to stress and similarly blunted their response to their symptoms.

The theme desensitization to stress (or stressful events) and its relationship to inadequate self-care management could be explained by the patients' lack of acknowledgement of worsening symptoms. Patients may have developed a coping mechanism of dealing with their heart failure symptoms similar to those strategies that they developed to deal with their stress. Subsequently, they became desensitized to their symptoms. Subjects were typically experiencing accelerating symptoms for several days prior to admission, and they did have the opportunity to respond or intervene. Their extreme shortness of breath was the tipping point for most patients for coming to the emergency department, though the subjects had noted lower extremity swelling and increasing shortness of breath several days before. Prior studies have noted that patients delay intervening on symptoms with “waiting and watching;” however, the cause of delay among this patient population may be because the subjects have developed a practice of becoming “desensitized to their symptoms” and therefore only acknowledge them when they were extreme.

The difficulty in defining stress adds to the conflicting reports of the relationship between stress and heart failure and socioeconomic status. In one small study of 81 patients who were primarily Caucasian, stress and the associated cortisol level was not associated with cardiac rehospitalizations and mortality among HF patients. In another study examining the relationship between myocardial infarction and community factors such as neighborhood safety
and social cohesion, a relationship was found between stress and heart disease mortality and morbidity. In fact, another study demonstrated an inverse relationship between stress and all-cause mortality. In our study, there was not a relationship between stress and readmissions or stress and self-care management. However, this may be because the subjects who were highly stressed due to their sociodemographic issues and/or did not want to come to the hospital because they needed to be home to care for their family members. The subjects in the moderate readmission group frequently stated that they did not want to come to the hospital and someone else made them.

The absence of a relationship between stress and outcomes may also be related to the definition of stress, which includes the length of time the stressful events are experienced. Furthermore, stressful events can be chronic or traumatic. Among this patient population, who were from high-crime, low-SES communities, stress could be defined as both chronic and traumatic. Previous violence literature supports the relationship among traumatic events, PTSD, and cardiopulmonary disease burden in a minority Chicago population. However, the perception of stress from either chronic or traumatic events has not been examined among a large number of HF subjects from a minority low-SES community. The subjects in this study have developed a method for managing the stressful events in their lives and their perception of stress, and examination of these coping strategies is important. The subjects’ perception that they were not experiencing stress and how it impacted self-care management is worth investigating further.

The theme *resignation to fate* may have similarly impacted patients’ ability to intervene with their accelerating HF symptoms. Our study found that subjects frequently described the mortality of family members and acquaintances from cardiovascular disease, cancer, and stroke. African Americans experience a higher incidence of mortality from cardiovascular disease,
diabetes, and HF than their Caucasian counterparts.\textsuperscript{114} “Fatalism” is a concept defined as the inevitability of death and would be considered a similar concept to the theme \textit{resignation to fate}.\textsuperscript{115} Fatalism has been associated with poor medication adherence and inadequate self-care behaviors in adults with diabetes.\textsuperscript{116} The theme \textit{resignation to fate} was developed because subjects in our study frequently described their acceptance of their life situation because of their belief in a higher power. This acceptance of their life situation, community violence, and family dynamics may have helped subjects to develop a similar strategy to deal with their symptoms—that of acceptance and the feeling of the inability to impact or change an outcome. The subjects’ feelings of resignation to fate may have also been impacted by the number of deaths the subjects had experienced within their family and social circle as revealed in their stories. Almost all of the patients described deaths of family members or friends from diabetes, stroke, heart attacks, and heart failure. It is possible that the feeling of resignation to fate and the observation of family members and loved ones dying had left the subjects with the feeling that they cannot change their health outcome especially if a family member had died from a chronic disease similar to their own HF.

It has been recognized that social support has a role in the effect of stress on an individual. Social support can be defined as tangible or emotional and has been related to self-care and readmissions.\textsuperscript{117} Research on the relationship between social support and HF outcomes has been conflicted, but this may be related to the definition of social support. Social support has been defined as emotional, tangible, and instrumental. For example, subjects living alone have worse outcomes than those subjects living with others and family members who provide social support. In our study, very few subjects were married, though many were living with common-law spouses, children, or extended family members. Subjects in our study defined different types
of social support, and an important understanding gained was about emotional and tangible social support. In this study, emotional and tangible support was related to the subjects’ sociodemographic factors. Tangible support is related to transportation, housing and economic assistance. For example, subjects frequently described tangible support, such as a roommate who can help pay the rent or buy food. This type of tangible support played an important role in the subjects’ quality of life and ability to live comfortably in their communities because, without this type of tangible support, many subjects would be homeless. Subjects frequently described situations where they had tangible support such as someone dropping them off at the hospital of their choice. This type of tangible support was important because the patient could avoid an ambulance ride, which would take them to a hospital that they did not want to go to and where they did not have established care.

Equally important in this patient population is the role of emotional support; however, the subjects in this study were frequently providing emotional support for members of their own social network. In addition, several subjects described having psychological support, but not wanting to burden their loved ones with their health issues because they did not want to be perceived as a burden. However, those with psychological support still had fewer readmissions than those without such support. This finding emphasizes that having access to loved ones, even if their support is not used, may result in more positive health outcome. It is important that clinicians understand what type of social support their patients have when creating a care plan. Clinicians need to recognize that it is imperative to uncover the support that the patient is providing to other members of his or her family because the patient may be overlooking his or her own self-care to assist others.
Negative Perceptions of Health Care Organizations

Distrust of health care organizations by African Americans has been well documented in previous research.\textsuperscript{118} Lower institutional trust plays a role in health-seeking behaviors and has been related to patients changing physicians\textsuperscript{119} and increased emergency room visits.\textsuperscript{120} The patients in this study frequently described distrust of health care organizations because of previous negative interactions with the health care system. This distrust may have been compounded by the distrust felt by the subjects toward other governmental institutions such as the police. It has been theorized that African Americans who live in communities that experience high crime and high unemployment rates may have more distrust of government institutions than those individuals who live in stable communities.\textsuperscript{121} During the time of this study, the distrust of police and the government was well publicized, and this distrust may have extended to health care institutions. While some subjects explicitly stated their distrust of certain hospitals, many expressed trust in the current institution where they were being interviewed. This may be explained by several factors: (1) an attempt by the subject to provide socially acceptable answers to the interviewer (because the interview occurred in the hospital) or (2) because the subjects' symptoms were improved at the time of the interview.

