University of Kentucky
UKnowledge

Theses and Dissertations--Nursing College of Nursing

2020

RESPONSES TO SYMPTOMS AMONG PATIENTS WITH HEART FAILURE

Chin-Yen Lin
University of Kentucky, cli276@g.uky.edu
Author ORCID Identifier:
https://orcid.org/0000-0003-1774-1991
Digital Object Identifier: https://doi.org/10.13023/etd.2020.503

Right click to open a feedback form in a new tab to let us know how this document benefits you.

Recommended Citation
Lin, Chin-Yen, "RESPONSES TO SYMPTOMS AMONG PATIENTS WITH HEART FAILURE" (2020). *Theses and Dissertations--Nursing*. 56.
https://uknowledge.uky.edu/nursing_etds/56

This Doctoral Dissertation is brought to you for free and open access by the College of Nursing at UKnowledge. It has been accepted for inclusion in Theses and Dissertations--Nursing by an authorized administrator of UKnowledge. For more information, please contact UKnowledge@lsv.uky.edu.

STUDENT AGREEMENT:

I represent that my thesis or dissertation and abstract are my original work. Proper attribution has been given to all outside sources. I understand that I am solely responsible for obtaining any needed copyright permissions. I have obtained needed written permission statement(s) from the owner(s) of each third-party copyrighted matter to be included in my work, allowing electronic distribution (if such use is not permitted by the fair use doctrine) which will be submitted to UKnowledge as Additional File.

I hereby grant to The University of Kentucky and its agents the irrevocable, non-exclusive, and royalty-free license to archive and make accessible my work in whole or in part in all forms of media, now or hereafter known. I agree that the document mentioned above may be made available immediately for worldwide access unless an embargo applies.

I retain all other ownership rights to the copyright of my work. I also retain the right to use in future works (such as articles or books) all or part of my work. I understand that I am free to register the copyright to my work.

REVIEW, APPROVAL AND ACCEPTANCE

The document mentioned above has been reviewed and accepted by the student's advisor, on behalf of the advisory committee, and by the Director of Graduate Studies (DGS), on behalf of the program; we verify that this is the final, approved version of the student's thesis including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Chin-Yen Lin, Student

Dr. Debra Moser, Major Professor

Dr. Debra Moser, Director of Graduate Studies

RESPONSES TO SYMPTOMS AMONG PATIENTS WITH HEART FAILURE

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Nursing at the University of Kentucky

By

Chin-Yen Lin

Lexington, Kentucky

Director: Dr. Debra K. Moser, Professor of Nursing

Lexington, Kentucky

2020

Copyright © Chin-Yen Lin 2020
https://orcid.org/0000-0003-1774-1991

ABSTRACT OF DISSERTATION

RESPONSES TO SYMPTOMS AMONG PATIENTS WITH HEART FAILURE

Patients with heart failure (HF) suffer from chronic and progressive symptoms. Failure to respond appropriately to escalating symptoms of HF causes a delay in seeking care, which results in worse symptom status, frequent rehospitalizations, and contributes to higher mortality. In order to enhance HF self-care, promote timely care-seeking, and improve outcomes, identification of factors that affect patients' responses to symptoms and their decisions to seek care is essential. Thus, the purposes of this dissertation were to (1) identify factors associated with patients' responses to worsening HF symptoms, and (2) determine the impact of responses to symptoms on outcomes in patients with HF.

A mixed-methods and three quantitative research studies were conducted in this dissertation. The first study was a cross-sectional comparative, mixed-methods study to (1) compare perceptions, evaluations, and responses to worsening HF symptoms before a hospital admission between older and younger patients and (2) examine patients' responses when they perceived higher symptom distress. The second study was a cross-sectional exploratory study to (1) investigate patients' reasons for delay in seeking medical care and (2) determine which of the delay reasons were predicted by psychological factors. The third study was a longitudinal predictive study to (1) identify factors predicting care-seeking delay and (2) determine the impact of care-seeking delay on subsequent cardiac events. The fourth study was a cross-sectional correlational study to evaluate the associations of perceived control to symptom status, of perceived control to self-care, and of self-care to symptom status.

Results from the first research study indicated that despite few age-related differences in somatic awareness and symptom experience between older and younger patients, the majority of patients, regardless of age, failed to recognize, interpret, and respond appropriately to their escalating HF symptoms. The second study found that the most common reasons patients cited for delays were symptom-related and included "symptoms seemed vague", "not sure of symptoms", "symptoms didn't seem to be serious enough", and "symptoms were different from the last episode". Depressive symptoms and anxiety predicted patients' reasons for delay in seeking medical care. In the third study, New York Heart Association functional class, depressive symptoms, HF knowledge, and HF somatic awareness were significant predictors of delay in seeking medical care. Delay in seeking medical care predicted subsequent cardiac rehospitalization and death. The final

study demonstrated that higher levels of perceived control were associated with better self-care, and better self-care was associated with better symptom status in patients with HF.

The findings of this dissertation suggest the importance of prompt symptom responses among patients, enhancement in patients' symptom appraisal abilities, improvement in patients' mental health, timely care-seeking, and appropriate HF self-care to avoid further deterioration. Subsequently, an effective intervention should be developed and tested to promote HF self-care focused on a timely response to worsening HF symptoms to improve outcomes in patients with HF.

KEYWORDS: care-seeking delay, heart failure, outcomes, psychological distress, self-care, symptom experience

Chin-Yen Lin

11/06/2020

Date

RESPONSES TO SYMPTOMS AMONG PATIENTS WITH HEART FAILURE

By

Chin-Yen Lin

Dr. Debra K. Moser
Director of Dissertation

Dr. Debra K. Moser
Director of Graduate Studies

11/06/2020
Date

DEDICATION

To my beloved grandmother, my supportive parents,
my lovely husband Ming-Ru, and my dear daughters Ariel and Iris
for all the support throughout this PhD journey.

You are the light of my life.

To the memory of my grandmother

Ying-Mei Lin

ACKNOWLEDGMENTS

I would like to express my sincere gratitude and deep appreciation to my adviser, Dr. Debra Moser for her invaluable support and guidance. Dr. Moser has supported me throughout my doctoral studies by providing research direction, valuable insight, feedback, and countless opportunity in scholarly activities. She encouraged and guided me in the development of my research interests in the areas of heart failure and symptom research. Her contribution to my professional development has been invaluable and will be forever appreciated.

I would like to extend my appreciation to each member of my dissertation committee. I am so grateful for Dr. Moser and Dr. Muna Hammash for believing in me and giving me this great opportunity to work with them on a research project of acute exacerbation of heart failure. During the project work, I strengthened my research ability through subject recruitment, data collection, data management and analyses, and manuscript preparation. I am deeply thankful for the supportive and essential advice given to me by Dr. Gia Mudd-Martin and Dr. Martha Biddle during my doctoral journey. I would like to thank Dr. Mark Dignan for serving as the outside member of my dissertation committee for his support and advice throughout the dissertation process. I am grateful and fortunate to have you all as my dissertation committee members.

I would like to give special thanks to Dr. Terry Lennie, Dr. Michele Pelter, and Dr. Kathleen Dracup who shared their data with me and provided insightful comments to improve the quality of my manuscripts. During my PhD program, I have received help and support from several faculty members and colleagues from the RICH Heart Program; thank you for being there to support my journey towards the finished thesis. I must thank

all of the study participants; thank you for supporting research and sharing your experience, and your contributions make this thesis possible.

This journey would not have been possible without the support of my husband Ming-Ru and my daughters Ariel and Iris. Thank you for encouraging me in all of my pursuits and supporting me in pursuing my dreams. I could not have completed this degree without your unwavering love and sacrifices over these many years. I am especially grateful for my parents who supported me emotionally and financially. To my friends and sisters, thank you for listening and supporting me through this entire process. Finally, I dedicated this thesis to the memory of my loving grandmother who passed away while I was in the middle of a PhD program. She always believed in my ability to be successful in my studies. Her belief in me has supported me to move forward to achieve my goals. I love you with my entire being.

TABLE OF CONTENTS

ACKNOWLEDGMENTS……..iii

LIST OF TABLES vii

LIST OF FIGURES viii

CHAPTER ONE: Introduction 1

1.1 The Impact of Heart Failure 1

1.2 Delayed Care-seeking in Heart Failure 2

1.3 Factors that Contribute to Delayed Care-Seeking to Worsening Heart Failure Symptoms 3

1.4 Self-care in Heart Failure 12

1.5 The Revised Symptom Management Conceptual Model 14

1.6 Purpose of Dissertation 16

1.7 Summary of Subsequent Chapters 17

CHAPTER TWO: Older and Younger Patients' Perceptions, Evaluations, and Responses to Worsening Heart Failure Symptoms 20

2.1 Introduction 20

2.2 Methods 22

2.3 Results 26

2.4 Discussion 32

2.5 Limitations 36

2.6 Conclusions 37

CHAPTER THREE: Impact of Psychological Distress on Reasons for Delay in Seeking Medical Care in Rural Patients with Worsening Heart Failure Symptoms 48

3.1 Introduction 48

3.2 Methods 50

3.3 Results 54

3.4 Discussion 57

3.5 Limitations 61

3.6 Conclusions 61

CHAPTER FOUR: Impact of Psychological Distress on Reasons for Delay in Seeking Medical Care in Rural Patients with Worsening Heart Failure Symptoms 68

4.1 Introduction 68

4.2 Methods 69

4.3 Results 76

4.4 Discussion 78

4.5 Limitations 81

4.6 Conclusions 81

CHAPTER FIVE: Perceived Control Predicts Symptom Status in Patients with Heart Failure…….. 93

5.1 Introduction 93

5.2 Methods 95

5.3 Results 100

5.4 Discussion 102

5.5 Limitations 105

5.6 Conclusions 105

CHAPTER SIX: Discussion and Conclusions…….112

6.1 Background and Purpose …….112

6.2 Summary of Findings……...113

6.3 Impact of Dissertation on the State of the Science ……..116

6.4 Recommendations for Nursing Practice and Research……117

6.5 Limitations…….……..119

6.6 Conclusion and Future Research Plan……..……..120

APPENDICES 121

APPENDIX A: Self-check Plan for Heart Failure Management 121

APPENDIX B: Copyright Permission 122

REFERENCES 128

VITA……147

LIST OF TABLES

Table 2.1 Sociodemographic and clinical characteristics of heart failure patients admitted to the hospital for an acute exacerbation (*N* = 185) 38

Table 2.2 Initial symptom attribution of patients hospitalized for a heart failure exacerbation (*N* = 185) 41

Table 2.3 Symptoms and duration before hospital admission from heart failure patients admitted for an exacerbation of heart failure (*N* = 185) 42

Table 2.4 Initial response to escalating heart failure symptoms (*N* = 185) 44

Table 2.5 Comparison of symptom perception scores between older and younger patients by responding to their symptoms (*N* = 185) 45

Table 3.1 Sample characteristics (*N* = 611) 62

Table 3.2 Patient-reported reasons for delay in seeking treatment in relation to depressive symptoms and anxiety (*N* = 611) 66

Table 3.3 Multiple regression analysis of factors predicting a greater number of reasons one may delay seeking care for heart failure (*N* = 611) 67

Table 4.1 Characteristics of the sample of 153 patients with heart failure 83

Table 4.2 Factors associated with delayed care-seeking 86

Table 4.3 Association of care-seeking delay with subsequent cardiac event-free survival (rehospitalization or death attributed to heart failure and cardiac causes) adjusting for relevant covariates 88

Table 5.1 Sample Characteristics (*N* = 115) 107

Table 5.2 Multiple Regression Analysis of Predictors of Heart Failure Symptom Status (*N* = 115) 108

Table 5.3 Multiple Regression Analyses of Prediction of Self-care Confidence and Self-care by Perceived Control (*N* = 115) 110

Table 5.4 Multiple Regression Analyses of Prediction of Symptom Status (Total Score) by Self-care Confidence and Self-care (*N* = 115) 111

LIST OF FIGURES

Figure 1.1 The Revised Symptom Management Conceptual Model 16

Figure 4.1 Conceptual model of factors predicting delayed care-seeking and subsequent cardiac events 89

Figure 4.2 Consort diagram 90

Figure 4.3 Distribution of delay time between perceived worsening symptom onset and hospital admission 91

Figure 4.4 Cardiac event-free survival between two care-seeking delay groups categorized by median delay time 92

CHAPTER ONE: Introduction

1.1 The Impact of Heart Failure

Heart failure (HF) is an important global health issue, with an estimated 26 million people with HF worldwide.[1] In the United States, over 6.5 million American adults have HF, and the lifetime risk of developing HF is about one in every five adults at age 40 years.[2,3] The prevalence of HF will keep growing in the next decade and beyond. According to the American Heart Association, the prevalence of HF in adults aged 18 and above will increase by 46% from 2012 to 2030, increasing the number of people with HF to more than eight million.[2,4] The total costs of HF are projected to increase to approximately $70 billion by 2030.[2] Patients with HF have a poor prognosis and health outcomes, characterized by frequent rehospitalization, high mortality, and impaired quality of life.[5-7]

Heart failure is common in older adults and worsens with increasing age. After 65 years of age, the incidence of HF is close to 21 per 1000 people.[2] Heart failure is a leading cause of hospitalization in the elderly and it has been reported at approximately one million HF hospitalizations every year.[8] The mortality in HF is excessively high and increases with age; five-year mortality is 24.4% for those aged 60 years and approaches greater than 50% for those aged 80 years.[9]

Comorbidities have an important impact on HF management and outcomes. Most patients with HF have at least two comorbid conditions.[10] Comorbidities are of particular concern in patients with HF who are greater than 65 years of age as more than 40% of patients have five or more comorbidities.[11] Hypertension, hyperlipidemia, and

arrhythmias are common cardiac comorbidities in HF.[12] Common non-cardiac comorbidities include arthritis, anemia, chronic renal failure, diabetes mellitus, depression, and cognitive dysfunction.[11-13] Notably, an increased number of non-cardiac comorbidities was associated with a greater risk of 30-day death and rehospitalization.[14]

1.2 Delayed Care-seeking in Heart Failure

One of the most significant problems in patients with worsening HF symptoms is delay in seeking medical care. Delayed care-seeking has a negative impact on clinical outcomes. A longer length of delay has been associated with a longer length of hospital stay and a higher plasma values of brain natriuretic peptide at hospital discharge.[15] Delay also is associated with increased mortality. Delay in initiating HF therapy was associated with an increased risk of in-hospital death.[16]

The American Heart Association has published a self-check action plan for HF management, which recommends prompt response to HF symptoms as essential to prevent further exacerbations.[17] The action plan suggests that appropriate response measures should be taken to correspond to the different levels of symptom severity (Appendix A). As an example, for shortness of breath, three appropriate patient actions associated with three different levels of shortness of breath are as follows: (1) patients with no new or worsening shortness of breath are recommended to keep doing daily breathing checks; (2) patients who perceive increased shortness of breath with activity are recommended to contact their healthcare provider; and (3) patients who perceive sudden and severe shortness of breath or shortness of breath at rest are recommended to seek an immediate evaluation from a healthcare professional, or to call 911 or to go to the emergency department. Despite the wide dissemination of guidelines such as this, there is

growing concern that clinical practice recommendations alone have failed to promote timely care-seeking because patients continue to delay seeking prompt care for worsening symptoms of HF and their delays are commonly several days to several weeks.[18-20]

It is important to note that patients shouldn't wait to see if symptoms improve or try to treat themselves unless they have received prior instructions from their healthcare provider because immediate medical attention is required when worsening HF symptoms occur. In this dissertation, I aimed to explore patients' response to worsening HF symptoms and the consequences brought on by delays in seeking medical care. I focused on patients admitted to the hospital for an acute exacerbation of HF symptoms. Delay, accordingly, was defined as an amount of time between onset of worsening symptoms and hospital arrival. A prompt response is required to impede further exacerbation when patients perceive worsening HF symptoms. If a prompt response is not taken at once, delays arise. Understanding the factors that contribute to delay responses to worsening HF symptoms is a priority so that effective interventions that promote timely care-seeking can be developed.

1.3 Factors that Contribute to Delayed Care-Seeking to Worsening Heart Failure Symptoms

1.3.1 Demographic Factors

Demographic factors, such as age, race, or gender are thought to be determinants of care-seeking. Investigators have reported conflicting findings with regard to age and race and their associations with delayed care-seeking, but findings are more consistent with regard to gender. Some researchers have found longer care-seeking delays in younger patients than older patients[15,20-26] and suggested that younger patients may have

difficulty in determining the seriousness of their HF symptoms.[21] Others found that older patients were more likely to delay in seeking care,[27] which could be attributed to poor cognitive function due to aging.[28] The normal aging process produces changes in cognitive function; one of the significant changes is a decline in the ability to quickly process information to make a decision.[29,30] Mild cognitive impairment is a common condition in older patients with HF, which may affect patients' ability to recognize early signs of worsening symptoms and respond appropriately.[31,32] One HF study has shown that patients who delay longer were more likely to be white;[27] however, in a study of retrospective chart review of 753 patients hospitalized with HF, delay times were significantly longer for African Americans than for Caucasians, Asians, and Hispanics.[33] Despite conflicting findings in age and race, the findings on gender are clearer. Male gender has been commonly reported to be associated with delay.[20,25,28]

1.3.2 Social Support

Researchers have found that social support is an important factor related to care-seeking behaviors. Informal caregivers (e.g., family members, partners, significant others, or friends) play an important supportive role in assisting patients with HF in a range of activities including assisting patients to recognize HF symptoms, advising patients to seek timely medical help, and encouraging patients to engage in HF self-care.[34-36] One group of HF investigators found that delay was shorter in those patients who contacted family or friends before going to the hospital;[27] however, for those patients worried about disturbing a family member, the delay was longer.[37]

1.3.3 Advice from others

Advice from others influences patients' decisions to seek timely care. Family members are often the first to be informed when patients perceive that their symptoms have worsened. They may also be the first to give patients advice before patients contact healthcare providers or take care-seeking actions.[19] Receiving passive responses to symptoms from others (e.g., being told to wait, relax, or not to worry instead of seeking medical help) increased delay time.[18] There are conflicting findings about the association of advice from physicians with the timeliness of care-seeking. For example, in a comparative study of patients with or without an HF history, most patients with a history of HF were advised to call 911 by their physicians; instead, those with no history of HF were usually advised to come to the office or wait till next doctor appointment.[19] Heart failure patients who were seen by a primary care physician as opposed to a cardiologist had a longer delay time before arriving at the hospital for treatment for a HF exacerbation.[27,38]

1.3.4 Access to Healthcare

Access to healthcare remains a key factor in timely care-seeking. It is theorized that access to healthcare consists of five system supply dimensions (i.e., approachability, acceptability, availability and accommodations, affordability, and appropriateness) and five patients demand dimensions (i.e., ability to perceive, seek, reach, pay, and engage).[39] Common barriers to access to healthcare include two system supply dimensions, affordability (patient financial concerns) and approachability (transportation issues); these barriers are worse in rural dwellers who are more likely to have low incomes and not own car or be able to afford gas.[40,41] Having to travel long distances to access medical

services because they are unavailable close by (availability and accommodation) is also a barrier to timely care-seeking. Particularly in rural areas, patients may need to spend double or triple the travel time to seek care from medical specialists compared to their urban counterparts.[42] In a study of patients with HF, delay time from symptom onset to arrival to hospital increased by nearly 57 hours for those patients who lived in a rural setting compared to those who lived in a suburban setting.[18]

1.3.5 Clinical Characteristics

A patient's medical history or comorbidity can influence one's decision-making in seeking care. Prior studies have shown that a short delay was more often seen in patients with a history of myocardial infarction,[25,27] stroke,[25] ischemic heart disease,[15,24] renal failure,[43] hypertension,[27,43] and peripheral vascular disease.[27] A long delay was more often exhibited in patients who had a history of atrial fibrillation.[15,24] Having a history of diabetes was found in one study to be associated with an increased delay time;[27] but in another study, a history of diabetes predicted a shorter delay.[25]

