HEART FAILURE PATIENT SELF-CARE DECISION MAKING PRIOR TO REHOSPITALIZATION

By
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A dissertation submitted to Johns Hopkins University in conformity with the requirements for the degree of Doctor of Philosophy

Baltimore, Maryland

August, 2015

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ABSTRACT

Background

Rehospitalizations among patients with heart failure (HF) are common and costly. Current hospitalization prediction models for HF do not consistently or strongly predict rehospitalization.

Purpose

To examine and explore HF patient self-care decision making prior to rehospitalization. Building on Riegel's HF naturalistic decision making model, we examined the role of HF self-care on two outcomes: (1) 30 day rehospitalization status and (2) decision delay.

Method

The study used a cross-sectional, convergent mixed methods design [QUAN+QUAL] with a quantitative survey and qualitative in-depth interviews. Quota sampling (for quantitative survey) and purposive sampling (for qualitative interviews) were used to recruit participants who had been rehospitalized within and beyond 30 days of their last hospitalization. Inclusion criteria were HF patients who: had a diagnosis of HF and past hospitalization for HF, spoke English, and were cognitively intact. Logistic regressions, content analysis and data matrices were used to analyze the quantitative and qualitative data.

Results

There were 127 participants in the quantitative sample and fifteen for the qualitative sample. Approximately 60% of participants were rehospitalized beyond 30 days of their last hospitalization. Survey participants were predominantly male (65%), unemployed (79%), older (mean 58.14 ±13.59), and insured (97%). The odds of being rehospitalized

within 30 days was two times higher among those with high depressive symptoms (OR= 2.31, 95% CI: 1.00 - 5.31). The odds of decision delay was five times higher among those with high depressive symptoms (OR= 5.33, 95% CI: 2.14 - 13.28) and decreased by 80% among those reporting shortness of breath (OR= 0.20, 95% CI: 0.08 - 0.49). HF self-care decision making (reactive vs proactive) was different by 30 day rehospitalization status and by manifestation of acute vs. chronic symptoms. Participants with decision delay reported a sense of devastation and uncertainty about their future with HF.

Conclusions

A patient centered approach is needed to assist HF patients in identifying and self-managing symptoms other than shortness of breath. There is a critical need for clinicians to carefully assess and address depressive symptoms among HF patients.

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DEDICATIONS

To nana –

May your spirit always be with us & guide me

Funding for this dissertation work was provided by the National Institutes of Health [NIH 1 F31 NR014750-01, NIH/NINR T32 NR012704, NIH/NINR T32 NR 007968,]; American Nurses Foundation/Southern Nursing Research Society Research Award; Sigma Theta Tau International Nu Beta Chapter Research Award, and the Jonas Nurse Leaders Scholar Program

ACKNOWLEDGEMENTS

This dissertation was possible because of the tremendous support and mentorship I received from many people. First I want to acknowledge the patients for taking time out of their day to participate in the study. I am grateful for their willingness to participate and letting us learn from your experience.

A special thank you to my advisor Dr. Hae-Ra Han and my Dissertation Chair Dr. Marie Nolan. Thank you both for being excellent mentors and being gracious, patient, and encouraging. I have learned much from both of you and am forever grateful for having the chance to work with both of you. I also want to thank the other members of my dissertation committee for their invaluable contributions and support – Dr. Joe Gallo, Dr. Laura Gitlin, Dr. Cheryl Dennison, Dr. Sarah Szanton, and Dr. Katherine Smith. To Dr. Jennifer Wenzel and Dr. Barbara Riegel and all the other faculty members (too many to list here) who have taught me and offered advice thank you.

Thank you to my research assistants, Laura Fisher, Sofia Arruda, Kelsey Bower, and Kaylin Rodriguez, for your dedication and hard work. To Dierdre Flowers, you have been a tremendous help in teaching me about heart failure and provided emotional support during difficult recruitment days.

I would like to thank my fellow PhD students, who were always there for emotional support and advice. I would not have survived the program without you. Every one of you has touched my life in ways that words cannot express. In particular, I acknowledge Gyasi Moscu-Jackson, Kyounghae Kim, Grace Ho, Yvonne Commodore Mensah, Katia Reinhart, and Martha Abshire for their friendship, laughter, and support.

Finally, I would like to thank my family and friends. To my parents, Jingyi and Jufen, thank you for teaching me to never give up and to give back to humanity. Thank you for letting me dream and encouraging me to work hard towards my dreams. To nana, whom I dedicated this dissertation to, thank you for your love and unending support. You will always be with me and the inspiration for my research. To the rest of my family in China, thank you for waiting for me to finish my dissertation before I spend time with you. Grandma and grandpappy I cannot wait to hang out again! To Sue and John, the best neighbors one could ever ask for and being my surrogate Baltimore parents. To Chantal, Sarah, Jenny, and MinJoo thank you for listening patiently, and always believing in me. And to Yi, you were a wonderful, unexpected addition to my life and I am very fortunate to have you. Thank you for taking time to read through my grants, patience on the days when I needed to work, and seeing the humor in everything.

TABLE OF CONTENTS

ABSTRACT II

DEDICATIONS IV

ACKNOWLEDGEMENTS V

LIST OF TABLES XI

LIST OF FIGURES XI

CHAPTER 1: INTRODUCTION 1

Introduction 1

Aims 2

Conceptual Framework 3

Main Study Concepts 5

Dissertation Organization 10

CHAPTER 2: MANUSCRIPT ONE DECISION MAKING AMONG PATIENTS LIVING WITH HEART FAILURE: AN INTEGRATIVE REVIEW 22

Abstract 23

Introduction/Background 25

Methods 26

Results 27

Discussion 32

Limitations 36

Conclusions....36

CHAPTER 3: MANUSCRIPT TWO VIGNETTES TO UNDERSTAND HF SELF-CARE DECISIONS....51

Abstract....52

Introduction/Background....54

Methods....55

Analysis....57

Results....57

Discussion....59

Conclusions....62

ADDENDUM TO CHAPTER 3....69

CHAPTER 4: MANUSCRIPT THREE SELF-CARE AS A PREDICTOR OF 30 DAY HOSPITALIZATION AND DECISION DELAY....76

Abstract....77

Introduction/Background....79

Methods....80

Measurements....83

Analysis....86

Results....88

Discussion....93

Strengths & Limitations....95

Conclusion....96

ADDENDUM TO CHAPTER 4: THE INFLUENCE OF DEPRESSIVE SYMPTOMS ON 30 DAY REHOSPITALIZATION....112

Quantitative Findings....112

Mixed Methods Findings....113

Discussion....114

Limitations....115

CHAPTER 5: DISCUSSION....121

Quantitative Aim: To compare HF self-care by 30 day rehospitalization status and decision delay....121

Qualitative Aim: To explore the HF patient decision making process prior to rehospitalization focusing on self-care and decision delay....122

Mixed Methods Aim: To describe the decision making processes and patient characteristics in relation to HF self-care and 30 day rehospitalization....123

Limitations & Strengths....125

Implications....126

APPENDIX A: STUDY INSTRUMENTS....132

Mental Cognition: The Mini Cog....132

Demographics, HF experience, and Decision Delay....133

Decision Regret....137

Depression: Center for Epidemiologic Studies Short Depression Scale (CES-D 10) 138

Social Support: Modified MOS Social Support Scale 139

HF Knowledge: The Dutch HF Knowledge Scale (DHFKS) 140

HF Self-Care: The Self-Care of Heart Failure Index (SCHFI) version 6 143

Health Literacy: The short form Test of Functional Health Literacy (S-TOFHLA) 146

Interview Guide* 153

CURRICULUM VITAE 159

LIST OF TABLES

Table 1. Study Summaries From Literature Review 39

Table 1. Demographic characteristics 63

Table 1. Two cases to display the analysis process 73

Table 2. Decision Triggers Identified by Study Participants 74

Table 3. Key players and their Roles in Hospitalization Decision 74

Table 1. Sample Interview Questions 98

Table 2. Survey Sample Characteristics by 30 day rehospitalization status and 2 day decision delay reported as Mean±SD or %(n) 99

Table 3. Logistic Regression Model Predicting 30 Day Rehospitalization Status 100

Table 4. Data Matrix of Quotes by 30 Day Rehospitalization Status and Self-care Management Scores 101

Table 5. Logistic Regression Model Predicting 2 Day Decision Delay 102

Table 6. Depressive Symptom and Symptoms Prior to Hospitalization Quotes by 2 Day Decision Delay 102

Table 1. Quotes by 30 day Rehospitalization Status and Depressive Symptoms 117

LIST OF FIGURES

Figure 1. Adapted Situation-Specific Theory of HF Self-Care 10

Figure 1. Article Selection Process 38

Figure 1. Data Display of Vignettes: Participants Action quotes by Vignette and 30 Day Hospitalization Status 63

Chapter 1: Introduction

Introduction

The heart failure (HF) prevalence is 5.7 million costing $30.7 billion (Mozaffarian et al., 2014) annually with the majority of the costs attributable to rehospitalization. Rehospitalizations among patients with HF (HF patients) are common due to a HF disease trajectory characterized by sudden, acute exacerbations of illness (Goldstein & Lynn, 2006). Hospitalization prediction models for HF do not consistently predict rehospitalization (Kansagara et al., 2011; Rahimi et al., 2014), suggesting the need to examine and explore patient characteristics other than biological markers and general demographic characteristics (e.g., age, sex), such as medical decision making.

HF self-care is defined as the practices and decisions patients engage in to maintain and manage their health (Riegel, Dickson, & Faulkner, 2015). HF self-care requires many illness management decisions such as recognizing worsening HF symptoms, judging symptom severity, and deciding on the appropriate course of action (Riegel, Lee, & Dickson, 2011a). Although HF self-care may decrease unnecessary rehospitalizations (Jovicic, Holroyd-Leduc, & Straus, 2006),(McAlister, Stewart, Ferrua, & McMurray, 2004), HF patient decision making as part of HF self-care is not well understood. Making decisions such as determining when to seek medical attention can be particularly difficult because many HF patients do not consider HF as a chronic illness, resulting in decreased recognition of worsening symptoms during the acute stages of illness (Riegel, Vaughan Dickson, Goldberg, & Deatrick, 2007). Consequently, HF patients on average delay seeking care for 13 hours to 16 days (Gravely-Witte, Jurgens, Tamim, & Grace, 2010) despite the presence of worsening physical symptoms.

In 2012, the American Heart Association (AHA) scientific report on decision making in advanced HF identified the critical need for clinicians to understand HF patient decision making to promote effective, timely, efficient, and safe patient-centered care (Allen et al., 2012). However, the way in which HF patients make self-care decisions prior to rehospitalization and its association with 30 day rehospitalization status and decision delay – the amount of time from worsening symptoms to hospitalization (Sethares, Chin, & Jurgens, 2015) – is not well understood. Timely care can potentially help patients resolve HF exacerbations earlier and avoid unnecessary rehospitalizations. Therefore, understanding how and when these two HF patient groups decide to seek medical attention as part of HF self-care is critical for both healthcare providers and patients (Go et al., 2013).

Aims

Quantitative Aim: To compare HF self-care by 30 day rehospitalization status and decision delay.

Hypothesis 1: HF patients rehospitalized within 30 days of their last hospitalization will exhibit less HF self-care than those rehospitalized beyond 30 days for their last hospitalization, after adjusting for covariates.

Hypothesis 2: HF patients who have decision delay will exhibit less HF self-care than those without decision delay, after adjusting for covariates.

Qualitative Aim: To explore the HF patient decision making process prior to rehospitalization focusing on self-care and decision delay. The following topics were explored: (1) responses/actions to different HF self-care scenarios, (2) daily self-care behaviors prior to rehospitalization, (3) characteristics of successful and unsuccessful HF

self-care, (4) triggers and delays in seeking for help, and (5) barriers and facilitators related to help-seeking and rehospitalization.

Mixed Methods Aim: To describe the decision making processes and patient characteristics in relation to HF self-care and 30 day rehospitalization.

Hypothesis 1: HF patients who are rehospitalized within 30 days for their last hospitalization will describe different decision making processes and vary in patient characteristics compared to those rehospitalized beyond 30 days of their last hospitalization.

Hypothesis 3.2: HF patients who have high self-care will describe different decision making processes and vary in patient characteristics compared to those who have low self-care.

Conceptual Framework

This study was guided by an adapted Situation-Specific Theory of Heart Failure Self-Care (Riegel et al., 2015) (Figure 1), presented in 2006 and updated in 2015 by Dr. Barbara Riegel and colleagues. The Theory explains HF self-care as a naturalistic decision making process, postulating that individuals make decisions based on: (1) their own characteristics (knowledge, experience, and skills), (2) the medical problem they are facing, and (3) the physical and social environment they are in. Under a naturalistic decision making framework, HF patients make real-life self-care decisions under conditions of uncertainty, limited resources, and within different settings/environment. Hence, a similar situation can result in different decision outcomes between HF patients. The Theory has been used extensively in HF research to study how HF patients make

decisions about their symptoms and to describe HF self-care (Riegel, Dickson, & Topaz, 2012; Riegel et al., 2011a; Riegel & Dickson, 2008).

Following an extensive literature review, we selected variables that were related to the Theory's concepts of the person (i.e. HF knowledge, past experiences, health literacy, and depression) and the environment (i.e. social support) and hospitalizations. In addition, we added decision delay and 30 day hospitalization status as outcomes of self-care decision making. A recent review on HF self-care (Riegel et al., 2011a) identified HF knowledge (Annema, Luttik, & Jaarsma, 2009; Field, Ziebland, McPherson, & Lehman, 2006; Rodriguez, Appelt, Switzer, Sonel, & Arnold, 2008), HF experience (Cameron et al., 2010), depression (Holzapfel et al., 2009; Riegel et al., 2009), and social support (Gallagher, Luttik, & Jaarsma, 2011) as factors influencing HF self-care. Health literacy is defined as the capacity to obtain, process, and understand health information and services in order to make sound health decisions (Andrus & Roth, 2002). Although not a predictor of HF self-care in the recent review (Riegel et al., 2011a), the 2009 AHA report identifies health literacy as a critical attribute to performing self-care (Riegel et al., 2009). Decision delay and its relationship with HF rehospitalization have not been well investigated in the literature. Nonetheless, available research indicates that patients with poor HF knowledge (Jurgens, Hoke, Byrnes, & Riegel, 2009; Patel, Shafazand, Schaufelberger, & Ekman, 2007; Schiff, Fung, Speroff, & McNutt, 2003), less experience with HF (Goldberg et al., 2008), more depressive symptoms (Johansson, Nieuwenhuis, Lesman-Leegte, van Veldhuisen, & Jaarsma, 2011), and less social support (Gallagher et al., 2011) have longer decision delays. While no studies have investigated the direct relationship between health literacy and decision

delay, one study found that HF patients with low health literacy had an increased risk for hospitalizations (incidence rate ratio: 1.36) (Wu, Holmes, et al., 2013).

[Insert Figure 1]

Main Study Concepts

Heart Failure

HF is a progressive, chronic disease that ultimately leads to death. There are multiple causes of HF, with the most common causes being ischemic heart disease and hypertension (Mosterd & Hoes, 2007). It is an increasing public health concern with the incidence and prevalence being 870,000 and 5.7 million, respectively (Mozaffarian et al., 2014). Rates of HF are increasing among women and the elderly (Mozaffarian et al., 2014). Nearly half of the HF population has HF with preserved ejection fraction (HFpEF) or diastolic HF (Owan & Redfield, 2005). This is a particular concern because it is more difficult to diagnose HFpEF than systolic HF and more challenging to treat because HF clinical guidelines were largely developed for systolic dysfunction (Yancy et al., 2013). HF patients can experience many symptoms (e.g., fluid retention, shortness of breath, sleep disturbances, fatigue, etc.) that limit their daily functional ability and decrease their quality of life. Unfortunately, the prognosis of HF is extremely difficult to predict and usually complicated by the presence of comorbidities. The majority of patients are managed with medication until transplants or a left ventricular assistive device (LVAD) is required to prolong life.

30 Day Hospitalization

HF is one of the most common diagnoses/reasons for hospitalization, with 22.7% of HF patients rehospitalized 30 days after their previous hospitalization (Centers for Medicare & Medicaid Services, 2013). Since 2012, when Medicare began reducing

reimbursements to hospitals if patients had an unplanned rehospitalization within 30 days of their last hospitalization (Centers for Medicare & Medicaid Services, 2014), US hospitals have been rapidly developing strategies to decrease hospitalizations among HF patients. Risk calculators, using biological markers and general demographic characteristics (e.g., sex, age), which are used to predict individual persons with HF who are at an increased risk for becoming rehospitalized yield inconsistent results (Kansagara et al., 2011; Rahimi et al., 2014). There has been an explosion of studies aimed to examine factors that influence hospitalizations and interventions to decrease rehospitalizations in the HF population. A meta-analysis published in 2014 found that home-visiting programs and multidisciplinary HF clinics reduced HF patient mortality and hospitalization rates (Feltner et al., 2014). Strategies such as outpatient diuresis clinics have also become popular to help decrease rehospitalization rates and costs (Makadia et al., 2015). However, the long term sustainability of these high resource strategies in a strained health care system is yet to be determined. At Johns Hopkins Hospital, from which the study sample was recruited, strategies include a home tele-monitoring system, an outpatient HF clinic managed by HF nurse practitioners, a specialized HF nurse educator, and multiple education formats (paper, video, tablet device).

Decision Delay

Decision Delay as a concept, is ill-defined and consequently, no gold standard instrument exists to measure this concept. Although no valid or reliable measures exist, past studies have defined this as the time from symptom onset to seeking help (going to hospital/clinic) (Sethares et al., 2015). The concept is particularly difficult to measure

because HF patients often have daily/chronic symptoms and may struggle to determine when symptoms become acute. Nevertheless, decision delay is important to study because inordinate delays can result in worsening symptoms and longer hospitalizations (Sethares et al., 2015). HF patients have reported decision delays of up to 7 days even with worsening symptoms, and studies have consistently reported HF patient's inability to interpret symptoms as HF symptoms and lack of social support increase delays (Clark et al., 2012; Sethares et al., 2015).

Heart Failure Self-Care

Once individuals are diagnosed with HF, they are advised to adhere to behaviors that often require major lifestyle changes. HF patients must have the adequate skills to follow the rules and regulations of a HF regimen, identify and react to symptoms, and have confidence in choosing an appropriate course of action. Self-care specific to HF refers to the behavioral skills and decisions HF patients take to maintain (e.g., medication taking, decreasing sodium and fluid intake) and manage (e.g., symptom recognition, interpretation, and response) their health (Riegel et al., 2015). Although interventions aimed at improving HF self-care and subsequently patient outcomes such as hospitalization rates have yielded variable outcomes, (DeWalt et al., 2012; Dracup et al., 2014; Jones et al., 2014; Powell et al., 2010; Shao, Chang, Edwards, Shyu, & Chen, 2013; Smith et al., 2014) the findings suggest that HF self-care may decrease hospitalization rates. Multiple factors are known to contribute to self-care including physical and cognitive function, depression, social support, daytime sleepiness, and attitudes/beliefs about HF (Riegel, Lee, & Dickson, 2011b).

Heart Failure Knowledge

HF knowledge refers to HF patient's understanding of their illness. Knowledge can be gained from health care providers, family members, friends, and/or the internet. Lower HF knowledge was associated with decreased HF self-care (Kato et al., 2013) and knowledge deficits has been noted to be a barrier to performing self-care behaviors (Sethares, Flimlin, & Elliott, 2014).

Health Literacy

The World Health Organization defines health literacy as the "cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in which promote and maintain good health" (WHO, n.d.). Health literacy is a multidimensional concept consisting of components such as numeracy—the ability to interpret numbers, and reading comprehension—the ability to read and understand writing. A recent review of literature on health literacy and HF estimated that 39% of HF patients to have low health literacy, and patient characteristics (age, race, education level) and cognition predict low health literacy (Cajita, Cajita, & Han, 2015). Low health literacy is associated with increased mortality (McNaughton et al., 2015; Peterson et al., 2011; Wu, Holmes, et al., 2013) and hospitalizations (McNaughton et al., 2013; Wu, Holmes, et al., 2013) among HF patients.

Depression

Depression and HF are known to coexist with an estimated prevalence rate of 21.5% of persons with HF having depression (Rustad, Stern, Hebert, & Musselman, 2013). Many of the depression/depressive symptom scales in existence, such as the PHQ-9 and CESD-10, include items which represent typical HF symptoms (e.g., feeling everything requires extra effort, difficulty sleeping). Therefore it is possible the use of

such scales may be an inaccurate representation of true depressive symptom levels in the HF population. Within HF, higher depressive symptoms have been associated with higher rates of hospitalizations, longer length of stays, and all-cause mortality (Johnson et al., 2012; Versteeg et al., 2013).