There were various opinions among the subjects about their insurance. While many expressed satisfaction with their insurance coverage, many also expressed frustration. Several subjects described situations where their insurance was cancelled, the deductible was increased, or the insurance carrier was changed and they were not notified. Despite increased health insurance coverage among this patient population, some subjects still experienced trust issues with governmental health systems. These trust issues may be related to the inconsistencies that these patients had experienced in another government run program—Medicaid. In a qualitative
study of 100 patients with Medicaid, subjects frequently reported they were treated differently because of their Medicaid insurance. In this study, subjects did not report this feeling, and this may be because both hospitals primarily service a publicly insured low-SES patient population, and these subjects would be considered the norm.

Many of these subjects were not engaged in their own self-care management. That is, they were experiencing diminished health care autonomy. Diminished health care autonomy could be attributed to lifetime experiences (e.g., multiple comorbidities, lack of social and economic resources, and previous negative experiences with the health care system). Diminished health care autonomy in these subjects, and in this patient population as a whole, could also be attributed to lack of knowledge about HF. However, we propose that, even if the subjects in this study had the self-efficacy, knowledge, and motivation to manage their own health, they still would not have had the ability to perform adequate self-care: the subjects in this study would not have been able to act on the knowledge.

This concept of diminished health care autonomy is a theme unique to this patient population, and we propose that it has developed because of the cumulative effects of negative life circumstance and family dynamics. Furthermore, although diminished health care autonomy is a concept that is similar to the concept of self-efficacy, self-efficacy does not define the whole concept of diminished health care autonomy. Self-efficacy is subsumed by diminished health care autonomy. Powerlessness is another concept that is linked to low-SES patient populations and diminished health autonomy, but powerlessness addresses the feeling that the patient is unable to change. So it is this unique finding of diminished health care autonomy that would explain the mixed outcomes of studies examining interventions to improve self-efficacy.
We propose that the patients may have wanted to improve their engagement with their health but were unable to change because of experiences over time that limited them in their participation in their own health care. This lack of participation, or engagement, may explain the mixed results from documented interventions meant to improve the care transition process and decrease UHRs. For example, in one of the largest randomized controlled trials of remote patient tele-monitoring of HF patients, the authors did not find significant effects of the intervention on all-cause readmissions. In the intervention arm, 715 low-SES patients were randomized and received regularly scheduled telephone coaching, home tele-monitoring of weight, and pre-discharge HF education. Adherence to the intervention occurred in only 55.4% of patients in the intervention arm despite deploying several intense strategies to encourage adherence.107 As one facet of health care autonomy, lack of engagement by subjects to the health care system observed in the referenced study also was observed in our study. The combination of the themes resignation to fate and sociodemographic factors affecting self-care both played a role in patients having diminished health care autonomy.

Urban Hospitals and Fragmented Care

In Chicago, there are a multitude of hospitals, and most subjects in this sample came from a geographic area that had five hospitals within a 1-mile radius. In this study, patients went to different hospitals for different reasons: (1) previous negative experience at another hospital, (2) proximity of the hospital to where they were staying, (3) ambulance service being required to transport patient to nearest hospital, and (4) the social norm of going to different hospitals. Because this patient population was located near so many hospitals, visiting different hospitals was not considered a negative aspect of health care for them. In fact, because there were so many hospitals in close proximity to one another, patients perceived themselves as having choices for
their health care needs. Having timely access to a hospital is usually associated with positive patient outcomes among patients with myocardial infarctions and strokes. However, in this study, the proximity and sheer number of hospitals near patients potentially led to negative patient outcomes. Fragmented care is associated with negative health outcomes such as increased readmissions.\textsuperscript{125} Previous research has explored the relationship between visiting multiple hospitals and negative patient outcomes and has found that patients with chronic diseases are especially vulnerable to the negative outcomes associated with visiting multiple hospitals.\textsuperscript{126}

The proximity and availability of hospitals near the communities where this patient sample resided reinforced the concept of \textit{going to the hospital} as a self-care management strategy. Other factors that reinforced \textit{going to the hospital} as a self-care strategy were easy access to the ED and lack of access by phone to a health care provider. If the patient could access the ED easily and because the patient lacked access to the health care provider by phone, many simply used the ED as a primary source of care. Proximity, availability (i.e., perceived choice, easy access to the ED, and inaccessibility of a health care provider) all reinforced \textit{going to the hospital} as a self-care management strategy to such an extent that patients may have delayed acting on their symptoms because they felt the ED was an appropriate use of the health care system.

In a subset of patients in this study, lack of access to the provider by phone was frequently cited as a barrier to health care. Though patients had the phone number of the hospital, patients were referred through complicated phone trees to leave a message for a health care provider. Patients frequently cited that they did not receive a return phone call, and this validated patients' lack of trust in their health care provider and health care systems. The alternative plan was to visit the ED or wait for their scheduled clinic visit to have their symptoms assessed. Our
findings underscore the importance of establishing a HF provider network by phone that is easily accessible to this patient population.

**Substance Abuse**

Substance abuse has been identified as a risk for UHR, and this was confirmed in our study. We also found that a history of substance abuse was a risk for UHR’s. History of substance abuse may be an indicator of several factors traditionally related to high UHR. In both of our tools to assess alcohol intake, very few patients yielded abnormal results. We did not perform any objective testing for other illicit drug use; therefore, we cannot determine its impact on UHR in this cohort. Depression and anxiety are related to poor self-care and UHR’s, these conditions may be the undiagnosed component of the patient’s readmission. In this study, very few subjects were diagnosed with a mental health disorder, however an undiagnosed mental health disorder may have been present Future research should examine the prevalence of mental health disorders among HF patients who have a history of substance abuse.

**Policy Implications**

This study has implications for both policymakers and health care providers. The Hospital Readmissions Reduction Program from Center for Medicare and Medicaid Services fails to take into account the unique sociodemographic factors experienced by patients who have low SES and live in a large urban city. Despite the creation and development of multiple initiatives by hospitals to improve transitions of care, there has been no significant decrease in hospital readmissions among HF patients in minority-serving institutions. Policy makers need to implement policies that create an environment for communities, patients, and policy makers to influence health equity. Progress has been limited in improving the health outcomes of patients who live in low-SES communities, although some initiatives by Affordable Care
Organizations (ACOs) are showing promise.\textsuperscript{128} While these programs may prove to be successful, the sustainability of these programs with the incoming governmental structure will need to be seen. However, at this time, our suggestions include the following: reimburse hospitals for developing specific community-targeted programs for patients from impoverished communities. This would motivate hospitals to address community issues that have traditionally remained outside the purview of hospitals in those communities. The development of a communication structure to ease the transferring of patient information between health care organizations is fundamental to reduce fragmented and duplicate hospital care. Finally, policy makers need to recognize the need for multidisciplinary teams that involve health care organizations and to develop solutions for this complicated patient population.