History of previous admissions for HF predicted a shorter delay time compared to delay time seen in those without a previous HF admission.[21,38] In contrast, those patients with a history of HF had a longer duration of worsening HF symptoms before hospital admission than those with no prior HF history.[26] It is expected that patients with a history of HF may benefit from previous experience with HF and will contact healthcare providers or seek treatment more quickly than those without a history of HF;[20] however, other researchers who compared patients with or without a HF history found that there were no significant differences between these patients in the time between the onset of worsening symptoms and the time a physician was contacted.[19,25]

The evidence is inconsistent in the relationship between New York Heart Association (NYHA) functional class and care-seeking delay, with some researchers finding that patients with worse functional status (NYHA III/IV) had a longer delay time[25,38] and others finding that those with better functional status (NYHA II) were more likely to delay longer.[15,24]

1.3.6 Symptom Recognitions, Evaluations, and Responses

Symptoms are the dominant factor in the decision to initiate care-seeking.[44] Patients with poor symptom recognition and interpretation, such as lack of awareness of symptoms as deteriorating HF,[28,37] misattribution of symptoms to other conditions unrelated to HF,[27,28,37] or being uncertain whether symptoms warranted emergency care[37] have delays in seeking medical care. Moreover, investigators from several HF studies have pointed out fresh insights into symptom characteristics and care-seeking behaviors. First, Jurgens and colleagues found that higher HF somatic awareness and higher symptom distress were associated with a longer duration of acute HF symptoms (e.g., acute dyspnea) prior to admission, suggesting that somatic awareness and perception of high symptom distress did not necessarily trigger or motivate patients to seek care in a timely manner.[21,28,45] Second, the pattern of symptom onset is related to care-seeking delay. Friedman et al. reported that simultaneous onset of multiple symptoms was positively related to a longer length of time before admission compared to the gradual development of symptoms.[26] Altice et al. found that patients who experienced a pattern called acute symptom onset (symptoms present 2 weeks or less) or who had a greater number of acute symptoms were more likely to seek urgent medical attention (e.g., call 911 or go to the emergency department); conversely, patients who experienced a pattern

called chronic symptom onset (symptoms lasted more than 2 weeks) or who had a greater number of chronic symptoms were more likely to call their healthcare providers than seek urgent care.[46] Jurgens also found that a gradual onset of symptoms was associated with a long delay, and a sudden onset of symptoms was associated with a 4-day decrease in delay in responding to symptoms.[21]

Several studies have shown that the presence of symptoms was associated with care-seeking decisions. Symptoms associated with a higher likelihood of prehospital delay included the presence of orthopnea,[20,24] edema/swollen ankles,[24,25,27,38] fatigue,[23-25] and cough.[24] Other symptoms associated with a lower likelihood of delay were the presence of palpitations[27] and chest pain/discomfort.[22,27,38] Findings for the presence of dyspnea and loss of appetite were not consistent, with some studies showing them being related to increased delay time[24,25,38] while others showing the contrary.[27,47]

Researchers have found that patient transport by ambulance (as opposed to a private car or other means) predicted a shorter prehospital delay.[20,27] In addition, the timing of acute symptoms onset can influence delay in seeking treatment. Researchers in one study found that time of acute symptoms onset between 12:00 a.m. and 6:00 a.m. was associated with delay.[20] Others found that delay occurred during business hours;[22,27] for example, the onset of acute symptoms between 12:00 p.m. and 6:00 p.m. prolonged delay.[27]

Delay in seeking treatment was found when patients adopted waiting or avoidance coping strategies which include waiting until the next scheduled appointment with their primary care physician,[37,48] waiting for family members to be free to accompany them to seek care,[28,37] waiting to see if their symptoms would improve or go away,[18,28,49] or

wanting to avoid hospitalization.[28,49] Additionally, inactive strategies, such as taking medication other than those prescribed, resting, trying to calm down, praying, reducing normal activities, or elevating legs in the face of escalating HF symptoms prolonged delay in seeking medical help.[28,48]

Person-related factors and previous healthcare experiences also drive care-seeking decisions. Several qualitative studies have revealed that patients who did not want to miss work,[27] were embarrassed to call an ambulance,[27] believed that they had little or no control over their symptoms,[28,49] felt hopelessness about their illness condition, felt it useless to seek care,[37] had poor trusting relationships with providers,[50] or had prior unpleasant experiences with hospital care delayed in seeking care.[28,37,50]

1.3.7 Depression

Depression is a consistent predictor of care-seeking delay. Researchers have found that patients who delay longer reported more depressive symptoms compared to those who have shorter delays.[15,25] A large body of evidence indicates that patients with higher levels of depression have an increased delay time before presenting to the hospital. Wu et al. found that high levels of depressive symptoms were positively associated with delay in time from patients' first awareness of worsening symptom onset to seeking treatment.[43] Johansson et al. reported that patients with depressive symptoms had a 1.5-times higher risk of delaying seeking treatment more than 3 days than those without depressive symptoms.[24] Xu and colleagues reported that patients with depressive symptoms had a 5 times increased risk for delay in the decision to seek care compared to those without depression.[47] Moreover, other researchers provided evidence that depressed patients had poor health perceptions, had worse functional status, reported greater fatigue,

were more concerned about being a burden, and often lived alone, thus increasing the likelihood of delaying in seeking care.[51-53]

1.3.8 Anxiety

Anxiety disorders are important mental health issues and have been found to be associated with care-seeking delay. According to the findings from a study using national surveys of individuals with anxiety, unipolar depression, or substance use disorders, individuals with anxiety disorders reported longer delays in the treatment-seeking process and had lower treatment-seeking rates than individuals with depression and substance use disorders.[54] In contrast, in patients with cardiac disease, anxiety was a significant predictor of shorter delays.[27] One HF study showed that lower levels of anxiety were associated with a longer duration of delay.[28] Similar findings are seen from a study of patients with acute myocardial infarction where patients who sought care early reported feeling more anxious when they first noticed their symptoms.[55] Based on that, a plausible explanation may be that as patients with cardiac illness perceive their symptoms to be less severe, they are less likely to feel anxious and to seek treatment, resulting in delays.

1.3.9 Health Literacy

Health literacy plays a significant role in responding to HF symptoms and deciding when to seek care. Health literacy refers to an individual's ability to access, understand, and use information to make decisions about health and treatment. The associations between health literacy and access to care have been documented in a study of 22,000 community-dwelling adults aged 50 and above, in which individuals with low health literacy were more likely to delay needed care, to report difficulty finding a provider, or to lack a usual source of care compared to individuals with adequate health

literacy.[56] The relationship between health literacy and delay in seeking care in HF patients was demonstrated in a study which showed that lower levels of health literacy were associated with longer delays.[57]

1.3.10 Heart Failure Knowledge

It is expected that more knowledge in HF, including knowledge of HF symptoms, is associated with a shorter delay.[58] However, in a HF study by Nieuwenhuis et al., a greater degree of HF knowledge was independently associated with longer patient delays.[25] In this study, they also found that patients who had a higher education level were delaying longer.[25] The authors explained that patients may have enough general HF knowledge, but lack the ability to recognize their worsening HF symptoms or have insufficient information about self-care management. In other words, one with more knowledge or higher education does not mean that one has the skills to engage in sufficient self-care. Knowledge transfer is not enough to promote timely care-seeking; thus, self-management skills focusing on recognizing early signs of worsening HF symptoms are key.

1.3.11 Heart Failure Self-care

A prompt response to worsening HF symptoms has been linked to better self-care behaviors.[59] That is, patients with better self-management will recognize escalating HF symptoms quickly and report them promptly. Although a weak relationship between consulting behaviors (i.e., contacting a healthcare provider for guidance in response to worsening symptoms) and self-management was reported in one prior HF study, investigators suggested that the results need to be interpreted with caution as consulting behaviors and self-management were not completely distinguished in the measures they

used to collect this information.[60] Self-care can be described as a series of behaviors and decisions made by patients to improve HF; consequently, it is vitally important in symptom management and strongly predicts patient outcomes.[61]

1.4 Self-care in Heart Failure

1.4.1 Introduction to Self-care in Heart Failure

Heart failure self-care involves performing activities that prevent acute exacerbations, delay HF progression, and improve health outcomes. One theory of HF self-care by Riegel et al. posits that self-care is a naturalistic decision-making process in which active engagement, effective evaluation, and timely decisions with regard to HF symptoms and HF treatment regimens optimize outcomes.[59] The process of self-care includes self-care maintenance, self-care management, and self-care confidence. Self-care maintenance refers to monitoring HF symptoms daily and adhering to the HF treatment plan. Self-care management includes recognizing the occurrence of HF symptoms, evaluating any changes in these symptoms, implementing a treatment plan for HF, and evaluating the effectiveness of the treatment plan. Self-care confidence refers to a patient's level of self-efficacy with regard to self-care. Symptom perception is a component of the self-care process to detect and interpret physical sensations.[62] As a consequence, active engagement in self-care can promote symptom recognition, facilitate a timely response to worsening symptoms, and avoid delays in receiving appropriate treatment.

1.4.2 The Impact of Heart Failure Self-care on Outcomes

Effective self-care in HF improves outcomes, with a reduction in rehospitalization and mortality.[63] Researchers have found that the effectiveness of self-management

interventions significantly decreased the risk of all-cause hospital readmissions and HF readmissions.[64,65] A systematic review study of disease management programs focused on promoting self-care behaviors in older patients with HF showed that a significant reduction in post-discharge mortality rate by 28% to 78%.[66]

In addition to readmissions and death, adequate self-care improves patients' quality of life, functional status, and symptom burden. Auld et al. found that self-care maintenance and management significantly moderated the relationship between physical HF symptoms and emotional health-related quality of life.[67] Buck et al. reported that a higher degree of confidence in performing HF self-care was associated with a better quality of life.[68] Seto et al. identified that older age, better functional capacity, lower left ventricular ejection fraction, and better quality of life were the factors significantly correlated with better self-care.[69] Furthermore, Wang et al. suggested that patients in the intervention group had a significant improvement in symptom distress, 6-minute walk test, and quality of life compared to those in control group among a three-month post-discharge self-management program.[70]

1.4.3 Predictors of Adherence to Heart Failure Self-care

Uncovering the determinants of HF self-care behaviors is a priority to promote engagement in self-care. Previous studies have shown that patients who were diagnosed with HF for a longer time had better self-care maintenance, indicating that patients' experience with HF is a facilitator to maintain self-care.[71] Family support is also an important factor for better self-care. Family members, especially spouses, assisted patients in performing self-care activities in maintaining medication and dietary regimen adherence, making medical decisions, contacting healthcare providers for weight gain,

limiting fluid intake, and exercising regularly.[72,73] Lack of family support, such as living alone or being unmarried was found to be related to poor self-care.[74]

Psychological risk factors (i.e., Type-D personality and depression) have been found to be predictive of inadequate self-care. Type-D personality was negatively associated with consulting behaviors, in which Type-D patients were less likely to consult healthcare providers for their HF symptoms, as compared to non-Type D patients.[75,76] Depressive symptoms were found to be a significant predictor of poor self-care in several HF studies, with higher levels of depressive symptoms associated with lower levels of self-care.[77-79]

Perceived ability, such as perceived self-care confidence (also called self-efficacy) or perceived control, plays a vital role in implementing HF self-care. In several HF studies, self-care confidence was consistently associated with better HF self-care.[79-82] Patients with high levels of self-care confidence were confident in making self-care decisions, performing appropriate self-care, and adhering to self-care regimens. In addition, perceived control has been suggested as a predictor of better self-care and an essential strategy in the symptom management program to enhance patients' perception of perceived control over their heart disease.[83,84]

1.5 Theoretical Framework: The Revised Symptom Management Conceptual Model

The Revised Symptom Management Conceptual Model has been widely used to guide symptom assessment and management in various patient populations.[85] It was modified from the Symptom Management Model[86] which was first published in 1994 by the School of Nursing Symptom Management Faculty Group at the University of

California, San Francisco. In the revised model, three major dimensions (i.e., symptom experience, symptom management strategies, and outcomes) were interrelated and influenced by factors in the person, health/illness, and environment domains. The goal of symptom management is to improve outcomes through appropriate interventions and self-care activities. Outcomes are results of symptom experience and symptom management strategies.

Several concepts from the revised symptom management model (Figure 1.1) were used to guide this dissertation. In chapter two, the dimension of symptom experience was adopted to examine patients' perceptions, evaluations, and responses to worsening symptoms of HF. In chapter three, the relationship between psychological factors [person domain] and the reasons one may delay seeking care [self-care] in rural patients with HF [environment domain] was examined. Factors [person domain] predicting care-seeking delay [self-care] and the impact of care-seeking delay [self-care] on subsequent cardiac events [outcome: rehospitalizations and mortality] were determined in chapter four. Chapter five reveals the association of perceived control [person domain] to HF self-care [symptom management strategies], the association of HF self-care [symptom management strategies] to HF symptom status [outcome: symptom status], and the association of perceived control [person domain] to HF symptom status [outcome: symptom status]. Evidence gathering from each chapter will transform into important components to design interventions and develop symptom management strategies for my future research.

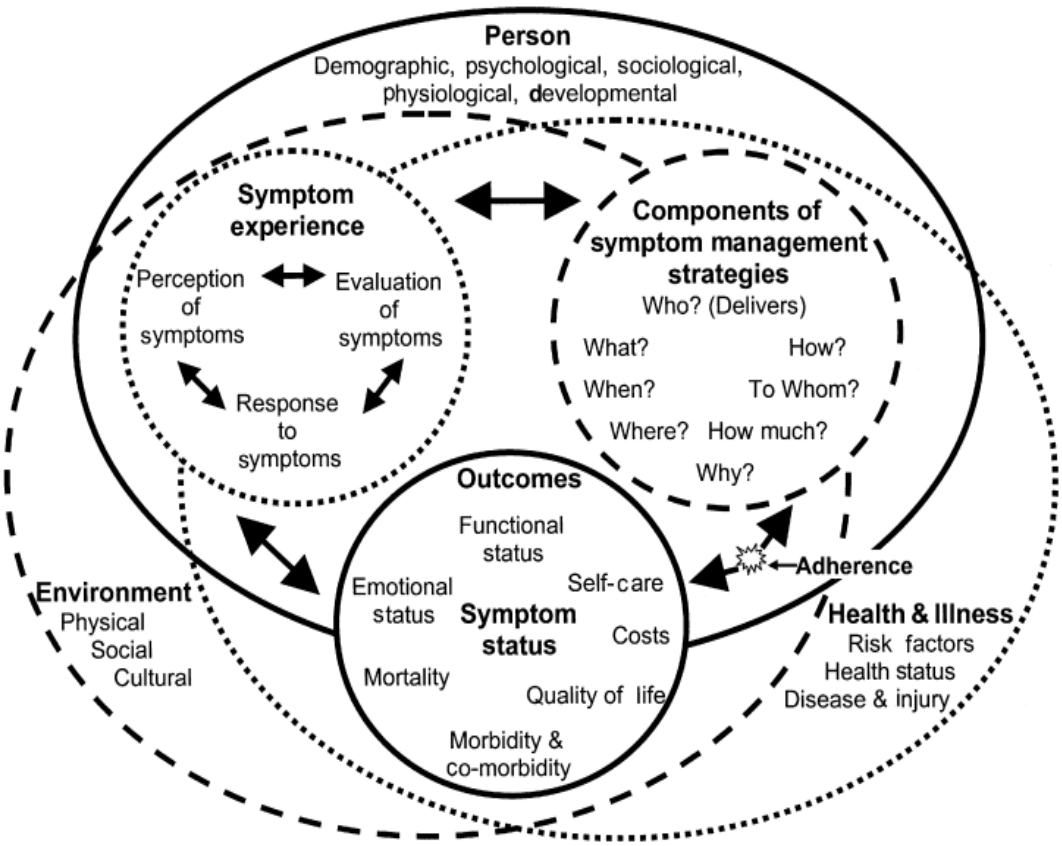

Figure 1.1 The Revised Symptom Management Conceptual Model.[85] Copyright permission obtained (see Appendix B).

1.6 Purpose of Dissertation

Patients with HF face several difficulties in self-care with regard to care-seeking, symptom recognition, and responses to worsening HF symptoms. To promote effective self-care which is an important determinant of outcomes, some of the variables that affect patients' responses to worsening HF symptoms need to be elucidated. The purposes of this dissertation were to (1) identify factors associated with responding to worsening HF symptoms, and (2) determine the impact of responses to symptoms on outcomes in

patients with HF. The chapters of this dissertation examining patients' responses to worsening HF symptoms along with subsequent outcomes are described below.

1.7 Summary of Subsequent Chapters

In chapter two, a cross-sectional comparative mixed-methods study is reported in which patients' perceptions, evaluations, and responses to worsening HF symptoms were compared between 78 older patients, aged 65 years or above and 107 younger patients, aged 18 to 64 years. It has been suggested that patients with HF have difficulty recognizing and responding to worsening symptoms promptly and this problem seems to be worse in older compared to younger patients.[28,30] To develop a tailored symptom management program and promote effective self-care, investigating whether recognition and prompt response to worsening symptoms are worse in older compared with younger patients with HF is essential. Quantitative analyses were conducted to compare older and younger patients' somatic awareness, initial symptom attribution, symptom experience before hospitalization, initial responses to escalating HF symptoms, and responses when they perceived high symptom distress. A qualitative approach using a semi-structured interview also was performed to further understand patients' symptom experience as well as supplement and validate quantitative findings.

Chapter three, a secondary analysis of data from 611 participants in the study of Rural Education to Improve Outcomes in Heart Failure,[87] is a cross-sectional exploratory study to examine rural patients' reasons for delay in seeking care for worsening HF symptoms. Depressive symptoms and anxiety are prevalent in rural residents with chronic diseases including HF, and as such emotional distress can and does affect patients' determination of care-seeking.[24,88,89] Chi-square analysis was used to compare reasons for

delay based on the presence or absence of depressive symptoms and anxiety. Multiple linear regression was conducted to examine whether depressive symptoms and anxiety predicted number of reasons for delay in seeking treatment for deteriorating symptoms. This study is important because patients with HF living in rural locations are more likely to suffer from emotional distress and face more barriers to timely care-seeking than their urban counterparts. Investigating rural patients' specific reasons for delay and determining whether depressive symptoms or anxiety predict patients' reasons for delay in seeking medical care for worsening symptoms are beneficial to the development of an intervention to promote timely care-seeking.

Chapter four is a report of a prospective, correlational, and predictive study of 153 hospitalized patients with an exacerbation of HF. Despite the current recommendations and guidelines to promote timely care-seeking,[17] care-seeking delay among patients with worsening HF symptoms ranges from days to weeks. In addition, the association of delay in seeking medical care to subsequent cardiac events in those with HF remains unknown. Therefore, the aims of this study were to identify factors predicting care-seeking delay and examine the impact of care-seeking delay on subsequent cardiac rehospitalization or death in patients with worsening HF symptoms. Because multiple demographic, clinical, psychological, cognitive, and behavioral factors may determine the decisions of care-seeking of HF patients at any point of time, a comprehensive model including the most relevant modifiable predictors related to delay in seeking care was proposed to guide this study. Care-seeking delay was measured as time between first noticing onset of worsening symptoms to hospital admission. Non-linear regression analysis was used to examine the association between time of patient delay in seeking treatment for escalating

symptoms and demographic, clinical, psychosocial, cognitive, and behavioral variables. Patients were followed for 3 months after discharge to determine time to the first cardiac rehospitalization or death. Cox proportional hazards regression was used to examine the impact of care-seeking delay on subsequent rehospitalization or death.

In chapter five, a secondary analysis of data from 115 participants in the study of nutrition intervention on HF symptoms, health-related quality of life, and clinical outcomes,[90] I examined the relationship of perceived control, HF self-care, and HF symptom status. Symptom status is an important indicator of disease progression and outcome in patients with HF. Effective self-care is key to reducing symptom distress and improving outcomes.[91] Perceived control is a target of most self-care interventions; however, little is known about the relationship between perceived control and symptom status. Determining the association of perceived control, self-care, and symptom status could provide vital information for developing interventions. Multiple linear regression analyses were conducted to determine whether perceived control predicted HF symptom status, perceived control predicted HF self-care, and HF self-care predicted HF symptom status after controlling covariates.