Social Support

Social support is a multidimensional concept that positively influences patient outcomes, especially among individuals with chronic disease. In particular, emotional (love, caring, and trust), instrumental/tangible (goods and services), informational (information during stressful situations), and appraisal support (assistance with self-assessments and self-affirmation) have been found to improve outcomes in persons with HF (Graven & Grant, 2013). Social support can either have a positive or negative effect on health. Studies have found lower social support predicts the development of significant depressive symptoms (Shimizu, Suzuki, Okumura, & Yamada, 2014) and increases the risk of cardiac events (e.g., emergency department visits, hospitalization, and death) (Wu, Frazier, et al., 2013). There is increasing evidence supporting that caregivers contribute substantively in maintaining and managing the HF patient's health (Buck et al., 2015). However, few studies have measured caregiver contribution to self-care quantitatively due to the lack of instruments available to measure this phenomenon. In 2013, the widely used Self-care of Heart Failure Index (SCHFI), which measures HF patient self-care, was modified into the Caregiver Contribution to Self-Care of Heart Failure Index (CC-SCHFI) (Vellone et al., 2013). The CC-SCHFI was found to be valid and reliable; however, it was validated and found reliable in a study conducted in Italy.

Due to cultural differences, it is possible that the scale would have different psychometric properties among caregivers in the United States.

Dissertation Organization

This dissertation consists of five chapters. Chapter one provides an overview of the study, with a description of the purpose and aims of the dissertation, the conceptual framework, and important concepts.

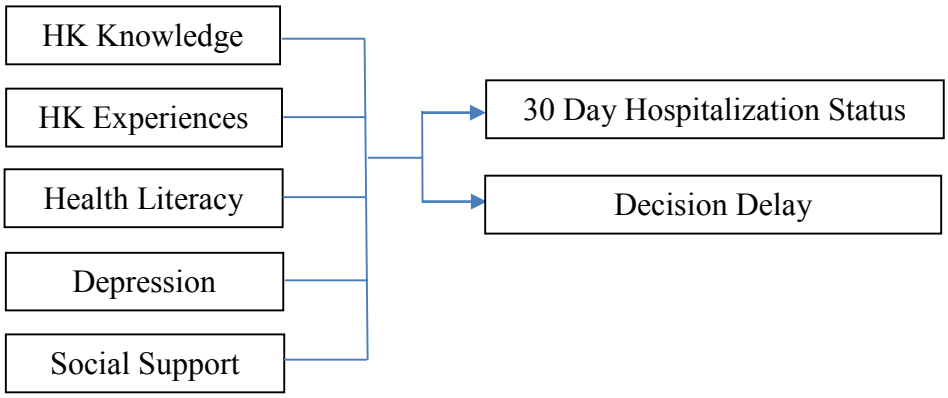
Chapter two (manuscript one) is a review of the relevant quantitative literature on decision making among HF patients. It is a critical review of the articles and provides recommendations for studying decision making in heart failure patients. This manuscript is being prepared for resubmission to the Journal of Cardiovascular Nursing.

Chapter three (manuscript two) is based on the qualitative HF self-care vignette findings comparing self-care decision making between patients who were hospitalized beyond and within 30 days of their last hospitalization. The manuscript details the creation of the vignettes, reports the findings, and suggests future uses for the vignettes. An addendum provides further information on the decision making process prior to hospitalization elicited from the qualitative interviews.

Chapter four (manuscript three) reports the mixed methods findings from the quantitative survey and the qualitative interviews. It compares participants by 30 day rehospitalization status and 2 day decision delay.

Chapter five presents: (1) a concise summary of the dissertation findings reported in Chapters three and four and the addendum; (2) study strengths and limitations; (3) and study implications.

Figure 1. Adapted Situation-Specific Theory of HF Self-Care



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Chapter 2: Manuscript One

Decision Making among Patients living with Heart Failure: An integrative review

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Abstract

Background

Patients with heart failure (HF patients) are required to make decisions on a daily basis related to their declining health and make urgent decisions during acute illness exacerbations. However, little is known about the types of patient decisions reported in the HF literature.

Objective

To critically evaluate the current quantitative literature related to decision making among HF patients and suggest areas of development in HF decision making research.

Methods

A systematic search of literature about HF patient decisions was conducted in the PubMed, CINAHL, and PsychINFO databases. The following inclusion criteria were used: sample comprised of at least 50% HF patients, concrete decisions were made, and a quantitative study design. Two authors performed title, abstract, and full text reviews independently to identify eligible articles.

Results

Twelve quantitative articles were included. Study samples were predominately older, White, male, and married. Two thirds of the articles focused on decisions related to the end of life topics (i.e. resuscitation decisions, advanced care planning). The other one third focused on decisions about care seeking, patient's involvement in treatment decisions during their last clinic visit, and self-care behaviors.

Conclusions

Within the HF literature, the term decision is often ill-defined or not defined. Limitations in methodological rigor limit definitive conclusions about HF decision making. Future studies should consider strengthening study rigor and examining other decision topics such as inclusion of family in self-care decisions as HF progresses. Research rigorously examining HF decision making is needed to develop interventions to support HF patients.

Key Words: decision making; heart failure; palliative care; review literature as topic

Introduction/Background

Approximately 5.1 million people in the United States have heart failure (HF) (Go et al., 2014), with the prevalence expected to increase to more than 8 million people by 2030 (Go et al., 2014). Patients living with HF (HF patients) are expected to adequately manage their illness independently in the community. Due to the unique HF trajectory—unlike a typical chronic or acute illness (Goldstein & Lynn, 2006)—and the complex nature of HF management (T. E. Meyer, Kiernan, McManus, & Shih, 2014), HF patients may find making decisions related to their illness particularly challenging. Not only are HF patients required to make decisions on a daily basis related to their steady decline in health, but also make urgent decisions during acute exacerbations of illness.

For this article, decision making is defined as a dependent variable where a concrete outcome was measured in a past or hypothetical situation, such as Do Not Resuscitate (DNR) orders, resuscitation wishes, care-seeking, and life style choices. This is different from preferences, which is defined as the tendency to "consider something desirable or undesirable" (Warren, McGraw, & Van Boven, 2011). Preferences were conceptualized as a precursor (or an independent variable) to making an actual decision and part of the process in making decisions (Warren et al., 2011). For example a patient who is considering the options of (a) writing an advanced directive and (b) not writing an advanced directive will have a preference for one of the options. This is different from a patient who makes a decision to have an advanced directive, which means he/she has written and formalized an advanced directive for medical use.

In the last ten years, the number of studies on decision making has doubled in major research article databases such as PubMed. However it is unclear what type of decisions

have been explored within the HF literature. Therefore, the purpose of this article is to critically evaluate the current quantitative literature related to decision making among HF patients and suggest areas of development in HF decision making research.

Methods

Selection of Articles

A systematic search of literature about HF patient decisions was conducted in January 2014. The search was conducted in the PubMed, CINAHL, and PsychINFO databases using the following criteria: articles published up to January 2014, in the English language, and about humans. The search terms used for each database can be found in appendix A. The initial search resulted in 1,383 articles from all three databases (not excluding duplicates). Two of the authors (JX and MA) then performed title, abstract, and full text reviews independently to identify eligible articles. Articles were included if they met the following inclusion criteria: sample comprised of greater than or equal to 50% HF patients, concrete decisions (either actual or hypothetical scenarios) were made by patients, and a quantitative study design. Articles were excluded if they were case studies, did not report on the percent of HF patients in the sample, and only included information about patient preferences. A total of 12 articles met the inclusion criteria and were included in this review. Figure 1 depicts the article selection process.

[Figure 1]

Quality ratings

Two of the authors (JX and MA) independently scored the methodological quality of the included articles based on the Johns Hopkins Nursing Evidence Based Practice Research Appraisal form (The Johns Hopkins Hospital/The Johns Hopkins, n.d.). The

following factors were used to determine the quality rating: (1) the rigor in the study design (e.g. power analysis for samples, valid/reliable measures), (2) if the results and analysis were well described, and (3) if the conclusions were reasonable. The initial agreement rate was 75%. Discrepancies were resolved through discussions between the two raters until a 100% agreement rate was achieved. Articles were rated A/High (n=5), B/Good (n=2), or C/Low (n=5) (See Table 1). The authors funding had no role in the review.

Results

Articles overview

Of the 12 articles, 5 were surveys, 1 was a chart review, 2 were secondary analyses of data, 2 were interventions, and 2 used multiple methods (i.e. chart review and survey, mixed methods). The samples were recruited from inpatient hospital visits (n=9, 75%), outpatient clinics (n=2, 17%), and chart reviews (n=1, 8%). Sample sizes ranged from 8 to 539 totaling 1,715 patients. Participants were generally older adults (54-81 years old), male (42%-94%), White (60%-95%), and married (45%-69%). Table 1 summarizes study characteristics.

Eleven studies were conducted exclusively among HF patients, and one study included 64% HF patients. Two thirds of the articles focused on decisions related to the end of life such as resuscitation decisions (n=5), advanced care planning (n=2), implantable cardioverter defibrillator deactivation (n=2), location of death (n=2), and identification of a substitute decision maker (n=1). The other one third of articles focused on decisions about care seeking (n=2), patient's involvement in treatment decisions during their last clinic visit (n=1), and self-care behaviors (n=1). Given the large number of articles

addressing end of life decisions, decisions reported in the articles were summarized in two categories: end of life decisions and non end of life decisions.

[Table 1]

End of life Decisions

Resuscitation Decisions

Resuscitation decisions such as DNR orders and CPR usage were examined in five studies. In comparison to participants without DNR orders (n=349), those with DNR orders (n=26) were more likely to die within 6 months of hospitalization (Dev et al., 2012) or within one year of enrolling in a research study of 539 HF patients (Levenson, McCarthy, Lynn, Davis, & Phillips, 2000). Approximately half (40%-57%) of HF participants hospitalized for acute HF exacerbation stated they would refuse resuscitation (F Formiga et al., 2004; Levenson et al., 2000), with more DNR orders as death approached (Levenson et al., 2000). In contrast, 94% of the deceased HF patients whose medical records were reviewed (n=65) had written DNR instructions (Francesc Formiga et al., 2007). The question of who should be responsible for making resuscitation decisions was addressed in two cross sectional surveys. Both studies found approximately half the participants wanted to share the responsibility with their doctor and/or family (Agård, Hermerén, & Herlitz, 2000; F Formiga et al., 2004). The studies reported differing percentages of participants who wanted to make CPR decisions independently (39% vs.12%) or depend on the doctor (17% vs. 37%) and included small samples of participants (N=80 and 40, respectively) recruited from two countries with different cultural backgrounds – Spain (F Formiga et al., 2004) and Sweden (Agård et al., 2000).

Advanced Care Planning

Of the eleven studies conducted exclusively among HF patients, two focused on decisions related to advanced care planning. A quasi-experimental study (N=36) assessed the completion of an advanced directive after a palliative care consultation (Evangelista et al., 2012), and a descriptive survey (N=41) completion of an estate will (Habal, Micevski, Greenwood, Delgado, & Ross, 2011). A palliative care consultation significantly increased the completion of advanced directives from 28% to 47% ($p=0.016$) in the first study (Evangelista et al., 2012). The majority of participants (76%) had completed an estate will in the other study (Habal et al., 2011). Both studies included a small sample of predominantly male patients with no power analysis.

ICD deactivation

Two studies examining if HF patients would deactivate their ICDs prior to death had mixed results (Habal et al., 2011; Kobza & Erne, 2007). One cross-sectional study (N=41) reported 47% of participants wanted ICD deactivation (Habal et al., 2011), while in another study using retrospective chart review of 8 patients none of the participants wanted ICD deactivation at the time of death (Kobza & Erne, 2007). Of note, participants in both studies were in different phases of their illness trajectory. Not all the participants in Habal's study were at the end of life (Habal et al., 2011), whereas participants in Kobza's study were at the end of life (Kobza & Erne, 2007). Additionally, participants in Habal's study were given a hypothetical situation (Habal et al., 2011), while participants in Kobza's study decided on ICD deactivation based on their current state of health (Kobza & Erne, 2007).

Location of death

Two studies examined participants' decisions about the location of death. When given a hypothetical scenario anticipating death, 40% of HF participants in a cross-sectional survey decided to die at the hospital (F Formiga et al., 2004). In a caregiver survey one month post-patient death, Formiga et al. found that only 26% of patients independently chose to die in the hospital (Francesc Formiga et al., 2007). The articles differed in how they measured the location of death, one was via patient survey using a hypothetical scenario (F Formiga et al., 2004) and the other caregiver report on actual decisions made by the patient at the time of death (Francesc Formiga et al., 2007).

Surrogate decision maker

Patients with chronic heart failure may identify a surrogate decision maker in the event they cannot make their own decisions once their illness progresses. One study (N=41) investigated HF patients' decision about who would be their surrogate decision maker (Habal et al., 2011). The findings indicated that 88% of participants had a surrogate decision maker, with 72% identifying their spouse as the surrogate.

Non End of Life Decisions

Care Seeking

Two correlation studies with predominantly (85%-95%) white samples (N=75 and 201, respectively) examined when HF patients decided to seek care prior to being hospitalized (Altice & Madigan, 2012; Jurgens, 2006). Acute symptoms such as dyspnea were a common cue which led HF patients to seek care in both studies. In comparison to participants with chronic/progressive symptoms, those with acute symptoms sought care earlier (Altice & Madigan, 2012; Jurgens, 2006). Older age and a history of HF

hospitalizations were additional factors associated with decreased delay in care seeking (Jurgens, 2006).

Treatment Decision

Using a telephone survey, one study (N=90) examined HF patient involvement in making medical care decisions during an outpatient clinic visit (Rodriguez, Appelt, Switzer, Sonel, & Arnold). Nearly half (46%) of participants reported expressing some opinion with an additional 30% suggesting or insisting on specific medical treatment. Although the study examined decisions during a specific clinic visit, the term, "care decision" was not clearly defined. In addition, the Perceived Involvement in Care Scale subscale, used to measure participant's involvement in decisions, had a very low Cronbach's alpha of 0.49 in this sample.

Self-Care Behavior Decisions

A multifaceted intervention (education plus support program) study of 128 HF patients asked why they did not follow recommended HF self-care behaviors at three time points (Jaarsma, Abu-Saad, Dracup, & Halfens, 2000). Participants listed the following reasons: limited knowledge on what behaviors needed to be changed after a HF diagnosis, false perceptions of what was acceptable (e.g., fluid intake), job restrictions (e.g., could not rest due to work requirements), and physical disabilities (e.g., limited eyesight). The number of reasons mentioned by the participants did not significantly differ between the control and intervention groups at 3 or 9 months (Jaarsma et al., 2000). The authors identified participant fatigue as a major concern because researchers asked participants why they did not follow self-care recommendations multiple times in each interview (up to 19 times). The fatigue caused some participants to become irritated and

not mention reasons. In addition, it is unclear which parts of the multifaceted intervention was the most effective in promoting HF self-care behavior decisions.

Discussion

Decision science among HF patients is important to study in order to understand if HF patients are making the best choices for their health and how clinicians can help HF patients make informed health care decisions. While the number of articles about HF patient decisions was limited, two thirds of the studies included in the review addressed topics related to end of life decisions. Although end of life decisions are important, there is a great need to understand the broader spectrum of decisions HF patients make outside of end of life. Qualitative studies have already explored decision topics not found in the quantitative literature, such as the family dynamics surrounding genetic testing in HF (Etchegary, Pullman, Simmonds, Young, & Hodgkinson, 2014) and when to begin advanced care planning (Lowey, Norton, Quinn, & Quill, 2013). Future studies should consider examining these decisions and the factors which influence them quantitatively. In addition, building on validated decision theories, such as naturalistic decision making (Riegel & Dickson, 2008), may be a useful approach in developing future research to better understand the nature and mechanism of decision making amongst HF patients. The confusing nature of how decisions are defined in HF research became apparent early in the search process. The majority of studies included in the review did not clearly conceptualize the decision being investigated. Instead, terms such as preference, attitude, wishes, and decision were used interchangeably. Some articles described decisions as preferences, even though concrete or hypothetical decisions were made by patients. Consequently, it was challenging to determine if some of the articles were eligible

without carefully and extensively discussing the study design and outcomes within the writing team. To advance decision science in the field of HF, it is imperative to clearly describe how a decision is defined and for future work to examine the decision making process of how preferences become decisions.

Limited methodological rigor was also of concern for studies included in the review; 5 out of 12 studies received a methodological quality rating of C (poor). In general, studies had small sample sizes, with 67% of studies including less than 100 participants. Only 2 studies (Altice & Madigan, 2012; Jurgens, 2006) reported estimating sample sizes with a power analysis. The small samples and lack of power analyses in the majority of the articles makes the validity of the findings and conclusions drawn questionable. Similarly, half the studies (n=6) did not report the racial and/or sex breakdown or the educational level of the sample. The majority of studies reporting race, sex, and age had a sample with more than 70% Whites (n=5, 83%) and more than 50% males (n=9, 64%). Unfortunately, these sample characteristics are not comparable to general HF population characteristics where 47% of HF patients are females,(Go et al., 2014) limiting the generalizability of the study findings. The lack of studies with sufficient representation of minorities and females results in a paucity of subgroup comparisons, by ethnicity and by sex. Subgroup comparisons are important to examine due to differences in risk for HF and treatment patterns between minority groups and by sex (Go et al., 2014; Jurgens, 2006; S. Meyer et al., 2013). In order to improve sample representativeness and increase subgroup comparisons, researchers should attempt to recruit sufficient numbers of minorities and females. Additionally, future researchers

should consider calculating and reporting the use of power analyses to determine adequate study sample size.

Another key methodological concern was related to study design. The majority of the studies were designed or analyzed cross-sectionally (Altice & Madigan, 2012; Dev et al., 2012; Evangelista et al., 2012; F Formiga et al., 2004; Francesc Formiga et al., 2007; Habal et al., 2011; Jaarsma et al., 2000; Jurgens, 2006; Kobza & Erne, 2007; Rodriguez et al.), limiting our understanding of if and how decisions change over time. More studies are needed to determine when and how patients make key HF decisions and what influences their decisions over time. For instance, patients with decompensated HF have highly impaired cognitive functioning (Kindermann et al., 2012), highlighting the importance of examining how HF patients involve family members in self-care decisions as their illness progresses and if HF patients have the capacity to make informed decisions. Other decision topics in need of further development and study include: decisions around the use of life-saving technologies such as left ventricular assistive devices (LVADS), how HF patients make treatment decisions when multiple health care providers suggest different treatments, and when and how HF patients decide to enroll in palliative care. Such decisions are especially critical for clinicians to understand with rapid advances in technology for HF patients, increasing numbers of HF treatment options, and more complex HF patients who are often older adults with multiple comorbidities (Stewart & Givertz, 2012; van Deursen et al., 2014).

Understanding decision triggers, which cause a patient to make or not make decisions, would be especially helpful in developing targeted, clinical interventions to improve health behaviors and patient outcomes. Although studies on self-care such as the

ones by Altice (Altice & Madigan, 2012) and Jurgens (Jurgens, 2006), identified symptoms which prompted patients to seek care from health providers, it is unclear if there are any modifiable variables (such as ability to identify and assess symptoms in a timely manner, problem solving skills, communication skills about symptoms) influencing HF patient's decisions to engage in self-care. Future studies are warranted to further examine modifiable decision triggers and explore how these triggers can be integrated into clinical interventions to promote healthy behavior decisions among HF patients, prevent inappropriate health care utilization, and reduce negative health outcomes.

Out of all the studies, only three used reliable and valid instruments designed to measure decisions. In the remaining studies, the authors generated their own questions to ask about decisions. Author generation of their own decision making questions may be due to the lack of a "gold standard" for measuring decisions. The creation of a standard measurement tool may be challenging since the types of decisions HF patients make are heterogeneous. Nevertheless, researchers should consider systematic approaches to assess the validity and reliability of their decision measurements. Additionally, researchers should be encouraged to measure various decision concepts such as decisional conflict, regret, or satisfaction to better understand the mechanism of decision making. Measuring these decision concepts would help explain the decision process when making concrete/hypothetical decision, allowing us to gain more insight into the entire decision making process. There are reliable and valid instruments which measure aspects of decisions such as the Satisfaction with Decision Instrument (Holmes-Rovner et al., 1996), Decision Self-Efficacy Scale (Bunn & O'Connor, 1996), and Decision Regret

Scale (Brehaut et al., 2003). The use of the same decision tools in a multitude of studies, examining the same type of decision, would allow researchers to more easily compare HF decision processes and outcomes.

Limitations

Only articles published in the English language were included in this review and articles not published in databases that were searched were missed. It is possible that articles related to HF patient decisions may have been excluded if they did not use common decision making terms (e.g. decision, choice) in the title or abstract. Efforts to minimize this possibility were made by working with an experienced health sciences librarian to compile a list of comprehensive database search terms, and by having two individuals identify eligible articles independently. It is also possible that some articles may have had a sample with more than 50% HF patients, but were excluded because they did not specify the type of patients recruited. We tried to minimize this possibility by carefully reviewing sampling procedures through full text reviews of articles included after the title and abstract screenings.