One implication of this study for health care providers is to address patients’ social factors when developing a care plan for patients with HF. It is likely that many of these factors play some role across all socioeconomic groups but may be accentuated in low-SES populations. Race and ethnicity are also likely factors in mitigating or worsening these issues. Access to providers and transitions of care are two areas that providers should address with this patient population. Currently, most hospitals depend upon already established community programs to support patients' social factors; however, hospitals may need to consider methods that they will develop and financially support. For example, most clinics rely upon patients arranging their own transportation to their clinic visit, when possibly the clinic could arrange the transportation. Another strategy to consider is having hospitals send their own clinicians to patients’ homes for those patients who are frequent users of the health care system. Frequently, patients state they have a person on whom they depend for social support when in reality they have someone who helps them with the rent but not self-care. Though tangible support is important, health care
providers need to identify whether the patients have identified a person, and if not, the health care provider needs to encourage a stronger link between a person the patient could depend upon as psychological support.

As was observed in this study, the barriers for these patients are numerous. In addition to having significant medical comorbidities, their ability to recognize and manage illness is limited. Existing clinical HF guidelines are not sufficient for two reasons: they do not provide any insight or direction to assist in the management of these patients, and a one-size-fits-all approach is not appropriate nor fair to those centers that treat these patients. Homeless individuals and those HF patients who are experiencing traumatic events should not be expected to weigh themselves daily or adhere to a low-salt diet. The findings from this study reveal that HF is not a priority for this patient population.

Health care providers may consider the development of programs to engage or strengthen patients’ ability to perform self-care. Some small studies have shown promising results in improving patients' motivation to engage in their own health care. In a small study of 67 patients with HF, an RCT showed that patients who received motivational interviewing had improvements in their self-care maintenance that exceeded that of usual care.\(^\text{129}\) Another option for health care providers to improve the patient’s engagement in their health care is to engage the patients’ social networks during the hospitalization or clinic visit. This concept of social networks is similar to social support but differs in that it focuses on groups of people.\(^\text{9}\) Engaging family members, friends, and other people connected to the patient may be beneficial for the patient by having those individuals influence the patient’s health through social influence and other resources available from social networks.
**Societal Factors**

The influence of social issues such as poverty, racism, and violence cannot be understated. As illustrated in Appendices J and K, the patients came from areas with high crime rates and poverty. The majority of patients were African American. Examples of institutional bias and disparities based on race and income abound in health care.\(^{39,130-132}\) Not to mention, their limited community resources and support as compared to safer and more affluent areas of the city.\(^{133}\) Each of these issues contributes to loosen the safety net that many people rely on. Cultural norms and practices influence practices, behaviors, and attitudes toward health care.\(^{17}\) This was not directly studied in this study but must be appreciated.

**Future Research**

There is growing literature linking the relationship between sociodemographic factors and HF self-care; however, many questions remain. Recommendations for future research depend on the development of a standardized measure of sociodemographic factors. For example, currently, billing and coding data are frequently used to analyze large sets of HF data, but these data do not capture whether patients are homeless, have a history of substance abuse, and/or have a physical disability. Future research should develop interventions that address the modifiable social determinants of health that have the largest impact on self-care.

**Limitations**

The limitations of this study include the convenience sampling strategy. The sample was restricted to a patient population at two urban hospitals. Studies with larger sample sizes and including patient populations with varied sociodemographic characteristics is needed to further understand the impact that sociodemographic factors on HF outcomes. A second limitation is that, similar to other qualitative studies, social desirability by the subjects may have occurred,
especially in response to the question regarding how they perceive their care at the current institution. Even though the interviewer took measures to assure the subjects that their responses to the interview would not impact their health care, this should be taken into consideration. Finally, due to the small sample size, inferential statistics could not be performed in the mixed methods study.

**Summary**

Findings from this study corroborate existing evidence that explains the impact that sociodemographic factors have on HF readmissions and self-care. However, this study is unique in that it was performed after the enforcement of the Affordable Care Act, and almost all of the patients had insurance. Our study extends what is known about sociodemographic factors impacting subjects’ ability to perform adequate self-care and also suggests some new areas for further research. The findings from this study support the growing body of literature that attempts to explain why persistently high readmission rates continue for patients with HF and low SES continue to exist despite well thought-out interventions to improve the transition of care process.\(^{107}\)
Appendix A

Medical Record Review

Age _________ Ht _________ Wt _________ NYHA on admission _________

Last adm ADHF (date)__________

LOS for last HF admission__________

Number of admissions in last 6 months__________

Number of HF admissions in last 6 months__________

Dates and discharge diagnosis of admissions__________

Clinic appointment scheduled after last HF admission Y/N

Did not go to last clinic appointment Y/N If no, rescheduled? Y/N

Etiology: Ischemic/ Non ischemic _________ Yrs with HF _________

Date of last echo:_______ Hfpef vs HFrEf _________ Documented EF %: _________

Medications prescribed and taking at home: (list name, dose and frequency)

<table>
<thead>
<tr>
<th>Documented reason for admission:</th>
<th>Y/N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Progression of disease</td>
<td></td>
</tr>
<tr>
<td>Dietary non-compliance</td>
<td></td>
</tr>
<tr>
<td>Medication non-compliance</td>
<td></td>
</tr>
<tr>
<td>Substance abuse</td>
<td></td>
</tr>
<tr>
<td>Social issues</td>
<td></td>
</tr>
</tbody>
</table>
### Comorbid conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Y/N</th>
<th>Condition</th>
<th>Y/N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>Y/N</td>
<td>Atrial fibrillation</td>
<td>Y/N</td>
</tr>
<tr>
<td>CAD</td>
<td>Y/N</td>
<td>Atrial flutter</td>
<td>Y/N</td>
</tr>
<tr>
<td>CABG (date)</td>
<td>Y/N</td>
<td>ICD</td>
<td>Y/N</td>
</tr>
<tr>
<td>Hyperlipidemia</td>
<td>Y/N</td>
<td>Bi-V</td>
<td>Y/N</td>
</tr>
<tr>
<td>Diabetes (I/II)</td>
<td>Y/N</td>
<td>Pneumonia</td>
<td>Y/N</td>
</tr>
<tr>
<td>COPD</td>
<td>Y/N</td>
<td>HIV</td>
<td>Y/N</td>
</tr>
<tr>
<td>Asthma</td>
<td>Y/N</td>
<td>Gout</td>
<td>Y/N</td>
</tr>
<tr>
<td>Anemia</td>
<td>Y/N</td>
<td>Obesity</td>
<td>Y/N</td>
</tr>
<tr>
<td>Sickle Cell</td>
<td>Y/N</td>
<td>History of cancer</td>
<td>Y/N</td>
</tr>
<tr>
<td>CKD</td>
<td>Y/N</td>
<td>Active cancer</td>
<td>Y/N</td>
</tr>
<tr>
<td>ESRD on HD</td>
<td>Y/N</td>
<td>Obesity</td>
<td>Y/N</td>
</tr>
<tr>
<td>Kidney Transplant</td>
<td>Y/N</td>
<td>Amputation</td>
<td>Y/N</td>
</tr>
<tr>
<td>Lupus</td>
<td>Y/N</td>
<td>Rheumatoid arthritis</td>
<td>Y/N</td>
</tr>
</tbody>
</table>