Chapter six provides the summary and integration from the findings of previous chapters of this dissertation. Implications for clinical practice and recommendations for future research are suggested. Findings from this dissertation demonstrate that a tailored and effective intervention should be developed to promote timely and appropriate responses to worsening HF symptoms and ultimately improve outcomes.

Copyright © Chin-Yen Lin 2020

CHAPTER TWO: Older and Younger Patients' Perceptions, Evaluations, and Responses to Worsening Heart Failure Symptoms

2.1 Introduction

Heart failure (HF) is a major cause of hospitalization worldwide, especially among the elderly. In the United States, HF is the most common cause of hospitalization in adults aged over 85 and the second-leading in adults aged 65 to 84.[1] Between 2001 and 2014, there were an estimated 14.6 million HF hospitalizations.[2] The total medical expenses related to HF will increase to $53 billion by 2030, and 80% of these expenses are hospitalization-related.[3] The prognosis of patients with HF is poor and worsens with age, with pooled survival rates of 91.5% at one-year and 78.8% at five-year among adults aged under 65, compared to 83.3% at one-year and 49.5% at five-year for those aged 75 years and older.[4] Patients with HF also have impaired quality of life accompanied by high physical symptom distress with dyspnea, edema, or fatigue and frequently recurring stays in the hospital.[5-7]

Appropriate symptom perception, accurate symptom evaluation, and prompt response to symptoms are important determinants of self-care management to improve clinical outcomes.[8] Symptom perception plays a key role in the self-care process and has been shown to predict physical and mental health.[9] Evaluation for HF symptoms is warranted to track HF progression as well as manage symptoms better.[10] Patients with HF who respond more appropriately to worsening symptoms have a better event-free survival over 12 months of follow-up.[11]

Aging is associated with decreased interoceptive sensations and impaired cognition, resulting in a reduced ability to detect early symptoms of deterioration and respond to them appropriately.[12,13] Researchers have found that older patients have more difficulty recognizing and interpreting their HF symptoms, particularly shortness of breath, compared to younger patients.[14] In one study of individuals with asthma, scores on an instrument used to measure dyspnea at rest were significantly lower among older than among younger persons, indicating a blunted sensation of dyspnea in the elderly.[15] Mild cognitive impairment is also prevalent among older patients with HF, which not only impedes patients' ability to make decisions in responding to increased symptom severity and performing self-care actions, but also increases the risk of having clinical events.[16-18]

High rates of HF hospitalizations, increases in healthcare spending, and associated adverse patient outcomes as well as frequent readmissions and high mortality, are critical issues driving the need for in-depth examination of symptom appraisal and responses in patients suffering worsening symptoms. Evidence has shown that elderly HF patients have altered symptom perceptions and interpretations, and delayed responses to symptoms;[19] however, research on patients' initial response to worsening HF symptoms and their responses when they perceived higher symptom distress remains unclear. Further, knowing whether there is a difference between older and younger patients in their symptom experiences and responses would help to develop tailored symptom management programs to promote more effective self-care. The aims of this study were (1) to compare perceptions, evaluations, and responses to worsening HF symptoms before a hospital admission between older and younger patients, and (2) to compare older

and younger patients' responses when they perceived higher symptom distress. To better understand patients' symptom experience, which is difficult to fully capture using quantitative analyses, we additionally conducted open-ended interviews about patients' symptom experiences to supplement our quantitative data.

2.2 Methods

2.2.1 Design and sample

This was a cross-sectional comparative study in which mixed-methods research techniques (quantitative and qualitative semi-structured interviews) were used. The symptom experience dimension of the Symptom Management Model was adopted to guide this study as it consists of three important components to describe an individual's subjective experience in dealing with symptom scenarios: perception of symptoms, evaluation of symptoms, and response to symptoms.[20] Perception of symptoms describes patients' ability to recognize symptoms or symptom changes. Evaluation of symptoms refers to the judgments that patients make based on presence or absence, frequency, intensity, and distress of their symptoms. Response to symptoms involves patients' responses when they perceive the onset of symptoms.

Patients were recruited from one university hospital and one community hospital in Kentucky from 2014 to 2017. Eligible patients were those who were 18 years of age or older and had a confirmed diagnosis of HF. Patients were excluded if they had a history of a heart transplant, had a co-existing terminal illness, or had a diagnosis of dementia or major psychiatric illness.

2.2.2 Procedures

Institutional Review Board approval was obtained from both sites. Patients who were hospitalized with an HF exacerbation were screened and contacted by trained research assistants. After eligible patients who agreed to participate in the study gave informed consent, each patient completed a sociodemographic form and questionnaires in relation to their perceptions, evaluations, and responses to HF symptoms prehospitalization. Qualitative interviews were also conducted with patients at this time. Each interview took about 20-40 minutes and was conducted in the patient's room in the hospital. The interviews included qualitative questions about the symptom experience. Research assistants assessed patients' functional class using the New York Heart Association (NYHA) classification[21] during the patient interview.

2.2.3 Measures

Perception of HF symptoms

The 12-item self-reported HF Somatic Awareness Scale was used to measure patients' ability to recognize symptom onset, awareness of symptom changes, and perception of the severity of HF symptoms.[22] In our study, patients were asked to rate how much they were bothered by each symptom on a 6-point Likert scale from 0 (don't have this symptom) to 5 (extremely bothersome). Scores were summed and ranged from 0 to 60, with a higher score indicating higher perceived somatic awareness and symptom distress. The HF Somatic Awareness Scale is a valid and reliable scale with theta reliability of 0.71.[22] In our study, internal consistency reliability was supported by Cronbach's alpha at 0.79.

Evaluation of HF symptoms

Patients' evaluation and interpretation of HF symptoms were assessed using two sets of questionnaires: 1) symptom appraisal (attribution of symptoms) was assesses using the cognitive dimension of the Modified Response to Symptoms Questionnaire.[19,23] It consists of 7 items (rated yes/no) regarding initial symptom attribution, in which patients were asked about potential causes of worsening symptoms; 2) a 16-item HF symptom checklist (rated yes/no) asking if patients had experienced any of 16 symptoms that led to their coming to the hospital, and the number of hours for which each symptom bothered them before hospitalization. It was extended from a 13-item HF checklist which was developed based on the symptoms listed in the HF treatment guideline.[24] We added three additional symptoms of fainting, sleeplessness, and changes in cognition to cover symptoms commonly occurred in elderly patients with HF.

Response to HF symptoms

Response to HF symptoms was measured using the behavioral responses to symptoms dimension of the Modified Response to Symptoms Questionnaire.[19,23] This instrument includes 10 items with yes/no response options used to assess how patients responded to symptoms when they perceived that symptoms were getting worse. Examples of items include: "at first did nothing, hoped symptoms would go away," and "called the doctor or nurse." The content validity of the original and modified Response to Symptoms Questionnaire was supported.[25,26] This instrument has been used in several acute myocardial infraction and HF studies with good reliability.[19,23]

Sociodemographic characteristics

Sociodemographic characteristics (i.e., age, gender, race, education, marital status, living arrangements, financial status, and health status) were collected using a sociodemographic questionnaire.

Qualitative component

Open-ended questions were used to capture detailed information regarding the experience of worsening symptoms and to identify determinants of the decision-making process before seeking treatment. Patients were asked to answer questions that started with "tell us the story of what led up to your hospital admission." Their answer was followed with further exploratory questions as needed to define their symptom experience. Specific questions included "How long ago did you notice the change in your symptoms that brought you to the hospital?" "Did your symptoms change, but you did not notice them right away?" "What had been happening? Where were you when you noticed your symptoms changed/worsened? What you were doing? Who was with you? How you were feeling in the days to weeks before coming to the hospital?" "What thoughts did you have about what you were feeling?" "What you might have thought was causing it?" "What remedies you tried to make your symptoms go away?"

2.2.4 Data analysis

Quantitative data analysis was conducted using IBM SPSS Statistics for Windows, version 26.0 (Armonk, NY: IBM Corp. Released 2018). Descriptive statistics were conducted to describe sociodemographic and clinical data using means and standard deviations, or frequencies and percentages as appropriate. Independent *t*-tests for

continuous variables and chi-square tests for nominal variables were used to compare younger (aged 18 to 64 years) and older (aged ≥ 65 years) on initial symptom attribution, symptom experience before hospitalization, and initial response to escalating HF symptoms. Multiple two-way ANOVAs were used to examine the effects of age groups and response to symptoms on symptom perception.

In the qualitative analysis, to achieve trustworthiness, content analysis was performed by two investigators using the following steps.[27] At the beginning of the analysis, codes were created by the first investigator based on interview data. Examples of these codes included noticing a symptom worsening, perceived causes for current admission, and actions or strategies for worsening symptoms. In order to ensure reliability, interview data were also coded by the second investigator. Two investigators reviewed each patient's statements and labeled the meaning units with codes individually. Codes generated by each investigator were then examined and, for any codes for which there was disagreement, codes were discussed until consensus was reached. Once all the data had been analyzed and coded, similar coding units were then classified into content categories using the concepts of perceptions, evaluations, and responses. Findings were validated by an expert in qualitative methods who reviewed the analytic process and the subsequent findings.

2.3 Results

2.3.1 Sample characteristics

A total of 185 patients with HF were studied, including 78 older patients and 107 younger patients. The mean age of all patients was 61.6 ± 13.1 years. Patients were

primarily Caucasian, most lived with another person, and were classified as NYHA functional class III/IV. A comparison of older and younger patients' financial status revealed that older patients reported better financial status than did younger patients. There were no significant differences in sex, race, educational level, marital status, whether or not they lived with another person, health status, and NYHA functional class between older and younger patients (Table 2.1).

2.3.2 Perception of HF symptoms

The average score for HF somatic awareness of participants was 31.7 ± 12.0 (possible range 0 to 60 with higher scores representing greater somatic awareness). Younger patients had higher somatic awareness scores than older patients (33.5 ± 12.8 vs 29.2 ± 10.6, t (176.711) = 2.474, P = 0.014).

Overall, patients reported being extremely bothered by not being able to do usual activities due to shortness of breath (48.6%), being tired (43.6%), not being able to catch their breath (37.0%), and feet being swollen at the end of the day (36.5%). Younger age patients perceived and were bothered more often by fast heartbeat (χ^2 (5) = 12.700, P = 0.026) and feeling discomfort or pain in their chest (χ^2 (5) = 17.350, P = 0.004) compared to older aged patients (data not shown in tables).

Qualitative interviews revealed that most patients (81%) reported escalating symptoms to which they did not respond until the symptoms became acutely unbearable leading to their going to the hospital. One 50-year-old woman stated, "On Sunday, I woke up gasping for breath. I could not even talk. My legs were very swollen. I had my Mom call an ambulance. But I had noticed that about 3 days ago my legs were more

swollen and then I started getting more shortness of air." Another 69-year-old woman pointed out, "I got to where I could not breathe about a month ago. I used to not have to use my nebulizer then I had to use it once a week for 2 weeks then every other day for one week and then everyday this last week. I had swelling of my feet, ankles, and legs and fell on Tuesday. Then I got more shortness of air overnight and called an ambulance."

A small number (n = 6) of patients did not recognize their symptoms until their family members noticed that their symptoms had worsened and that they needed urgent medical attention. One 82-year-old woman said, "I took a shower and became short of breath. My daughter was present and said I should go to the hospital," and another 78-year-old man said, "My wife found me become tired, sleeping up 20 hours a day, and holding up fluid in my belly and back area so she called the ambulance to bring me to the emergency room."

2.3.3 Evaluation of HF symptoms

We asked patients to what they attributed their worsening symptoms. The top choices reported were their heart (57.8%), lungs (32.4%), aging (18.4%), stress/emotions (17.3%), and getting a cold (15.1%; Table 2.2). Compared with younger patients, older patients were more likely to attribute their symptoms to aging (χ^2 (1) = 8.681, P = 0.003). There were no other significant differences between older and younger patients in symptom attributions (Table 2.2).

Table 2.3 shows that the most common symptoms that led to patients coming to the hospital in both age groups included dyspnea (81.6%), fatigue (73.5%), edema

(63.2%), and inability to sleep lying flat (49.7%). Orthopnea, inability to sleep lying flat, weight gain, and fatigue were the symptoms that bothered patients the longest before admission. A significantly greater number of patients in the younger age group experienced paroxysmal nocturnal dyspnea (χ^2 (1) = 7.777, P = 0.005), chest pain (χ^2 (1) = 7.647, P = 0.006), and nausea/vomiting (χ^2 (1) = 11.571, P = 0.001) that led them to come to the hospital compared to the older age group.

The qualitative data showed that patients cited a variety of factors that may have caused the change in their HF symptoms and led to this current admission. “I was taking more fluid or not watching my salt intake.” “Not the right lifestyles, not eating the right food, and not keeping your sugar under control.” “My legs started swelling. I knew I wasn't getting enough fluid off.”

Some (n = 15) mentioned that the deterioration of HF was rapid and uncontrollable. “I could not breathe. I was in bed and don't know if it woke me up or if I woke up before I got short of breath. It came on all of a sudden.” “Because I was sick and just seem to get worse daily, I could not go out and do anything. Actually, sort of when they start coming on, they (symptoms) start coming on faster.” “I was unable to breathe or cough, was dizzy and trembling and my chest got so tight I thought I was going to die.”

A few patients (n = 9) also stated that they could not identify their symptoms as HF-related or did not know what was causing the symptoms to get worse. One 67-year-old woman said, “I had been short of breath for a while but thought it was because I was getting older.” Another 33-year-old man stated, “I came to the hospital because I thought I had the flu but I didn't.” The other 49-year-old woman said, “I notice my feet swelling

and I thought it was weight gain. That has been going on for a year, I have. I did not expect a weight gain is something wrong with me." Hence, these patients demonstrated limited symptom evaluation abilities or inaccurate interpretations of symptoms.

2.3.4 Responses to HF symptoms

Table 2.4 illustrates how patients responded to escalating HF symptoms initially. The most common responses were that they told someone including family or friend (47.6%), at first did nothing, hoped symptoms would go away (47.0%), laid down and tried to relax (38.4%), or went to the hospital on his/her own (37.3%). Comparing the two age groups, no statistically significant differences were found in patients' responses to escalating HF symptoms.

The results of two-way ANOVA are presented in Table 2.5. There was no statistically significant interaction between the two age groups and response to symptoms in the company of symptom distress, which indicated that the effect on response to symptoms of symptom perceptions was the same for older and younger patients. However, there were statistically significant main effects of response to symptoms of higher symptom distress, regardless of age grouping. In response to higher perceived symptom distress, patients at first did nothing and hoped their symptoms would go away ($F(1,177) = 8.592$, $p = 0.004$), ignored symptoms and continued doing what they were doing ($F(1,177) = 10.031$, $p = 0.002$), or laid down and tried to relax ($F(1,177) = 12.889$, $p < 0.001$). The remaining responses including telling someone (family/friend), going to the hospital on his/her own, calling an ambulance, visiting the doctors or nurses, calling the doctors or nurses, taking an extra water pill, or self-medicated with other medication were not significantly associated with higher symptom distress.

Analyses of qualitative data indicated that about one-third of patients reported that they were advised to go to the hospital immediately for treatment by a family member (*n* = 23) or their healthcare providers (*n* = 38) in response to their symptoms. Some patients tried to self-manage at home by reducing fluid intake or taking additional medication. One 59-year-old man said, “I tried to increase some of my water pills, did not drink that much, and no extra salt in my food.” Another 75-year-old man pointed out, “The diuretics that I was taking actually change the swelling and once the swelling will go away my energy will come back somewhat.” A 65-year-old man stated, “I thought I had a cold coming on so I was taking antibiotics, cold medicine, and allergy pills. I was trying to get whatever was wrong but nothing works.”

Other patients took a wait-and-see strategy before coming to the hospital. A 46-year-old man said, “I waited four weeks and it just got worse. I think I will be better tomorrow but it did not happen.” Another reason that patients waited to seek medical care was because the problem was not acute or did not occur all the time. A 49-year-old woman stated, “I had shortness of breath for two weeks but the breathing wasn’t getting worse all the time so I don’t think I have to go to the hospital until I cannot breathe and then I am going and that’s more me.”

The main reason patients finally decided to go to the hospital was because their symptoms seemed out of control. One 50-year-old woman stated, “I was at home sitting at my kitchen table and noticed my left arm was moving up for about 30 seconds. I was not in control of this movement and it felt like it was someone else's arm. Next, I was in the shower, felt dizzy, and tingling from the waist down. As this started to resolve, I felt nauseous and then suddenly became short of breath. I thought maybe my blood sugar was

low and ate a snack. Later when I went to bed, I again felt dizzy and shortness of breath when lying down. I went to the ED and felt dizzy a few times on the way." Another 56-year-old woman pointed out, "I started feeling bad and it seems like every day it got worse and worse. I waited to see if it could just go away and finally after 4 weeks and it just kept getting worse. I told my husband it is time to go. I said something is really wrong and it turned out it was really wrong." These statements indicated that patients were uncertain whether they needed care at an earlier time.

Another possible reason that patients postponed seeking medical care was because they felt that their situation was hopeless or they had financial concerns. A 51-year-old man said, "I don't think they can do anything. I think it is a personal thing. My heart is sick and in a bad way. They have done everything they could for me." Another 52-year-old woman reported, "I have gained over 40 pounds in the last 2 months. I was in the hospital for about 7 days and came home weighing more than when I went in. I was home about a week, had called my nurse practitioner but I couldn't afford to come there to see her so she told me to increase my Lasix. I just kept getting worse so my daughter drove me to the emergency room."

2.4 Discussion

In this study, we examined age differences in symptom perceptions, evaluations, and responses among patients admitted for an exacerbation of chronic HF. We found few age-related differences. Older patients had lower somatic awareness than younger patients, but this did not result in better symptom evaluation and response by younger patients. Older patients were more likely to attribute their HF symptoms to aging, and younger patients were more likely to report being bothered by tachycardia and chest

discomfort as well as more likely to experience paroxysmal nocturnal dyspnea, chest pain, and nausea/vomiting than older patients during an HF exacerbation. Despite these differences, the combination of quantitative and qualitative data suggest that older and younger patients are quite similar in their perceptions, evaluations, and responses to HF symptoms. The majority of patients, regardless of age, failed to recognize escalating HF symptoms initially. Patients also interpreted and responded inappropriately to their HF symptoms. Thus, our results suggest the need to improve symptom monitoring, recognition, interpretation, and response in adult patients with HF across all ages.

Patients' ability to evaluate progressive HF signs and symptoms early is an important component in HF self-care.[28] The majority of patients in this study had difficulty recognizing acute exacerbations of HF symptoms, contributing to delayed responses to HF symptoms until their symptoms were unbearable or even life-threatening. Riegel et al. found that age-related declines might be a cause of poor early symptom recognition.[14] Yet, we found few differences based on age in patients' abilities to identify symptoms. Both older and younger patients had difficulty recognizing their symptoms. Lee et al. reported that mild cognitive dysfunction in patients with HF was associated with poor self-care behaviors regarding symptom recognition and response.[17] Mild cognitive dysfunction is common in patients with HF regardless of age,[29] and could at least partially explain our findings.

Some patients in our study stated that they found it difficult to identify their symptoms as being related to their HF. Patients often linked their symptoms to other illness (e.g., common cold, flu, or pneumonia) or comorbid conditions (i.e., asthma or chronic obstructive pulmonary disease), and were unaware that their symptoms were also

related to HF. We also found that older patients were more likely to attribute their HF symptoms to normal aging, a finding seen in other studies of elderly patients with HF.[30-32] As symptom evaluation and self-care are important predictors of HF outcomes,[10] our findings have important implications for recognition by healthcare providers that patients with HF have difficulty identifying escalating HF symptoms. Special attention needs to be given to enhancing patients' symptoms appraisal skills. Healthcare providers need to teach patients how to recognize symptoms of HF exacerbation and they should provide strategies (e.g., symptom tracker, symptom diary, or telemonitoring) to help patients monitor changes in symptoms more effectively.[33-35] It is also important to enlist family members and other informal caregivers in assisting patients to appraise their symptoms.[19]

A key finding from this study was that patients reported being uncertain whether their symptoms required medical attention and being uncertain of when to seek treatment even when they eventually noticed that their symptoms had worsened over several days. Some of our study participants indicated that their family members noticed deteriorating HF symptoms that needed medical help earlier than the patients themselves. Family members can play an important role in assisting patients to recognize changes in HF symptoms.[19,30,36] Our findings reveal that symptom perception is the key to timely care-seeking during an HF exacerbation. Promoting symptom recognition skills in family caregivers is suggested.