Conclusions

A review of literature on decisions of HF patients revealed that the term decision is often ill-defined/not defined in the HF literature. Limitations in methodological rigor identified in the articles limit conclusions made in the studies and the generalizability of findings. Future studies should consider strengthening study rigor through the use of techniques such as: power analysis to ensure adequate sample sizes, including sufficient numbers of females and minorities in the study sample, and using reliable and valid instruments to measure decisions. Further studies examining decision topics such as:

changes in decision making over time, the inclusion of family members in self-care decisions, decisions surrounding use of life-saving technology, use of palliative care, and modifiable factors prompting care seeking are needed. Research rigorously examining HF decision making may be used to advance patient education and interventions to support HF patients as they navigate their illness.

Figure 1. Article Selection Process

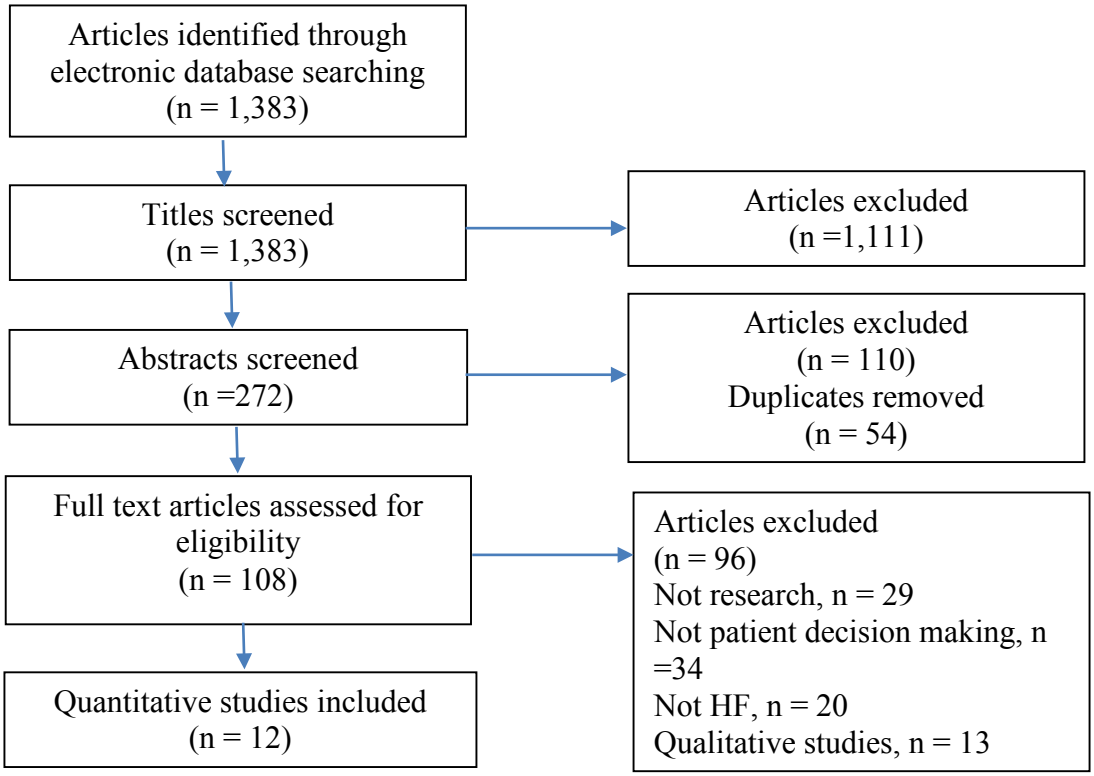

Table 1. Study Summaries From Literature Review

End of Life Decisions					
Ref Quality rating*	**Purpose**	**Design Setting**	**Sample**	**Decision Topic**	**Main Results**
Dev et al., 2012 Quality rating: B	Determine association of HF patient resuscitation orders with individual characteristics	Secondary analysis of data from an RCT **Time points:** 1, 2, 3, 6 months post discharge **Setting:** United States Canada	**DNR group** N= 26 Median age: 64 Male: 65% White: 77% Married: not reported Education: not reported HF patients: 100% **Full code group** N=349 Median age: 56 Male: 74% White: 60% Married: Not reported Education: Not reported HF patients: 100%	Resuscitation orders	DNR patients were older, more likely to have comorbid conditions, lower exercise capacity (6 min walk distance), and longer initial hospitalizations than Full Code patients DNR patients had a higher 6 month mortality (34% higher, $p<0.0001$; 6.88 hazard ratio)
Levenson et al., 2000 Quality rating: B	Characterize patient experiences with HF in last 6 months of life	Secondary analysis of data of a prospective cohort study **Time points:** 3-6 months, 1-3 months, 3 days-1	N=539 Mean age: Not reported Male: 64% White: 78% Married: Not reported Education: Not reported	Resuscitation orders	Written DNR orders increased as death approached: 30%, 36%, 57%, respectively at 3-6 months, 1-3 months, and 3 days–1 month before death DNR orders more likely to be written at baseline for patients who died

		month before death Info about last 3 days of life came from after death interviews with surrogates **Setting:** United States	HF patients: 100%		within first year of enrollment (P<0.001)
Formiga et al., 2004 Quality rating: C	Determine CPR and end of life care wishes	Descriptive, cross-sectional survey **Setting:** Spain	N= 80 Mean age: 79 Male: 42% White: Not reported Married: 45% Education: Not reported HF patients: 100%	Resuscitation orders Location of death	Who decides on resuscitation: patient 39%, doctor 17%, family 2%, all together 42% If cardiac arrest, 40% did not want to be resuscitated If recovery is unlikely patients wanted to be treatment at home (50%) versus the hospital (40%)
Formiga et al., 2007 Quality rating: C	Evaluate end of life circumstances	Chart review & cross-sectional caregiver survey one month post-patient death **Setting:** Spain	Patients, N=102 Mean age: 81 Male: 43% White: Not reported Married: Not reported Education: Not reported HF patients: 64%	Resuscitation orders Location of death	94% of HF patients had DNR instructions on medical record Who made decision to die in hospital: patient (26%), family (31%), doctor (15%), joint (30%)

Agård et al., 2000 Quality rating: A	Examine patient understanding, attitudes, decision making towards CPR	Concurrent mixed methods **Setting:** Sweden	N=40 Mean age: 75 Male: Not reported White: Not reported Married: Not reported Education: Not reported HF patients: 100%	Resuscitation orders	Physician (37%), patient (12%), patient and physician (47%) decide on performing CPR
Evangelista et al., 2012 Quality rating: C	Assess impact of palliative care intervention on health perceptions, attitudes, knowledge, and completion of advance directives	One group, pre-post-test design **Time points:** Baseline 3 months **Intervention:** Referral to outpatient palliative care specialist consultation **Setting:** United States	N=36 Mean age: 54 Male: 72% White: 61% Married: 69% HS or less: 64% HF patients: 100%	Advance directives	47% of the participants completed advanced directives at 3 months follow-up (19% increase) (p=0.016) At 3 month follow up, Whites and those who discussed advance directives with family members were more likely to complete advance directives (all p<0.05)
Habal et al., 2011 Quality rating: C	Determine patients' awareness, comprehension, and utilization of	Descriptive, cross-sectional, survey (part of convergent mixed methods study)	N= 41 Mean age: 57 Male: 83% White: Not reported Married: Not reported	Estate will Substitute decision maker	76% had a will 88% had a substitute decision maker with spouse being most common (n=26)

	advanced directives	**Setting:** Canada	Education: Not reported HF patients: 100%	ICD deactivation	For ICD patients: If condition deteriorated, 47% wanted defibrillator turned off; 26% wanted to keep it activated; 16% undecided; 11% did not want to answer question
Kobza & Erne, 2007 Quality rating: C	Evaluate ICD deactivation wishes	Retrospective chart review **Setting:** Switzerland	N=8 Mean age at death: 67 Male: 88% White: Not reported Married: Not reported Education: Not reported HF patients: 100%	ICD deactivation	No patients wanted ICD deactivated 6 patients felt active withdrawal meant giving up hope for a cure
Non End of Life Decisions					
Altice & Madigan, 2012 Quality rating: A	Evaluate contributions of symptom recognition and clinical factors to care-seeking decision delays	Descriptive, cross-sectional survey **Setting:** United States	N=75 Mean Age: 75 Male: 52% White: 85% Married: 48% HS or less: 69% HF patients: 100%	Care-seeking	93% of patients experienced dyspnea symptoms and described it as reason to seek care Patients with more acute symptoms were more likely to seek emergent care (p=0.04) Patients with more chronic symptoms were more likely to proactively seek care (p=0.001)
Jurgens, 2006 Quality rating: A	Explore relationships among somatic awareness, uncertainty,	Descriptive, cross-sectional survey **Setting:** United States	N=201 Mean age: 70 Male: 56% White: 95% Married: 49%	Care-seeking	78% participants to sought care because of dyspnea Older adults, patients with a history of HF hospitalizations, and acute

	symptom pattern, age, sex, history of HF, and care-seeking delay patterns		HS or less: 63% HF patients: 100%		symptoms decreased delay in care seeking
Rodriguez et al., 2008 Quality rating: A	Assess involvement in treatment decisions	Descriptive, cross-sectional, telephone survey **Setting:** United States	N=90 Mean Age: 70 Male: 94% White: 86% Married: 57% HS or less: 61% HF patients: 100%	Treatment decisions	Involvement in medical decision making during last clinic visit: 46% expressed some opinion, 20% suggested a certain kind of care, 20% expressed doubt about provider's recommendations, 10% insisted on a particular kind of care Preference in level of involvement in decisions making explained 17% of variation in level of Involvement in last clinic visit
Jaarsma et al., 2000 Quality rating: A	Test the effect of education and support intervention on HF self-care behavior	Randomized control Trial **Time points:** Baseline, 1, 3, and 9 months post discharge **Intervention:** Education and support from hospitalization to home	N=128 Mean age: 73 Male: 60% White: Not reported Married: 56% Education: Not reported HF patients: 100%	Care-seeking Self-care behavior decisions	Patients did not contact doctor for symptoms because of limited knowledge and awareness of symptoms Did not follow fluid restrictions, adapt lifestyle, weight oneself, exercise, and/or take medications properly due to false perceptions, job restrictions, lack of knowledge, or physical disability

		Setting: Netherlands			

* A = High, B = Good, C = Low

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Appendix A. Database Search Terms

PubMed:

(("Heart Failure"[Mesh] OR "heart failure" [tiab])) AND ("Decision Making"[Mesh] OR "decision making")

Preference AND ("Heart Failure"[Mesh] OR "heart failure" [tiab])

PsychINFO:

(DE "Decision Making" OR DE "Choice Behavior" OR "decision making") AND "heart failure"

(DE "Preferences" OR preferences OR preference) AND “heart failure”

CINAHL:

((MH "Decision Making+") OR "decision makingi) AND ((MH "Heart Failure+") OR "heart failure")

(Preference OR Preferences) AND ((MH "Heart Failure+") OR "heart failure")

Chapter 3: Manuscript Two

Vignettes to understand HF self-care decisions

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Abstract

Background

Persons with HF must make critical health care decisions on a daily basis, such as responding to acute symptom exacerbations, distinguishing acute and chronic symptoms, and adopting new health behaviors to maintain their well-being. Understanding how persons with HF make medical decisions surrounding self-care behavior is critical to increase their capacity to manage their own health and improve their ability to make critical decisions in response to symptom exacerbations.

Purpose

The purpose of this study is to explore how persons with HF make self-care decisions. This article will report on the results of three HF self-care decision making vignettes from a larger, mixed-methods HF study.

Method

We embedded HF self-care vignettes in semi-structured qualitative interviews to understand how persons with HF interpreted and reacted to worsening symptoms. A total of three clinically different vignettes were developed to represent three different clinical situations: requiring urgent care, requiring contact with physician and/or increased self-care measures, and requiring usual self-care measures. We used content analysis to extract quotes describing the actions participants would pursue in each vignette situation.

Results

A total of 20 participants completed the semi-structured interviews. Interview participants were older, male, African American, unemployed, and highly symptomatic (New York Heart Association Classification III and IV). Overall participants could

identify when symptoms required urgent medical attention, but had difficulty identifying and responding appropriately to less acute symptoms. Often, they did not identify the need to contact their primary care doctor/cardiologist.

Conclusions

From these vignettes, we found participants understood when a situation was acute/emergent, but were more uncertain in responding to symptoms that were not as clearly related to HF. Participants with multiple chronic diseases seemed to have more challenges in determining which disease(s) the symptoms were associated with. To assist persons with HF in interpreting symptoms and determining when to seek for appropriate help, the use of vignettes as an educational tool may be especially useful.

Introduction/Background

Heart failure (HF) is a progressive, chronic disease impacting 5.7 million Americans (Mozaffarian et al., 2014). As the global population ages rapidly, the number of HF cases is estimated to increase by 46% to more than 8 million people by 2030 (Mozaffarian et al., 2014). The management of HF is challenging for both persons with HF and clinicians caring for HF patients, as evidenced by HF being one of the leading causes of hospitalization (Pfunter, Wier, & Stocks, 2013). In the United States, HF management is a pressing challenge due to insurance regulations that penalize medical institutions when individuals are frequently rehospitalized (Centers for Medicare & Medicaid Services, 2014). As we work to develop effective strategies to decrease HF rehospitalizations and increase HF self-care in the community, it is critical to understand how persons with HF make decisions about their health.

Persons with HF must make critical health care decisions on a daily basis, such as responding to acute symptom exacerbations, distinguishing acute and chronic symptoms, and adopting new health behaviors to maintain their well-being. However, within the extant HF literature a limited number of studies report decision making from the patient point of view; the available studies remain predominately clinician focused, examining clinician decision making (Swennen et al., 2013). Understanding how persons with HF make medical decisions surrounding self-care behavior is especially critical to increase their capacity to manage their own health and improve their ability to make critical decisions in response to symptom exacerbations. Despite the importance of adequate HF self-care on maintaining health, HF self-care remains poor among persons with HF (Holden et al., 2015; Sethares, Flimlin, & Elliott, 2014; Skaperdas et al., 2014). A 2014

meta-analysis of randomized trials found interventions addressing HF patient's capacity for self-care (e.g. potential for self-care management), decreased the relative risk for hospitalization (Leppin et al., 2014). It is unclear what promotes or inhibits these individuals in making self-care decisions when symptoms worsen.

Therefore, the purpose of this study is to explore how persons with HF make self-care decisions from their perspectives. The study team recently completed a mixed methods study in which we investigated HF self-care decision making prior to hospitalization. This article will report on the results of three HF self-care decision making vignettes from the HF study.

Methods

Study design

The main study employed a cross-sectional, concurrent, mixed-methods design in which participants completed a quantitative survey and qualitative semi-structured interview. The HF self-care decision making vignettes were incorporated into the qualitative semi-structured interviews.

Sample

Eligible persons with HF were recruited from inpatient clinical units in a large, urban, teaching hospital in the Northeastern United States. Inclusion criteria included: over the age of 21, a previous documented diagnosis of HF in the medical chart, a previous hospitalization due to HF exacerbation, English speaking, and community dwelling. Exclusion criteria included: currently on dialysis, born with congenital heart disease, visual or hearing deficits that precluded ability to participate in the study, or residing in an extended care or assisted living facility.

Vignettes

Vignettes are short stories given to individuals to elicit a response, either from their own perspective or the perspective of the character in the story. Historically, they have been used in social and health science to gain information from individuals when observation is not possible or unethical (Barter & Renold, 1999). They are a valuable technique to explore perceptions, beliefs, and meanings of specific situations (Barter & Renold, 1999). In instances where researchers or clinicians are interested in learning about sensitive topics, vignettes can offer a non-threatening technique to prompt open discussions.

To gain a deeper understanding of how patients interpret and react to symptom exacerbations we created HF self-care vignettes, which were incorporated into the qualitative interviews. A total of three clinically different vignettes were developed based on past research delineating best practices in vignette development (Braun & Clarke, 2013). In order to generate situations that would be realistic and relevant to persons with HF, the vignettes were developed with a team of qualitative methods experts and HF clinicians. The vignettes were purposefully written to represent three different clinical situations: requiring urgent care, requiring contact with physician and/or increased self-care measures, and requiring usual self-care measures.

Study Procedures

Participants completed a quantitative survey consisting of a demographics questionnaire and psychosocial variables including the Self-Care of Heart Failure Index (SCHFI) (Riegel, Carlson, & Glaser, 2000). A subset of participants was purposefully selected to participate in the qualitative interviews based on their self-care maintenance

subscale score from the SCHFI (high and low scores) and 30 day rehospitalization status (current hospitalization within or beyond 30 days of their last hospitalization). Participants were asked to envision themselves as the individual described in the vignettes, and describe their response to each vignette situation. Example questions included: "If you were in this situation, tell me what you would do. Starting with what you would do first?" Participants responded by listing and describing what they would do in a sequential manner. The interviews were 60-90 minutes long, audio-recorded, and transcribed verbatim.

The study was approved by the affiliate university's Institutional Review Board. Prior to enrollment, the study was described, informed consent signed, and participants advised of their rights including the ability to cease study participation without any effect on their care. Each study participant received ten dollars for their time.

Analysis

We used content analysis to extract quotes describing the actions participants would pursue in each vignette situation (Hsieh & Shannon, 2005). For each interview, at least two researchers (JX, SA, or MA) used excel spreadsheets to extract action quotes. The quotes were then summarized with phrases. An example of this spreadsheet and relevant findings of several example cases are presented in the results section. The research team wrote field notes, kept a reflexive diary, and wrote memos while reading and analyzing the transcriptions.

Results

Table 1 summarizes demographic characteristics of the participants. A total of 20 participants completed the semi-structured interviews. Ten participants were

rehospitalized within 30 days of their last hospitalization and 10 participants beyond 30 days of their last hospitalization. Similarly, ten participants had high self-care maintenance scores (≥70) and low self-care maintenance scores (<70). Interview participants were older, male, African American, unemployed, and highly symptomatic (New York Heart Association Classification III and IV). About half the participants had a high school education or less and married.

[Insert Table 1 here]

Figure 1 displays the vignettes used in the study and examples of how participants responded to the vignettes. The bulleted points listed under each vignette are summary statements representing what participants stated they would do in each self-care situation. Exemplars (action quotes) were selected to demonstrate the variability and similarity in participant's self-care decisions.

[Insert Figure 1 here]

Overall participants could identify when symptoms required urgent medical attention, but had difficulty identifying and responding appropriately to less acute symptoms. In Vignette A which represented a clinical situation requiring urgent care, most participants identified the situation as urgent and stated their decision to seek help at a hospital or call 911. Participants were able to recognize acuity in the situation by the presence of shortness of breath. In Vignette B which represented a situation requiring contact with a physician and/or increased self-care measures, most participants did not realize the need to contact a physician and hence did not make a decision to seek care. They were uncertain if the symptoms in the situation were due to HF and cited the use of self-directed treatments without the guidance of a health care professional. In Vignette C

which represented a situation requiring usual self-care measures, participants did not recognize the connection between ankle swelling and weight monitoring. Consequently, participants did not report monitoring weight carefully. Although participants realized something was wrong, they did not know how to respond to the symptom. They sought for help from others because they themselves were uncertain and/or took measures to immediately relieve excessive pressure on their feet by wearing slippers.

Discussion

Responses from the vignettes indicated participants had difficulty making decisions and identifying appropriate steps of action if their HF symptoms were exacerbated, regardless of rehospitalization status (i.e. within 30 days of their last hospitalization vs. beyond 30 days of their last hospitalization). Often, they did not realize their symptoms were related to HF and/or identify the need to contact their primary care doctor/cardiologist. Although clinicians who helped to develop the vignettes did not feel the situations were acute, participants interpreted the symptom exacerbations as both acute and not acute. The result might have been due, in part, to the HF symptoms not being clear indications of worsening HF and may have been interpreted as everyday fatigue, weight gain from overeating, or pedal edema from being on one's feet. The responses from participants in each of the Vignettes are similar to what has been reported in the literature. Persons with HF often seek help emergently when they had difficulty breathing (Altice & Madigan, 2012), however help seeking with other HF symptoms (i.e. fatigue, weight gain, edema) is less clear (Clark et al., 2012). Two literature reviews examining help seeking and self-care behavior among persons with HF

also found the interpretation of the presence and significance of symptoms to be a struggle for this population (Clark et al., 2012; Zavertnik, 2014). Given the association between various HF symptoms (Altice & Madigan, 2012; Clark et al., 2012; Zavertnik, 2014) and rehospitalization, future intervention research is warranted to promote better symptom interpretation.