CAD - coronary artery disease, CABG - Coronary Artery Bypass Graft, COPD - Chronic Obstructive Pulmonary Disease, CKD - Chronic kidney disease, ESRD - End stage renal disease, HD - Hemodialysis, ICD - Implantable cardioverter defibrillator

**Comorbid documented mental health conditions** (Per DSMV Criteria as documented in the medical record)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Y/N</th>
<th>Condition</th>
<th>Y/N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>Y/N</td>
<td>Alcoholism (Past or present)</td>
<td>Y/N</td>
</tr>
<tr>
<td>Depression</td>
<td>Y/N</td>
<td>Illicit drug use (past or present)</td>
<td>Y/N</td>
</tr>
<tr>
<td>Bi-polar disorder</td>
<td>Y/N</td>
<td>Mood disorders</td>
<td>Y/N</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>Y/N</td>
<td>Other</td>
<td>Y/N</td>
</tr>
<tr>
<td>Substance Abuse</td>
<td>Y/N</td>
<td></td>
<td>Y/N</td>
</tr>
</tbody>
</table>

### Heart failure symptoms on admission

<table>
<thead>
<tr>
<th>Condition</th>
<th>Y/N</th>
<th>If yes</th>
<th>If yes- how long?</th>
</tr>
</thead>
<tbody>
<tr>
<td>SOB</td>
<td>Y/N</td>
<td>1/2/3 blocks or ADLs</td>
<td></td>
</tr>
<tr>
<td>Orthopnea</td>
<td>Y/N</td>
<td>1/2/3 pillow</td>
<td></td>
</tr>
<tr>
<td>PND</td>
<td>Y/N</td>
<td>Nightly/weekly/monthly</td>
<td></td>
</tr>
<tr>
<td>LE swelling</td>
<td>Y/N</td>
<td>+1, +2, +3</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>Y/N</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SOB - Shortness of breath, PND - Paroxysmal nocturnal dyspnea, LE - Lower extremity, ADL’s - Activities of daily living
Was alcohol use assessed during hospitalization? () Yes () No

IF YES

<table>
<thead>
<tr>
<th>What was the documented alcohol use prior to admission?</th>
<th>Past 24hrs</th>
<th>Past 1 week</th>
<th>Past 1 month</th>
<th>Past 1 year</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If used, was the following documented in the medical record?

<table>
<thead>
<tr>
<th>Please indicate the type of alcohol consumed (mark all that apply)</th>
<th>Beer</th>
<th>Wine</th>
<th>“Hard” liquor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pattern of use</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Was illicit drug use assessed during hospitalization? () Yes () No

IF YES, was the following documented?

<table>
<thead>
<tr>
<th>Past 24hrs</th>
<th>Past 1 week</th>
<th>Past 1 month</th>
<th>Past 1 year</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marijuana</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cocaine or Crack</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescription Pain medications</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heroin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Did the patient have a drug screen this hospitalization? () Yes () No

If yes, was it positive? () Yes () No

For what.
Appendix B

Sociodemographic Questionnaire

Address

When was your most recent hospitalization?
   Was most recent hospitalization for heart failure?
   Was most recent hospitalization at the current hospital?

Do you have a significant other? (I.e., wife/husband/girlfriend/boyfriend)

How many people live in your house?

How do you get to your doctor appointments?

How did you get to the emergency department for this admission?

Do you have a regular place where you go for your outpatient doctor appointments?

How many years of school did you complete?

In the last year, how much money did your family make?
Appendix C

SCHFI

Think about how you have been feeling in the last month or since we last spoke as you complete these items

Section A (Self care maintenance)

Listed below are common instructions given to persons with heart failure. How routinely do you do the following?

1. Weigh yourself
   ____ 1=Never or Rarely  ____ 2=Sometimes  ____ 3=Frequently  ____ 4=Always/Daily

2. Check your ankles for swelling
   ____ 1=Never or Rarely  ____ 2=Sometimes  ____ 3=Frequently  ____ 4=Always/Daily

3. Try to avoid getting sick (e.g., flu shot, avoid ill people)
   ____ 1=Never or Rarely  ____ 2=Sometimes  ____ 3=Frequently  ____ 4=Always/Daily

4. Do some physical activity
   ____ 1=Never or Rarely  ____ 2=Sometimes  ____ 3=Frequently  ____ 4=Always/Daily

5. Keep your doctor or nurse appointments
   ____ 1=Never or Rarely  ____ 2=Sometimes  ____ 3=Frequently  ____ 4=Always/Daily

6. Eat a low-salt diet
   ____ 1=Never or Rarely  ____ 2=Sometimes  ____ 3=Frequently  ____ 4=Always/Daily

7. Exercises for 30 min
   ____ 1=Never or Rarely  ____ 2=Sometimes  ____ 3=Frequently  ____ 4=Always/Daily

8. Forget to take one of your medicines
   ____ 1=Never or Rarely  ____ 2=Sometimes  ____ 3=Frequently  ____ 4=Always/Daily

9. Ask for low-salt items when eating out or visiting others
   ____ 1=Never or Rarely  ____ 2=Sometimes  ____ 3=Frequently  ____ 4=Always/Daily

10. Use a system (pillbox, reminders) to help you remember your medicines
    ____ 1=Never or Rarely  ____ 2=Sometimes  ____ 3=Frequently  ____ 4=Always/Daily
Section B (Self-care management)

Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure. In the past month, have you had trouble breathing or ankle swelling? (Circle one)

____0=Yes ______1=No

11. If you had trouble breathing or ankle swelling in the past month…. (Circle one number), How quickly did you recognize it as a symptom of heart failure:

<table>
<thead>
<tr>
<th>Have not recognize it</th>
<th>I did not recognize it</th>
<th>Not quickly</th>
<th>Somewhat quickly</th>
<th>Quickly</th>
<th>Very quickly</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Listed below are remedies that people with heart failure use. If you have trouble breathing or ankle swelling how likely are you to try one of these remedies (circle one number for each remedy)

12. Reduce the salt in your diet

____1=Not Likely ______2=Somewhat Likely ______3=Likely ______4=Very Likely

13. Reduce your fluid intake

____1=Not Likely ______2=Somewhat Likely ______3=Likely ______4=Very Likely

14. Take an extra water pill

____1=Not Likely ______2=Somewhat Likely ______3=Likely ______4=Very Likely

15. Call your doctor or nurse for guidance

____1=Not Likely ______2=Somewhat Likely ______3=Likely ______4=Very Likely

16. Think of a remedy you tried the last time you had trouble breathing or ankle swelling, (circle one number)

How sure were you that the remedy helped or did not help?