In our study, most patients reported being extremely distressed by fatigue, being unable to do usual activities due to shortness of breath, being unable to catch their breath, and having swollen feet at the end of the day before their hospital admission. Our findings are in line with those of previous investigators who found that fatigue, dyspnea,

and edema were the most distressing symptoms in patients with HF.[6,37] Yet, despite this distress, our patients with HF did not respond appropriately to escalating HF symptoms. Older patients had lower somatic awareness, which may partially explain their lack of appropriate response, but younger patients with better somatic awareness did not respond any more appropriately. It has been suggested that a variety of factors may affect patients' decisions of prompt care-seeking, such as healthcare access, financial concern, feeling of being a burden on others, or feeling hopeless.[19,30,38] Despite this, ignoring bodily sensations, delaying responses, or taking inactive approaches to exacerbated HF symptoms may lead to further worsening of HF symptoms. A prompt response (e.g., contacting healthcare providers or calling 911 for emergency services) is recommended in patients noticing a warning sign of worsening HF symptoms;[39] however, delayed response to symptoms is still common in patients with HF.[40] Our data, along with existing data suggest that interventions must be developed and tested that promote symptom recognition and overcome patients' reluctance to seek care with escalating symptoms.

Younger patients were more likely than older patients to perceive and be distressed by cardiac symptoms (i.e., tachycardia and chest discomfort) during an exacerbation of HF. This finding may reflect data about the effect of aging on cardiac sensation. Evidence shows that age is associated with a decreased ability to perceive heartbeat sensations.[12] In studies of patients with acute myocardial ischemia, the perception of chest pain in elderly patients is delayed and less severe compared to younger patients.[41,42]

Similar to previously published findings,[32,43,44] fatigue, weight gain, orthopnea, and inability to sleep lying flat were the symptoms that patients reported being bothered by yet experiencing longer than other symptoms prior to their hospital admission in this present study. Jurgens et al. reported that patients who experienced fatigue, weight gain, and edema had a longer median duration of 7 to 9 days before hospital admission and concluded that the stimulus from the physical symptom experience was insufficient to promote timely care-seeking.[43] It may be that patients become inured to persistent symptoms even though they are bothered by them, and do not respond appropriately because they are used to feeling distressed and bothered by symptoms. These data suggest that symptom management by clinicians could be improved, and that clinicians should also emphasize to patients the importance of prompt symptom reporting when symptoms seem to worsen.

2.5 Limitations

There were limitations to this study. First, our sample was mostly white and enrolled from one state, which limited generalizability. Second, we tried to equally divide the sample into two groups for the purpose of statistical analysis; thus, we used a cut-off age at 65. Although the United Nations has suggested that 65 years and older be denoted as older age and people over age 65 years have been defined as older adults in many countries, perceptions of what is older are changing. Setting a higher cut-off age may provide different perspectives on symptom experiences in this population.

2.6 Conclusions

This study revealed that both older and younger patients had difficulties in their perceptions, evaluations, and responses to HF symptoms. Regardless of age, responses to escalating symptoms were problematic among these patients with HF. Our findings suggest that symptom management needs to focus on promoting symptom recognition, symptom interpretation, and appropriate symptom response across all ages of HF patients. Future research is needed to identify effective strategies or interventions to improve symptom recognition, interpretation, and response among patients with HF.

Copyright © Chin-Yen Lin 2020

Table 2.1 Sociodemographic and clinical characteristics of heart failure patients admitted to the hospital for an acute exacerbation (*N* = 185)

	All (*N* = 185)	**Young (*n* = 107)**	**Old (*n* = 78)**	***P* value***
	Mean ± *SD* or *n* (%)			
Age, years	61.6 ± 13.1	52.7 ± 8.3	73.7 ± 7.4	<0.001
Gender				0.684
Male	94 (50.8)	53 (49.5)	41 (52.6)	
Female	91 (49.2)	54 (50.5)	37 (47.4)	
Race				0.214
Black	44 (23.8)	29 (27.1)	15 (19.2)	
White	141 (76.2)	78 (72.9)	63 (80.8)	
Education, years	12.6 ± 2.7	12.5 ± 2.5	12.6 ± 3.0	0.877
Marital status				0.669
Single/Divorced/Widowed	103 (55.7)	61 (57.0)	42 (53.8)	
Married/Cohabitate	82 (44.3)	46 (43.0)	36 (46.2)	

Table 2.1 (continued)

Live with another person				0.290
No	54 (29.2)	28 (26.2)	26 (33.3)	
Yes	131 (70.8)	79 (73.8)	52 (66.7)	
Financial status				0.007
More than enough to make ends meet	30 (16.2)	10 (9.4)	20 (25.6)	
Have enough to make ends meet	77 (41.6)	46 (43.0)	31 (39.7)	
Do not have enough to make ends meet	75 (40.6)	50 (46.7)	25 (32.1)	
Missing	3 (1.6)	1 (0.9)	2 (2.6)	
Health status				0.254
Excellent/Good	23 (12.4)	11 (10.3)	12 (15.4)	
Fair/Poor	149 (80.6)	90 (84.1)	59 (75.6)	
Missing	13 (7.0)	6 (5.6)	7 (9.0)	

Table 2.1 (continued)

NYHA class				0.338
Class I/II	48 (25.9)	31 (29.0)	17 (21.8)	
Class III/IV	122 (66.0)	69 (64.5)	53 (67.9)	
Missing	15 (8.1)	7 (6.5)	8 (10.3)	
Symptom perception score	31.7 ± 12.0	33.5 ± 12.8	29.2 ± 10.6	0.014
Missing	4 (2.2)	3 (2.8)	1 (1.3)	
*P value is for the comparison of younger (aged 18 to 64 years) and older patients (aged ≥ 65 years).				

Table 2.2 Initial symptom attribution of patients hospitalized for a heart failure exacerbation (*N* = 185)

	All (*N* = 185) *n* **(%)**	**Young (*n* = 107)** *n* **(%)**	**Old (*n* = 78)** *n* **(%)**	***P* value***
Heart problem	107 (57.8)	63 (58.9)	44 (56.4)	0.737
Lung problems	60 (32.4)	35 (32.7)	25 (32.1)	0.925
Aging	34 (18.4)	12 (11.2)	22 (28.2)	0.003
Emotions/stress	32 (17.3)	22 (20.6)	10 (12.8)	0.169
Getting a cold	28 (15.1)	19 (17.8)	9 (11.5)	0.244
Gastrointestinal problem	21 (11.4)	15 (14.0)	6 (7.7)	0.180
Eating too much recently	12 (6.5)	7 (6.5)	5 (6.4)	0.971

**P* value is for the comparison of younger (aged 18 to 64 years) and older patients (aged ≥ 65 years); percentages add to more than 100% because patients could pick more than one answer.

Table 2.3 Symptoms and duration before hospital admission from heart failure patients admitted for an exacerbation of heart failure (*N* = 185)

	All (*N* = 185) *n* (%)	**Median duration (hours)**	**Young (*n* = 107) *n* (%)**	**Median duration (hours)**	**Old (*n* = 78) *n* (%)**	**Median duration (hours)**	***P* value***
Dyspnea	151 (81.6)	24	90 (84.1)	24	61 (78.2)	48	0.250
Fatigue	136 (73.5)	72	78 (72.9)	72	58 (74.4)	72	0.839
Edema	117 (63.2)	48	66 (61.7)	48	51 (65.4)	48	0.674
Can’t sleep lying flat	92 (49.7)	72	54 (50.5)	72	38 (48.7)	24	0.765
Sleeplessness	83 (44.9)	48	52 (48.6)	48	31 (39.7)	72	0.251
Weight gain	80 (43.2)	72	48 (44.9)	72	32 (41.0)	132	0.589
Cough	76 (41.1)	48	46 (43.0)	48	30 (38.5)	60	0.444
Paroxysmal nocturnal dyspnea	67 (36.2)	48	48 (44.9)	48	19 (24.4)	9	0.005
Palpitation	66 (35.7)	24	40 (37.4)	24	26 (33.3)	24	0.559

Table 2.3 (continued)

Chest pain	56 (30.3)	24	41 (38.3)	24	15 (19.2)	16	0.006
Dizziness	48 (25.9)	24	28 (26.2)	24	20 (25.6)	24	0.927
Anorexia/no appetite	47 (25.4)	54	29 (27.1)	36	18 (23.1)	72	0.586
Trouble remembering /focusing/concentrating	45 (24.3)	48	25 (23.4)	24	20 (25.6)	48	0.700
Orthopnea	44 (23.8)	72	28 (15.1)	72	16 (20.5)	176	0.412
Nausea/vomiting	36 (19.5)	24	30 (28.0)	24	6 (7.7)	24	0.001
Fainting	18 (9.7)	4.5	11 (10.3)	4.5	7 (9.0)	3	0.801

*P value is for the comparison of younger (aged 18 to 64 years) and older patients (aged ≥ 65 years) in each symptom experience; percentages add to more than 100% because patients could pick more than 1 answer.

Table 2.4 Initial response to escalating heart failure symptoms (*N* = 185)

	All (*N* = 185) *n* **(%)**	**Young (*n* = 107)** *n* **(%)**	**Old (*n* = 78)** *n* **(%)**	***P* value***
Told someone – family/friend	88 (47.6)	56 (52.3)	32 (41.0)	0.128
At first did nothing, hoped symptoms would go away	87 (47.0)	54 (50.5)	33 (42.3)	0.272
Laid down and tried to relax	71 (38.4)	47 (43.9)	24 (30.8)	0.069
Went to hospital on his/her own (without ambulance)	69 (37.3)	45 (42.1)	24 (30.8)	0.117
Called an ambulance	62 (33.5)	30 (28.0)	32 (41.0)	0.065
Visited the doctor/nurse	55 (29.7)	35 (32.7)	20 (25.6)	0.299
Called the doctor/nurse	53 (28.6)	32 (29.9)	21 (26.9)	0.658
At first ignored the symptoms and continued what he/she was doing	51 (27.6)	33 (30.8)	18 (23.1)	0.243
Took an extra water pill	40 (21.6)	26 (24.3)	14 (17.9)	0.300
Self-medicated with other medication	18 (9.7)	12 (11.2)	6 (7.7)	0.425

**P* value is for the comparison of younger (aged 18 to 64 years) and older patients (aged ≥ 65 years); percentages add to more than 100% because patients could pick more than 1 answer.

Table 2.5 Comparison of symptom perception scores between older and younger patients by responding to their symptoms (*N* = 185)

	All (*N* = 185) Mean score	**Younger Age < 65 (*n* = 107) Mean score**	**Older Age ≥ 65 (*n* = 78) Mean score**	***P* value, main effect of response group on symptom perception score**	***P* value, interaction effect of variable of interest**
Told someone – family/friend				0.871	0.074
No	31.7	35.4	28.0		
Yes	31.4	31.9	30.9		
At first did nothing, hoped symptoms would go away				0.004	0.765
No	29.0	31.1	26.8		
Yes	34.2	35.8	32.6		

Table 2.5 (continued)

Laid down and tried to relax				< 0.001	0.365
No	29.0	31.3	26.8		
Yes	35.6	36.2	35.0		
Went to hospital on his/her own (without ambulance)				0.993	0.091
No	31.6	34.9	28.3		
Yes	31.6	31.7	31.5		
Called an ambulance				0.808	0.961
No	31.2	33.4	29.1		
Yes	31.7	33.9	29.4		
Visited the doctor/nurse				0.732	0.299
No	31.6	34.4	28.9		
Yes	30.9	31.6	30.3		

Table 2.5 (continued)

Called the doctor/nurse				0.742	0.232
No	31.6	34.4	28.8		
Yes	30.9	31.4	30.5		
At first ignored the symptoms and continued what he/she was doing				0.002	0.462
No	29.7	32.0	27.4		
Yes	36.0	36.8	35.2		
Took an extra water pill				0.070	0.721
No	30.5	32.3	28.6		
Yes	34.5	37.1	31.9		
Self-medicated with other medication				0.201	0.339
No	31.0	33.4	28.7		
Yes	35.0	34.4	35.7		
Number of missing data for symptom perception score: 4					

CHAPTER THREE: Impact of Psychological Distress on Reasons for Delay in Seeking Medical Care in Rural Patients with Worsening Heart Failure Symptoms

3.1 Introduction

Patients with heart failure (HF) who live in rural areas face more barriers to timely care-seeking and less access to health care than those in urban areas.[1,2] Rural patients with HF are at risk for a particularly high rate of mortality and adverse health outcomes compared to non-rural patients.[3,4] A prompt response to symptoms, especially in patients with HF, is essential to prevent exacerbations.[5] A HF self-check plan from the American Heart Association recommends that when patients perceive the onset of signs and symptoms of worsening HF, depending on the severity, they should take appropriate measures such as adjusting medications, calling their healthcare provider, or going to the hospital immediately.[6] Yet evidence reveals that patients with HF are unable to recognize or respond to the early signs of worsening symptoms in a timely manner, and this can result in care-seeking delays of a few days to several weeks.[7-9] Previous research has shown that delays may be related to patients' sociodemographic characteristics (e.g., younger age or male gender),[10,11] a gradual onset of symptoms,[10,12] more HF knowledge,[13] or living in a rural environment;[14] however, there have been no studies of reasons for delay seeking care in rural HF patients.

The prevalence of depression is higher in rural populations than urban populations in the United States, with an estimated 2.6 million rural residents screening positive for depression.[15,16] Depressive symptoms are also common in HF patients, with a prevalence rate of approximately 22%.[17] Patients with HF are more likely to have depression than those with other chronic diseases, and they are twice as likely to have depression as

people in the general population.[18] Importantly, depressive symptoms are associated with rehospitalization and mortality; HF patients with depressive symptoms have more than a 40% risk of readmission or death within 18 months after hospital discharge.[19,20] Anxiety is often comorbid with depression, and it is also associated with increased cardiac-related rehospitalization and poor quality of life.[21] In addition, depressive symptoms and anxiety are predictors of poor adherence to recommended treatment and other self-care activities in patients with HF. Patients with HF who have depressive symptoms delay seeking medical care for worsening HF symptoms longer than those without depressive symptoms, with a 1.5 times higher risk for a delay of more than three days.[12] Thus, depressive symptoms and anxiety not only lead to poorer outcomes but also affect patients' ability to implement appropriate self-care behaviors, such as timely care-seeking for escalating symptoms.

A prompt response to worsening HF symptoms can lead to better outcomes, such as a shorter hospital stay,[22] reduced mortality,[23] improved quality of life,[24] and savings on medical expenses.[25] Thus, research centered on care-seeking behaviors and processes is essential. There is considerable research available about length of delay and factors associated with delay in seeking care in patients with HF.[11,13,14] Research is limited, however, that focuses on the reasons rural HF patients delay seeking care. This becomes even more important to study because higher levels of depressive symptoms are associated with longer length of delay in patients with HF;[12,26,27] however, the reasons for delay are unknown. Furthermore, anxiety and its impacts on treatment-seeking delay have not been studied in rural HF patients. Uncovering the reasons for delay among patients with depressive symptoms and anxiety, particularly in rural areas, will provide

important data with which to design interventions to promote prompt and appropriate treatment-seeking among patients with worsening symptoms of HF. Therefore, the purposes of this study were to (1) investigate rural patients' specific reasons for delay, and (2) examine which of these reasons were predicted by depression and anxiety among rural HF patients.

3.2 Methods

3.2.1 Design

This was a secondary data analysis from the clinical trial, Rural Education to Improve Outcomes in Heart Failure (REMOTE-HF), a study designed to test an intervention to reduce hospital readmission and mortality for rural patients with HF.[28] Patients were recruited from rural clinics or hospitals located in California, Kentucky, and Nevada. Adults aged 18 years or older who had a hospitalization for HF within the past six months and who were dwelling in a rural location defined as a town of < 2,500 people or a metropolitan area of < 50,000 people were eligible. Patients were excluded if they had renal disease requiring dialysis; if they did not speak English or had any other communication barrier; if they had a coexisting terminal illness; psychotic illness; or cognitive impairment. Cognitive impairment was measured using the Mini-Cog.[29]

3.2.2 Procedure

Institutional Review Board approval for conducting the study was obtained from each participating institution. Patients who had a confirmed diagnosis of HF were screened and approached. Each patient gave informed written consent to participate in the study. At the time of enrollment, cognitive function was evaluated with the Mini-Cog test

by a trained research nurse. The Mini-Cog test includes a three-word recall test for memory and a clock-drawing test for clarifying scores when the scores of a three-word recall are less than or equal to 2. The scores on the Mini-Cog consist of 3 points for the three-word recall test and a normal or abnormal clock-drawing. Patients from this study were excluded if they had a word recall score of 0 or a word recall score of ≤ 2 with an incorrect clock-drawing. Baseline data on sociodemographic characteristics, clinical variables, psychological factors, cognitive and behavioral factors, and reasons for patient delay were used in the current study.

3.2.3 Measures

Reasons for patient delay

Reasons for patient delay in seeking early care for worsening HF symptoms were assessed by asking patients which of a list of reasons best applied to them. Patients we recruited from the hospitals were asked about their reasons for delaying seeking care for the current admission, while patients recruited from clinics were asked about reasons for delaying seeking care based on the most recent hospitalization. Reasons for patient delay in seeking medical care were collected using the REMOTE-HF Reasons for Delay Questionnaire. This instrument is a nine-item self-report questionnaire designed to determine the reasons that patients with HF delay seeking medical care for their worsening symptoms. The questionnaire regarding reasons for delay consists of the following questions, the first eight of which are “yes/no” and the last of which is an open question: (1) Symptoms are vague or come on gradually; (2) Not sure of symptoms; (3) The symptoms don't seem to be serious enough; (4) Symptoms are slightly different from last time; (5) Embarrassment/unease about calling for help; (6) Don’t want to second

guess my doctor; (7) Financial concerns; (8) Transportation issues; and (9) Other reason-please describe. Content validity of the instrument was established using a panel of HF specialists that included five physicians and nurses. In this sample, internal consistency as measured using Kuder-Richardson Formula 20 was 0.75.

Psychological factors

Depressive symptoms were assessed using the Patient Health Questionnaire-9 (PHQ-9) which is a nine-item self-reported screening instrument.[30] Each symptom is rated on a four-point Likert scale from 0 (not at all) to 3 (nearly every day), with a total score ranging from 0 to 27. A higher score on the PHQ-9 indicates more severe depressive symptoms. A cut point score of 10 or higher, which has been found in patients with major depression,[30,31] was used in this study to differentiate HF patients with depressive symptoms (≥ 10) from HF patients without depressive symptoms (< 10). The PHQ-9 has shown good reliability and validity in HF.[32]

Patients' anxiety was measured using the anxiety subscale of the Brief Symptom Inventory (BSI).[33] The BSI anxiety subscale is a six-item self-report instrument. Each item is rated on a five-point Likert scale from 0 (not at all) to 4 (extremely). The subscale score is the mean score of the six items and is ranging from 0 to 4. A higher score on the BSI anxiety subscale indicates worse anxiety. A cutoff score of 0.35 or higher on the BSI anxiety subscale has been suggested as an indicator of the presence of anxiety;[34] thus, this cutoff score was adopted to classify HF patients with anxiety (≥ 0.35) and HF patients without anxiety (< 0.35) in this study. The BSI has well-established reliability and validity in HF.[35]

Sociodemographic, clinical, and cognitive and behavioral covariates

Sociodemographic data (e.g., age, gender, educational level, number of people in the household, annual household income, and health insurance information) were obtained by patient interviews using a demographic survey. Clinical data were collected and included New York Heart Association (NYHA) functional classification[36] and the Charlson Comorbidity Index (CCI).[37] The NYHA classification was used to classify patients into one of four categories based on the extent of symptoms during physical activity from class I (no symptom limitations to performing physical activity) to class IV (unable to perform any activity and symptoms present even at rest).[36] The NYHA classification for each patient was determined by the patient's physician or a trained research nurse via careful interview. The CCI was used to measure comorbidity burden and data were collected through medical record review by a trained research nurse. The CCI has well-documented reliability and validity across a wide variety of disease states.[37]

Cognitive and behavioral covariates included cognitive function, HF knowledge, and health literacy. Cognitive function was determined by the Mini-Cog. Heart failure knowledge was measured using the Heart Failure Knowledge Scale.[38] It is a 20-item instrument used to assess patients' knowledge about HF (three true/false questions), HF symptoms (14 yes/no questions), and HF self-care (three multiple-choice items). The scores can range from 0 to 20 with higher scores representing higher HF knowledge. Health literacy was assessed using the Short-form Test of Functional Literacy in Adults questionnaire.[39] It has 36 cloze-type items consisting of 16 items with questions regarding X-ray preparation and 20 items with questions regarding Medicaid rights and

responsibilities. Possible scores range from 0 to 36, with higher scores indicate greater health literacy.