Other factors influence how patients approach HF self-care, such as presence of comorbidities, severity of HF, functional limitations, memory and cognitive deficits (Holden et al., 2015). Indeed, some of our interview participants stated the use of non HF medications and treatments to alleviate their symptoms. The inability or difficulty to identify and distinguish HF symptoms from symptoms due to other chronic illnesses is a global issue among persons with HF (Jurgens et al., 2009). Similar to this study, other studies have shown that persons with HF often experience other comorbidities and their symptoms may be undertreated (Janssen, Spruit, Uszko-Lencer, Schols, & Wouters, 2011). Clinicians need to find strategies to help persons with HF understand their illness within the context of having multiple chronic conditions, and collaborate with them to establish patient-centered care plans for seeking help according to different clinical manifestations. For example, a systematic review of interventions for managing patients with multiple chronic conditions found the most effective interventions were ones that targeted areas patients had difficulty with (Smith, Soubhi, Fortin, Hudon, & O'Dowd, 2012). Future research is warranted to continue identifying effective strategies for HF patients to better interpret their symptoms within the context for multiple chronic conditions.

Although vignettes have been criticized for their potential inability to portray real situations that participants can identify with, the majority of our participants could personally relate to the vignettes in this study. Persons with HFs may have been especially receptive to the self-care vignettes presented in this article, as they were created in collaboration with HF clinicians, expert researchers, and persons with HF. Despite attempts by clinicians to increase the type and extent of education provided to persons with HF, persons with HF still have difficulty interpreting their symptoms and determining when assistance is needed. Although the majority of participants in the study had received HF education in varying formats through hospital education or community programs, they still had challenges performing adequate self-care. These challenges can potentially be mitigated by using vignettes as a patient-centered education tool to assess how persons with HF understand HF and interpret symptom exacerbations. This strategy may be especially useful in opening discussions (Barter & Renold, 1999) with individuals who may feel particularly sensitive to questioning about their HF, such as individuals with lower health literacy. Vignettes have been successfully used to improve patient communication skills among physicians (Brown et al., 2014), suggesting the use of vignettes as an education tool between patients and providers may build stronger, collaborative patient-provider relationships. This method of learning may help persons with HF increase their HF self-care abilities, increase their health care decision making capacity, and decrease inappropriate health care utilization.

Several study limitations need to be discussed. The data ultimately reflects the participant's reaction to hypothetical situations; therefore, it is possible participants may reason differently when faced with real-life HF symptom exacerbations. Social

desirability bias may have influenced how participants responded to the vignettes. Findings may not be relevant to the overall HF population due to the sample being predominately elderly, urban, male, and African American.

Conclusions

From these vignettes, we found participants understood when a situation was acute/emergent, but were more uncertain in responding to symptoms that were not clearly related to HF. Participants with multiple chronic diseases had more challenges in determining which disease(s) the symptoms were associated with. To assist persons with HF in interpreting symptoms and determining when to seek for appropriate help, the use of vignettes may be especially useful. The self-care decision making vignettes can be used as an education/assessment tool for Persons with HF. Among individuals who have lower health literacy and a poor understanding of HF, vignettes can be especially helpful in promoting patient-provider communications, and prompt targeted discussions about self-care management.

Acknowledgement

Financial support for this study was provided by: the National Institutes of Health [NIH 1 F31 NR014750-01, NIH/NINR T32 NR012704, NIH/NINR T32 NR 007968; American Nurses Foundation/Southern Nursing Research Society Research Award; Sigma Theta Tau International Nu Beta Chapter Research Award; and the Jonas Nurse Leaders Scholar Program

Table 1. Demographic characteristics

Characteristic	Percent (n)
Age (mean±SD)	60.6±12.68
Male	80% (16)
African American	60% (12)
≤ High School Education	40% (8)
Married	50% (10)
Employed	20% (4)
NYHA Class*	
I	20% (4)
II	10% (2)
III	45% (9)
IV	25% (5)

*NYHA – New York Heart Association Classification

Figure 1. Data Display of Vignettes: Participants Action quotes by Vignette and 30 Day Hospitalization Status

Vignette A

Last night you had a hard time sleeping because of breathing problems. You ended up falling asleep only after propping yourself up with two pillows. This morning you're feeling very tired, have a cough that won't go away, and have a hard time breathing sitting on a chair.

Expected Actions: Go to ER or call ambulance

Rehospitalized within 30 days	Rehospitalized beyond 30 days
• Call doctor or go to ER if he feels panicky • Take Lasix pills	• Go to PCP if PCP is available within a day • If still gasping continuously or PCP not available, go to ER
• Stand up and take "real heavy breaths and try to gain my breath" • Call 911 if that doesn't work	• Take nitro, metoprolol, and baby aspirin (because doctor told him about "things I can do when it gets severe")
• Call cardiologist for advice to improve sleep • Call sister in law if cardiologist office isn't open	• Go to ER
• Go to hospital	• Dial 911 • Ask for an ambulance

	• Wash up and get dressed
Vignette B A few days ago, you went out with friends to a birthday party. You had a lot of fun and ended up eating more salty foods than expected. This morning you're feeling more tired than usual, and when you weighed yourself you find out you have gained 3 pounds from yesterday. **Expected Actions: Contact physician for advice, Monitor Weight**	
Rehospitalized within 30 days	**Rehospitalized beyond 30 days**
• Go to work and take more Lasix than usual • Try to pee out fluid	• Decrease salt intake • Drink water "not sure if it's good because drinking water means havi ng more fluid in the body but felt li ke he needs to "flush" the salt out"
• Call 911 to go to hospital	• Take diabetes medication and BP medication, exercise, drink water
• Contact the doctor and "confess my sins to the doctor"	• Do not eat salty foods • Weigh and monitor weight in morn ing and night • Not eat much to see if the weight is from food or fluid
• Use the nebulizer – wouldn't kn ow weight was gained because d oesn't weigh oneself	• Call PCP for recommendation
Vignette C You notice your feet feel tight in your shoes, but you feel better after taking your shoes off. You see that your ankles are little bigger than usual and remember you have gained 2 pounds in the last week. **Expected Actions: Monitor Weight**	
Rehospitalized within 30 days	**Rehospitalized beyond 30 days**
• Take shoes off • Put on a pairs of sandals	• Cut down on salt
• Call 911	• Call CV doctor because poor circulation in ankle and feet could trigger a stroke • Exercise and take medications
• Don't know what he's do	• Get a pair of slippers
• Go to hospital because wife nags if feet start to swell	• Call doctor

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Addendum to Chapter 3

In addition to the self-care decision making vignettes, the 20 qualitative participants also told us stories or narratives about their current hospitalization experiences. In particular, these stories provided further insight into the participant's decision making prior to hospitalization, when and how they decided whether or not to seek care. While the vignettes provided us with information on how participants made decisions based on a set of hypothetical symptom exacerbation situations, their own hospitalization stories allowed us to understand their decision making process in real life.

For the analysis of the stories, we used elements of narrative and content analysis. First, we read each transcription to gain a general overview of the participant's hospitalization experience; second, we determined reoccurring concepts that were relevant to the majority of the hospital experiences; and last, we extracted quotes related to each of the concepts. After reading the stories, we noticed the following reoccurring concepts: symptoms prior to hospitalization, trigger to seeking help initially, trigger to go to the hospital, reason(s) for waiting, participants and roles, other outcomes, and patient reflection. Table 1 is a data display with examples of the quotes we extracted and summarized for each of the concepts. We chose two extreme cases to showcase the differences in the participant's hospitalization experience.

[Insert Table 1]

Case one is a 57 year old, single, male who was told by his primary care physician (PCP) that his health would return back to his pre-HF status within two years. He was able to identify when his symptoms were worsening and was proactive in scheduling regular doctor appointments.

Case two is an 82 year old, married, male who described his illness and his functional limitations as "trash". He frequently expressed frustration with his inability to "prevent symptoms from returning" and disappointment with the health care system.

From literature reviews and cross sectional studies, we know a multitude of factors increase decision delay prior to hospitalization, such as having more chronic symptoms (Altice & Madigan, 2012; Gravely-Witte, Jurgens, Tamim, & Grace, 2010), having poor mental health (Gravely-Witte et al., 2010), and contacting a primary care physician (Gravely, Tamim, Smith, Daly, & Grace, 2011). However, the process by which patients make decisions about their hospitalization is rarely reported. The stories elicited from the interviews gave us a rare opportunity to learn about their entire self-care decision making process prior to hospitalization – from onset of worsening symptoms (as defined by the participant) to hospitalization. Participants described a multitude of factors that influenced their decision to go to the hospital from medical (e.g. shortness of breath, edema, pain, etc.) to non-medical (e.g. not wanting to miss work, needing to care for family members, etc). The participant's stories regarding the triggers to seek initial help, trigger to go to the hospital, and participants and roles were especially enlightening. We defined the trigger to seek initial help, as the reason that prompted participants to contact a health care provider, outpatient clinic, and/or family member for advice. Table 2 is a display with decision triggers to seek initial help and to go to the hospital. We purposefully displayed the decision triggers for both of these concepts side by side for a visual comparison.

[Insert Table 2]

Participants initially sought help due to symptom exacerbations, but went to the hospital due to symptoms and advice from family, friends, and health care providers. It is critical to point out that the symptoms these participants identified as triggers for help seeking were not only physical symptoms. The psychological symptom of fear was frequently cited as a pressing concern. Participants often linked fear and fluid overload, describing a deep fear that the fluid in their legs (pedal edema) would eventually move up their body and envelop their heart, causing them to suffocate and die. The following quote is an example of this fear:

> "[describing movement of fluid from legs] "So then I was thinking, 'Man, it's moving up.' I said, 'Now, this will get round my heart…and then if my heart start hurting like my legs is, I'm going to die.' So that's when: Lightbulb! Ping!" – Participant 103

Hospitalization decisions were instigated by both symptoms and the participant's social support networks, highlighting the importance of social support in helping persons with HF identify and assess symptoms. Table 3 provides more examples of how participants described the roles of other individuals who were involved in the decision making process prior to their hospitalization. Spouses were heavily involved in assisting participants in identifying when they should go to the hospital, and navigating the health care system when participants were incapacitated by their symptom exacerbations. This finding is supported in the current HF research, which identifies the importance of spouses in helping persons with HF maintain and manage their illness. A recent systematic review on contributions to HF self-care by caregivers, found caregivers substantially contribute to self-care by providing concrete and emotional support to

persons with HF (Buck et al., 2015). Among participants who took the initiative to go to an outpatient clinic or call their PCP, they were often advised by their health care providers (HCP) (i.e. home health nurses and outpatient physicians) to go to the hospital or the HCP facilitated the participant's transportation to the hospital.

[Insert Table 3]

Table 1. Two cases to display the analysis process

symptoms prior to hospitalization	trigger to seeking help initially	trigger to go to the hospital	reason(s) for waiting	Key players and roles	other outcomes	patient reflection
Participant 192						
"it feels like that … It's almost if you try to blow up a balloon is someone who is holding so you can't really…blow it up completely so it's painful."	shortness of breath	PCP told him to go	Did not want to miss more days of work, since he had missed many for his heart surgery Had an appointment with his PCP in several days	PCP - told him to go to hospital	N/A	Would not have changed anything unless PCP appointment wasn't within the same week, in which case he would've called his PCP
Participant 238						
Chills, sick to stomach, lack of appetite "brain was not with it," swollen right leg, sore ankle, "holding water in body" - gaining weight about 2 lbs every 2-3 days	Thought he had the flu – called PCP for this reason	Wife said "you don't look so good" and suggested he go to the hospital	Waiting for symptoms to resolve	Wife – suggested he go to the hospital	Feels like he "lost time and money" "haven't gained a thing"	"hoping to get ahead of problem [shortness of breath]"; doesn't feel like he's receiving any answers on how to prevent his symptoms from coming back

Table 2. Decision Triggers Identified by Study Participants

To Seek Initial Help	To go to the Hospital
▪ Shortness of breath ▪ Fluid overload ▪ Pain ▪ Fear ▪ Cough ▪ Hypertension ▪ Unsteadiness on feet ▪ Feeling unwell ▪ Weakness	▪ Shortness of breath ▪ Unsteadiness on feet ▪ Feeling unwell ▪ Frustration or worry ▪ Outpatient health care providers told patient/called ambulance ▪ Family member told patient to ▪ Acute event while at a medical facility

Table 3. Key players and their Roles in Hospitalization Decision

Key player	Role(s)
Spouse	• Provided transport to the hospital • Assisted participant with dietary restrictions (sodium and fluid intake) • Contacted cardiologist when symptoms worsened • Advised participant to go to the hospital
Daughter	• Contacted physicians to schedule appointments • Provided transport to the hospital
Sibling	• Called participant's cardiologist to have him transferred to his cardiologist's hospital • Called ambulance to transport participant to the hospital
Grandmother	• Constantly reminded participant to follow doctor's recommendations
Friends	• Constantly reminded participant to follow doctor's recommendations
Outpatient HCPs	• Called ambulance to transport participant to the hospital • Advised participant to go to hospital • Referred participant to a HF specialist
Psych hospital HCPs	• Called ambulance to transport participant to a medical hospital
Nurse Case Manager	• Called ambulance to transport participant to the hospital
Home health nurse	• Advised participant to call 911

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Chapter 4: Manuscript Three

Self-Care as a Predictor of 30 Day Hospitalization and Decision Delay

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Abstract

Background

Rehospitalizations among patients with heart failure (HF) are common and costly. Current hospitalization prediction models for HF do not consistently or strongly predict rehospitalization, suggesting the need to examine and explore other patient characteristics such as self-care decision making.

Purpose

The purpose of this study was to examine and explore HF patient's self-care decision making prior to rehospitalization. Building on Riegel's HF naturalistic decision making model, we were particularly interested in examining the role of HF self-care on two outcomes: (1) 30 day rehospitalization status and (2) decision delay.

Methods

The study used a cross-sectional, convergent parallel mixed methods design [QUAN+QUAL] and an adapted version of the Situation-Specific Theory of HF Self-Care. We included HF patients who had a previous diagnosis of HF, had a previous hospitalization for HF, spoke English, and scored over a three on the Mini-Cog™ assessment. In addition to demographic information, we collected quantitative data on HF self-care, HF knowledge, past medical experiences, health literacy, depressive symptoms, social support, 30 day rehospitalization status, and decision delay. For the qualitative interviews, we used purposive sampling based on 30 day rehospitalization status and decision delay. Logistic regressions for the quantitative data, and data matrices to display both quantitative and qualitative data were used.

Results

The final quantitative analysis sample included 127 participants. Approximately 60% of participants were rehospitalized beyond 30 days of their last hospitalization. Survey participants were predominantly male (65%), unemployed (79%), older (mean 58.14 ±13.59), and insured (97%). Approximately half of the participants were African American (60%), had a high school education or more (51%), and were married or living with a significant other (40%). Fifteen qualitative in-depth interviews were conducted. The qualitative interview participants had similar demographic characteristics. The odds of being rehospitalized within 30 days was more than 2 times higher among those with high depressive symptoms (OR= 2.31, 95% CI: 1.01 - 5.31).

The odds of decision delay was 5.3 times higher among those with high depressive symptoms (OR= 5.33, 95% CI: 2.14 - 13.28) and decreased by 80% among HF patients who had shortness of breath (OR= 0.20, 95% CI: 0.08 - 0.49). Those who were rehospitalized within and beyond 30 day of their last hospitalization exhibited different HF self-care decision making characteristics (reactive versus proactive). Participants who waited for more than two days felt a sense of devastation and uncertainty about their future with HF. Shortness of breath was described as a state of panic among participants who did not have decision delay.

Conclusions

A patient centered approach needs to be taken to help HF patients identify and adequately self-manage symptoms other than shortness of breath. The drastic influence of high depressive symptoms on the likelihood of being rehospitalized within 30 days and decision delay emphasizes the critical need for clinicians to carefully assess and address depression among HF patients.

Introduction/Background

Rehospitalizations among patients with heart failure (HF patients) are common due to a HF trajectory marked by sudden, acute exacerbations of illness (Goldstein & Lynn, 2006). Despite efforts to prevent unnecessary HF hospitalizations through: (1) home-visiting programs (Feltner et al., 2014), (2) multidisciplinary HF clinics (Feltner et al., 2014), and (3) outpatient diuresis clinics (Makadia et al., 2015), rehospitalization rates remain high. Approximately 1/5 of HF patients with Medicare are rehospitalized within 30 days of discharge (Centers for Medicare & Medicaid Services, 2013), contributing to the 30.7 billion dollars spent on HF annually (Mozaffarian et al., 2014). With the aging baby boomer population, the costs will only rapidly increase in the future. Medicare reimbursement policies now place heavy penalties for 30 day rehospitalizations, increasing the financial burden of HF on a strained United States health care system.

Current hospitalization prediction models for HF predominately use patient characteristics (e.g., age, race, comorbidities) that do not consistently or strongly predict rehospitalization (Kansagara et al., 2011; Rahimi et al., 2014), suggesting the need to examine and explore other patient characteristics such as self-care decision making. According to the Situation-Specific Theory of Heart Failure Self-Care, self-care is defined as a naturalistic decision making process, in which individuals take actions to maintain physiological stability, facilitate perception of symptoms, and manage symptoms (Riegel, Dickson, & Faulkner, 2015). HF self-care is a predictor of outcomes such as improved medication adherence (Granger et al., 2015), and decreased hospitalizations (Smith et al., 2014). Self-care behavior, an outcome of self-care decision

making, has been studied extensively. Help seeking is a form of self-care behavior and timely help-seeking within the context of worsening HF symptoms may prevent worsening symptoms and hospitalizations (Schiff, Fung, Speroff, & McNutt, 2003; Sethares, Chin, & Jurgens, 2015). Acute symptoms, such as shortness of breath, are common reason cited by HF patients to seek help without delay (N. F. Altice & Madigan, 2012; Jurgens, 2006). Despite its potential key role in HF outcomes, the HF self-care decision making process prior to rehospitalization is not well understood.

To better understand the influence of modifiable psychosocial variables on 30 day rehospitalizations and decision delay, a mixed methods study was designed. The purpose of this study was to examine and explore HF patient's self-care decision making prior to rehospitalization. Using a quantitative investigation, we investigated if HF self-care and other selected study variables were predictors of 30-day rehospitalization and decision delay. Using a qualitative investigation, we then explored how the HF self-care decision making process influenced rehospitalization in HF patients who had been rehospitalized within and beyond 30 days of their last hospitalization. Building on Riegel's HF naturalistic decision making model, we were particularly interested in examining the role of the HF self-care, a modifiable variable patients have control over.

Methods

Design/Sample

The study used a cross-sectional, convergent parallel mixed methods design [QUAN+QUAL] (Creswell & Plano Clark, 2011). This design allowed us to gain an in-depth understanding of the participant's decision making process by using the qualitative data to explain the statistical results from the quantitative data (Creswell & Plano Clark,

2011). We adapted a Situation-Specific Theory of Heart Failure Self-Care (Riegel et al., 2015) to select study variables and determine which relationships to statistically analyze (Figure 1). According to the theory, the self-care decisions are made under conditions of uncertainty, limited resources, and within different settings/environment; therefore, a similar situation can result in different decision outcomes (Riegel et al., 2015). In the original Theory, the constructs of the person, problem, and physical/social environment were postulated to influence HF self-care decisions. However, the three constructs were not mutually exclusive from which to derive measures. Therefore, we adapted the Theory by selecting concepts pertaining to the person (HF knowledge, HF experiences, health literacy, and depression) and the environment (social support) which have been shown to influence HF self-care and/or hospitalizations. Since we designed the study within the context of self-care decision making before a problem (i.e., needing to be hospitalized), we conceptualized the problem construct as the context in which HF patients made decisions. The outcomes of 30 day rehospitalization and decision delay were included in the adapted Theory, as outcomes of self-care decision making.

We included HF patients who had a previous diagnosis of HF on their medical chart, had a previous hospitalization for HF, spoke English, and scored over a three on the Mini-Cog™ assessment. We excluded HF patients hospitalized for acute conditions (N. F. Altice & Madigan, 2012) and/or had congenital heart disease because they may have different behaviors than HF patients hospitalized for exacerbations of chronic HF. Patients with LVADS and/or severe renal insufficiency requiring dialysis are managed differently in comparison to typical HF patients (Burke & Givertz, 2014; Hunt et al., 2005). We enrolled 186 participants for the quantitative survey section. For the

qualitative interviews, we used purposive sampling to build a qualitative sample with similar numbers of patients who were rehospitalized beyond or within 30 days of their last hospitalization and those who had high or low HF self-care maintenance defined by a cutoff score of 70. A total of 15 survey participants also completed individual interviews.

Setting

Participants were recruited from an urban, East Coast, teaching Hospital.