<table>
<thead>
<tr>
<th>I Did Not Try Anything</th>
<th>Not Sure</th>
<th>Somewhat Sure</th>
<th>Sure</th>
<th>Very Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Section C (Confidence)

In general, how confident are you that you can:

17. Keep yourself free of heart failure symptoms?
   Not Confident Somewhat Confident Very Confident Extremely Confident
   1 2 3 4

18. Follow the treatment advice you have been given?
   Not Confident Somewhat Confident Very Confident Extremely Confident
   1 2 3 4

19. Evaluate the importance of your symptoms?
   Not Confident Somewhat Confident Very Confident Extremely Confident
   1 2 3 4

20. Recognize changes in your health if they occur?
   Not Confident Somewhat Confident Very Confident Extremely Confident
   1 2 3 4

21. Do something that will relieve your symptoms?
   Not Confident Somewhat Confident Very Confident Extremely Confident
   1 2 3 4

22. Evaluate how well a remedy works?
   Not Confident Somewhat Confident Very Confident Extremely Confident
   1 2 3 4
Appendix D

PSS-10

The questions in this scale ask you about your feelings and thoughts during the last Month. In each case, please indicate with a check how often you felt or thought a certain way.

1. In the last month, how often have you been upset because of something that happened unexpectedly?

   0= Never  1=Almost never  2=Sometimes  3=Failure often  4=Very often

2. In the last month, how often have you felt that you were unable to control the Important things in your life?

   0= Never  1=Almost never  2=Sometimes  3=Failure often  4=Very often

3. In the last month, how often have you felt nervous and "stressed"?

   0= Never  1=Almost never  2=Sometimes  3=Failure often  4=Very often

4. In the last month, how often have you felt confident about your ability to handle Your personal problems?

   0= Never  1=Almost never  2=Sometimes  3=Failure often  4=Very often

5. In the last month, how often have you felt that things were going your way?

   0= Never  1=Almost never  2=Sometimes  3=Failure often  4=Very often

6. In the last month, how often have you found that you could not cope with all the Things that you had to do?

   0= Never  1=Almost never  2=Sometimes  3=Failure often  4=Very often

7. In the last month, how often have you been able to control irritations in your life?

   0= Never  1=Almost never  2=Sometimes  3=Failure often  4=Very often

8. In the last month, how often have you felt that you were on top of things?

   0= Never  1=Almost never  2=Sometimes  3=Failure often  4=Very often

9. In the last month, how often have you been angered because of things that were Outside of your control?

   0= Never  1=Almost never  2=Sometimes  3=Failure often  4=Very often

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

    0= Never  1=Almost never  2=Sometimes  3=Failure often  4=Very often
Appendix E

AUDIT

1. How often do you have a drink containing alcohol?
   (0) Never (Skip to Q’s 9-10)
   (1) Monthly or less
   (2) 2-4 times a month
   (3) 2-3 times a week
   (4) 4 or more times week

2. How many drinks containing alcohol do you have on a typical day when you are drinking?
   (0) 1 or 2
   (1) 3 or 4
   (2) 5 or 6
   (3) 7,8 or 9
   (4) 10 or more

3. How often do you have six or more drinks on one occasion?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily

Skip to questions 9 and 10 if total for questions 2 and 3 =0

4. How often during the last year have you found that you were not able to stop drinking once you had started?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily

5. How often during the last year have you failed to do what was normally expected from you because of drinking?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily

6. How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily
7. How often during the last year have you had a feeling of guilt or remorse after drinking?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily

8. How often during the last year have you been unable to remember what happened the night before because you had been drinking?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily

9. Have you or someone else been injured as a result of your drinking?
   (0) No
   (2) Yes, but not in the last year
   (4) Yes, during the last year

10. Has a relative or friend or a doctor or another health worker been concerned about your drinking or suggested you cut down?
    (0) No
    (2) Yes, but not in the last year
    (4) Yes, during the last year
Appendix F

Semi-structured Interview

Hell, my name is Carolyn Dickens and I am going to ask you some questions about your heart failure. I am also going to ask you some questions about your neighborhood, family and responsibilities in your life and how they relate to your health.

What brought you to the hospital this time?

What do you think is caused your symptoms?

How long were you experiencing these symptoms before you came to the hospital?

What is the name of your illness?

Is your illness temporary, or do you think it will last a long time?

How is your health different now than it was 1 year ago?

Why do you think it is different?

How well do you think you care for yourself?

How did you choose to come to this hospital over another hospital?

What other hospitals have you been admitted to in the last 6 months?

Was there anything that could have been differently during your last hospitalization to prevent this hospitalization?

Do you have a regular doctor?

(Yes)

Can you tell me about conversations you may have had with your doctor about taking care of your illness.

What of those do you do?

(Why or why not)

How do you decide when to call your doctor?

(No)

How do you take care of your illness?

(Both)
What things in your life would make it easy to see your regular doctor in clinic?

What things make it harder?

Tell me about your neighborhood.

How long have you lived in your neighborhood?

What things in your neighborhood make it easy for you to stay healthy?

Can you give me an example?

What things in your neighborhood make it hard for you to stay healthy?

Can you give me an example?

Tell me about the people you care about.

What do they expect from you?

Do any of those responsibilities affect your health?

How do they support you?

Tell me how you cope with stress.

Prior to your admission to the hospital this time, think of the things that “stressed you out”. What were they?

How do those things that “stress you out” relate to your health?

Some people mentioned prayer or faith helping them deal with stress. Does your faith help you manage your heart failure?

(Yes) In what way?

Can you tell me about your financial responsibilities in your life?

What is the biggest financial issue you had to face this last year?

Does anyone help you with the costs of your medicines?

Do you have co-pays with your clinic visits?

(Yes) How do you feel your co-pays impact your ability to care for yourself?
Do you drink alcohol or use drugs?

(if yes)
How has it affected your health?

Does anyone you care about drink alcohol or use drugs?

(if yes)
How has it affected your health?

What is the name of your insurance?

Has your (name of insurance company) changed within the last year?