3.2.4 Data analysis

Data were analyzed using IBM SPSS Statistics for Windows, version 25.0 (Armonk, NY: IBM Corp. Released 2017). Descriptive statistics were used to summarize the demographic characteristics of the study population. Reasons for delay in seeking medical care were analyzed using descriptive statistics and were reported as frequencies and percentages. Chi-square analysis was performed to compare reasons for delay based on the presence or absence of depressive symptoms and anxiety. Multiple linear regression was applied to examine whether psychological distress (i.e., depressive symptoms and anxiety) predicted number of reasons for delay in seeking treatment for deteriorated symptoms. In the regression model, we included factors potentially predicting the number of reasons one may delay seeking care including age, gender, education level, number of people in the household, annual household income, on Medicare coverage, on Medicaid coverage, NYHA functional class, comorbidity burden, cognitive function, health literacy, HF knowledge, depressive symptom, and anxiety. Backward stepwise selection was used in the regression model; variables greater than or equal to 0.10 level of significance were excluded. No significant violations of the assumptions for linear regression were observed.

3.3 Results

3.3.1 Sample characteristics

A total of 611 rural HF patients (Table 3.1) were enrolled in the study. The patients were predominantly Caucasian (89%), male (59%), and married (56%). The mean age of the sample was 66 ± 13 years. Most lived with someone (77%) and had a household income of less than $40K / per year (65%).

3.3.2 Reasons patients with HF may delay seeking care

Among the 611 rural HF patients, 14.6% of patients (*n* = 89) selected 'no' to all of the reasons that patients may delay seeking medical care when their HF symptoms worsen. The remaining 85.4% of patients (*n* = 522) selected at least one reason for delaying. Among these 522 HF patients, 10.7% of patients (*n* = 56) reported only one reason for their delay, while 11.3% of patients (*n* = 59) had two reasons, 17.8% (*n* = 93) reported three reasons, 23.4% (*n* = 122) reported four reasons, 17.4% (*n* = 91) reported five reasons, and 19.4% (*n* = 101) reported six to nine reasons for delaying.

The most common reasons for not seeking early medical care were that symptoms seemed vague or came on too gradually (67.4%), not sure of symptoms (62.2%), symptoms didn't seem to be serious enough (62.4%), and symptoms were slightly different from last episode (55.2%). Other reasons included embarrassment about calling for help (24.1%), not wanting to second guess the doctor (21.6%), financial concerns (20.1%), transportation issues (16.5%), and other (10.8%). Other reasons included while small proportionally were, afraid of/don't like doctors or hospitals (1.3 %), family/pets need them (1.0%), not wanting to bother others (1.2%), denial/don't want to know/fear of knowing (2.9%), busy (2.1%), stubborn (1.2%), weather (0.7%), poor recognition/poor knowledge (0.3%).

3.3.3 Psychological distress and the specific reasons for delay seeking care

Patients' psychological status related to specific reasons one may delay is presented in Table 3.2. Patients with depressive symptoms were more likely to endorse three reasons: embarrassment, financial concerns, and transportation issues as reasons for delay compared to those without depressive symptoms. Patients with anxiety selected more reasons one may delay seeking care than patients without anxiety. Reasons included symptoms were vague, being unsure about their symptoms, symptoms didn't seem to be serious enough, symptoms were different from last time, embarrassed about calling for help, didn't want to second guess their doctors, financial concerns, and transportation issues as reasons for delay in seeking treatment as compared to those without anxiety.

3.3.4 Predictors of number of reasons patients may delay in seeking treatment for worsening HF symptoms

Depressive symptoms, anxiety, and HF knowledge were significant predictors of the number of reasons one may delay seeking medical care, independent of other covariates (Table 3.3). Patients with greater depressive symptoms, higher levels of anxiety, and lower HF knowledge had more reasons for their delay. Every one unit increase in depressive symptom score was associated with a 5% increase in the number of reasons one may delay seeking treatment while other covariates were held constant (unstandardized $B = 0.054$, $P = 0.003$). Every one unit increase in anxiety score was associated with a 29% increase in the number of reasons one may delay seeking treatment while other covariates were held constant (unstandardized $B = 0.287$, $P = 0.023$). Every one unit decrease in HF knowledge score was associated with a 9% increase in the

number of reasons one may delay seeking treatment while other covariates were held constant (unstandardized B = -0.089, P = 0.008).

3.4 Discussion

The results of this study indicated the common reasons why rural patients with worsening HF symptoms may delay seeking medical care. Of the 522 patients, over three-quarters reported three or more reasons for delay in care-seeking. Depressive symptoms, anxiety, and HF knowledge were independent predictors for having more reasons one may delay. This is important because a greater number of reasons one might delay seeking care for worsening HF symptoms could translate into worse patient outcomes. Additionally, this imposes potential barriers to educating patients about avoiding delay in seeking treatment for escalating HF symptoms. Healthcare providers should not only assess patients' psychological states (i.e., depression and anxiety) and their level of knowledge about HF symptoms and self-care, but act on these to uncover and address all of the reasons these vulnerable patients may delay seeking care.

Based on the common-sense model of self-regulation theory, illness behavior and care-seeking process are influenced by situational stimuli (e.g., symptom occurrence), illness perceptions (e.g., symptom identification), emotional responses (e.g., worry), coping strategies (e.g., to seek care or to avoid care), and action appraisals (e.g., evaluation of coping strategies).[40] This theory illustrates that the care-seeking process is complicated and interactive, demonstrating how illness perceptions and emotional responses involved in coping strategies affect decisions to seek care. Our findings are supportive of this theory and demonstrated that even though patients perceived stimuli from symptoms, they evaluated and considered many alternative and time-consuming

responses before taking care-seeking action, which could lead to substantial delays. In particular, we demonstrated that lack of HF knowledge and psychological distress contribute substantially to reasons for care-seeking delays. We also demonstrated that the symptom appraisal process in patients with HF could contribute to delays.

Similar to prior HF studies in which depressive symptoms contributed to increasing delay time,[12,27] our findings revealed that depressive symptoms and anxiety were a precipitating factor for increasing the number of reasons for delay. In addition, patients with depressive symptoms have three non-symptom related reasons for delay: embarrassment, financial concerns, and transportation issues. In fact, patients with depression are more likely to feel guilty, feel bad about being ill, or feel worthless, thus making them less likely to seek help.[41] Patients' anxiety also contributed negatively to decisions to seek care. The reasons for delay in rural HF patients with anxiety not only included non-symptom related reasons but also involved symptom-related reasons. Hence, depressive symptoms and anxiety lead to a negative impact on the decision to seek medical care and affect patients' ability to interpret symptoms. It is vital for health care providers to promote mental health (especially focusing on depression and anxiety), including screening, consultation, and treatment in rural patients with worsening HF symptoms, to avoid delay in seeking care.

More than 50% of the reasons reported for not seeking early care were related to symptom appraisal: symptoms seemed vague, not sure of symptoms, symptoms didn't seem to be serious enough to seek care, or symptoms were slightly different from the last episode. Symptom appraisal is subjective, and is comprised of the elements of recognition, identification, evaluation, and interpretation in which a patient appraises

symptoms after noticing they occur. In our study, “symptoms seemed vague” was the primary reason for delay, especially if symptoms increased gradually. Corresponding with a prior HF study, a gradual onset of symptoms increased the length of delay in seeking treatment.[10] Patients may feel hesitant or wait for a while to see if the symptoms will improve.[7,9,14] An ambiguous or slow to develop symptom makes it difficult for patients to recognize the early symptom of HF exacerbation and determine the appropriate time to seek care. Our findings provide insights for healthcare providers who can teach patients to appraise their symptoms more critically to avoid discounting the importance of symptoms.

“Not sure of symptoms”, also known as “symptom uncertainty”, was another common reason for delay. In other studies, the most frequent symptoms that HF patients reported were shortness of breath, swelling in legs, weight gain, or fatigue.[8,9] These symptoms are similar to those seen in aging, comorbid conditions, or colds and flu;[42] therefore, patients may have trouble identifying their symptoms as HF-related. This finding was also supported by studies of elderly patients with HF, in which patients postponed seeking medical care because they were not able to properly appraise the meaning of their symptoms,[7] or they attributed the symptoms they were experiencing to respiratory problems or general fatigue rather than HF.[14]

Patients were also confused and unsure about whether to call for treatment if their current symptoms differed from a previous episode. In fact, HF symptoms can vary from time to time. It is hard for patients to interpret the meaning of symptoms if they are not the same every time. This problem is compounded in rural patients who commonly do not have routine access to HF specialists or cardiologists and thus may not receive the

training needed to properly appraise their symptoms.[43,44] Consequently, monitoring HF symptoms using, for example, a symptom diary may help patients better appraise their symptoms, by promoting careful observation and recording of symptoms and their changes.[45,46]

Several non-symptom related factors for delay in seeking care were also important and need to be addressed. We found embarrassment/unease about calling for help because patients did not want to be seen by any neighbors as needing assistance to be a common reason for delay. Self-sufficiency is a common characteristic among rural individuals[47] and may hinder appropriate care-seeking. Additionally, patients in our study did not want to been seen as second-guessing their doctor. It is difficult for patients to make decisions to seek care in a timely manner if they have marginal health literacy, inadequate self-care abilities, or low education, and these characteristics are common in rural residents.[1,48] Our findings provide useful information for healthcare providers trying to teach patients good self-care.

Financial concerns were an important reason for delay in our study that has been found by others in studies of both rural and non-rural patients where worries about the costs of hospital visits or other medical care costs resulted in delay.[7,49,50] In our study, about 65% of participants had an annual household income of less than $40K. Individuals living in rural areas suffer a greater burden from low income, where it results in more uninsured and underinsured, and worse healthcare access. Finally. transportation issues are often cited as barriers to healthcare access.[51] Rural patients need to travel two to three times farther than urban patients to seek care from a medical specialist.[2] Further, a

number of participants lived alone (23.3%) in our study, limiting their ability to access transportation easily.

3.5 Limitations

A large sample of white patients was included in this study. Data from the 2010 Census of Population and Housing report that 77.8% of the population in rural and small-town communities are white in the United States.[52] Our findings limit generalizability because our sample was 89% white.

3.6 Conclusions

Responding properly to symptoms that can be an early sign of exacerbation is important in patients with HF. The findings of this study suggest that promoting attention to psychological states (i.e., depressive symptoms and anxiety) and improving psychological distress in rural patients with HF may enhance symptom appraisal and facilitate timely care-seeking to avert further deterioration.

Copyright © Chin-Yen Lin 2020

Table 3.1 Sample characteristics (*N* = 611)

Characteristics	**Mean ± *SD* or *N* (%)**
Age, years	66 ± 13
Gender	
Male	359 (58.8)
Female	252 (41.2)
Race	
White	542 (88.7)
Black and other minorities	69 (11.3)
Education level	
≤ High school	409 (66.9)
> High school	202 (33.1)

Table 3.1 (continued)

Marital status	
Married / cohabitating	345 (56.4)
Divorced / widowed	238 (39.0)
Never married	28 (4.6)
Number of people in the household	
Alone	142 (23.2)
One other	317 (51.9)
Two or more	152 (24.9)
Employment	
Employed	90 (14.7)
Disabled	162 (26.5)
Retired	322 (52.7)
Other	37 (6.1)

Table 3.1 (continued)

Annual household income	
< $20,000	216 (35.4)
$20,001 - $40,000	180 (29.5)
$40,001 - $75,000	95 (15.5)
> $75,000	46 (7.5)
Do not know/decline to report	74 (12.1)
Medicare	
Yes	402 (65.8)
No	209 (34.2)
Medicaid	
Yes	102 (16.7)
No	509 (83.3)
Charlson comorbidity index	3.36 ± 1.79

Table 3.1 (continued)

NYHA classification	
I / II	396 (64.8)
III / IV	215 (35.2)
Ejection fraction (%)	
≥ 40	298 (48.8)
< 40	304 (49.8)
missing	9 (1.4)
Psychological factors	
Depressive Symptoms	7.37 ± 6.37
Anxiety	0.82 ± 0.93
Cognitive and behavioral characteristics	
HF knowledge	13.90 ± 2.59
Health literacy	25.55 ± 8.81
HF, heart failure; NYHA, New York Heart Association	

Table 3.2 Patient-reported reasons for delay in seeking treatment in relation to depressive symptoms and anxiety (*N* = 611)

Reasons for delay in seeking care	**Depressive symptoms**		***P* value**	**Anxiety**		***P* value**
	PHQ-9 score < 10 (*n* = 419) *n* (%)	**PHQ-9 score ≥ 10 (*n* = 192) *n* (%)**		**BSI score < 0.35 (*n* = 291) *n* (%)**	**BSI score ≥ 0.35 (*n* = 320) *n* (%)**	
Symptoms are vague or come on gradually	280 (66.8)	132 (68.8)	0.638	184 (63.2)	228 (71.3)	0.035
Not sure of symptoms	251 (59.9)	129 (67.2)	0.085	161 (55.3)	219 (68.4)	0.001
The symptoms don't seem to be serious enough	254 (60.6)	127 (66.1)	0.191	166 (57.0)	215 (67.2)	0.010
Symptoms are slightly different from last time	221 (52.7)	116 (60.4)	0.077	137 (47.1)	200 (62.5)	< 0.001
Embarrassment/unease about calling for help	80 (19.1)	67(34.9)	< 0.001	43 (14.8)	104 (32.5)	< 0.001
Don’t want to second guess my doctor	85 (20.3)	47 (24.5)	0.242	45 (15.5)	87 (27.2)	< 0.001
Financial concerns	74 (17.7)	48 (25.0)	0.035	44 (15.1)	78 (24.4)	0.004
Transportation issues	54 (12.9)	47 (24.5)	< 0.001	25 (8.6)	76 (23.8)	< 0.001

BSI, Brief Symptom Inventory; PHQ-9, Patient Health Questionnaire-9.

Table 3.3 Multiple regression analysis of factors predicting a greater number of reasons one may delay seeking care for heart failure (*N* = 611)

Variables	***B***	***SE***	***β***	**95% *CI***	***P* value**
Depressive symptoms	0.054	0.018	0.155	0.018 to 0.089	0.003
Anxiety	0.287	0.128	0.120	0.035 to 0.538	0.025
HF Knowledge	-0.089	0.034	-0.104	-0.155 to -0.023	0.008

Model $R^2 = 0.090$; Adjusted $R^2 = 0.078$; F (8, 602) = 7.472; P value < 0.001

B, unstandardized coefficients; *β*, standardized coefficients; *CI*, confidence interval; HF, heart failure; *SE*, standard error

CHAPTER FOUR: Delay in Seeking Medical Care for Worsening Heart Failure Symptoms: Predictors and Association with Cardiac Events

4.1 Introduction

Heart failure (HF) is a major public health concern associated with high rates of death and rehospitalization. In the United States, about 6.2 million adults have HF and the prevalence of HF is increasing.[1] The mortality rate for patients with HF has been rising since 2012, especially among males, African Americans, and the elderly.[2,3] Recent data from the Centers for Disease Control and Prevention show a 38% increase in the number of HF deaths from 2011 to 2017.[4] The mortality rate after a hospitalization for HF is around 10.4% at the 30-day mark, 22% at one year, and 42.3% at five years.[5] Patients diagnosed with HF have poor prognoses, not only because of the high rates of mortality but also due to frequent HF-related rehospitalization.[6,7] Readmission rates after an HF-related hospitalization at 21% within 30 days, and 60% at one year.[8]

Researchers have examined factors contributing to delay, and demonstrated that demographic (e.g., general younger age and male gender), clinical (e.g., more comorbidities and worse New York Heart Association [NYHA] functional class), psychological (e.g., worse depression and anxiety), and cognitive and behavioral (e.g., low somatic awareness) variables are associated with longer delays.[9-14] These variables are important for identifying individuals at risk for delay; however, to fully understand the phenomenon of patient delay in seeking treatment for worsening HF symptoms, we propose a comprehensive conceptual model to investigate demographic, clinical, psychosocial, cognitive, and behavioral predictors of delayed care-seeking (Figure 4.1).

A comprehensive model of modifiable predictors can be used to guide the design and testing of interventions to promote timely care-seeking.

Prompt treatment-seeking in patients with worsening HF symptoms is a determinant of better clinical outcomes.[15,16] Patients who delayed a shorter amount of time to seek HF treatment had a shorter length of hospital stay and lower brain natriuretic peptide levels at discharge compared to patients who delayed longer.[10] Delays in receiving intravenous HF therapy (i.e., diuretics or vasoactive medications) were associated with increased risk of in-hospital deaths and longer length of hospital stay.[17] Despite this, delays in seeking medical care are still common among patients with HF, and the delay time can range up to several weeks.[13,18] Furthermore, delay in seeking medical care is associated with in-hospital death and length of hospital stay;[10,17] however, the relationship between delay in seeking medical care and subsequent cardiac events (specifically rehospitalization or death) remains unknown. Accordingly, the purposes of this study were to (1) determine factors contributing to care-seeking delay using a conceptual model, and (2) determine the impact of care-seeking delay on subsequent cardiac events (i.e., rehospitalization or death) in patients with worsening HF symptoms.

4.2 Methods

4.2.1 Design, Sample, Setting, and Procedure

This was a prospective, correlational, and predictive study. We enrolled 185 patients hospitalized with an exacerbation of HF and followed them for 3 months after discharge. Patients were recruited from two hospitals located in two urban cities in Kentucky between 2014 and 2017. Inclusion criteria were (1) a confirmed diagnosis of

HF, (2) admitted with HF exacerbation, (3) adult aged 18 years or older, and (4) able to read and speak English. Exclusion criteria included patients who had (1) a diagnosis of dementia, (2) a history of left ventricular assist device placement or heart transplant, (3) a co-existing terminal illness or hospice care, and (4) severe psychiatric disorders other than depression.

This study was approved by the Institutional Review Board at the University of Kentucky for conducting research and recruitment in both hospitals. Patient eligibility was confirmed by research assistants using patient interview and medical record review. Patients who agreed to participate in this study signed a written informed consent form and answered the questionnaires during their hospital stay. Patients were followed for three months after hospital discharge to obtain data on subsequent cardiac events. After completing the survey questionnaire and follow up, each patient was given a $25 gift card for his/her time.

4.2.2 Measures

Delayed Care-seeking

Time of care-seeking delay was defined as the amount of time between first noticing the onset of worsening symptoms and being admitted to the hospital. Patients were asked to answer the question, “On what date and time did you first begin to notice the symptoms that led to your current hospital admission?” Delay time was measured in hours by subtracting the date/time of symptom onset from the date/time of hospital admission and then multiplying the result by 24 hours.

Subsequent Cardiac Events

Subsequent cardiac event-free survival was defined as the time after discharge to first rehospitalization or death attributed to HF and cardiac causes. Data about the dates and reasons for readmission and death were obtained at one and three months after hospital discharge via follow-up phone calls to patients and their families, and reconfirmed by reviewing patients' medical records.