Procedures

Upon approval from the Hopkins Institutional Review Board, data collection began. First, the primary investigator screened HF patients for eligibility via chart review. Then potentially eligible HF patients were approached and introduced to the study by a study team of trained research assistants. To account for patient fatigue, every effort was made to approach HF patients who were beyond their first day of hospitalization. HF patients who were interested in the study went through the consent process and then screened for cognitive impairment using the Mini-Cog™ test. The Mini-Cog™ measures memory, language comprehension, visual-motor skills, and executive function (Borson et al., 2000). Those who scored over a 3 on the Mini-Cog™ proceeded to the quantitative survey. We used an online survey hosted on a website called Qualtrics (http://www.qualtrics.com) to collect the survey data. All of the survey questions were verbally read to all the participants, except for the health literacy reading comprehension questions. Participants were not paid for completing the quantitative survey.

From the quantitative study sample we purposefully selected participants for individual in-depth interviews based on 30 day rehospitalization status and self-care management

scores. This resulted in four types of participants those who were: (1) hospitalized within 30 days and scored high for self-care, (2) hospitalized within 30 days and scored low for self-care, (3) hospitalized beyond 30 days and scored high for self-care, and (4) hospitalized beyond 30 days and scored low for self-care. Sample interview questions can be found in Table 2. Individual interviews lasted on average of 60 minutes. Interviews were audio recorded if permitted by the interview participant, and transcribed verbatim. Participants received ten dollars in cash for their participation in the qualitative interviews.

Typically, participants completed the quantitative survey in one time point and were interviewed at another time point for the qualitative in-depth interviews. However, some participants became fatigued during the study and needed to complete the survey and/or in-depth interview at multiple time points.

[Insert Table 1]

Sample size

For the quantitative sample, a power analysis based on analysis of covariance (ANCOVA) with two groups, alpha of 0.05, power of 0.8, and a medium effect size of 0.25, yielded a total of 128 participants. For the qualitative sample, an estimated 20-32 participants were needed to reach data saturation (Crabtree & Miller, 1999).

Measurements

Individual characteristics were assessed via medical record review and the study questionnaire. The study questionnaire included questions about sociodemographics (e.g., age, sex, race, education, income, employment status) and medical history (e.g., number of past hospitalizations for HF, years with HF, comorbidities, and symptoms prior to

hospitalization, decision delay). Other main study variables were measured via established instruments, which are listed in detail below.

HF knowledge

The Dutch HF Knowledge Scale (DHFKS) used to measure general HF, symptom, and treatment knowledge. The scale has a total of 15 questions in a multiple choice format. Scores range from 0-15, with higher scores indicating more HF knowledge. Content, face, and construct validity has been established and the Chronbach's alpha is 0.62 (van der Wal, Jaarsma, Moser, & van Veldhuisen, 2005).

Health literacy

The short form Test of Functional Health Literacy (S-TOFHLA) is a 36 item tool consisting of 2 subscales measuring functional health literacy/reading ability and numeracy/ability to interpret numbers. The numeracy items, which were originally based on diabetes, were adjusted to be relevant to individuals with cardiovascular disease. Scores range from 0-36 for the functional health literacy scale and 0-8 for the numeracy scale, with higher scores indicating higher health literacy. A score of 23 or more on the functional health literacy scale indicates adequate health literacy. It has construct validity and a Chronbach's alpha ranging from 0.95-0.96 (Aguirre, Ebrahim, & Shea, 2005).

Depression

The CESD-10 measures the depressive symptoms within the last week on a 10 item 4 point likert scale. Scores range from 0-30, with higher scores indicating the presence of more depressive symptoms. A score of 10 is used as the cutoff, with scores greater than or equal to 10 as a possible indication of significant depressive symptomatology. It has a Chronbach's alpha of 0.78 (Boey, 1999) and has convergent

and discriminant validity (Amtmann et al., 2014; Andresen, Malmgren, Carter, & Patrick, 1994).

Social support

The Modified MOS Social Support Scale has eight items measuring emotional and tangible support. Emotional support is the provision of support involving caring, love, and empathy (Sherbourne & Stewart, 1991). Tangible support relates to material aid (Sherbourne & Stewart, 1991). Scores range from 0-100, with higher scores indicating greater social support. The scale has construct and discriminant validity, and a Chronbach's alpha from 0.88 to 0.93 (Moser, Stuck, Silliman, Ganz, & Clough-Gorr, 2012).

HF self-care

The Self Care of Heart Failure Index (SCHFI) version 6 was used to measure self-care in three subscales: (1) management – how patient's respond to symptoms, (2) maintenance – performing daily HF specific activities to maintain health, and (3) confidence – amount of self-efficacy patients have in caring for their HF. The scale consists of 17 items, with a standardized score of 0-100 for each subscale. A score of 70 or greater indicates adequate self-care. Construct validity is established and Chronbach's alpha ranges from 0.56 to 0.83 (Riegel et al., 2004; Vellone et al., 2013).

Decision delay

No valid or reliable measures exist. As in past studies, delay was measured via self-report about the time from symptom onset to arrival at the hospital (Sethares et al., 2015). Decision delay for this study was defined as waiting for more than two days (coded as 1) versus waiting for less than or equal to two days (coded as 0).

Decision regret

The Decision Regret scale was used to ask participants to reflect on the decisions they made before coming to the hospital. To help participants understand what was meant by decisions prior to hospitalization, the example of making the decision to come to the hospital was used. The scale has five items on a 5 point likert scale, with scores ranging from 0-100 and a Chronbach's Alpha ranging from 0.81 to 0.92 (Brehaut et al., 2003). Convergent validity has been established with decision satisfaction, and quality of life (Brehaut et al., 2003). In the HF population, the scale has a Chronbach's alpha of 0.86 and discriminant validity (Hickman, Pinto, Lee, & Daly, 2012).

Analysis

The final analysis sample included 127 participants, after removing 59 participants due to cognitive impairment, screening errors, or dropping out. We used the regression method to impute missing data for four people on major logistic regression variables. Our analytic approach consisted of three phases. In phase one, in addition to descriptive statistics to summarize our data, we used t-tests or Chi-squared tests to compare the characteristics of participants by 30 day rehospitalization status and by two day decision delay. After discussing the expected time HF patients would wait before going to the hospital with HF nurse practitioners, we decided to dichotomize the decision delay variable at 2 days with those who waited for more than 2 days being coded as 1 (decision delay) and those who waited for 2 days or less being coded as 0 (no delay). We posited HF patients would wait for at least one day for symptoms to improve before seeking care the second day of symptoms. We then tested a best fitting logistic regression model. The HF self-care subscales, along with the demographic and

psychosocial variables found to be significant at the bivariate level at $p \leq 0.10$, were included as covariates in logistic regressions to predict 30 day rehospitalization status. To ease interpretation of results, variables were dichotomized when possible. We used backward stepwise logistic regression, in which all variables were included in a multivariate logistic model and extracted at different steps if they did not reach a significance level of $p = 0.10$. The same approach was used in a multivariate logistic regression model to predict decision delay/no decision delay. The HF self-care subscales were included as covariates in both of the logistic regressions for theoretical reasons, even if the self-care scores were not statistically significantly different in the bivariate analysis (Jones et al., 2014; Lee, Lennie, Warden, Jacobs-Lawson, & Moser, 2013).

In phase two, we used a qualitative descriptive analysis approach. Steps in the qualitative analysis included: (1) reading the interview transcriptions to gain a general understanding of the content, (2) using an open coding method to code blocks of text (i.e., single words, short phrases, or passages of data), (3) generating an initial code book based on 5 interviews, (4) grouping similar codes into categories to express the latent concept of grouped codes (Burnard, 1996; Graneheim & Lundman, 2004). Through the process, we constantly compared the codes with the interview transcripts to derive categories which were representative of the interviews. Reflexivity occurred through written memos and coding discussions. Trustworthiness was achieved by reviewing the codes and codebook with the study team. We have included detailed inclusion and exclusion criteria of the sample and sample interview questions to increase transferability of findings.

In phase three, congruence between the quantitative findings and qualitative data were placed in mutual context through matrices. Based on the quantitative study findings, the matrices were constructed to compare and contrast participants by (1) self-care management scores and 30 day rehospitalization status, (2) depressive symptoms and decision delay, and (3) symptoms prior to hospitalization and decision delay. These displays allow us to easily examine if the qualitative data helped to explain the significant results from the quantitative data. We used the following steps to extract relevant participant quotes for the matrices: (1) reading quotes in the categories from phase two (2) using content analysis to extract phrases and/or passages relevant to self-care management, depressive symptoms, and symptoms prior to hospitalization.

Results

Sample characteristics

The survey participants were predominantly male (65%, n= 83), unemployed (79%, n= 100) and insured (97%, n= 122). On average participants were 58.14 of age, had HF for 6.5 ±8.56 years, and had been hospitalized 3.7±3.28 times for HF. Approximately half the participants were African American (60%, n= 74), had a high school education or more (51%, n= 65), were married or living with a significant other (40%, n= 51), had an annual income of less than $20,000 (44.4%, n= 56), had adequate functional health literacy (58%, n= 73), and scored over 10 on the CESD-10 instrument (60%, n= 76). Table 3 compares the demographic and psychosocial variable characteristics of patients by 30 day rehospitalization status and decision delay. Thirty eight percent (n=48) were rehospitalized within 30 days of their last hospitalization and 62% (n=79) beyond 30 days of their last hospitalization. Out of the 127 participants, 125

were used for the decision delay analysis because two individuals were unable to specify their decision delay in days. 54% (n= 68) of participants waited with worsening symptoms for more than 2 days before hospitalization.

[Insert Table 2]

The average age for the fifteen qualitative interview participants was 58.6±11.43, 87% (n= 13) were male, 53% (n= 8) Caucasian, 60% (n= 9) had some college education or greater, 47% (n= 7) were unmarried, and 80% (n= 12) unemployed. 53% (n=8) were hospitalized within 30 days of their last hospitalization, 67% (n=10) had decision delay, 60% (n=9) had high self-care management scores, and 80% (n=12) had high depressive symptoms.

Logistic regression for 30 day rehospitalization

Seven covariates that were associated with 30 day rehospitalization at the bivariate level ($p<0.10$), were used in the regression model predicting 30 day rehospitalization. The covariates were categorized as follows: (1) HF self-care maintenance: 1= high, 0=low, (2) HF self-care management: 1= high, 0=low, (3) HF self-care confidence: 1= high, 0= low, (4) social support, (5) NYHA class: 1= Class III and IV, 0 = Class I and II, (6) depressive symptoms: high=1, low=0, and (7) education level: 1= more than high school education, 0=less than high school education. The odds of being rehospitalized within 30 days of the last hospitalization was 53% lower among HF patients with high HF self-care management (OR= 0.47, 95% CI: 0.21 - 1.042) and 2.3 times higher among those with high depressive symptoms (OR= 2.31, 95% CI: 1.01 - 5.31) after adjusting for covariates. See table 4 for the logistic regression model details.

[Insert Table 3]

To help explain the significant logistic regression finding, table 5 is a data matrix with quotes extracted from the qualitative interviews divided by 30 day rehospitalization status and high/low self-care management. Participants who were rehospitalized within and beyond 30 days of their last hospitalization exhibited different self-care management techniques.

For example, participants who were rehospitalized within 30 days tended to be reactive towards symptom exacerbations. Those with high self-care management scores made depended on their previous experiences and/or suggestions from their friends and family to make decisions rather than seeking help from a health care professional. One of the interview participants who fit in this category said: "I had some problems in my stomach area and I didn't know whether it was the medication or what, but my sister in law told me it was the laxative that I was using - that I was using too much of it, and so I backed off for that." Meanwhile, those with low self-care management scores exhibited uncertainty in how to respond. One participant in this category indicated confusion over his symptoms: "Dad, something's wrong with me, you gotta take me to the emergency room. They gotta re-trouble shoot me. What's wrong with me?" I felt like I was dying again."

Participants who were rehospitalized beyond 30 days with high self-care management scores tended to be proactive and actively sought professional advice before making decisions. For instance, one participant said she calls her outpatient doctor if she experiences shortness of breath for more than 1-2 days. The participants who contacted their outpatient doctors for help generally reported having an established relationship with those doctors prior to the symptom exacerbation. Those with low self-care

management waited for symptoms to worsen before seeking immediate help as exemplified by this quote: “I thought I was just sick so I took a hot bath, got out of the bathtub, I'm not feeling right, I'm not feeling good, this is not right ... so I got dressed, told my roommate, my roommate gave me, ten to fifteen bucks to go to the hospital.” Table 5 is a data matrix displaying quotes related to self-care management by 30 day rehospitalization status.

[Insert table 4]

Logistic regression for longer decision delay

Seven covariates that were associated with decision delay at the bivariate level ($p<0.10$), were used in the regression model predicting decision delay. The covariates were categorized as follows: (1) HF self-care maintenance: 1= high, 0=low, (2) HF self-care management: 1= high, 0=low, (3) HF self-care confidence: 1=high, 0=low, (4) number of dependents living at home, (5) depressive symptoms: 1=high, 0=low, (6) employment: 1=employed, 0=unemployed, and (7) shortness of breath as the self-identified cause for hospitalization: 1=shortness of breath, 0=other symptom. Depressive symptoms and shortness of breath were significant covariates of the likelihood of decision delay. The odds of decision delay increased by 433% among those with higher depressive symptoms (OR= 5.33, 95% CI: 2.14 - 13.28) after controlling for the other covariates. The odds of decision delay decreased by 80% among HF patients who had shortness of breath (OR= 0.20, 95% CI: 0.08 - 0.49) after controlling for the other covariates. See table 6 for the logistic regression model details.

[Insert table 5]

Among participants who completed the qualitative interviews, those who did not have decision delay expressed a strong will to live and believed the hospital system would help relieve their symptoms based on past hospitalization experience A participant who fit into this category said "I don't want to die. That's reason enough. I don't, I don't want to die. Cause I really just feel like I'm too young to die." In comparison, those who had decision delay felt a sense of devastation and uncertainty about their future with HF. An individual described his despair with the following quote:

> "Well, whenever you've been sick, most people have dark thoughts and I felt like, if I'm gonna feel like this every day of my life- like I'm hungover, I've got the flu, and I'm dying, you know nobody can fix me- what's the sense of being here. I mean I'm dying, my body is screaming in agony. So yeah, I had dark thoughts, you know, suicide. Um, but you know, I never- the thoughts go through your head, but I never planned on doing it." – Participant 161

Those who did not have decision delay described their shortness of breath exacerbation as a state of panic with quotes such as: "it's like to the point where I'm scared I'm getting ready to die." Participants who waited for a longer time before hospitalization described their symptoms in less urgent terms as described by this quote "Anytime we had desserts and stuff, I'd chunk right up but I thought ok, I'm just eating too many calories but in fact it was just more fluid that's coming on." Table 7 is a data matrix displaying quotes related to depressive symptoms and symptoms prior to hospitalization (shortness of breath or other symptoms) by decision delay.

[Insert table 6]

Discussion

In our sample of HF patients (N=127), we found that high self-care management reduced the likelihood of being rehospitalized within 30 days of a previous hospitalization and that having more depressive symptoms and shortness of breath significantly influenced patient's decision delay. By integrating the quantitative scores of self-care management and the qualitative interviews, it became evident that those who were hospitalized within days of their last hospitalization exhibited different decision making characteristics than those hospitalized beyond 30 days. Regardless of self-care management scores, participants who were rehospitalized within 30 days were reactive to symptom exacerbations and attempted to alleviate symptoms through self-doctoring. Participants who had high self-care management and were hospitalized beyond 30 days were proactive in seeking medical attention from health care providers they had established relationships with. This finding highlights the importance of having a trusting and positive relationship between HF patients and their outpatient health care providers, in a way that enables and encourages them to contact their providers in times of need. A literature review on the interactions between HF patients and clinicians revealed that responsive clinicians who showed an interest in the patient's individual needs and shared information improved HF patient self-care (Currie et al., 2014). By actively involving health care providers when making self-care management decisions regarding symptom exacerbations, these participants increased their likelihood of appropriately reacting to symptoms (e.g. adjusting medications, going to an outpatient diuresis clinic) in a timely manner.

The relationship between self-care management and 30 day rehospitalization was not significant. A possible explanation might be that HF patient self-care management might have been a reflection of the participant's management ability in conjunction with their caregiver's rather than their independent self-care management abilities. Indeed, individual in-depth interviews revealed that participants heavily depended on family caregivers for assistance with making self-care decisions. Studies have reported the importance of caregivers in assisting with HF self-care management activities such as motivating patient's to improve their self-care and navigating the health care system for HF patients (Buck et al., 2015). However, it is unclear how caregiver HF management skills impacts patient outcomes such as being rehospitalized within 30 days. Future studies are needed to understand the potential influence of family caregiver's HF management skills on rehospitalization status.

The presence of more depressive symptoms drastically increased the likelihood of participants waiting for more than two days before going to the hospital in this study. Meaning, participants with more depressive symptoms suffered from exacerbated symptoms for a longer time than those without depressive symptoms. Studies have reported similar findings, in which depression increased risk of hospitalizations among HF patients (Jiang et al., 2001; Moraska et al., 2013). The high prevalence of depression (about 20%) among HF patients (Rustad, Stern, Hebert, & Musselman, 2013) and the high proportion of participants who scored high on the depressive symptom measurement in this study (about 60%) emphasizes the critical need for clinicians to assess and address depression in HF patients.

Consistent with the existing literature, we found patients who identified shortness of breath as their primary reason for hospitalization felt this symptom was urgent (Altice, 2012) and were more likely to be hospitalized within 2 days. Meanwhile, patients who identified other symptoms such as changes in functional status were more likely to wait beyond 2 days prior to hospitalization. Studies have found similar results, in which HF patients have a difficult time interpreting and understanding how to respond to symptoms other than shortness of breath (Clark et al., 2012). The findings draw attention to the need for clinicians to develop strategies with HF patients to identify and adequately manage symptoms other than shortness of breath. Telehealth programs may be especially useful in helping clinicians closely monitor the progression of symptoms with their HF patients and problem solve in real time (Radhakrishnan & Jacelon, 2012). Through this patient centered approach, HF patients can actively learn how to identify and respond to symptoms with guidance from their clinician, and gain the confidence to adequately manage their future HF symptom exacerbations.

Strengths & Limitations

Limitations include having a relatively small sample size, potential for self-report biases such as social desirability bias when responding to survey questions, and the presence of cognitive impairment which may have influenced the participant's responses. Although the sample was small, we had a diverse sample with approximately half being African American. The small sample may also have increased the likelihood that a significant relationship between self-care management and 30 day rehospitalization was not detected. During the quantitative survey, we tried to decrease social desirability bias by reminding participants there was not a correct or wrong answer and we were only

interested in what their experience is like as a HF patient. Cognitive impairment has been reported to range from 30-80% and mental cognition can fluctuate daily (Dardiotis et al., 2012). Although we initially screened HF patients for cognition, it is possible that the mental status of participants changed when we completed the survey with participants who could not finish at one time point. It is important to point out that many HF patients became visibly distressed when they failed to pass the cognition screening. Future researchers should be mindful of this response and build strategies in recruitment protocols to combat this. We had originally conducted a power analysis with the assumption that the decision delay variable would be treated as a continuous, normally distributed variable. However, the decision delay variable was heavily skewed, thus we used logistic regression for the analysis rather than ANCOVA.

Despite the study's limitations, the integration of quantitative and qualitative findings was a major strength. By using a mixed methods design, we were able to explain the quantitative results with the qualitative data among the same participants. The qualitative data provided context to the participant's quantitative scores, resulting in a richer and deeper understanding of why depressive symptoms, and shortness of breath were significant predictors of our main outcome variables.

Conclusion

From this study we found HF self-care management, depressive symptoms, and the presence of shortness of breath influenced participant's 30 day rehospitalization status and decision delay. A patient centered approach needs to be taken to help HF patients improve their self-management in areas self-identified as challenging, and to ensure adequate identification and self-management of symptoms other than shortness of breath.

The strong influence of high depressive symptoms on the likelihood of decision delay emphasizes the critical need for clinicians to carefully assess and address depression among HF patients.

Table 1. Sample Interview Questions

What's your daily routine like as a person with heart failure?

- *What do you do on a usual basis to take care of yourself?*
- *What happens when you aren't feeling well?*

Tell me what you know about heart failure?

- *How did you learn this?*

Describe what you did from when you realized something was wrong to when you came to the hospital?

a. Tell me about what you did when you realized you weren't feeling like your normal self.

- *What do you think was happening? …Tell me about what was going on with your body at the time?*

b. What did it feel like for you?

- *How is that different from how you normally feel?*
- *Out of all things you were feeling, which one was the most concerning to you?*

c. What was your response?

- *How did you know to do that? Who was involved? What did they do?*
- *What kept you from responding in this situation? Who was involved? What did they do?*

d. With the way that you were feeling, what do you think went well in this situation? What might have been better?