Can you tell me about ways (name of your insurance company) has helped you be successful in managing your heart failure?

How has your insurance made it difficult to manage your heart failure?
# Appendix G

<table>
<thead>
<tr>
<th>013</th>
<th>Self-Care Maintenance</th>
<th>Self Care Management</th>
<th>Self Care Confidence</th>
<th>Knowledge Explanation Causes</th>
<th>Stress Coping</th>
<th>SDH</th>
<th>Intrapersonal &amp; Interpersonal Support</th>
<th>Organization</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>50</td>
<td>SCHF1 Maintenance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Maintenan</td>
<td></td>
<td></td>
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<td>States the stress of finally being kicked out of his homeloss is trying, but is basically just surviving</td>
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## Appendix H

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## Appendix I

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109
Appendix J
Appendix K

### Subject Bios and Overarching Themes

#### Appendix 1

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<th>Location</th>
<th>Health Status</th>
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<th>Social Support</th>
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<th>Overarching Themes</th>
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<td>House</td>
<td>Disabled from obesity</td>
<td>Morbidly obese</td>
<td>Living in senior building</td>
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<td>Resignation to Fate</td>
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The document contains detailed bios for three subjects, each with an overview of their circumstances, health status, and mental health. The subjects face significant challenges, including disability, social isolation, and mental health issues, which are highlighted in the Overarching Themes column. The Overcoming Barriers section addresses strategies and support mechanisms subjects use to navigate these challenges.
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<td>36</td>
<td>Heart Failure</td>
<td>Recently got out of jail for drug dealing.</td>
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<tr>
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<td>72</td>
<td>Heart Failure</td>
<td>Lives by himself in apartment, Led to a real social support.</td>
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</tbody>
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- **4/61/M**: Homeless and recently lost his pill box at the homeless shelter. Walks around with a catheter and Foley bag for the last 6 months due to prostate cancer. Abuses crack cocaine. Admits he doesn't know how to navigate insurance companies or health care, and feels he doesn't have enough power to navigate the system to get disability.
- **5/81/F**: Lives upstairs from her daughter, takes care of her grandkids and great grandkids because her daughter is working. Debts collectors calling her. Kids stole her credit card. Visiting multiple hospitals because of ambulance. Neighbors dealing with drug and alcohol issues, nearby multiple hospitals because of kids. Worried about kids. Prays a lot and sometimes helps her stress. "We have to take care of each other's kids more than her own." Mentions gangs have killed all his kids.
- **6/36/M**: Recently got out of jail for drug dealing. Wife has breast cancer. Doing community service for a reduced sentence. Got HF for heavy drinking after he got out of jail. Worried about kids. Distrusted the hospital because they misdiagnosed him in the past. Only comes to the hospital when he is feeling really bad. Cries and prays a lot and prays a lot. Mentions the hospital sends him to the ER, where they say why did he wait so long? He didn't want to go because of his wife's cancer. His kids all lived in New Orleans. Powerless but scared of death and prays. "We have to take care of each other's kids more than her own."
- **7/72/M**: Lived by himself in apartment with end stage HF. His kids all lived in New Orleans. No plumber with 4th grade education. End stage HF. Mentioned being impregnated with the son of the homeless shelter. Walks around with a catheter and Foley bag for the last 6 months due to prostate cancer. Admits he doesn't know how to navigate insurance companies or health care.
Appendix L (Continued)
L (Continued)

12/56/F Woman whose son was there during the interview and he just got out of jail and had been shot. She was trying to keep him out of the gangs. She is more worried about him than her own health. Nephew recently killed in car accident. Used to work in home care but had to quit because of SOB. No social support. More concerned about her kids. Disinterested about learning more about heart health food. I talk to god every night for help, even just to go to sleep. Worried about keeping her son safe/alive and he just got out of jail and had an injury and he just got out of jail and had an injury. Woman whose son was there during the interview.

13/36/M Homeless after squatting in an apartment then someone kicked through the wall. Depressed but want to talk about it. Mom died three years earlier and that sent him into a negative spiral. He is responsible for taking care of grandson. He doesn’t know how to cook and feels he needs so he gave up cooking. Insurance was switched so didn’t know what to do. Not able to take meds all the time. No money. Insurance wouldn’t replace meds. Unable to cook low salt meals. God is giving him strength and will help him get through this. He doesn’t know how to cook at all. Did not have money for funeral and did not get paid for funeral. Homeless and crack addiction. Drinks 2 L of soda a day for crack addiction. Wears no gloves when cooking because of crack addiction. Pray for strength to stay off crack.

14/60/M Daughter just died two weeks before admission at the age of 26 from brain aneurysm. He is responsible for taking care of grandson. He doesn’t know how to cook at all. Didn’t have money for funeral and played open air funeral at all. God is giving him strength and will help him get through this. He doesn’t know how to cook at all. Doesn’t have money for funeral. Depressed, new guardian for 9-year-old grandson. Homeless, depressed, angry.

15/78/M Gave one-word answers because he appeared mildly demented, though none documented in chart. He stated that his wife makes all the decisions and he doesn’t know how to cook at all. Wife makes all decisions. States wife makes all decisions. His wife makes all the decisions. God is giving him strength and will help him get through this. Homeless after squatting in an apartment.


Appendix (Continued)
Lives with daughter who is nurse. Other daughter died. Appeared to have case of dementia, though none documented in her chart. Unable to care for herself. Daughter working full time and takes care of her.

Without god she would not be able to make it. Talks to god every day. Tapes to god neighborhood. Not provided anything about her meds when he saw he was feeling ok. Did not call provider for meds when he saw he was not feeling ok. Lives alone without social support. His mom was crack addicted and appears to be explosive during interview. Multiple incarcerations. Kept talking about his girlfriend who was a prostitute. Questionable living situation and may have been homeless. 89 yo mom lives across the street. She is too busy working, drinking and taking care of grandkids. 4 grown kids. Didn't call anyone for refills before but ran out of water pills 5 days before.