Sociodemographic and Clinical Variables

Sociodemographic characteristics including age, gender, race, marital status, and education were collected using a survey questionnaire. Data on clinical factors, such as left ventricular ejection fraction (LVEF), NYHA functional classification, and comorbidity, were obtained by trained research assistants through careful review of medical records.

The NYHA functional classification is the most widely used classification system in clinical practice to measure functional status and the extent of HF. It contains four classes and classifies patients in one of four categories based on the level of limitations caused by HF symptoms during ordinary physical activity: class I (no limitation), class II (slight limitation), class III (marked limitation), and class IV (severe limitation, suffering from HF symptoms at rest, and have increased discomfort during physical activity). The NYHA functional classification system is a valid and reliable assessment tool in patients with HF.[19]

Comorbidity was evaluated using the Charlson Comorbidity Index (CCI), which consists of 19 common comorbid conditions, such as cerebrovascular accidents, diabetes,

and HF.[20] Each comorbid condition has a different and weighted score based on the seriousness of the condition. Total scores are the sum of 19 comorbid conditions ranging from 0 to 37, with higher scores indicating more comorbid burden. The validity and reliability of the CCI have been established across a wide range of illnesses, including HF.[21]

Psychosocial Variables

Depressive symptoms were measured using the nine-item Patient Health Questionnaire (PHQ-9).[22] The PHQ-9 has been commonly used in clinical practice and research for screening, diagnosing, and measuring the levels of depression. Each item of the PHQ-9 is self-rated on a 4-point Likert scale from 0 (not at all) to 3 (nearly every day). Total scores are the sum of nine items that range from 0 to 27, with higher scores representing more depressed. A cutoff score of 10, which has been recommended as an indicator score of depression, was used to categorize patients into lower levels of depression (scores <10) and higher levels of depression (scores ≥ 10). The PHQ-9 is a valid and reliable measure and widely used in patients with HF.

The anxiety subscale of the Brief Symptom Inventory (BSI) was used to assess patients' anxiety.[23] This is a six-item subscale rated by patients using a five-point Likert scale (0 = not at all to 4 = extremely). Scores of the anxiety subscale of the BSI are the average scores of the six items. The range of the possible scores is 0 to 4, with higher scores indicating that the patient is more anxious. The anxiety subscale of the BSI has good validity and reliability in patients with HF. A cutoff score of 0.35 or higher indicates the presence of anxiety[24] and was adopted for this study. The internal

consistency of the anxiety subscale in our study was good, with a Cronbach's alpha of 0.84.

The Multidimensional Scale of Perceived Social Support Scale (MSPSS) was an instrument used to assess perceived social support from family, friends, or another significant person.[25] For example, one of the items is "There is a special person who is around when I am in need." The MSPSS consists of 12 items that are rated by patients on a 7-point Likert scale from 1 (very strongly disagree) to 7 (very strongly agree). Total scores are the sum of 12 items and range from 7 to 84, with higher scores reflecting more perceived social support. The reliability and validity of MSPSS have been supported in HF studies.[26]

Cognitive and Behavioral Variables

The Dutch Heart Failure Knowledge Scale was used to measure HF knowledge.[27] It contains 15 multiple-choice items regarding HF knowledge: four items in general, six items related to HF treatment, and five items about HF symptoms/symptom recognition. Each item has three response options, one of which is correct. Scores are summed and transformed linearly to a 0 to 100 range, with a cutoff score of 70 or higher to demonstrate adequate HF knowledge. This instrument has demonstrated reliability and validity in studies of patients with HF.[27]

Heart failure somatic awareness was assessed using the Heart Failure Somatic Awareness Scale (HFSAS), which is a 12-item, 5-point Likert scale.[28] Patients were asked to rate symptom presence and symptom severity on how much they were bothered by each symptom at any point during the previous week, on the following scale: 0

(symptoms not experienced), 1 (not at all), 2 (slightly), 3 (moderately), 4 (quite), and 5 (extremely, could not have been worse). Total scores are the sum of 12 items ranged from 0 to 60, with higher scores indicating higher perceived symptom burden. Theta reliability and construct validity have been supported.[28] In our study, Cronbach's alpha of the scale was 0.77.

Self-care confidence was measured using the six-item confidence subscale of the Self-Care of Heart Failure Index (SCHFI).[29] Patients rate how confident they are when they engage in HF self-care using a 4-point Likert scale ranging from 1 (not confident) to 4 (extremely confident). Examples of items include: "keep yourself healthy and free of heart failure symptoms," and "recognize changes in your health if they occur." Scores are summed and transformed linearly on a 0 to 100 range. A cutoff score of 70 or higher indicates adequate confidence in self-care engagement.[30] The reliability and validity of this subscale have been supported.[29] In our study, internal consistency reliability was supported by Cronbach's alpha at 0.81.

Self-care adherence was assessed using adherence behavior subscale of the Medical Outcome Study Specific (MOS) which is designed to assess patients' adherence to treatment/medical recommendations specific to HF.[31] It consists of eight items including regular exercise, taking prescribed medication, cutting down on alcohol drinking, cutting down on smoking, following a low-fat diet, following a low-salt diet, daily weighing, and daily symptom monitoring. Patients were asked to rate how often they have followed each medical recommendation in the past 4 weeks using a 6-point Likert scale from 0 (none of the time) to 5 (all of the time). It has a minimum score of 0 and a maximum score of 40, with higher scores indicating better adherence to treatment

recommendation. The reliability and validity of MOS have been established.[31,32] In our study, the internal consistency of the adherence behavior subscale was acceptable with Cronbach's alpha of 0.70.

4.2.3 Data Analyses

Data were analyzed using IBM SPSS Statistics for Windows, version 26.0 (Armonk, NY: IBM Corp. Released 2018). Descriptive statistics were used to describe the demographic characteristics of the sample (means with standard deviations and frequencies with percentages) and were used to summarize the delay time (median and interquartile range). Delay time in hours was markedly non-normally distributed and skewed to the right; therefore, we adopted a non-linear regression model using gamma distribution with log link function to examine the association between time of patient delay in seeking treatment for escalating symptoms (in hours) and demographic, clinical, psychosocial, cognitive, and behavioral variables.

To determine whether shorter patient delay in seeking treatment predicts a longer time to first rehospitalization or death after hospital discharge compared with longer patient delay, delay time in hours was converted into a dichotomous variable. Because no standard cutoff point existed, delay time was dichotomized as a shorter delay and a longer delay using the median value. Cox proportional hazards regression was used to examine the impact of care-seeking delay on subsequent rehospitalization or death after controlling for age, gender, LVEF, and HF somatic awareness. We included four covariates in our survival analysis following the rule of one predictor for every ten events. The selection of covariates was based on previous studies.[3,33]

4.3 Results

4.3.1 Sample Characteristics

Of the 185 patients enrolled, 32 patients had one or more missing data points; thus, 153 patients with complete data were included in the analysis (see Figure 4.2 for Consort diagram). The estimated sample size for this study was 100 based on a moderate effect size for the relationship of select predictors with rehospitalization and mortality, a two-tailed alpha of 0.05 and a statistical power of 0.80.[34] The mean age of the 153 patients was 61 ± 13 years. More than half of the patients were men (54.2%). The majority of patients were Caucasian (83%), had at least a high school degree (82%), lived with someone (71%), and were in NYHA functional class III and IV (72.5%). Detailed information regarding patients' characteristics and scores on each variable is presented in Table 4.1.

Compared with patients who had missing data points, patients with complete data were more likely to be male (54.2% vs 34.4%), white (83.0% vs 43.8%), and married or cohabitating (48.4% vs 25.0%). There were no significant differences in the delay time, age, comorbidity scores, educational level, whether they lived with another person, LVEF, or NYHA functional class between those who did and did not have missing data points.

4.3.2 Factors Associated with Delay in Seeking Care

Among the 153 hospitalized patients, the median delay time was 134 hours. The 25th and 75th interquartile delay times were 49 and 364 hours, respectively (Figure 4.3). About 16% of patients sought medical care within 24 hours (1 day) whereas almost 36%

of patients delayed seeking care for more than 120 hours (5 days). The non-linear regression model testing predictors of delay time was statistically significant ($P < 0.001$; Table 4.2). The NYHA functional class, depressive symptoms, HF knowledge, and HF somatic awareness were significant predictors of increased delay time in seeking medical care for worsening HF symptoms. Compared to patients with NYHA class I and II, patients with NYHA class III and IV delayed longer ($P = 0.001$). Patients with higher levels of depressive symptoms and greater HF knowledge had a higher risk of increased delay time ($P = 0.004$ and $P = 0.003$, respectively). Lower HF somatic awareness was associated with a higher likelihood of longer delay ($P = 0.033$).

4.3.3 Impact of Care-Seeking Delay on Subsequent Cardiac Events

Of the 153 patients, five patients died and three patients received a heart transplant during hospitalization; the remaining 145 patients were followed for three months after hospital discharge to obtain data on subsequent cardiac events. Forty-five events occurred during the three-month follow-up period. Of these events, 15.6% (7/45) were HF-related deaths, 4.4% (2/45) were cardiac-related deaths, 62.2% (28/45) were HF-related rehospitalizations, and 17.8% (8/45) were cardiac-related rehospitalizations. The Cox proportional hazards regression analysis demonstrated that longer delay was associated with a shorter cardiac event-free survival (i.e., HF-related and cardiac-related hospitalization or death) after controlling for age, gender, LVEF, and HF somatic awareness ($P = 0.007$; Table 4.3). Compared to patients with shorter delays (Figure 4.4), patients with longer delays had a 1.96-fold higher risk of experiencing cardiac events (hazard ratio = 1.961, 95% CI = 1.049 to 3.666, $P = 0.035$).

4.4 Discussion

We investigated delays in seeking care for worsening HF symptoms in hospitalized patients. We found a relationship between delay in seeking medical care and subsequent cardiac events in patients with worsening HF symptoms. Patients with worsening HF symptoms who delayed longer (more than 134 hours) in seeking medical care were approximately twice as likely to experience cardiac rehospitalization or cardiac death after discharge compared to patients who delayed less (less than 134 hours). This not only provides evidence of the possible adverse consequences brought on by delays in seeking care, but also points to the importance of seeking medical help early when patients perceive that their HF symptoms are worsening. Our findings demonstrate the need to help patients improve their care-seeking decision-making related to worsening HF symptoms.

An unexpected finding, that patients with worse or higher NYHA class (class III/IV) delayed longer, was consistent with findings from some previous HF studies.[11,12] It is difficult to explain why patients with worse NYHA class waited to seek care without qualitative research. Results from other studies suggest, possible explanations for delaying could include waiting to see if their symptoms improve, not perceiving waiting as a delay, fear of knowing their illness is getting worse, feeling hopeless about their illness, avoiding going back to the hospital, not wanting to lose control over their health and independence, and fear of not returning home or dying at the hospital.[35-37] Patients with worse NYHA class may be used to having moderate to severe symptoms and may not perceive that they are worsening as easily as those with better NYHA class. Because NYHA class is one of the important indicators of symptom severity, patients with worse

NYHA class need to seek medical attention at an earlier time to prevent further exacerbation. Thus, qualitative research to investigate and understand the causes of prolonged delay among patients with worse functional status is needed.

Psychological distress, especially depression, plays a vital role in driving care-seeking decisions. Our finding that higher levels of depressive symptoms were associated with a longer delay in seeking care was also in line with the findings of prior research.[13,38] Johansson et al. reported that patients with higher levels of depressive symptoms had a 1.5-fold delay over 72 hours compared with patients with lower levels of depressive symptoms.[13] Xu et al. reported that the odds of delaying in making care-seeking decisions was 5.3 times higher among those HF patients with higher depressive symptoms.[14] Albert et al. found that the more depressive symptoms patients had, the less confidence they had in their ability to control HF conditions.[39] Our findings extend this research by demonstrating the strength of the association of depressive symptoms with delay in the face of a more comprehensive model of delay. Patients with depressive symptoms have been shown to have low mood, feelings of hopelessness, and lack of coping behaviors, which may affect patients' judgment and decision to seek care.[40] Therefore, reducing the severity of depression with appropriate intervention not only improves quality of life and mortality,[41,42] but may also make a significant impact on proper care-seeking decisions.

Similar to findings from a prior HF study, patients with greater HF knowledge had increased delay time in seeking medical care.[11] A potential reason for this finding is that general knowledge of HF does not mean that patients have the ability to identify or recognize the early signs of symptom exacerbation.[35] Moreover, most patients with HF

waited to see if symptoms would improve before deciding to seek care.[18,37,43] Patients were more likely to try to alleviate symptoms through self-medication or take some remedies (such as increasing diuretic doses, avoiding water intake, elevating legs, trying to relax, or taking medications other than those prescribed) when they first perceived their symptoms worsening, rather than calling for medical help.[36,43] Patients also waited to evaluate the effectiveness of these strategies and then considered whether to seek medical care, and this resulted in delays.[44] Based on these findings, the development of effective interventions to address the importance of seeking medical advice and timely pursuit of appropriate treatment is a priority.

Awareness of symptoms is one of the determinants of care-seeking decisions. Some patients with HF have difficulty sensing their own symptoms,[45] and thus are unable to make appropriate decisions about care-seeking. Our finding that patients with lower HF somatic awareness had a longer delay in seeking care was supported in other studies. When acute or unbearable symptoms were present such as chest discomfort or acute dyspnea, patients sought medical care early.[46,47] In contrast, they did not recognize chronic and progressive symptoms (e.g., fatigue, edema, or weight gain) that required urgent medical attention because they treated these symptoms as aging or as an expected part of illness progression.[36,48] The number of acute or chronic symptoms were also related to the types of care-seeking. Altice et al. reported that patients with more acute symptoms were more likely to call 911 or go to the emergency department, whereas those with more chronic symptoms were more likely to contact a healthcare provider first and thus caused delays.[49] Our findings suggest that intervention strategies focusing on

assisting symptom recognition, symptom appraisal, and timely symptom response are essential to enhance symptom awareness and improve symptom management.[44]

4.5 Limitations

One of the limitations of this study is that the time of worsening symptom onset was measured by patients' recall. However, the perception of symptoms is subjective, and in order to investigate delay time between patients first noticing the onset of worsening symptoms and being admitted to the hospital, relying on the patients' memory of symptom onset is unavoidable. Therefore, we recruited patients and collected data during their hospital stays to ensure better memory related to the time of symptom onset. Another limitation is that the sample in our study was mostly white and from two medical centers located in urban Kentucky. Although the percentage of white people in our study reflects that of the state of Kentucky as a whole, this lack of diversity in the sample still limits the generalizability of our findings.

4.6 Conclusions

This study has provided important information on factors contributing to care-seeking delay to subsequent cardiac events. Our findings that care-seeking delay was significantly associated with an increased risk of rehospitalization and mortality after discharge have highlighted the importance for healthcare providers to educate and assist timely care-seeking to patients with worsening HF symptoms. Furthermore, NYHA functional class, depressive symptoms, HF knowledge, and HF somatic awareness were the significant independent predictors of delay in seeking medical care. Interventions

targeting these modifiable factors should be developed and implemented to reduce delay in seeking medical care and thereby improve outcomes.

Copyright © Chin-Yen Lin 2020

Table 4.1 Characteristics of the sample of 153 patients with heart failure

Characteristics	**Mean ± *SD* or *n* (%)**
Sociodemographic Characteristics	
Age, years	61 ± 13
Female	70 (45.8)
Race	
White	127 (83.0)
Black and other minorities	26 (17.0)
Marital Status	
Married / Cohabitation	74 (48.4)
Divorced / Widowed	59 (38.5)
Single	20 (13.1)
Education ≥ high school	125 (81.7)
Live with another person	108 (70.6)

Table 4.1 (continued)

Clinical Characteristics	
LVEF less than 40%	81 (52.9)
NYHA functional class	
I / II	42 (27.5)
III / IV	111 (72.5)
Charlson Comorbidity Index	4.7 ± 5.1
Psychosocial variables	
Depressive symptom scores	10.6 ± 5.9
≥ 10	87 (56.9)
< 10	66 (43.1)
Anxiety scores	1.1 ± 0.9
≥ 0.35	101 (66.0)
< 0.35	52 (34.0)
Social support scores	69.8 ± 16.3

Table 4.1 (continued)

Cognitive and behavioral variables	
HF knowledge	69.8 ±15.9
≥ 70	84 (54.9)
< 70	69 (45.1)
HF somatic awareness	31.7 ± 11.5
Self-care confidence	64.2 ± 21.0
≥ 70	65 (42.5)
< 70	88 (57.5)
Self-care adherence	25.9 ± 7.6

HF, heart failure; LVEF, left ventricular ejection fraction; NYHA, New York Heart Association

Table 4.2 Factors associated with delayed care-seeking

Variables	*β*	*SE*	95% Confidence Interval	*P* Value
Demographic and clinical variables				
Age, years	0.007	0.010	-0.013 to 0.026	0.492
Gender[a]	-0.172	0.246	-0.654 to 0.310	0.483
NYHA functional class[b]	0.902	0.282	0.349 to 1.455	0.001
Comorbidity	-0.008	0.033	-0.072 to 0.057	0.819
Psychosocial variables				
Depressive symptoms[c]	0.689	0.242	0.216 to 1.163	0.004
Anxiety[c]	-0.393	0.281	-0.945 to 0.158	0.162
Social support	-0.002	0.008	-0.017 to 0.013	0.818
Cognitive and behavioral variables				
HF knowledge[c]	0.736	0.252	0.242 to 1.229	0.003
HF somatic awareness	-0.025	0.012	-0.048 to -0.002	0.033
Self-care confidence[c]	0.267	0.285	-0.291 to 0.824	0.349

Table 4.2 (continued)

Self-care adherence	0.328	0.287	-0.235 to 0.891	0.253

HF, heart failure; NYHA, New York Heart Association; *β*, regression coefficient; *SE*, standard error

[a]Reference category: male; [b]Reference category: class I and II; [c]Reference category: lower

Table 4.3 Association of care-seeking delay with subsequent cardiac event-free survival (rehospitalization or death attributed to heart failure and cardiac causes) adjusting for relevant covariates

Variables	**Adjusted Hazard Ratio**	**95% Confidence Interval**	***P* Value**
Age	1.043	1.015 – 1.071	0.003
Gender			
Male	1.000		
Female	1.361	0.738 – 2.508	0.324
LVEF	0.967	0.943 – 0.991	0.007
HF somatic awareness	0.616	0.331 – 1.148	0.127
Care-seeking delay			
Short	1.000		
Long	1.961	1.049 – 3.666	0.035
HF, heart failure; LVEF, left ventricular ejection fraction			