Table 2. Survey Sample Characteristics by 30 day rehospitalization status and 2 day decision delay reported as Mean±SD or %(n)

Characteristics	Total	30 day N=48	Non 30 day N=79	P-value	No decision delay N=57	decision delay N=68	P-value
Sex (male)	65.4 (83)	64.6 (31)	65.8 (52)	0.887	63.2 (36)	67.6 (46)	0.599
Age (years)	58.1 ± 13.6	56.3 ± 12.8	59.3 ± 14.0	0.223	58.3 ± 14.6	58.1 ± 12.5	0.916
Race							
Caucasian	37.9 (47)	37.5 (18)	36.7 (29)		36.8 (21)	36.8 (25)	
African American	59.7 (74)	56.2 (27)	59.5 (47)	0.818*	61.4 (35)	55.9 (38)	
Other	4.8 (6)	6.2 (3)	3.8 (3)		1.8 (1)	7.4 (5)	0.335
No. of Dependent (children/grandchildren)	1.4 ± 1.2	1.2 ± 1.1	1.5 ± 1.3	0.181	0.7 ± 1.3	0.5 ± 0.8	0.333
Caregiver in Residence							
Yes	52.8 (67)	52.1 (25)	53.2 (42)	0.906	49.1 (28)	55.9 (38)	0.451
Education							
HS education or less	48.8 (62)	37.4 (18)	55.7 (44)		54.4 (31)	44.1 (30)	
Some College or more	51.2 (65)	62.5 (30)	44.3 (35)	0.047	45.6 (26)	55.9 (38)	0.253
Marital Status							
Married/Living with Sig	40.2 (51)	43.8 (21)	38 (30)		42.1 (24)	38.2 (26)	
Widowed/separated/divorced	33.9 (43)	27.1 (13)	38 (30)	0.45	29.8 (17)	36.8 (25)	
Never Married	26.0 (33)	29.2 (14)	24.1 (19)		28.1 (16)	25.0 (17)	0.715
Employment Status							
Employed	21.3 (27)	16.7 (8)	24.1 (19)		28.1 (16)	16.2 (11)	
Unemployed	78.7 (100)	83.4 (40)	75.9 (60)	0.324	71.9 (41)	83.8 (57)	0.108
Annual Income							
0-20,000	44.4 (56)	50.0 (24)	41.0 (32)		47.4 (27)	41.8 (28)	
20,001 - 60,000	32.5 (41)	27.1 (13)	35.9 (28)		31.6 (18)	32.8 (22)	
60,001 +	18.3 (23)	18.8 (9)	17.9 (14)	0.710*	14.0 (8)	22.4 (15)	
don't know	4.8 (6)	4.2 (2)	5.1 (4)		7.0 (4)	3.0 (2)	0.507*
Time with HF (years)	6.5 ± 8.6	5.7 ± 7.4	7.0 ± 9.2	0.432	6.8 ± 10.8	6.3 ± 6.2	0.752
NYHA Class							
I	18.9 (24)	14.6 (7)	21.5 (17)		24.6 (14)	14.7 (10)	
II	21.3 (27)	14.6 (7)	25.3 (20)		21.1 (12)	20.6 (14)	
III	40.2 (51)	43.8 (21)	38.0 (30)		31.6 (18)	48.5 (33)	
IV	19.7 (25)	27.1 (13)	15.2 (12)	0.189	22.8 (13)	16.2 (11)	0.215

Number of past hospitalizations for HF	3.8 ± 3.3	3.9 ± 2.8	3.7 ± 3.5	0.689	3.6 ± 2.9	3.9 ± 3.5	0.637
Charleston Comorbidity Index	2.7 ± 1.7	2.7 ± 1.4	2.8 ± 2.0	0.905	2.6 ± 1.6	2.8 ± 1.9	0.672
Self-Care							
Maintenance	64.2 ± 17.2	62.8 ± 18.1	65.1 ± 16.8	0.487	63.2 ± 19.4	64.8 ± 15.5	0.626
Management	63.6 ± 21.7	62.6 ± 21.1	64.1 ± 22.2	0.716	61.4 ± 23.2	65.4 ± 20.8	0.338
Confidence	60.6 ± 19.0	56.2 ± 19.6	63.0 ± 18.3	0.058	62.3 ± 20.3	59.6 ± 18.1	0.439
Decision Delay (days)	16.1 ± 10.7	13.6 ± 23.5	17.5 ± 47.99	0.608	0.7 ± 0.8	29.0 ± 51.8	<0.001
HF Knowledge	10.3 ± 1.7	10.3 ± 1.9	10.2 ± 1.6	0.934	10.3 ± 1.7	10.3 ± 1.7	0.928
Decision Regret	11.2 ± 17.0	13.4 ± 22.0	9.8 ± 13.2	0.303	9.6 ± 17.1	12.5 ± 17.2	0.342
Depressive Symptoms	12.2 ± 7.0	13.9 ± 6.5	11.2 ± 7.1	0.033	10.2 ± 6.8	13.6 ± 6.7	0.005
Social Support	73.9 ± 26.1	68.3 ± 26.0	77.1 ± 25.8	0.068	74.8 ± 26.5	72.9 ± 26.3	0.694
Health Literacy							
Reading Comprehension	23.3 ± 9.8	24.1 ± 9.5	22.9 ± 10.0	0.501	22.6 ± 9.6	24.2 ± 10.0	0.378
Numeracy	5.9 ± 2.1	5.9 ± 2.0	5.8 ± 2.2	0.880	5.9 ± 2.0	5.9 ± 2.1	0.916

*Used Fisher's Exact test instead of Chi Squared test

Table 3. Logistic Regression Model Predicting 30 Day Rehospitalization Status

Covariates	**Odds ratio (95% CI)**	**P-Value**
Self-Care Management	0.47 (0.21-1.04)	0.063
Education	2.16 (0.98 - 4.73)	0.055
Depressive Symptoms	2.31 (1.01 - 5.31)	0.049

Table 4. Data Matrix of Quotes by 30 Day Rehospitalization Status and Self-care Management Scores

	30 day quotes	Non 30 day quotes
High self-care management	I knew from past experience that if I was retaining too much fluid they would increase my Lasix, which I did – *participant 154 (had severe HTN)* I couldn't breathe and even when I sat down on the couch I couldn't get no relief, and so I think it wasn't long … I think I tried the pillows, somebody told me to try the pillows, I don't know whether that was my sister-in-law or my wife or somebody – *participant 203* If I'm not doing well, I will sometimes call the doctor [at an outpatient HF clinic] and see if they can take me in or bring me in and have an appointment with them, where they can check things out and then see me and help troubleshoot what's going on. – *participant 249 [wife heavily influences this decision]*	I had to start getting lung taps to release the fluid out of my lungs and I had three lung taps to the left and 3 lung taps to the right. – *participant 246* I noticed it [shortness of breath] because I was doing [a recreational drug], I had started to a lot more. Then all of a sudden, something hit me and I didn't know exactly what it was. So, I called my doctor – *participant 193* When I walked to work on Monday, I could tell then it [symptoms] was starting to get a little worse than where it was. But it was only 2 days from my appointment [without outpatient doctor] and I knew I was off like Tuesday night. I knew I was off Tuesday and I was going to see her that Wednesday. – *participant 192*
Low self-care management	…just didn't realize, I just wasn't thinking straight mentally. Uh, I just didn't realize that it [symptoms] was my heart.—*participant 161* Some time it led up where I'll be having problems breathing, but not really, you know that serious and I'll just chill with it and try to like, get myself together. – *participant 240*	By Tuesday morning around 9 o', 8 o'clock, my breathing became more, um, more shallow, um, harder, much harder to take deep breaths. A tightness in my chest which I'm known to get every time that I have, what I call one of the CHF attacks…What I call an attack is when my breathing gets to the point where I can't breathe, where I have dialed 911 and I couldn't tell them my address. – *participant 151* If my chest starts hurting, or if I'm out of breath too much, I go to ER. That's the only place I really can go. That's the only place I feel safe that if anything is wrong I could be treated. – *participant 205*

Table 5. Logistic Regression Model Predicting 2 Day Decision Delay

Covariates	Odds ratio (95% CI)	P-Value
Depressive Symptoms	5.33 (2.13 - 13.28)	<0.001
Shortness of Breath	0.20 (0.08 - 0.49)	<0.001

Table 6. Depressive Symptom and Symptoms Prior to Hospitalization Quotes by 2 Day Decision Delay

	Waiting for 2 days N=5	**Waiting for more than 2 days** N=10
Depressive Symptoms[a]	I just gotta get my health together and get myself, you know. I got the will. I just. I can't go to work. Ain't nobody, ain't nobody gonna hire me if I start sweeping the floor and I gotta stop every two minutes to catch my breath...Or I, I call in sick cause I got chest pains. You know? I gotta get my health together and I'm gonna get me a job. – *participant 240* If my chest starts hurting, or if I'm out of breath too much, I go to ER. That's the only place I really can go. That's the only place I feel safe that that if anything is wrong I could be treated. -- *participant 205*	Now, I talked to the doctors. They got mad at me. I said, I know you're experts in your field. I said, but I'm pretty sad, treating the fluid is a band aid, the root cause is the heart. And the response was, we don't have technology. We do not have the technology to fix the heart. – *participant 246* I said the other day, I was like you know, if I can't ... If I got to feel like this the rest of my life, I'd rather be dead you know. To feel crappy like I do most of the time, not saying I would kill myself, but I, it's just, it ain't no way to live. You're not living, you're just you know, when you feel like that all the time man. It's, you're existing in pain and, and you're suffering really kind of. That's no way to live. – *participant 233*

Symptoms Prior to Hospitalization[b]	….my breathing became more shallow, much harder to take deep breaths. A tightness in my chest which I'm known to get every time that I have what I call one of the CHF attacks. What I call an attack is when my breathing gets to the point where I can't breathe, where I have dialed 911 and I couldn't tell them my address. – *participant 151* [describing shortness of breath] I would imagine it's like a person drowning with like a weight around they feet and then trying to get out from under that water. I can't, I can't say because I can't, I don't go swimming cause I can't swim. But from what I've seen like on TV or whatever, people swimming, like somebody drowning. – *participant 240*	I'm like okay, maybe it's depression. Mom just died and her death anniversary was a week or two before. And I didn't know. As far as I know, my heart stents were good and I'm going to cardio rehab. – *participant 161* [when asked how long symptoms lasted for] This was about, I think I'd say about a week altogether. But it wasn't that bad, it wasn't that bad, you know. I was like a little lightheaded but I was still moving, you know, light head, had a little pain, but nothing to worry about. - *participant 203*

[a]CESD-10 scores divided by a cutoff score of 10

[b]Symptoms prior to Hospitalization – defined as main reason for hospitalization via self-report; divided into two categories: shortness of breath and other

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Addendum to Chapter 4: The Influence of Depressive Symptoms on 30 Day Rehospitalization

This addendum provides additional information on the relationship between depressive symptoms and 30 day rehospitalization status. Before describing the relationship in detail, it is important to point out that this study did not measure clinical depression, or derive a clinical diagnosis. Rather, we used the CESD-10, an instrument that was designed to assess depressive symptoms. Depression is a commonly reported HF comorbidity (Gnanasekaran, 2011; Wallenborn & Angermann, 2013). The reason HF and depression often coexist is not well understood, and therefore it is unclear if one illness causes the other and vice versa (Gnanasekaran, 2011; Wallenborn & Angermann, 2013). In the HF literature, both depression and depressive symptoms have been reported to increase the likelihood of hospitalizations (Johnson et al., 2012; Sherwood et al., 2007). We are not aware of any HF studies which reported the relationship between depressive symptoms and 30 day hospitalizations, however.

Quantitative Findings

Approximately sixty percent (n=76) of participants scored above a 10 on the CESD-10 scale, which is possible indication of clinical depression. Through logistic regression analysis, which was detailed in Chapter 4, we found the odds of being rehospitalized within 30 days was 2.34 times higher (OR= 2.34, 95% CI: 1.02 - 5.39) among those with high depressive symptoms (CESD-10 $\geq$ 10), after adjusting for study covariates. This finding was statistically significant at a p-value of 0.046. Those with

high depressive symptoms were also more likely to have decision delay (OR= 5.33, 95% CI: 2.14 - 13.28).

Mixed Methods Findings

Using the qualitative data collected from the same HF participants, we created a data matrix (Table 1) to help explain why depressive symptoms were associated with decision delay and 30-day rehospitalization in the logistic regression analysis. Out of the fifteen qualitative interview participants, only three had low depressive symptom scores (<10 on the CESD-10) with the remaining having high depressive symptom scores. Overall, participants in each of the four categories noted changes in their functional status as a result of their HF. Their frustration with physical limitations is represented by the following quote:

> "I keep wanting to be able to do what I used to do, and do it better, but my body is saying no. That's the thing that's really humiliating and debilitating - that you can't function like you used to." – *Participant 246*

Individuals who had high depressive symptoms were more aware that their HF was progressive and of their poor prognosis. Participants described their HF as a condition that was not within their full control: "I just know that my condition is getting worse and that there's only so much I can do about it." Perspectives on their poor prognosis were different by 30 day rehospitalization status. Those who were rehospitalized within 30 days felt that death was approaching but wanted immediate relief from the symptoms they were experiencing. One man compared this urgency to be the opposite of waiting patiently for bacteria to grow on a petri dish:

> "It's [adjusting medication per doctor's advice] going to take too long …You know, I don't have that kind of time because this is like you're laying some bacteria in the dish and waiting for it to mold and do different things, you know? I've got to have something done now. I need something done. – *Participant 203*

Due to the participants' hope that their HF could improve, they expressed disappointment with their own body's inability to prevent HF decompensations and when they did not feel they were receiving appropriate health care. A participant described disappointment with his past hospitalizations as "lost time and money" and that he "hadn't gained a thing" because his symptoms continued to worsen. Participants who were rehospitalized beyond 30 days fell into a well of hopelessness about their life with HF. Several participants in this category specifically pointed out that they were too young to die: "I don't want to die. Cause I really just feel like I'm too young to die."

The three participants who had low depressive symptoms and were rehospitalized beyond 30 days had a poor understanding of HF and therefore maintained hopeful about the future. For example, a participant described how he could not rush his recovery from HF with the following: "I have to take my time and just, you know, let things go through …I can't rush it."

[Insert Table 1]

Discussion

Our findings indicate the negative influence depressive symptoms has on HF patient's self-care decision making and 30 day rehospitalizations. Specifically, the

presence of high depressive symptoms increased the likelihood of decision delay and 30 day rehospitalization, demonstrating the need for active screening and management of depressive symptoms among HF patients as part of routine care. By mixing the quantitative and qualitative data we also learned that those with high depressive symptoms felt disappointment with their body's inability to prevent symptoms from worsening and hopelessness about their future. This result suggests that HF patients have a difficult time coping with the prognosis of HF, and may benefit from services (i.e., palliative care) that would address their emotional distress and improve their coping techniques. Studies incorporating palliative care into HF patient care found improvements in quality of life and symptom burden (Evangelista, Liao, Motie, De Michelis, & Lombardo, 2014; Sidebottom, Jorgenson, Richards, Kirven, & Sillah, 2015). Additionally HF patients receiving palliative care also have decreased hospitalizations (Desrosiers et al., 2014; Wong et al., 2013). Clinicians should consider incorporating palliative care into usual HF patient care, specifically for patients who are having a challenging time coping with the illness.

Limitations

The qualitative sample with low depressive symptom scores was particularly small (n=3), therefore the mixed methods results should be interpreted with caution and may not be representative of the general HF population. We were unable to qualitatively describe participants who had low depressive symptoms and were rehospitalized within 30 days because none of the qualitative participants fell into this category. However, since this result was unplanned, it represents the strength of the relationship between depressive symptoms and the likelihood of 30 day rehospitalization.

The CESD-10 has limitations worth mentioning. The CESD-10 has three questions representing typical symptoms decompensated HF patients experience, such as: fatigue and sleepiness (Gnanasekaran, 2011). It is possible that the scores on the CESD-10 might have been artificially inflated. Due to the overlap in depressive symptoms and HF symptoms on the CESD-10, future studies should consider validating the use of population based depressive symptom tools among the HF population. For example, a study assessing the psychometrics of the Brief Symptom Inventory, an instrument used to assess depression and anxiety, found the instrument had excellent reliability but weak construct validity with HF patients (Khalil, Hall, Moser, Lennie, & Frazier, 2011). Despite these limitations, the CESD-10 had good internal consistency reliability in the study, with a Chronbach's alpha of 0.83.

Table 1. Quotes by 30 day Rehospitalization Status and Depressive Symptoms

	30 day	Non 30 day
High Depressive Symptoms	N=7 Well, whenever you've been sick, most people have dark thoughts and I felt like, if I'm gonna feel like this every day of my life- like I'm hungover, I've got the flu, and I'm dying, you know nobody can fix me- what's the sense of being here. I mean I'm dying, my body is screaming in agony. – *participant 161* The doctor would smile and talk over me, you know, because some of them have the tendency to do that. While you're talking they want to talk. See, in the end when they get done saying what they got to say, they don't have the time to listen and I do not like a doctor like that, you know? As much respect as I have for him as a doctor, you know, you're going to give me a chance to talk and you're going to respond. – *participant 203* You know, but they told me my heart condition, after all the repairs and things that were made, that there's really not much they do about it...just because I'm, I'm, I'm in heart failure doesn't mean I'm going to sit around and see how long it takes it to fail. If there's anything that can be done, you know, to help me, you know, then I'm going to try that. I'm not ready to give up living yet. – *participant 154*	N=5 I'm not getting enough push to get anything accomplished. So, I just feel hopeless. I don't know what I can do ... I've been thinking about this. I've been thinking about going to a gym and getting someone who specializes in cardio ailments. And would be able to tell me when I'm starting what my heart rate is and at the end what my heart rate is. And, as I move along, I can improve and get better. But I'm scared of that, because I don't know ... I think I'll probably just walk and then keel over on the whatever I'm walking on. It's that death thing that's out there. I never told anybody that. – *participant 193* I have called him [friend] sometimes to say, "Man, I'm so depressed, I really want to get drunk. But I know I don't need to," and it's more having an ear to listen to than him really expounding on the subject, so to speak. I mean, he might throw a little something here, a little something there. – *participant 151* I wanna be able to do what I used to do and do it better, but my body is saying no. That's the thing that's really humiliating and debilitating that you can't function like you used to. – *participant 246*

Low Depressive Symptoms	N=0	N=3 I asked Dr. C, you know, as to how long it's gonna take me to completely recover..., and she said probably in about 2 years. -- *participant 192* Heart failure means a section of the heart is getting weak…Don't know what is really wrong -- *participant 238*

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Chapter 5: Discussion

This study approached HF hospitalization from a self-care decision making perspective, adding to the limited decision making HF literature. Below we have summarized the main findings of the study by aims.

Quantitative Aim: To compare HF self-care by 30 day rehospitalization status and decision delay

The 30 day rehospitalization logistic regression revealed that high self-care management scores (i.e. patients who subjectively reported a high ability to identify and respond to HF symptoms) reduced the likelihood of being rehospitalized within 30 days of a previous hospitalization. By mixing the qualitative data with the quantitative result, we found HF patients exhibited different forms of self-care decision making depending on their 30 rehospitalization status. Further details are discussed under the Mixed Methods Aim.

From the quantitative decision delay logistic regressions, we found that most participants were able to identify acute situations which included shortness of breath, but had difficulty interpreting the severity of other symptoms. This was similar to our vignette findings which revealed that participants had difficulty distinguishing HF symptoms such as edema and weight gain from everyday fatigue, weight gain from overeating, or pedal edema from being on one's feet. Similar symptom responses have been reported in the HF literature – multiple studies found HF patients often seek help when they have acute symptoms such as shortness of breath (Altice & Madigan, 2012) while help seeking behavior with other symptoms is unclear (Clark et al., 2012). Two literature reviews published within the last 5 years found HF patients struggle to interpret

the presence and significance of symptoms (Clark et al., 2012; Zavertnik, 2014). HF patients also face challenges in interpreting symptoms due to the presence of multiple chronic diseases (Doos et al., 2014), as noted in our qualitative interviews where participants stated the use of non HF medications and treatments to alleviate their HF symptoms.

We found that those with higher depressive symptoms were more likely to suffer from symptom exacerbations for more than two days. This finding was supported in the qualitative interviews, in which participants identified despair and uncertainty in their future with HF as factors which negatively impacted with mental health. Similar findings have been reported in the literature, in which depression increased the risk for hospitalizations among HF patients (Jiang et al., 2001; Moraska et al., 2013). Feelings of uncertainty are likely the result of poor patient-provider communication about the prognosis of HF, which is a complicated phenomenon by itself. Physician estimates of a HF prognosis is frequently inaccurate (Zapka, Moran, Goodlin, & Knott, 2007), and from our qualitative interviews it was evident that most physicians made a concerted effort to avoid conversations about the future.