Married with husband and 4 grown kids. Very religious and believes in god will provide support. Lazy when she sees sister's foster kids. Family brings her to the hospital whenever she gets short of breath. Doesn't have any money. Brother has crack addiction and she is too busy working to help. Sister just died and she is trying to handle her affairs. She is too worried about sister who died and managing her children. Lack of access to provider by phone. She is too busy working and caring for her children. Lack of access to child care while she is at work. She is too busy working and believes god will provide support. She doesn't want to be a burden. This is the only patient who tested positive for PETH levels. Takes care of grandkids when not living in Michigan. Talks to god every day. Tapes to god neighborhood. Not provided anything about her meds when he saw he was feeling ok. Did not call provider for meds when he saw he was not feeling ok. Lives alone without social support. His mom was crack addicted and appears to be explosive during interview. Multiple incarcerations. Kept talking about his girlfriend who was a prostitute. Questionable living situation and may have been homeless. 89 yo mom lives across the street. She is too busy working, drinking and taking care of grandkids. 4 grown kids. Didn't call anyone for refills before but ran out of water pills 5 days before.
Appendix (Continued)
Appendix L (Continued)

119

31/67/F Multiple comorbidities, lives with husband in senior living facility. Don’t have money and says kids can’t help them financially or socially.维修者 of dementia. Lives in senior living facility. Doesn’t have doctors for all his illnesses. Goes to “too many” clinics. Calls ambulance for SOB or waits to be admitted from clinic. Calls ambulance for multiple dis. Frustrated health history. Doesn’t remember a lot of his past. Does not have kids or other family support. Has someone living with her to help with rent. No car, no money, no social support. Has someone doing domestic for the doctor. Dependent on others for the day. Lives in isolated social isolation and feels limited by her limited social support. No support for sick kids and no other social support. Believes in God. Goes to different hospitals. Lives with husband in multiple comorbidities.

32/80/F Other daughter recently died from heart attack. Isolated elder. Doesn’t see other person. Waits for someone else to tell her to go to the hospital. Calls ambulance because of dis. Calls ambulance for SOB or waits to be admitted from clinic. Has multiple comorbidities. Admitted 12x in 6 months. Doesn’t feel comfortable. Multiple recent moved to new neighborhood. Has three young children. At Mt Sinai for one month because of drug overdose. Doesn’t trust Mt Sinai or UIC. Claimed hospitals didn’t know what was going on. Can’t get to clinic. Just goes to hospital for care. Doesn’t believe in one answer. Doesn’t call hospital. Lives with her to help with rent. Has someone doing domestic for the doctor. Dependent on others for the day. Lives in isolated social isolation and feels limited by her limited social support. No support for sick kids and no other social support. Believes in God. Goes to different hospitals. Lives with husband in multiple comorbidities.

33/59/F Long history of crack abuse, but says she quit one year ago. Has someone living with her to help with rent. No car, no money, no social support. Has someone doing domestic for the doctor. Dependent on others for the day. Lives in isolated social isolation and feels limited by her limited social support. No support for sick kids and no other social support. Believes in God. Goes to different hospitals. Lives with husband in multiple comorbidities.

34/39/F Tested positive for PCP in drug screen. Recently moved to new neighborhood because kicked out of old house for unknown reasons. Has three young children. At Mt Sinai for one month because of drug overdose. Doesn’t trust Mt Sinai or UIC. Claimed hospitals didn’t know what was going on. Can’t get to clinic. Just goes to hospital for care. Doesn’t believe in one answer. Doesn’t call hospital.

35/59/F Multiple comorbidities. Doesn’t remember a lot of things (per patient) but doesn’t have a diagnosis of dementia. Lives in senior living apartment. Difficulty navigating social systems. Calls ambulance for SOB or waits to be admitted from clinic. Calls ambulance for multiple dis. Frustrated health history. Doesn’t remember a lot of his past. Does not have kids or other family support. Has someone living with her to help with rent. No car, no money, no social support. Has someone doing domestic for the doctor. Dependent on others for the day. Lives in isolated social isolation and feels limited by her limited social support. No support for sick kids and no other social support. Believes in God. Goes to different hospitals. Lives with husband in multiple comorbidities.


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**VITA**
Carolyn Ann Dickens, RN, PhD, ACNP-BC

**Curriculum Vitae**
University of Illinois Hospital and Health Sciences (MC 693)
1740 West Taylor Street, Chicago, IL 60612
312-413-3476 (TEL)
cdickens@uic.edu

**EDUCATION:**
<table>
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<tr>
<th>Institution</th>
<th>Degree</th>
<th>Year</th>
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<tbody>
<tr>
<td>University of Iowa, Iowa City IA</td>
<td>BSN</td>
<td>1994</td>
<td>Nursing</td>
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<tr>
<td>Johns Hopkins University, MD</td>
<td>MSN</td>
<td>1999</td>
<td>Acute Care Nurse Practitioner</td>
</tr>
<tr>
<td>University of Illinois Chicago, IL</td>
<td>PhD</td>
<td>2017</td>
<td>Nursing Science</td>
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**PROFESSIONAL LICENSURE/CREDENTIALING**
- Illinois Advanced Practice Nurse License
- Illinois Registered Nurse License
- Illinois Controlled Substance License, Mid Level Practitioner
- DEA: Controlled Substance License

**CERTIFICATION**
- AACN: Critical Care Registered Nurse (CCRN) Certification
- BLS/ACLS: American Heart Association
- ANCC: Acute Care Nurse Practitioner Certification

**EMPLOYMENT:**
- **2012-** Nurse Practitioner- Heart Failure, University of Illinois Hospital IL
- **2014-** Adjunct Faculty, Department of Biobehavioral Health Sciences IL
- **1999-2012** Nurse Practitioner- Cardiology, University of Illinois Hospital IL
- **1997-1999** Registered Nurse, CVICU and CCU Johns Hopkins Hospital, MD
- **1995** Registered Nurse, CVICU Huntsville Hospital, Huntsville AL
- **1994** Registered Nurse, CCU Kenosha Hospital, Kenosha WI

**HONORS and AWARDS:**
- **2017** Recipient of the Sigma Theta Tau Merit Award for the student qualities of Scholarship, Leadership and Service
- **2017** February Featured Researcher. Nurse Overestimation of Patient’s Health Literacy
- **2016** Award to attend the Student Policy Summit at the American Association of Colleges of Nurses in Washington DC
- **2013** First Place- Nurses Week poster presentation “Nurse’s Subjective Assessment of Patient’s Health Literacy”
- **2012** Recipient of travel stipend for abstract “Adverse Outcomes Among patients with End Stage Liver Disease who Undergo Cardiac Catheterization”
- **2012** Recipient of Honorable Mention for poster “Improving the Heart Failure Readmission Rate at an Urban Medical Center”
2011  Second Place, Nurses Week Poster Presentation “Improving the Heart Failure Readmission Rate at an Urban Medical Center”  University of Illinois Hospital

2009  First Place, Nurses Week Poster Presentation “Door to Balloon, Alliance in Action”  University of Illinois Hospital

2003  Caught in the Act  University of Illinois Hospital

1998  Recipient of the Professional Nurse Traineeship Grant for Academic Excellence  Johns Hopkins School of Nursing

1998  Recipient of the Education Advancement Scholarship  American Association of Critical Care Nurses

RESEARCH FUNDING:

2015-2016  Dickens, C. (PI) Nursing Research Award.  Heart Failure Society of America  $10,000

2015  Dickens, C. (PI)  Seth Rosen Research Award  $1000

2015  Dickens C., (PI)  UIC Nursing Alumni Research Award  $750

2015  Dickens, C., (PI)  Sigma Theta Tau Research Award  $1000

2014-2016  (Boyd, A., PI), Dickens, C. (co-I).  MY IDEA: A tailored patient cardiac catheterization application.  (Total costs $67,000) Roybal Funding

2010-2012  Hoobler, J. (PI).  Dickens,C.  (Nurse collaborator) Impact of Bullying and stressors on nursing and patient outcomes.  (Total costs, $35,000), National Occupational Research Agenda

ONGOING RESEARCH

6/2015- Present  Self-care among heart failure patients with low SES who experience an unplanned hospital readmission: A mixed methods study.  Role: Principal Investigator  Faculty Mentor: Dr Piano

6/2012- Present  Health literacy in an adult cardiac population- A prospective study  Role: Principal Investigator

6/2015- Present  Integrating patient perspectives with doctor and nurse documentation to create discharge narratives for patients with heart failure.  Role: Co-Investigator  Co-PI: A. Boyd MD  B. Di Eugenio PhD

11/2013- Present  Predictors of a 30-day readmission for heart failure in an economically disadvantage population  Role: Co-Investigator  PI: T. Stamos MD

PUBLICATIONS (All peer-reviewed manuscripts. *Indicates data-based)

Submitted

Published/In press


**EDITORIALS**


**ORAL PRESENTATIONS** (Presenting author underlined,*Research abstract/paper presentation at professional meeting, ‡ Invited presentations)


†Dickens, C. Nurse overestimation of patients’ health literacy. Health Literacy and Cultural Competence. UIHealth. October 2016.

†Dickens, C. Mr. G and the Revolving Door of Readmissions. National Press Club Washington DC March 2016

†Dickens, C. Nurse overestimation of patients’ health literacy. Department of Medicine Scholarly Days. UIC College of Medicine. March 2016

†Dickens, C. Nurse overestimation of patients’ health literacy. Midwest Nursing Research Society, Annual Meeting. Chicago IL 2012

† Dickens, C. Developing a Same Day Discharge Program. University Health Care Consortium: Cardiovascular Council Annual Meeting. October 2011

POSTER PRESENTATIONS (presenter underlined, *presented at professional meeting)


*Schuetz, R., Dickens, C., Groo, V., and Vuckovic, K. Substance Abuse is Associated with Observations Status of Patients with heart Failure at an Urban Academic Medical Center. American Heart Association Quality of Care and Outcomes Research Scientific Sessions, Phoenix: 2016


Dickens, C., Lulla, S., Katta, S., & Shroff, A. (May 2012). Use of the MELD score to predict adverse outcomes among patients with end stage liver disease undergoing cardiac catheterization. Abstract for poster presentation at American Heart Association Quality of Care and Outcomes Research, Atlanta Georgia.

Dickens, C., Franklin, C., Vuckovic, K., Nehmer, M. DiDomenico, R., Kerbow, D., Stamos, T., Kondos, G. Improving the Heart Failure Readmission Rate at an Urban Medical Center, University of Illinois Medical Center Nursing Research Symposium, May, 2011

Groo, V., William, K., Dickens, C., Stamos, T., & DiDomenico, R. (Oct 2010). 30-Day Heart Failure Readmission. Abstract for poster presentation at the American College of Clinical Pharmacy Annual Meeting, Austin TX.


NEWS and MEDIA
- Interviewed on UI Health Dr Paula Show. Hosted by Dr Paula Allen-Meares regarding health literacy and challenges of patients and health care systems. October 2016.
PROFESSIONAL ACTIVITIES:

Professional Memberships

2016- Present  Advanced Practice Providers Executives
2015- Present  Illinois Society of Advanced Practice Nurses
2015- Present  American Association of Nurse Practitioners
2013- Present  Heart Failure Society of America
2013- Present  American Nurses Association

2011- Present  American Heart Association
2002- 2006  Illinois Society of Advanced Practice Nurses/Charter Member

1998- Present  Sigma Theta Tau International
1994- Present  American Association of Critical Care Nurses

Reviewing and Editorial Experience:

2012-2016  Guest Manuscript Reviewer Annual Special Issue: Health Literacy
Journal of Health Communication

Membership on Professional Organizational Committees/Boards:

2015-present  Member, Government Relations Team. Illinois Society of Advanced Practice Nursing

UIC committees

2017- present  Nurse Practitioner Rep on Advanced Practice Provider Committee
2016- present  Co-chair of Optimizing the Provider Team
2016- present  Heart Failure Transitional Care Team-Director
2015- present  Member Advanced Practice Nursing Council
2015- present  College of Nursing Quality Council
2014- 2015  Multidisciplinary Heart Failure Program Development Committee
2013- present  Reducing Unwanted Heart Failure Readmissions-Co-chair and founding member

2008- present  Myocardial Infarction Quality Assurance Team-Co-chair and founding member
2002- 2013  Myocardial Infarction and Heart Failure Quality Improvement Team-Co-chair

2009- 2010  Unit Advisory Council-Chair
2009- 2011  Advanced Practice Nursing Council
1999- 2001  Advanced Practice Nursing Privileging and Credentialing Committee

TEACHING/PRECEPTOR EXPERIENCE (University of Illinois at Chicago)

2005- present  Preceptor of Acute Care Nurse Practitioner Students
2015  Preceptor for DNP students doctoral project

2013- present  Preceptor for Health Informatics Students Capstone Project
2013-2014  Assisted in the coordination and implementation of GEM students to perform home visits to Heart Failure patients recently discharged. (NURS 420).
B. Invited (guest) lecturer outside UIC at neighboring universities:
2013- Health Literacy- Adult Nurse Practitioner Students. Loyola College of Nursing, Maywood IL
2013- Pathophysiology of Heart Failure, Rush University, Chicago, IL.
2009- Hypertension and Coronary Artery Disease (3 hour lecture) Physical Therapy students. Midwestern University. IL (PTHED 617).

C. DNPs student thesis/project supervision within College of Nursing

<table>
<thead>
<tr>
<th>Student Name</th>
<th>Role on Project</th>
<th>Title</th>
<th>Year of Completion</th>
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<tr>
<td>Elwart, K</td>
<td>Committee member</td>
<td>Health Literacy in a Pediatric Population</td>
<td>2012</td>
</tr>
<tr>
<td>Vaez, K</td>
<td>Mentor</td>
<td>Heart Failure and Chronic Care Model</td>
<td>2015</td>
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