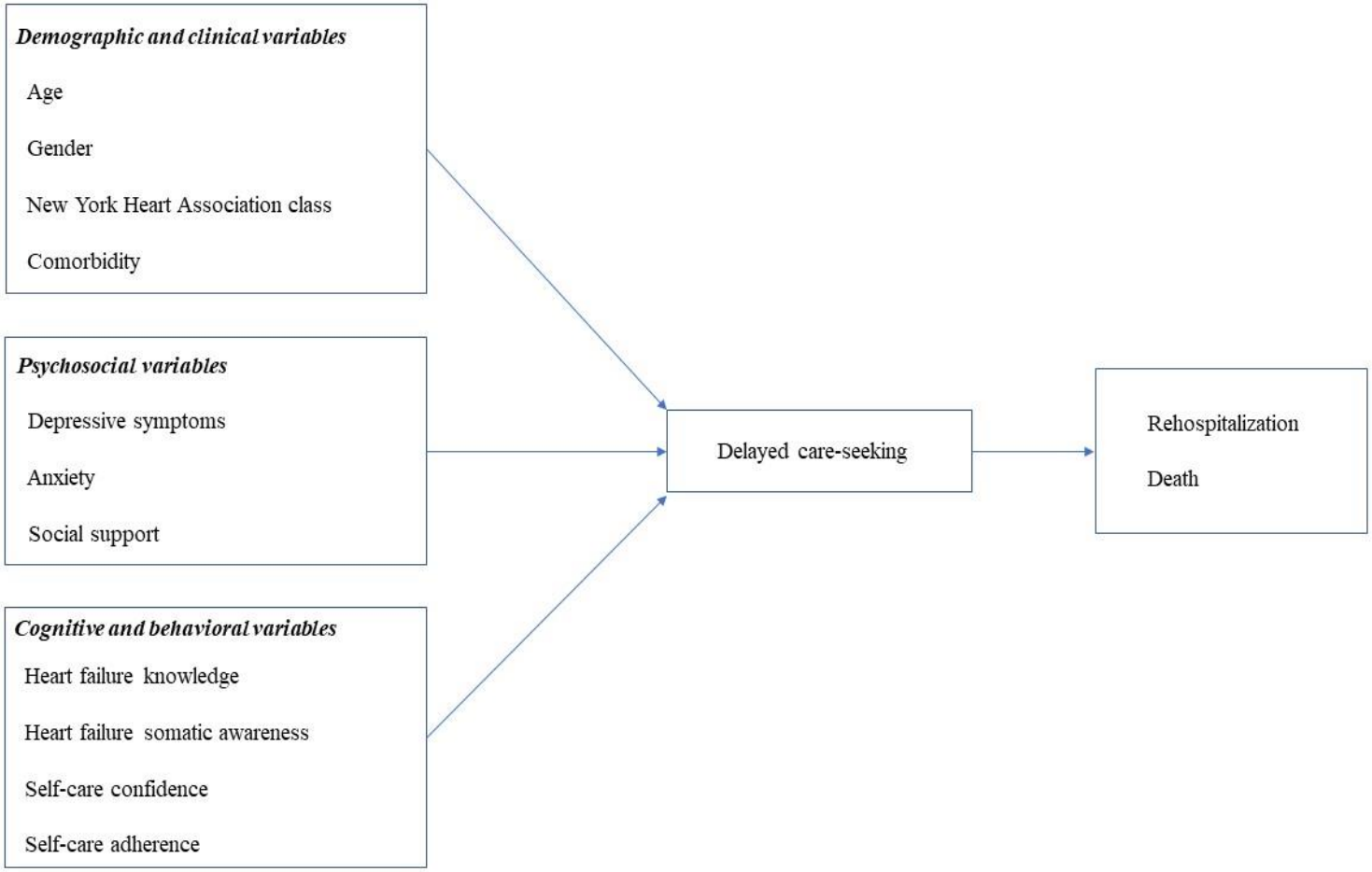

Figure 4.1 Conceptual model of factors predicting delayed care-seeking and subsequent cardiac events

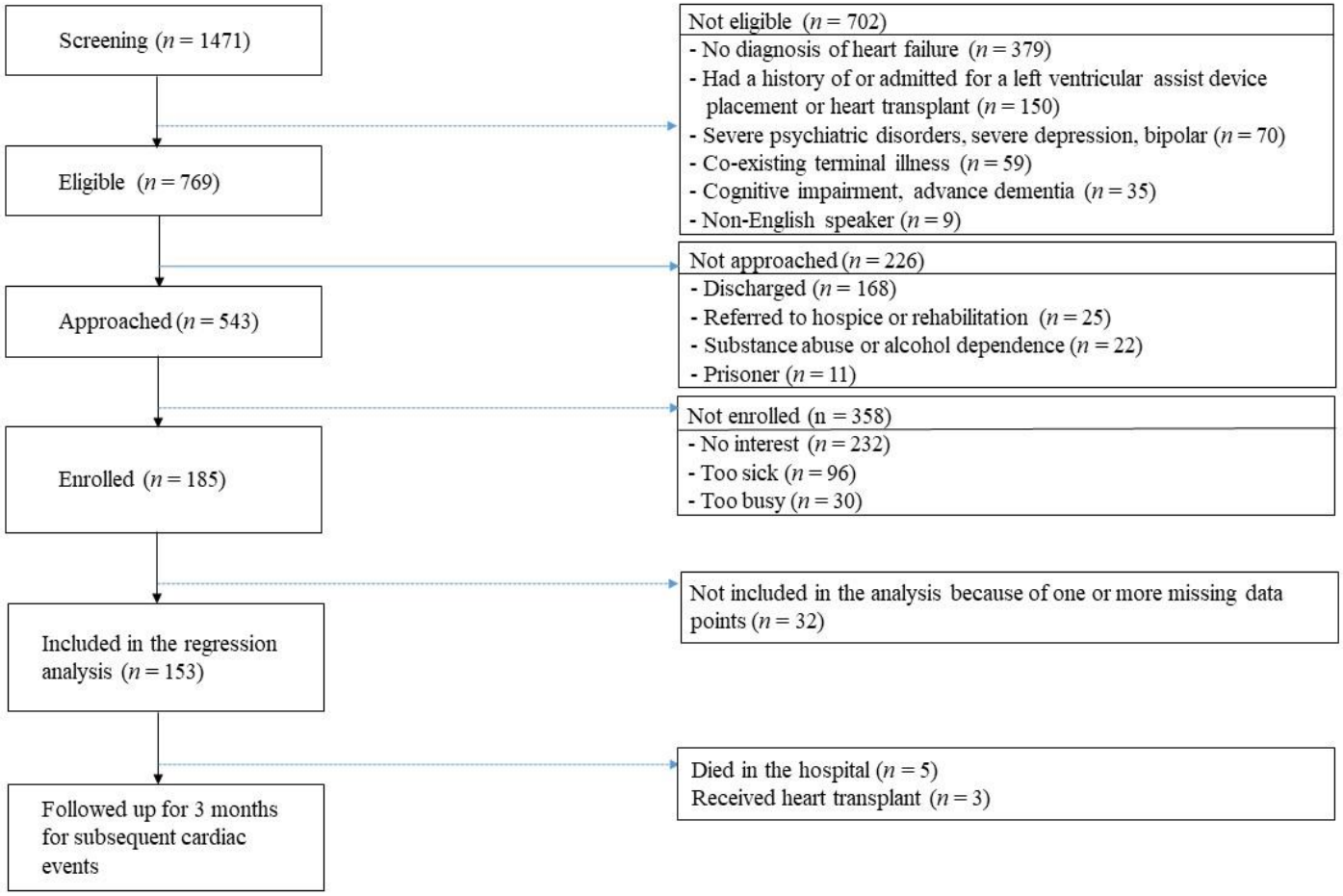

Figure 4.2 Consort diagram

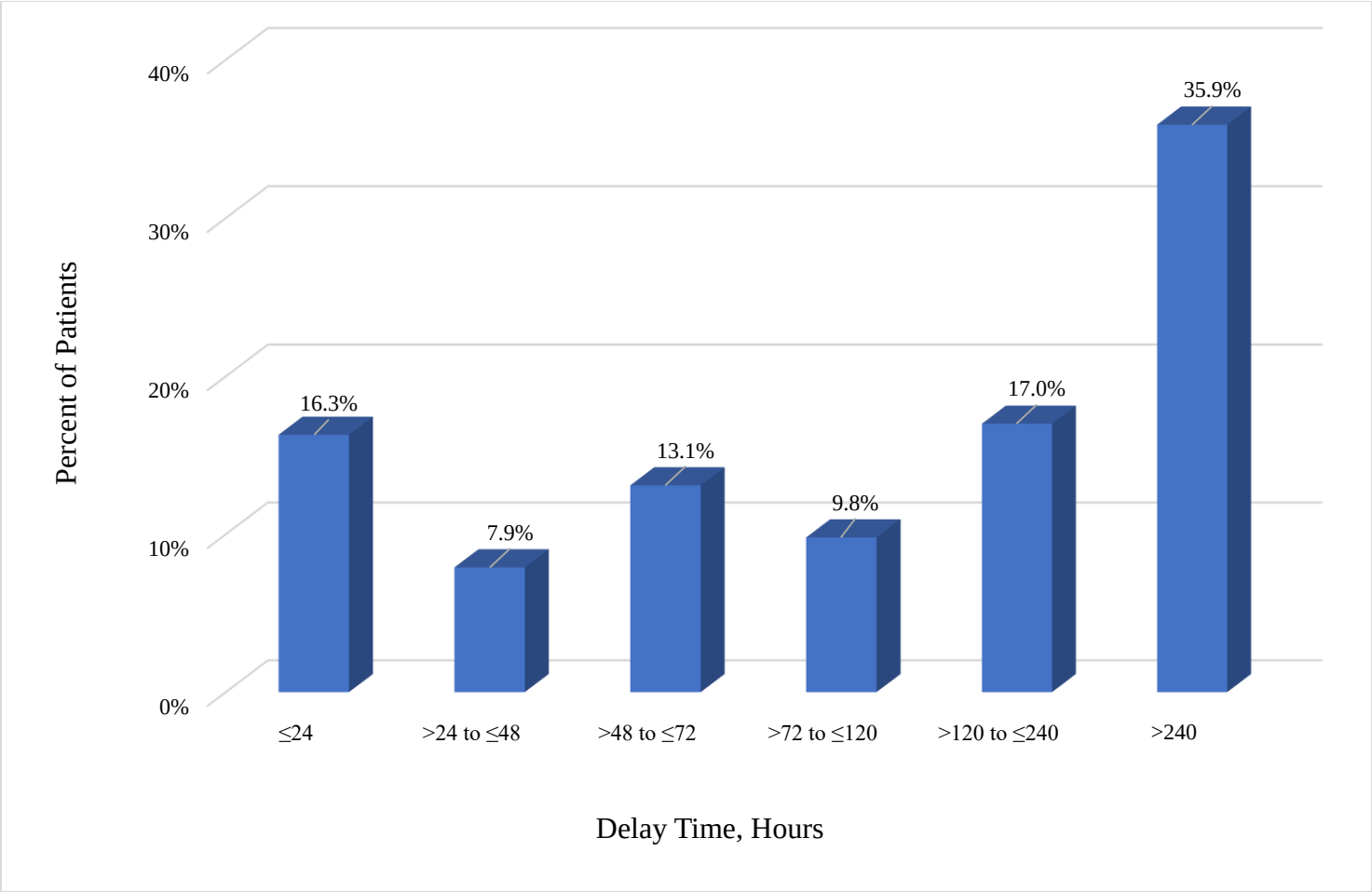

Figure 4.3 Distribution of delay time between perceived worsening symptom onset and hospital admission

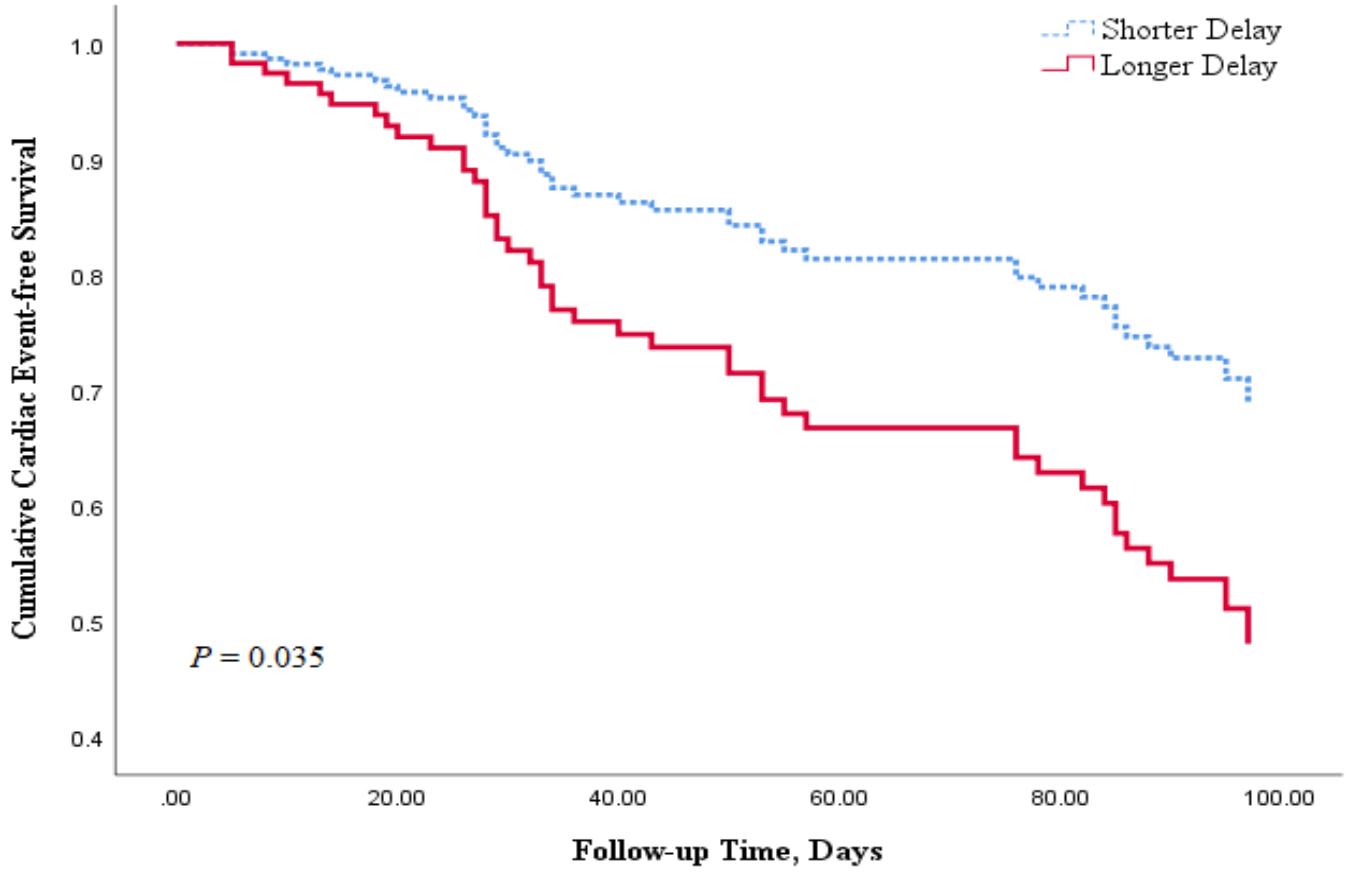

Figure 4.4 Cardiac event-free survival between two care-seeking delay groups categorized by median delay time

CHAPTER FIVE: Perceived Control Predicts Symptom Status in Patients with Heart Failure

Lin, C. Y., Miller, J. L., Lennie, T. A., Biddle, M. J., Mudd-Martin, G., Hammash, M. H., & Moser, D. K. (2020). Perceived Control Predicts Symptom Status in Patients with Heart Failure. *Journal of Cardiovascular Nursing.* Advance online publication. DOI: 10.1097/JCN. 0000000000000684

5.1 Introduction

Heart failure (HF) is a chronic, symptom-driven condition. More than 30 physical and psychological symptoms have been reported in HF.[1-5] The typical physical symptoms of HF include dyspnea, edema, sudden weight gain, and fatigue.[6,7] Patients with worse HF symptom status have reduced quality of life, more hospital readmissions, and increased mortality.[5-9] As a result, improving symptom status for patients with HF is important in order to reduce suffering and improve health outcomes.

Perceived control is a modifiable construct and it can be enhanced to improve health behaviors, including self-care, and thus improve health outcomes. Perceived control refers to an individual's belief that he or she has the ability to cope with negative events (for example, a diagnosis of HF) and bring about positive outcomes, such as improved symptom status. Patients' perceptions of control are at the root of good self-care because patients with higher levels of perceived control are more likely to fully engage in education and skill-learning opportunities that prepare them to better manage their health.[10] Indeed, promotion of control over a negative diagnosis is at the heart of most education and counseling interventions. It is theorized that patients with higher levels of perceived control will engage in better self-care, which includes optimal

symptom management and adherence to medications and diet, and thus have better symptom status than those who do not.[11,12]

Patients' perceptions of control are predictive of physical and psychological health.[13-15] In a study of patients with asthma, greater perceived control was related to lower asthma severity, fewer depressive symptoms, better physical health status, better asthma-specific quality of life, and decreased the likelihood of emergency department visits and hospitalizations.[16] Yet, lower levels of perceived control are common in patients with HF and have been shown to have an adverse impact on patients' health-related quality of life.[17,18] Higher levels of perceived control have been associated with reduced symptoms and complications in patients with coronary artery disease;[14] however, little is known about the relationship between perceived control and symptom status in patients with HF.

Perceived control is changeable and foundational to most education and counseling, and self-care interventions.[10] Determining the association of perceived control to symptom status could provide vital information for developing interventions. Therefore, the primary aim of this study was to determine whether perceived control independently predicted HF symptom status. In determining the independent association of perceived control with symptom status, we controlled for variables known to be associated with symptom status including age, gender, New York Heart Association (NYHA) functional class, comorbidity burden, and depressive symptoms.[19-21] A second aim was to determine the associations of perceived control to self-care, and of self-care to symptom status. On the basis of theories of perceived control,[22] which is derived from locus of control theory, we hypothesized that patients with HF who had higher levels of

perceived control would have better symptom status than those who had lower levels of perceived control.

5.2 Methods

5.2.1 Design, Sample, and Setting

In this study, we used baseline data from a prospective, longitudinal study designed to test the effects of a 6-month nutrition intervention on HF symptoms, health-related quality of life, and clinical outcomes.[23] All patients in the parent study (n = 115) were included in this cross-sectional secondary analysis. Patients were recruited from outpatient clinics or hospitals in Kentucky. Adult patients who were able to read and speak English and who were diagnosed with chronic HF of NYHA functional class of II, III, or IV were considered eligible. Patients were excluded from the parent study if they (1) had a body mass index [BMI] < 17 or > 46kg/m^2, (2) had a co-existing illness associated with systemic inflammation, (3) had decreased appetite or gastrointestinal absorption, (4) were taking dietary supplements that contained lycopene or omega-3 fatty acids, (5) were allergic to rice bran oil, (6) were referred for heart transplantation, or (7) had cognitive impairments.

5.2.2 Procedure

The University of Kentucky Institutional Review Board approved the study. Eligibility of patients was verified by a trained research nurse. Patients who agreed to participate in the study gave informed consent and signed the consent form. After receiving consent, patients were screened for cognitive function using the Montreal

Cognitive Assessment (MOCA).[24] Patients with MOCA scores of 16 or below were excluded from the study.

5.2.3 Measures

Symptom Status

Symptom status was measured using the Memorial Symptom Assessment Scale-HF (MSAS-HF), which is a 32-item questionnaire modified from the Memorial Symptom Assessment Scale.[25,26] The MSAS-HF contains three subscales that reflect physical, psychological, and HF-specific symptoms. Each item of the MSAS-HF consists of four domains: (1) presence or absence of the symptom (rated yes or no), (2) frequency of the symptom (rated 1 = rarely to 5 = all the time), (3) severity of the symptom (rated 1 = mild to 5 = extremely), and (4) distress associated with the symptom (rated 1 = a little bit to 5 = extremely). Symptom status scores are derived from the sum of each of the subscales of symptom prevalence, symptom frequency, symptom severity, and symptom distress. Total scores of MSAS-HF can range from 0 to 512, with higher scores indicating worse symptom status. The validity and reliability of this scale have been reported in HF patients.[26]

Perceived Control

Perceived control was measured with the Control Attitudes Scale-Revised (CAS-R), which is an 8-item questionnaire with good reliability and validity in cardiac patients, including those with HF.[27] Each item is rated on a five-point Likert scale from 1 (strongly disagree) to 5 (strongly agree). Examples of items include: “I can do a lot of things myself to cope with my heart condition”, and “I have considerable ability to control my

symptoms". The scores range from 8 to 40, with high scores reflecting greater perceived control.