Qualitative Aim: To explore the HF patient decision making process prior to rehospitalization focusing on self-care and decision delay.

The decision making process HF patients experience prior to their hospitalization has rarely been reported. The current literature reports different factors that influence delays in help seeking behavior prior to hospitalization including: a history of a myocardial infarction or stroke (Nieuwenhuis, Jaarsma, van Veldhuisen, & van der Wal, 2011), HF severity (Altice & Madigan, 2012; Gravely-Witte, Jurgens, Tamim, & Grace,

2010; Nieuwenhuis et al., 2011), contact with primary care providers (Gravely, Tamim, Smith, Daly, & Grace, 2011), mental health (Gravely et al., 2011), and supportive relationships (Sethares, Sosa, Fisher, & Riegel, 2014). Through the qualitative interviews, we were able to learn about the participant's entire self-care decision process prior to their hospitalization. In particular, participants identified different decision triggers, or reasons which caused them to make/not make decisions for: (1) seeking initial help, and (2) going to the hospital. The initial help seeking behavior was instigated by symptom exacerbations, while decisions to go to the hospital were a result of symptom exacerbations, influence from their social support network, and other realistic considerations such as needing to work, care for family members, etc. This finding highlights the importance of having a supportive social support network, and actively involving caregivers during HF education discussions and health care appointments (Albert et al., 2015).

Mixed Methods Aim: To describe the decision making processes and patient characteristics in relation to HF self-care and 30 day rehospitalization.

In the 30 day rehospitalization logistic regression, we found high self-care management scores reduced the likelihood of being rehospitalization within 30 days of a previous hospitalization. Through the qualitative interviews we found different forms of self-care decision making between those who were rehospitalized within and beyond 30 days of their last hospitalization. Specifically, participants who were rehospitalized within 30 days relied on the advice of others and past experiences to inform decisions, while those rehospitalized beyond 30 days sought for help by contacting an outpatient physician for advice. For individuals who were rehospitalized within 30 days, they may

have made decisions that negatively affected their health since they did not seek professional advice. The lack of difference in how participants described their self-care management among those who were rehospitalized within 30 days of their last hospitalization, suggests multiple factors that might influence how patients approach self-care, such as, functional limitations when performing daily activities of living, forgetfulness in keeping appointments and taking medications (Holden et al., 2015), and having/not having instrumental and emotional support from caregivers (Buck et al., 2015). Having a positive relationship with health care providers may be important to promote help seeking behaviors, as many participants mentioned the assistance they gained from outpatient physicians and nurses in identifying symptoms and advising them to go to the hospital. In support of this, a literature review found that responsive clinicians who individualize care and openly share information improve HF patient self-care (Currie et al., 2014). Although we did not measure functional limitations and did not recruit HF patients with current memory and cognitive deficits, participants discussed these topics during the qualitative interviews. Participants with caregivers who were invested in the participant's care and a strong social support system seemed to compensate for their functional and cognitive limitations. For example, caregivers actively assisted participants with their self-care activities by facilitating transportation to the HF patient's multiple doctor appointments, making meals, scheduling doctor appointments, and identifying symptom exacerbations. Similarly, a literature review of caregiver's contributions to HF patient self-care found caregivers assisted HF patients in three main categories: assisting with self-care activities involving measurement/quantitative skills such as daily weights, serving as health care system

navigators, and motivating patients to improve their self-care (Buck et al., 2015). Taken together, the findings suggest that patient self-care management scores may represent a combination of their caregiver HF self-care management skills along with their own self-care management skills.

Limitations & Strengths

Our small sample size and convenience sampling strategy limits the generalizability of the quantitative findings. The quantitative sample was younger than the general HF population and may only be similar to urban HF populations. The qualitative findings may not be transferable to other HF populations, since ours were predominantly male, African Americans, who lived in the city. Many participants openly admitted their history of illicit drug use, which is most likely not a global characteristic of HF patients. Selection bias may have occurred as HF patients self-selected not to participate. Those who opted out of the study may have different self-care and decision delay characteristics from those who joined. Indeed, during study recruitment, several HF patients who opted out of the stated they do not follow HF treatment recommendations at home and therefore did not feel they could answer any of the self-care questions. Potential predictors of 30 day rehospitalization and decision delay may not have been statistically significant because of our small sample size. Additionally participants may have been subject to recall bias as we asked them to respond to questions based on their past experience. Social desirability bias may have altered survey answers as well.

The study had several strengths. First, we used a mixed methods design which allowed us to understand the HF self-care decision making process in more detail and

explain why independent variables in the logistic regression models were statistically significant. We explored participant's decision making in two methods: using standardized HF self-care vignettes and asking participants to describe their own decision process prior to their hospitalizations. In this way, we were able to gain an understanding of the contextual factors that influence decision making in real life as well as compare decision making across similar situations in the vignettes.

Implications

Despite attempts by clinicians to increase the number of HF patients who receive specialized HF education, it is clear from these participants that they still have difficulty interpreting symptoms. There is a critical need for clinicians to develop strategies to assist HF patients to understand their illness within the context of multiple chronic diseases, rather than treating HF as a disease that exists by itself. The use of vignettes, such as the HF self-care vignettes developed for this study, as a patient-centered education tool, may be a useful addition to current HF education programs. Vignettes can be used a strategy to open discussions with individuals who may not be initially eager to discuss their self-care at home (Barter & Renold, 1999). There is also an opportunity to build a collaborative patient-provider relationship and tailor learning content by guided problem solving in real time with HF patients in each Vignette situation.

High depressive symptoms resulted in decision delay among the participants. In the qualitative interviews, even those who had low quantitative depressive symptom scores noted an underlying fear of their uncertain future masked by hope that their HF would improve. Due to the negative influence depressive symptoms have on HF patient health, clinicians should be careful not to undertreat HF patients for depression by

carefully assessing for depression even if it is not clearly evident. When performing assessments for depression, clinicians should be mindful that current depressive symptom measures include questions that represent typical HF symptoms (e.g. difficulty sleeping, fatigue).

Psychological symptoms such as fear from uncertainty about the future were commonly discussed in the qualitative interviews and seemed to negatively affect the participant's mental health. Unless physicians, especially cardiologists, become comfortable and skilled in having conversations with HF patients about their diagnosis and future, HF patients will continue to suffer from illness uncertainty without support from their health care providers. It is possible for nurses to advocate for HF patients and promote these discussions by alerting physicians when a HF patient does not seem to understand their diagnosis.

In this study, we found participants were motivated by both worsening symptoms, advice from others (caregivers and health care providers), and other practical considerations such as not wanting to miss work again before making the decision to go to the hospital. Additionally, support and assistance caregivers provided to the participants were integral to the participants' self-care. Considering the importance of caregivers in promoting HF self-care, it would be ideal for clinicians to include caregivers during education sessions with HF patients and during hospital discharge planning. Since, most HF patients and their caregivers are older adults (Aggarwal, Pender, Mosca, & Mochari-Greenberger, 2015), future studies should consider examining if and how HF patient outcomes change if their caregiver also becomes incapacitated due to illness, death, or other urgent family obligations.

Acknowledgement

Financial support for this study was provided by: the National Institutes of Health [NIH 1 F31 NR014750-01, NIH/NINR T32 NR012704, NIH/NINR T32 NR 007968; American Nurses Foundation/Southern Nursing Research Society Research Award; Sigma Theta Tau International Nu Beta Chapter Research Award; and the Jonas Nurse Leaders Scholar Program.

Thank you to the study participants and to Dr. Gyasi Moscou-Jackson for her assistance with the qualitative data analysis.

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Appendix A: Study Instruments

Mental Cognition: The Mini Cog

Administration:

1. Instruct the patient to listen carefully to and remember 3 unrelated words and then to repeat the words. The same 3 words may be repeated to the patient up to 3 tries to register all 3 words.

2. Instruct the patient to draw the face of a clock, either on a blank sheet of paper or on a sheet with the clock circle already drawn on the page. After the patient puts the numbers on the clock face, ask him or her to draw the hands of the clock to read a specific time. The time 11:10 has demonstrated increased sensitivity.

3. Ask the patient to repeat the 3 previously stated words.

Scoring: (Out of total of 5 points)

Give 1 point for each recalled word after the CDT distractor. Recall is scored 0-3. The CDT distractor is scored 2 if normal and 0 if abnormal.

(Note: The CDT is considered normal if all numbers are present in the correct sequence and position, and the hands readably display the requested time. Length of hands is not considered in the score.)

Interpretation of Results:

0-2: Positive screen for dementia

3-5: Negative screen for dementia

Demographics, HF experience, and Decision Delay

30 day or non 30 day

- 30 day
- Non 30 day

Illness that you currently have_____

Charleston comorbidity index number_____

Demographics

General Demographics

Sex

- Male
- Female
- Other

Year of Birth (yyyy)_____

Age (years)_____

Which race/ethnic group do you identify yourself with?

- Caucasian (non-Hispanic)
- Caucasian (Hispanic)
- African American (non-Hispanic)
- African American (Hispanic)
- Asian
- Multiracial
- Decline to respond
- Other

Highest educational level completed:

- less than grade school
- grade school

- high school
- some college
- college
- graduate/professional school or higher

Marital Status

- Married
- Widowed
- Separated
- Divorced
- Never married/single
- Living with significant other
- Other, please specify

Annual Income

- $0 - $20,000
- $20,001 - $40,000
- $40,001 - $60,000
- $60,001 - $80,000
- $80,001 - $100,000
- over $100,000
- don't know

At the end of the month:

- you have more than enough money to pay your bills
- you have enough money to pay your bills
- you do not enough money to pay your bills

Caregiver in residence

- Yes
- No

Who lives with you at home?_____

Employment Status

- Employed full time
- Employed part time
- Retired

- Not working
- Other, Specify

Occupation_____
_____

Type of Medical
Insurance_____

NYHA Class
- I
- II
- III
- IV

Do you have a primary care doctor?
- Yes
- No

How many doctors do you usually visit in one year for your heart?_____

How far from your doctor's office do you live (minutes)?_____

How far from the nearest hospital do you live (minutes)?_____

How would you describe your heart condition?_____

Past Experiences

Time (months) since HF diagnosis_____

Number of past hospitalizations for HF_____

Was a follow up appointment scheduled for you before you left your last hospitalization?

- Yes
- No

Did you go to your scheduled follow up appointment?

- Yes
- No, please state the reason

Did you have home care after your last hospitalization?

- Yes
- No

Current Hospitalization

What did you come into the hospital for this time?_____

Symptoms prior to hospitalization_____

Time (hours) from symptom onset to arrival at hospital_____

Decision Regret

Please reflect on the decision that you made to come to the hospital this time. Please show how strongly you agree or disagree with these statements by circling a number from 1 (strongly agree) to 5 (strongly disagree) which best fits your views about your decision.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
It was the right decision					
I regret the choice that was made					
I would go for the same choice if I had to do it over again					
The choice did me a lot of harm					
The decision was a wise one					

Depression: Center for Epidemiologic Studies Short Depression Scale (CES-D 10)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week by checking the appropriate box for each question.

Items:	**Rarely or none of the time** (less than 1 day)	**Some or a little of the time** (1-2 days)	**Occasionally or a moderate amount of time** (3-4 days)	**All of the time** (5-7 days)
1. I was bothered by things that usually don't bother me.				
2. I had trouble keeping my mind on what I was doing				
3. I felt depressed.				
4. I felt that everything I did was an effort.				
5. I felt hopeful about the future.				
6. I felt fearful.				
7. My sleep was restless.				
8. I was happy.				
9. I felt lonely.				
10. I could not "get going."				

Social Support: Modified MOS Social Support Scale

If you needed it, how often is someone available…

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. to help you if you were confined to bed?					
2. to take you to the doctor if you need it?					
3. to prepare your meals if you are unable to it yourself?					
4. to help with daily chores if you were sick?					
5. to have a good time with?					
6. to turn to for suggestions about how to deal with a personal problem?					
7. who understands your problems?					
8. to love and make you feel wanted?					

HF Knowledge: The Dutch HF Knowledge Scale (DHFKS)

How often should patients with severe heart failure weigh themselves?

- Every week
- Now and then
- Every day

Why is it important that patients with heart failure weight themselves regularly?

- Because many patients with heart failure have a poor appetite
- To check whether the body is retaining fluid
- To assess the right does of medicine

How much fluid are you allowed to take in at home each day?

- 1.5 to 2.5 liters at the most
- As little fluid as possible
- As much fluid as possible

Which of these statements is true?

- When I cough a lot it is better not to take my heart failure medication
- When I am feeling better, I can stop taking my medication for heart failure
- It is important that I take my heart failure medication regularly

What is the best thing to do in case of increased shortness of breath or swollen legs?

- Call the doctor or the nurse
- Wait until the next check-up
- Take less medication

What can cause a rapid worsening of heart failure symptoms?

- A high-fat diet

- A cold or the flu
- Lack of exercise

What does heart failure mean?

- That the heart is unable to pump enough blood around the body
- That someone is not getting enough exercise or is in poor condition
- That there is a blood clot in the blood vessels of the heart

Why can the legs swell up when you have heart failure?

- Because the valves in the blood vessels of the legs do not function properly
- Because the muscles in the legs are not getting enough oxygen
- Because of accumulation of fluid in the legs

What is the function of the heart?

- To absorb nutrients from the blood
- To pump blood around the body
- To provide the blood with oxygen

Why should someone with heart failure follow a low salt diet?

- Salt promotes fluid retention
- Salt causes constriction of the blood vessels
- Salt increases the heart rate

What are the main causes of heart failure?

- A heart attack (myocardial infarction) and high blood pressure
- Lung problems and allergy
- Obesity and diabetes

Which statement about exercise for people with heart failure is true?

- It is important to exercise as little as possible at home in order to relieve the heart
- It is important to exercise at home and to rest regularly in between
- It is important to exercise as much as possible at home

Why are water pills prescribed to someone with heart failure?

- To lower the blood pressure
- To prevent fluid retention in the body
- Because then they can drink more

Which statement about weight increase and heart failure is true?

- An increase of over 2 kilograms in 2 or 3 days should be reported to the doctor at the next check-up
- In case of an increase in over 2 kilograms in 2 or 3 days, you should contact your doctor or nurse
- In case of an increase in over 2 kilograms in 2 or 3 days, you should eat less

What is the best thing to do when you are thirsty?

- Suck an ice cube
- Suck a lozenge
- Drink a lot

HF Self-Care: The Self-Care of Heart Failure Index (SCHFI) version 6

SECTION A:

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

	Never or rarely	**Sometimes**	**Frequently**	**Always or daily**
1. Weigh yourself?	1	2	3	4
2. Check your ankles for swelling?	1	2	3	4
3. Try to avoid getting sick (e.g., flu shot, avoid ill people)?	1	2	3	4
4. Do some physical activity?	1	2	3	4
5. Keep doctor or nurse appointments?	1	2	3	4
6. Eat a low salt diet?	1	2	3	4
7. Exercise for 30 minutes?	1	2	3	4
8. Forget to take one of your medicines?	1	2	3	4
9. Ask for low salt items when eating out or visiting others?	1	2	3	4
10. Use a system (pill box, reminders) to help you remember your medicines?	1	2	3	4

SECTION B:

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) No

1) Yes

11. If you had trouble breathing or ankle swelling in the past month…

(circle **one** number)

	Have not had these	I did not recognize it	Not Quickly	Somewhat Quickly	Quickly	Very Quickly
How quickly did you recognize it as a symptom of heart failure?	N/A	0	1	2	3	4

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)

	Not Likely	Somewhat Likely	Likely	Very Likely
12. Reduce the salt in your diet	1	2	3	4
13. Reduce your fluid intake	1	2	3	4
14. Take an extra water pill	1	2	3	4
15. Call your doctor or nurse for guidance	1	2	3	4

16. Think of a remedy you tried the last time you had trouble breathing or ankle swelling,

(circle **one** number)

	I did not try anything	Not Sure	Somewhat Sure	Sure	Very Sure
How sure were you that the remedy helped or did not help?	0	1	2	3	4

SECTION C:

In general, how confident are you that you can:

	Not Confident	Somewhat Confident	Very Confident	Extremely Confident
17. Keep yourself free of heart failure symptoms?	1	2	3	4
18. Follow the treatment advice you have been given?	1	2	3	4
19. Evaluate the importance of your symptoms?	1	2	3	4

20. Recognize changes in your health if they occur?	1	2	3	4
21. Do something that will relieve your symptoms?	1	2	3	4
22. Evaluate how well a remedy works?	1	2	3	4

Health Literacy: The short form Test of Functional Health Literacy (S-TOFHLA)

Here are some other medical instructions that you or anybody might see around the hospital. These instructions are in sentences that have some of the words missing. Where a word is missing, a blank line is drawn, and 4 possible words that could go in the blank appear just below it. I want you to figure out which of those 4 words should go in the blank, which word makes the sentence make sense. When you think you know which one it is, circle the letter in front of that word, and go on to the other one. When you finish the page, turn the page and keep going until you finish all the pages.

Passage A: X-Ray Preparation

Passage B: Medicaid Rights & Responsibilities

PASSAGE A

Your doctor has sent you to have a _____ X-ray.

- stomach
- diabetes
- stiches
- germs

You must have an _____ stomach when you come for _____.

- asthma
- empty
- incest
- anemia

- is.
- am.
- if.
- it.

the X-ray will _____ from 1 to 3 _____ to do.

- take
- view
- talk
- look

- beds
- brains
- hours
- diets

THE DAY BEFORE THE X-RAY

For supper have only a _____ snack of fruit, _____ and jelly, with coffee or tea.

- ☐ little
- ☐ broth
- ☐ attack
- ☐ nausea
- ☐ toes
- ☐ throat
- ☐ toast
- ☐ thigh

After _____, you must not _____ or drink

- ☐ minute,
- ☐ midnight,
- ☐ during,
- ☐ before,
- ☐ easy
- ☐ ate
- ☐ drank
- ☐ eat

anything at _____ until after you have _____ the X-ray.

- ☐ ill
- ☐ all
- ☐ each
- ☐ any
- ☐ are
- ☐ has
- ☐ had
- ☐ was

THE DAY OF THE X-RAY

Do not eat _____.

- ☐ appointment.
- ☐ walk-in.
- ☐ breakfast.
- ☐ clinic.

Do not _____, even _____.

- ☐ drive,
- ☐ drink,
- ☐ dress,
- ☐ dose,
- ☐ heart.
- ☐ breathe.
- ☐ water.
- ☐ cancer.

If you have any _____, call the X-ray _____ at 616-4500.

- ☐ answers,
- ☐ exercises,
- ☐ tracts,
- ☐ questions,
- ☐ Department
- ☐ Sprain
- ☐ Pharmacy
- ☐ Toothache

PASSAGE B

I agree to give correct information to _____ if I can receive Medicaid.

- ☐ hair
- ☐ salt
- ☐ see
- ☐ ache

I _____ to provide the county information to _____ any

- ☐ agree
- ☐ probe
- ☐ send
- ☐ gain
- ☐ hide
- ☐ risk
- ☐ discharge
- ☐ prove

statements given in this _____ and hereby give permission to

- ☐ emphysema
- ☐ application
- ☐ gallbladder
- ☐ relationship

the_____ to get such proof. I _____ that for

- ☐ inflammation
- ☐ religion
- ☐ iron
- ☐ county
- ☐ investigate
- ☐ entertain
- ☐ understand
- ☐ establish

Medicaid I must report any _____ in my circumstances

- ☐ changes
- ☐ hormones
- ☐ antacids

☐ charges

within _____ (10) days of becoming _____ of the change.

- ☐ three
- ☐ one
- ☐ five
- ☐ ten
- ☐ award
- ☐ aware
- ☐ away
- ☐ await

I understand _____ if I DO NOT like the _____ made on my

- ☐ thus
- ☐ this
- ☐ that
- ☐ than
- ☐ marital
- ☐ occupation
- ☐ adult
- ☐ decision

case, I have the _____ to a fair hearing. I can _____ a

- ☐ bright
- ☐ left
- ☐ wrong
- ☐ right
- ☐ request
- ☐ refuse
- ☐ fail
- ☐ mend

hearing by writing or _____ the county where I applied.

- ☐ counting
- ☐ reading
- ☐ calling
- ☐ smelling

If you _____ TANF for any family _____, you will have to

- ☐ wash
- ☐ want
- ☐ cover
- ☐ tape
- ☐ member,
- ☐ history,
- ☐ weight,
- ☐ seatbelt,

_____ a different application form. _____, we will use

- ☐ relax
- ☐ break
- ☐ inhale
- ☐ sign
- ☐ Since,
- ☐ Whether,
- ☐ However,
- ☐ Because,

the _____ on this form to determine your _____.

- ☐ lung
- ☐ date
- ☐ meal
- ☐ pelvic
- ☐ hypoglycemia.
- ☐ eligibility.
- ☐ osteoporosis.
- ☐ schizophrenia.

These are directions you or someone else might be given at the hospital please read each direction yourself. Then I will ask you some questions about what it means.

You have 5 minutes to complete this section

GARFIELD IM 16 Apr 2014
FF941858 Dr. LUBIN MICHAEL

FUROSEMIDE (LASIX)
250 MG 40/0

Take one tablet by mouth three times a day

If you take your first tablet at 7:00am, when should you take the next one?

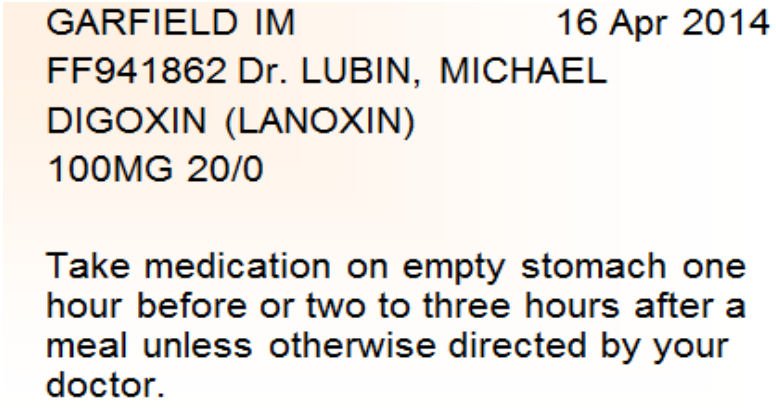
- Correct
- Incorrect

And the next one after that?

- Correct
- Incorrect

What about the last one for the day, when should you take that one?

- Correct
- Incorrect


GARFIELD IM 16 Apr 2014
FF941862 Dr. LUBIN, MICHAEL
DIGOXIN (LANOXIN)
100MG 20/0

Take medication on empty stomach one hour before or two to three hours after a meal unless otherwise directed by your doctor.

If you eat lunch at 12:00 noon, and you want to take this medicine before lunch, what time should you take it?

- Correct
- Incorrect

If you forgot to take it before lunch, what time should you take it?

- Correct
- Incorrect

CLINIC APPOINTMENT

CLINIC: Heart Failure LOCATION: 3rd floor

DAY: Thurs.
DATE: April 2nd HOUR:10:20 am

YOU MUST BRING YOUR PLASTIC CARD WITH YOU

When is your next appointment?

- Correct
- Incorrect

Where should you go?

- Correct
- Incorrect

Normal blood pressure is 120/80.
Your blood pressure today is 140/100.

If this were your score, would your blood pressure be normal today?

- Correct
- Incorrect

Interview Guide*

Qualitative Aim:

To explore the HF patient decision making process prior to rehospitalization focusing on self-care and decision delay. The following topics will be explored: (1) responses/actions to different HF self-care scenarios, (2) daily self-care behaviors prior to rehospitalization, (3) characteristics of successful and unsuccessful HF self-care, (4) triggers and delays in seeking help, and (5) barriers and facilitators related to help-seeking and hospitalization.

Sample Introduction:

Thank you for your time and participation in this study about how patients with heart failure make health care decisions. Today I am going to ask you a series of questions about decisions that you make to care for your health and decisions you made before coming to the hospital this time. Everything you say will be confidential and will not affect your hospital care in any way. Please let me know if a question makes you feel uncomfortable. You do not have to answer. You may stop at any time.

***Italicized questions are probes**

General health questions

What's your daily routine like as a person with heart failure?

1. *What do you do on a usual basis to take care of yourself?*
2. *What happens when you aren't feeling well?*

This hospitalization

3. What brought you to the hospital this time?
    a. *Tell me about what you did when you realized you weren't feeling like your normal self.*

- *What do you think was happening? …Tell me about what was going on with your body at the time?*

b. What did it feel like for you?

- *How is that different from how you normally feel?*
- *Out of all things you were feeling, which one was the most concerning to you?*

c. What was your response?

- *How did you know to do that? Who was involved? What did they do?*
- *What kept you from responding in this situation? Who was involved? What did they do?*

d. With the way that you were feeling, what do you think went well in this situation? What might have been better?

Vignettes

Next, we're going to read some short stories to help us think about what you would do in each story. After reading the story, I will give you a card with the story on it so you can read it or we can read it out loud again. Then I will ask you some questions about the story. There will be a total of 3 stories.

Situation A (On a notecard in 12 and 14 point font –patient's pick which size font he/she prefers)

Last night you had a hard time sleeping because of breathing problems. You ended up falling asleep only after propping yourself up with two pillows. This morning you're feeling very tired, have a cough that won't go away, and have a hard time breathing sitting on a chair.

Situation B (On a notecard in 12 and 14 point font –patient's pick which size font he/she prefers)

A few days ago, you went out with friends to a birthday party. You had a lot of fun and ended up eating more salty foods than expected. This morning you're feeling more tired than usual, and when you weighed yourself you find out you have gained 3 pounds from yesterday.

Situation C (On a notecard in 12 and 14 point font –patient's pick which size font he/she prefers)

You notice your feet feel tight in your shoes, but you feel better after taking your shoes off. You see that your ankles are little bigger than usual and remember you have gained 2 pounds in the last week.

Questions for Each Vignette	**Situation A**	**Situation B**	**Situation C**
4. If you were in this situation, tell me what you would do. Starting with what you would do first. • How did you know to do that? • Tell me why you would do that first? • Tell me what makes your responses the same in these situations?	1. 2. 3.	1. 2. 3.	1. 2. 3.
5. Have you ever experienced this or a similar situation before? If yes, please tell me your story of what happened. Describe what you did from when you realized something was wrong to when you came to the hospital? *a. Tell me about what you did when you realized you weren't feeling like your normal self.* • *What do you think was happening? …Tell me about what was going on with your body at the time?*			

b. What did it feel like for you? • *How is that different from how you normally feel?* • *Out of all things you were feeling, which one was the most concerning to you?* *c. What was your response?* • *How did you know to do that? Who was involved? What did they do?* • *What kept you from responding in this situation? Who was involved? What did they do?* *d. With the way that you were feeling, what do you think went well in this situation? What might have been better?*			

Past hospitalization(s)

6. Describe what you did from when you realized something was wrong to when you came to the hospital?

a. Tell me about what you did when you realized you weren't feeling like your normal self.

- *What do you think was happening? …Tell me about what was going on with your body at the time?*

b. What did it feel like for you?

- *How is that different from how you normally feel?*
- *Out of all things you were feeling, which one was the most concerning to you?*

c. What was your response?

- *How did you know to do that? Who was involved? What did they do?*

- *What kept you from responding in this situation? Who was involved? What did they do?*

e. *With the way that you were feeling, what do you think went well in this situation? What might have been better?*

More detail into past hospitalizations

7. In the situation…….., where you followed the advice of your HCP, tell me what helped you remember this?

8. When you felt……what helped you put it all together?

9. When you felt……how did you know that this was related to heart failure?

Living with Heart Failure

10. Tell me what you know about heart failure?

a. *How did you learn this?*

11. So you've told me about how it is living with heart failure, how was it different from before you had heart failure?

a. *Tell me about your family and heart failure?*

b. *Tell me about your friends and heart failure?*

c. *Tell me who are you most likely to call for help?*

12. Talk to me about your thoughts about the future?

a. Does your family ever talk to you about the future?

b. When you think ahead to the next 2 or 5 years, what are you thinking?

13. How has heart failure changed the money coming in or coming out?

14. If there was one thing that someone could do to help you live with heart failure every day, what would that be?

General probes:

How did you recognize…?

How did you know…?

What was the reason behind that…?

How does it work…?

What are the other times you had that feeling?

If people they were close to died before:

Did you ever talk to them about death and dying?

Curriculum Vitae

PERSONAL DATA

Name: Jiayun Xu
Home address: 6 East 30th Street Apt 301, Baltimore, MD 21218
Cell phone: 7178500057
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EDUCATION

2010-Present	Johns Hopkins University – Baltimore, Maryland Doctor of Philosophy, School of Nursing Summer 2015 – Expected graduation date
2006 – 2010	University of Pittsburgh – Pittsburgh, Pennsylvania Bachelor of Science Nursing Global Studies certificate, Global health focus on Asia and China Asian studies certificate, China focus
Summer 2008	Fudan University – Shanghai, China Study Abroad: Alliance for Global Education Intermediate mandarin language, Chinese society and culture focus

CURRENT LICENSE AND CERTIFICATION

06/25/10 –10/30/15	Maryland State Registered Nurse Maryland Board of Nursing License number: R191075
01/2013 – Present	End of Life Nursing Education (ELNEC-Gero) Trainer

PROFESSIONAL EXPERIENCE

10/11 – 12/13	**International Network for Doctoral Education in Nursing (INDEN)** Baltimore, MD *Executive Director*
06/09 – 08/09	**Mayo Clinic**, Rochester Methodist Hospital Rochester, Minnesota *Summer III Extern*, Hematology Oncology and Dermatology
5/08- 07/10	**University of Pittsburgh Medical Center**, Mercy Hospital Pittsburgh, Pennsylvania *Supplemental Staff*
06/07-12/07	**University of Pittsburgh**, School of Nursing Pittsburgh, Pennsylvania

Student Recruiter

01/07-01/09 **Home Care Nursing**
Pittsburgh, Pennsylvania
Nursing Assistant

HONORS AND AWARDS

9/12-8/14 Jonas Nurse Leaders Scholar Program
Recipient

9/12-9/13 Interdisciplinary Training in Cardiovascular Health Research Pre-doctoral Award
NIH/NINR T32 NR012704 PI, Allen J. K.
Predoctoral Fellow

6/11-8/11 Johns Hopkins Minority Global Health Disparities Research Training (MHIRT)
NCMHD/NIH 2T37MD001410-09, PI, Gaston-Johansson, F.
Recipient

9/10- 9/12 Health Disparities Pre-doctoral Award
NIH/NINR T32 NR 007968 PI, Allen J. K.
Predoctoral Fellow

9/08-12/08 University of Pittsburgh, University Center for International Studies
Global Studies Undergraduate Fellow

6/08-8/08 University of Pittsburgh, Nationality Rooms
John Tsui Memorial Scholarship

RESEARCH

9/14-Present **HF Patient Decision Making Prior to Rehospitalization**, Principal Investigator, Principal Investigator, Jiayun Xu, Sigma Theta Tau Nu Beta Chapter, $5,000
Role: Principal Investigator

12/13- Present **HF Patient Decision Making Prior to Rehospitalization**, Principal Investigator, Principal Investigator, Jiayun Xu, National Institute of Nursing Research, NIH, 1 F31 NR014750-01, $84,464
Role: Principal Investigator

9/13 – Present **HF Patient Decision Making Prior to Rehospitalization**, Principal Investigator, Principal Investigator, Jiayun Xu, American Nurses Foundation, $5,000
Role: Principal Investigator

9/12 – 12/14	**Crafting a Palliative Care Intervention for Surgical Intensive Care Unit Patients**, Principal Investigator, Rebecca Aslakson, Foundation for Anesthesia Education and Research, $175,000 total direct costs *Role: Graduate Student Investigator*
9/12-9/13	Interdisciplinary Training in Cardiovascular Health Research Pre-doctoral Award NIH/NINR T32 NR012704 PI, Allen J. K. *Role: Predoctoral Fellow*
02/11 – 12/14	**Enhancing Minority Participation in Clinical Trials (EMPaCT)**, Principal Investigator, Jean Ford, Regional consortia award from the National Center for Minority Health and Health Disparities, 1RC2MD004797, $350,000 total direct costs *Role: Graduate Research Assistant*
9/10 – 12/14	**Trial of Ascertaining Individual preferences for Loved Ones' Role in End-of-life Decisions (The TAILORED Study)**, Principal Investigator, Marie T. Nolan, National Institute of Nursing Research, NIH, 1R01 NR010733, $2,489,786 total direct costs *Role: Research Nurse*
9/10- 9/12	Health Disparities Pre-doctoral Award NIH/NINR T32 NR 007968 PI, Allen J. K. *Role: Predoctoral Fellow*
01/09-08/10	**Phase III Trial of Pocket PATH: A Computerized Intervention to Promote Self-Care**, Principal Investigator, Annette DeVito Dabbs, National Institute of Nursing Research, NIH, R01 NR010711, $2,352,215 total direct costs *Role: Undergraduate Researcher*
01/07 – 08/08	**Mitochondrial Genetics of Recovery After Brain Injury**, Genetics Lab, Principal Investigator, Yvette Perry Conley, NIH, 5R01NR008424 *Role: Research Assistant*

SCHOLARSHIP

PUBLICATIONS

Peer Review

Lu, Y., **Xu, J.**, Zhao, W., Han, H. (n.d.). Assessing self-care behaviour in type 2 diabetic patients: A systematic review. *Evaluation & the Health Professions*. Accepted.

Xu, J., Nolan, M. T., Heinze, K., Yenokyan, G., Hughes, M., Johnson, J., Kub, J., Tudor, C., Sulmasy, D., Lehmann, L., Terry, P. B., Gallo, J., Rockko, & Lee, M. C. (2015). Symptom frequency, severity, and quality of life among persons with three disease trajectories: Cancer, ALS and CHF. *Applied Nursing Research*. In press.

Xu, J., Han, H. (2014). Finding Disseration RAs within a PhD Student's Budget. *Advances in Nursing Doctoral Education & Research*, 2(3). Retrieved from http://nursing.jhu.edu/excellence/inden/documents/newsletters/November%20ANDER%202014%20ma.pdf

Wenzel, J., Mbah, O., **Xu, J.**, Moscou-Jackson, G., Saleem, H., Sakyi, K., & Ford, J. F. (2014). A Model of Cancer Clinical Trial Decision-making Informed by African-American Cancer Patients. *Journal of Racial and Ethnic Health Disparities*.

Xu, J., Adeboyejo, O., Wagley, E., Aubrecht, J., Song, M. K., Thiry, L., & Dabbs, A. D. (2012). Daily burdens of recipients and family caregivers after lung transplant. *Progress in Transplantation*, 22(1), 41-7; quiz 48.

Non Peer Review

Han, H., **Xu, J.** (2012). Methodological perspectives in doctoral education: Mixed methods in dissertation research. *International Network for Doctoral Education in Nursing December Newsletter*, 10(6). Retrieved from http://nursing.jhu.edu/academics/programs/doctoral/phd/inden/documents/december_newsletter_2012.pdf

CONFERENCE PRESENTATIONS

International

Summer 2013 **Xu, J.**, Nolan, M., Griffin, K., Hughes, M., Johnson, J. A., Lee, M. C. (July 2013). Symptom severity and QOL in patients with cancer, ALS, and CHF. Poster presentation, 2013 INDEN Biennial Conference, Prague, Czech Republic

Fall 2011 **Xu, J.**, Li, C., Kim, M., Cheon, J., Watlington, M.L., Hellmann, N., Jin, X. (September 2011). Training village doctors in disease management. Poster presentation, 2011 Modern Nursing Forum, Beijing, P.R. China

Fall 2011 Wagley, E., Aubrecht, J., **Xu, J.**, Adeboyejo, O., Song, M.K., Toyoda, Y., DeVito Dabbs, A.J. (September 2011). The importance of the marital dyadic relationship to adjustment and health management after lung transplantation. Podium presentation, 2011 20th Annual International Transplant Nurses Society Symposium and General Assembly, Göteborg, Sweden

Fall 2009 **Xu, J.**, Adeboyejo, O., Wagley, E., Aubrecht, J., Song, M.K. & DeVito Dabbs, A.J. (September, 2009). Assessing the daily burdens of recipients and family caregivers after lung transplantation. Podium presentation, 2009 18th Annual International Transplant Nurses Society Symposium and General Assembly, Montreal, Canada

National

Winter 2015 **Xu, J.**, Han, H. (February 2015). How patients with HF make self-care decisions prior to hospitalization. Transitions of Care in Older Adults: A Pressing Challenge symposium, 29th The Southern Nursing Research Society, Tampa, Florida

Winter 2015 Abshire, M., **Xu, J.**, Dennison Himmelfarb, C., Davidson, P., Sulmasy, D., Kub, J., Hughes, M. T., Nolan, M. T. (February 2015). Symptoms and fear in patients with heart failure approaching end of life: a mixed methods study. Poster discussion presentation, 29th The Southern Nursing Research Society, Tampa, Florida

Winter 2012 Moscou-Jackson, G., **Xu, J.**, Mbah, O., Saleem, H., Wenzel, J., Ford, J. (December 2012). "Staying ahead of the game"- A model of clinical trial decision-making informed by African American cancer patients. Poster presentation, 2012 Science of Eliminating Health Disparities: Building A Healthier Society Integrating Science, Policy, and Practice, National Harbor, Maryland

Fall 2012 **Xu, J.**, Nolan, M., Griffin, K., Hughes, M., Johnson, J.A., Lee, M.C. (September 2012). Symptom severity and QOL in patients with cancer, ALS, and CHF. Poster presentation, 2012 State of the Science Congress on Nursing Research, Washington, DC

Spring 2012 **Xu, J**., Ahmed, S., Mbah, O., Wenzel, J., Saleem, H., Phelan, D., Brahmer, J., Ford, J. (March 2012). Enhancing Minority Participation in Clinical Trials (EMPaCT) – Preliminary findings of the patient-level needs assessment. Poster presentation, 2012 American Society of Preventive Oncology Annual Meeting, Washington, DC

EDITORIAL ACTIVITIES

2015 Abstract reviewer for the Gerontological Society of America 68th Annual Scientific Meeting
2013 Lead poster abstract reviewer for the 2013 INDEN Biennial Conference
2013 Ad-Hoc Manuscript Reviewer for *Journal of Palliative Medicine*
2013 Lead poster abstract reviewer for the 2013 INDEN Biennial Conference
2013 Editorial board member for the *Advances in Nursing Doctoral Education & Research*
2012 Abstract reviewer for The Gerontological Society of America 65th Annual Scientific Meeting
2011 Ad-Hoc Manuscript Reviewer for *The Gerontologist*

2011 Ad-Hoc Manuscript Reviewer for *The Journal of Gerontology: Medical Sciences*
2011 Ad-Hoc Manuscript Reviewer for *Research in Nursing & Health*

PROFESSIONAL ACTIVITIES

Winter 2012 – Winter 2014	Maryland Action Coalition
Fall 2012 – Fall 2013	National Council on Family Relations
Fall 2012 – Fall 2013	International Family Nursing Association
Fall 2012 – Fall 2013	Heart Failure Society of America
Fall 2011 – Present	The Gerontological Society of America (GSA)
Fall 2010-Present	International Network for Doctoral Education in Nursing (INDEN)
Spring 2009-Fall 2010	International Transplant Nurses Society (ITNS)
Fall 2008-Present	Sigma Theta Tau International, Honor Society of Nursing (STTI)

EDUCATIONAL ACTIVITIES

Classroom Instruction – Classroom
Johns Hopkins University School of Nursing
Spring 2015, Statistical Literacy & Reasoning in Nursing Research
3 credits, Master's level, 30 students
Role: Teaching Assistant

Classroom Instruction – Classroom
Johns Hopkins University School of Nursing
Spring 2013, The Research Process in Nursing
3 credits, BSN level, 70 students
Role: Teaching Assistant

Classroom Instruction – Online and Classroom
Johns Hopkins University School of Nursing
Fall 2013, The Research Process in Nursing
3 credits, BSN level, 66 students
Role: Teaching Assistant

Classroom Instruction – Classroom
Johns Hopkins University School of Nursing
Fall 2012, Nursing Care for Older Adults across the Continuum
2 credits, BSN level, 129 students
Role: Teaching Assistant

Classroom Instruction – Classroom
Johns Hopkins University School of Nursing
Fall 2011 – Spring 2012
PhD level, 5 students
Role: Graduate Biostatistics Tutor

SERVICE & LEADERSHIP

Winter 2014-Present	Gerontological Society of America (GSA), Chinese Gerontology Interest Group Student Representative

Summer 2014- Present	International Network for Doctoral Education in Nursing (INDEN), Student Board member, 2015 Biennial Conference Awards Committee Chair, 2015 Biennial Conference Planning Committee member
Winter 2014- Present	Sigma Theta Tau International, Honor Society of Nursing (STTI), 2013-2015 Conference Planning Task Force member
Winter 2014 – Winter 2015	Sigma Theta Tau International Honor Society of Nursing (STTI) Nu Beta Chapter, Fundraising Chair
Winter 2011 – Fall 2012	Welch21 Committee, Graduate Student Representative
Fall 2011 –Fall 2012	School of Nursing, Johns Hopkins University, Doctoral Student Organization, President
Fall 2010 - Spring 2011	School of Nursing, Johns Hopkins University, Doctoral Student Organization, Vice-President