Heart Failure Self-Care

Self-care was evaluated by the Self-Care of Heart Failure Index (SCHFI) which has 22 items with well-supported reliability and validity in HF studies.[28] The SCHFI contains three subscales that consist of 11-items for self-care maintenance, five-items for self-care management, and six-items for self-care confidence. Self-care maintenance is the process of maintaining physiologic stability, which includes symptom monitoring and treatment adherence. Self-care management is the process of responding to symptoms and treatments, which involves symptom recognition, symptom evaluation, treatment implementation, and treatment evaluation. Self-care confidence reflects an individual's confidence in their ability to engage in self-care. The HF self-care subscales are scored separately, or self-care maintenance and self-care management are summed to produce a total score. Self-care confidence is not included in the HF self-care total score because self-care confidence has been identified as a mediator or a moderator of self-care behaviors.[29] In this study, we used the self-care confidence subscale score and the total self-care score composed of self-care maintenance and self-care management. Responses on each item are measured on a four-point Likert scale from 1 to 4. Scores of each subscale are calculated separately by summing each item in each subscale and transforming to a 100-point scale, with higher scores meaning better self-care maintenance, self-care management, or self-care confidence. Scores of less than 70 reflect inadequate self-care.[30]

Depressive Symptoms

Depressive symptoms were assessed using the Patient Health Questionnaire-9 (PHQ-9). The PHQ-9 consists of nine items that are based on the criteria for diagnosing clinical depression and that are rated by patients using a Likert scale response (0: not at all to 3: nearly every day). Total scores of PHQ-9 can range from 0 to 27 with a score of 10 or higher indicating moderate to severe depression.[31] This questionnaire has well-documented reliability and validity in patients with HF.[32]

Comorbidity Burden

Comorbidity burden was measured from patient interview and medical record review using the Charlson Comorbidity Index (CCI).[33] The CCI consists of 19 comorbid illness and each comorbid illness is assigned a different weight of 1, 2, 3, or 6 depending on illness seriousness. The scores of CCI can range from 0 to 37 with higher scores indicating higher comorbidity burden and representing an increased risk of death within one year.[33] The CCI is a valid and reliable measure and has been widely used in previous HF studies.[34-36]

Demographic and Clinical Characteristics

Demographic characteristics (i.e., age, gender, race/ethnicity, education, and marital status) were collected using a demographic questionnaire. New York Heart Association classification was determined by trained research assistants via a careful patient interview. Patients were classified into NYHA categories (class I to class IV) based on how much they are limited by experiencing symptoms during physical

activity.[37] The NYHA functional class is the most commonly used classification system in HF.[38]

5.2.4 Data Analyses

Statistical analyses were conducted using IBM SPSS Statistics for Windows, version 26.0 (Armonk, NY: IBM Corp. Released 2018). To assess our first aim, a multiple regression analysis was conducted to determine whether perceived control predicted symptom status after controlling for age, gender, NYHA functional class, total comorbidity scores, and total depressive symptom scores. The outcome variable was the sum scores of two subscales of MSAS-HF (i.e., physical and HF-specific symptoms). The psychological subscale of the MSAS-HF was not included in this analysis because items in the psychological subscale of MSAS-HF overlap with depressive symptoms. Predictors were entered into a regression model in four blocks in the following order: block 1 included age and gender; block 2 was NYHA functional class and comorbidity burden; block 3 was depressive symptoms and block 4 was perceived control. This sequence was used in order to determine the contribution of perceived control after controlling for demographic, clinical, and psychological covariates. To determine whether the symptom descriptors rendered different results from the total score for HF symptom status, multiple linear regression analyses were performed to examine the association between perceived control and the symptom descriptors of prevalence, frequency, severity, and distress after controlling for the same covariates (i.e., age, gender, NYHA functional class, total comorbidity scores, and total depressive symptom scores). To test our second aim, multiple linear regression analyses were performed to examine the associations of perceived control to self-care, and of self-care to symptom

status after controlling for age, gender, NYHA functional class, and total comorbidity scores. The assumptions of linear regression modeling including independence of the errors, linearity of the relationship between predictor variables and dependent variable, homoscedasticity of residuals, multicollinearity, and normality of the error distribution were checked, with no violations observed.

5.3 Results

5.3.1 Sample Characteristics

Sample characteristics are outlined in Table 5.1. The mean age of patients was 63 ± 12 years. The majority of patients were men (60%), Caucasian (70%), had at least a high school education (89%), and were classified in NYHA functional class III and IV (65%). The mean score of the PHQ-9 was 6.1 (± 5.0 *SD*) and 24.3% of patients had a PHQ-9 score of 10 or greater reflecting moderate to severe depressive symptoms (Table 5.1). The mean score of CAS-R for perceived control was 29.7 (± 3.8 *SD*; range from 19 to 39), reflecting relatively higher levels of perceived control.[27] The mean scores for self-care maintenance, management, and confidence were 61.3 (± 20.5 *SD*), 63.5 (± 19.9 *SD*), and 60.4 (± 15.6 *SD*) respectively, revealing inadequate self-care in HF. The average number of symptoms that patients had was 9.1 ± 5.9 (range 0-28) demonstrating a wide variety of symptoms experienced. Highly prevalent symptoms included shortness of breath (68.7%), lack of energy (64.3%), difficulty sleeping (52.2%), feeling drowsy (47%), and swelling of arms and legs (46.1%).

5.3.2 Prediction of HF Symptom Status

Table 5.2 shows the results of multiple regression analyses predicting HF symptom status from age, gender, NYHA functional class, total comorbidity scores, depressive symptom scores, and perceived control scores. Each block of the model was significant, as was the overall regression model ($P < 0.001$). The R^2 in the final model was 0.547 (adjusted $R^2 = 0.522$), indicating that approximately 52% of the variance in HF symptom status was explained by these predictors. Perceived control was an independent predictor of symptom status after adjusting for covariates ($P = 0.009$). Lower perceived control predicted worse symptom status. Every one-point increase in perceived control scores was associated with a 2.6-point decrease in the symptom status scores while other covariates were held constant.

Other predictive covariates were age, NYHA functional class, and depressive symptoms. When compared to older patients, younger patients had worse symptom status ($P = 0.015$). When compared to NYHA functional class II, NYHA functional class III and IV had worse symptom status ($P = 0.021$). Having greater depressive symptoms was predictive of worse symptom status ($P < 0.001$).

Perceived control was an independent predictor of the symptom frequency, severity, and distress (not shown in tables). Lower levels of perceived control were associated with greater symptom frequency ($F[6,105] = 16.608$, $R^2 = 0.487$, unstandardized $B = -0.741$, standard error (SE) = 0. 316, $P = 0.021$), as well as greater severity ($F[6,105] = 19.540$, $R^2 = 0.528$, unstandardized $B = -0.921$, $SE = 0.306$, $P = 0.003$), and greater distress ($F[6,105] = 20.690$, $R^2 = 0.542$, unstandardized $B = -0.904$, SE = 0. 318, $P = 0.005$). Perceived control was not a significant predictor of symptom

prevalence ($F[6,108] = 16.077$, $R^2 = 0.472$, unstandardized $B = -0.172$, $SE = 0.095$, $P = 0.074$).

5.3.3 Associations of Perceived Control, Self-Care, and Symptom Status

Perceived control was predictive of HF self-care confidence and HF self-care after controlling for covariates (Table 5.3). Higher levels of perceived control were related to better HF self-care confidence and HF self-care.

Heart failure self-care confidence and HF self-care were predictive of symptom status after controlling for covariates (Table 5.4). Both HF self-care confidence and HF self-care were negatively associated with symptom status, indicating that better HF self-care confidence and HF self-care were related to better symptom status.

5.4 Discussion

Results of this study suggest the importance of perceived control to symptom perception and expression. We found that lower levels of perceived control independently predicted total symptom status score as well as the symptom descriptors of frequency, severity, and distress from HF symptoms. Additionally, higher levels of perceived control were associated with better self-care and better self-care was associated with better symptom status. These data support the theoretical framework whereby perceived control is thought to improve engagement in self-care, thus resulting in improvement in symptom status.[10]

Given our findings, intervention strategies focused on enhancing the perception of control over symptoms may be essential to improve symptom status. Perceived control is a modifiable factor and may be increased with education and counseling that promotes

self-care ability, increases confidence, and improves self-management behavior. For example, Hwang et al. found that perceived control was a significant determinant of self-care in HF.[11] Westlake et al. found an improvement in perceived control after a 3-month web-based HF and symptom management education.[39] Evangelista et al. reported that interventions enhancing perceived control, patient activation, and disease management increased HF patients' confidence to actively engage in self-management of their condition to control their symptoms.[40]

Moreover, perceived control is a key element to reduce emotional stress (i.e., anxiety and depression).[13] In patients with HF and other cardiac illnesses, patients with higher levels of perceived control had less depression.[15,27] Perceived control also plays a vital role in decreasing symptom distress and severity.[16] In an HF study of patients receiving palliative care, greater improvement in perceived control was associated with greater reductions in symptom distress.[40] Among post-cardiac surgery HF patients, both perceived control and depression improved by three months after receiving psychoeducational interventions.[41] Accordingly, evidence suggests that patients' perception of control could be increased by means of interventions that strengthen patients' confidence and ability to cope with illness and adverse situations. Additional strategies, such as supportive interventions for depression which is also a significant predictor of symptom status, may enhance the effect of improving symptom status in patients with HF.

In addition to predicting HF symptom status, perceived control also predicted self-care suggesting that perceived control could be targeted in interventions to enhance patients' engagement in appropriate HF self-care. Other researchers have found that

greater perceived control was related to better self-care behaviors in patients with HF.[12] Another HF study revealed a significant association between health literacy and self-care among patients with greater perceived control.[42] Evidence suggests that as patients gain confidence in their ability to control their illness, their self-care engagement and performance are enhanced. Moreover, self-care is essential in helping patients to prevent HF exacerbations. Self-care interventions, which target improvement of patients' knowledge, ability, adherence, and confidence in maintaining health and managing illness, reduce hospital readmissions and all-cause mortality, as well as improvement in quality of life in patients with HF.[43,44] Consequently, our findings that perceived control, self-care, and symptom status are related suggest future research to determine whether self-care is a mediator or moderator between perceived control and symptom status.

Our findings that covariates in our model including age, NYHA functional class, and depressive symptoms were predictors of symptom status were consistent with previous studies. Park and colleagues reported that HF physical and psychological distress were significantly influenced by age and comorbidities.[21] In a study of HF symptom clusters, older patients experienced more symptom occurrence.[19] Evidence from one study indicated that NYHA class III and IV patients with HF experienced higher distress from physical symptoms than did NYHA class I and II patients.[20] Furthermore, prior investigators have demonstrated that depression was associated with symptom status in patients with HF, showing that patients who had more severe depression experienced more physical symptoms and higher symptom burden.[9,45] More importantly, the major finding in the present study revealed that perceived control

significantly predicted symptom status in the company of these covariates, which supported the association we hypothesized.

5.5 Limitations

There are some limitations that should be noted in this study. First, our sample in this study was primarily white, most had at least a high school education, and the sample was recruited from one southern state in the United States, which limited generalizability. Second, this was a secondary analysis study so variables (such as HF etiology or ejection fraction) that were not collected in the primary study were not included in our statistical analyses. Third, we only used baseline data in this study, our findings were cross-sectional and causality cannot be inferred. Future studies are recommended to examine how perceived control and symptom status may change over time, especially after implementation of interventions to increase perceived control. Our findings, along with previous research demonstrating that interventions can improve perceived control and health status,[46] suggest that enhancing perceived control may improve symptom status in patients with HF.

5.6 Conclusions

This study demonstrates that greater perceived control in patients with HF is associated with better HF symptom status. Even in the presence of depressive symptoms, a known, major predictor of worse symptom status, lower perceived control independently predicts worse symptom status. Moreover, higher perceived control predicted better self-care, suggesting a pathway whereby perceived control may improve

symptom status. Thus, interventions need to be tested that enhance patients' perceptions of control to improve self-care and symptom status in this patient population.

Copyright © Chin-Yen Lin 2020

Table 5.1 Sample characteristics (*N* = 115)

Characteristics	**Mean ± *SD* or *n* (%)**
Age, year	63 ± 12
Gender (male)	69 (60.0)
Ethnicity (Caucasian)	80 (69.6)
Education ≥ high school	102 (88.7)
Married / Cohabitating	57 (49.6)
NYHA class, III/IV	75 (65.2)
Charlson Comorbidity Index score	3.3 ± 1.8
Depressive symptom score (PHQ-9)	6.1 ± 5.0
Perceived control score (CAS-R)	29.7 ± 3.8
Self-care maintenance score (SCHFI)	61.3 ± 20.5
Self-care management score (SCHFI)	63.5 ± 19.9
Self-care confidence score (SCHFI)	60.4 ±15.6
Symptom status score (MSAS-HF)	85.3 ± 65.6

CAS-R= Control Attitudes Scale-Revised; HF= heart failure; MSAS-HF= Memorial Symptom Assessment Scale-Heart Failure; NYHA= New York Heart Association; PHQ-9= Patient Health Questionnaire-9; SCHFI= Self-Care of Heart Failure Index

Table 5.2 Multiple regression analysis of predictors of heart failure symptom status (*N* = 115)

Variable	*B*	*SE*	B	*P* value	R^2	Adjusted R^2	*F* statistic	*P* value
Step 1					0.119	0.104	$F(2,112) = 7.594$	0.001
Age	-1.434	0.413	-0.311	0.001				
Gender (female)	21.613	9.744	0.198	0.029				
Step 2					0.264	0.237	$F(4,110) = 9.857$	< 0.001
Age	-1.532	0.382	-0.332	< 0.001				
Gender (female)	12.545	9.439	0.115	0.187				
NYHA class (III/IV)	34.192	9.840	0.305	0.001				
Comorbidity	5.649	2.496	0.190	0.026				
Step 3					0.517	0.495	$F(5,109) = 23.374$	< 0.001
Age	-0.830	0.324	-0.180	0.012				
Gender (female)	11.806	7.678	0.108	0.127				
NYHA class (III/IV)	19.825	8.226	0.177	0.018				
Comorbidity	3.906	2.043	0.131	0.059				

Table 5.2 (continued)

Depression	5.813	0.768	0.544	< 0.001				
Step 4					0.547	0.522	$F(6,108) = 21.754$	< 0.001
Age	-0.781	0.316	-0.169	0.015				
Gender (female)	12.206	7.473	0.112	0.105				
NYHA class (III/IV)	18.829	8.013	0.168	0.021				
Comorbidity	3.563	1.992	0.120	0.077				
Depression	5.121	0.791	0.479	< 0.001				
Perceived control	-2.628	0.986	-0.188	0.009				

NYHA= New York Heart Association; *B*= unstandardized coefficient; B= standardized coefficient; *SE*= standard error

Table 5.3 Multiple regression analyses of prediction of self-care confidence and self-care by perceived control

(*N* = 115)

Variable	Self-care confidence				HF Self-care (maintenance and management)			
	B	***SE***	**B**	***P* value**	***B***	***SE***	**B**	***P* value**
Age	-0.088	0.126	-0.065	0.487	0.087	0.300	0.031	0.773
Gender (female)	-1.588	3.073	-0.050	0.606	2.413	7.254	0.036	0.740
NYHA class (III/IV)	-1.706	3.227	-0.052	0.598	5.766	8.212	0.079	0.484
Comorbidity	-0.235	-0.027	-0.027	0.774	0.953	1.994	0.052	0.634
Perceived control	1.144	0.383	0.280	0.003	1.820	0.890	0.217	0.044
Model summary	R^2 = 0.092, adj. R^2 = 0.051, F(5,109) = 2.222, P = 0.057				R^2 = 0.059, adj. R^2 = 0.005, F(5,87) = 1.090, P = 0.372			

HF= heart failure; NYHA= New York Heart Association; *B*= unstandardized coefficient; B= standardized coefficient; *SE*= standard error

Table 5.4 Multiple regression analyses of prediction of symptom status (total score) by self-care confidence and self-care (*N* = 115)

Variable	Symptom status				Symptom status			
	B	***SE***	**B**	***P* value**	***B***	***SE***	**B**	***P* value**
Age	-1.899	0.467	-0.336	< 0.001	-1.646	0.528	-0.291	0.002
Gender (female)	14.656	11.565	0.110	0.208	9.922	12.896	0.074	0.444
NYHA class (III/IV)	34.854	12.087	0.254	0.005	36.625	14.523	0.250	0.013
Comorbidity	6.288	3.060	0.173	0.042	9.942	3.533	0.268	0.006
Self-care confidence	-0.748	0.346	-0.178	0.033	___	___	___	___
HF Self-care (maintenance and management)	___	___	___	___	-0.393	0.186	-0.195	0.038
Model summary	R^2 = 0.270, adj. R^2 = 0.236, F(5,109) = 8.043, P = < 0.001				R^2 = 0.267, adj. R^2 = 0.225, F(5,87) = 6.327, P = < 0.001			

HF= heart failure; NYHA= New York Heart Association; *B*= unstandardized coefficient; B= standardized coefficient; *SE*= standard error

CHAPTER SIX: Discussion and Conclusions

6.1 Background and Purpose

The overall purposes of this dissertation were to identify factors associated with patients' responses to worsening heart failure (HF) symptoms and determine the impact of responses to symptoms on outcomes in patients with HF. Heart failure incidence and prevalence have increased persistently in the last decades in the United States and globally.[1,2] Although HF is a progressive and irreversible condition, effective self-care and symptom management can slow progression, improve quality of life, and reduce rehospitalizations and mortality. Growing evidence demonstrates that when patients experienced an acute exacerbation of HF symptoms, early initiation of medical therapy is associated with a decrease in mortality, length of hospital stay, and medical costs.[3-5] Although appropriate response (i.e., prompt care-seeking) to worsening HF symptoms has been suggested to substantially influence outcomes, patients with HF do not respond to their worsening HF symptoms quickly. Various reasons and factors related to delay in seeking medical care for worsening HF symptoms were explored and identified in this dissertation.

This dissertation consists of four manuscripts that integrate and unify the findings of factors associated with responses to worsening HF symptoms and subsequent outcomes. The first manuscript was a mixed-methods comparative study to compare older and younger patients' perceptions, evaluations, and responses to worsening HF symptoms, and patients' responses once worsening symptoms were perceived. The second manuscript was a cross-sectional exploratory study in which patients' reasons for delay in seeking medical care were investigated and whether depressive symptoms or

anxiety predicted patients' reasons for delay in seeking medical care were determined. The third manuscript was a longitudinal predictive study to identify factors predicting care-seeking delay and to determine the impact of care-seeking delay on subsequent cardiac events. The fourth manuscript was a cross-sectional correlational study in which the associations of perceived control to symptom status, the associations of perceived control to self-care, and the associations of self-care to symptom status were confirmed.

In this chapter six, findings from the previous studies conducted are summarized and synthesized to provide a greater understanding of factors influencing delayed responses to worsening HF symptoms and the impact of delayed responses to worsening symptoms on outcomes among patients with HF. I also discuss how the findings from this dissertation advance the current state of the science and provide implications for nursing practice and recommendations for future research.

6.2 Summary of Findings

Chapter two was the report of quantitative and qualitative semi-structured interviews in which symptom perceptions, evaluations, and responses were compared between 78 older patients and 107 younger patients. Findings from the quantitative data showed few age-related differences. Compared with younger patients, older patients had lower perceived somatic awareness and were more likely to attribute their symptoms to aging. Younger patients reported being extremely bothered by feeling their heart beating faster, and feeling chest discomfort, and they more often experienced paroxysmal nocturnal dyspnea, chest pain, and nausea/vomiting before a hospital admission compared to older patients. However, there were no significant differences between older and younger patients in their responses to worsening HF symptoms. In response to

perceived high symptom distress, regardless of age groups, patients at first did nothing and hoped their symptoms would go away, ignored symptoms and continued doing what they were doing, or laid down and tried to relax. No other strategies (i.e., self-medication, taking an extra water pill, or telling someone) and no proper strategies (i.e., calling healthcare providers, visiting healthcare providers, or making the choice to go to the hospital) were significantly associated with higher symptom distress.

Reports from the qualitative interviews revealed that many patients failed to recognize and interpret their worsening HF symptoms initially. Patients stated that they had difficulty recognizing early signs of worsening HF symptoms or their family members noticed symptoms that needed medical help earlier than the patients themselves. Patients also reported that they did not know what was causing the symptoms to get worse or they could not identify their symptoms as HF-related. Moreover, patients did not respond appropriately to worsening HF symptoms. Patients did not seek prompt care until the symptoms became acutely unbearable. They took a wait-and-see strategy or inactive strategies (e.g., laid down to relax) before coming to the hospital, contributing to delays. Accordingly, the combination of quantitative and qualitative data suggested the needs to improve symptom recognition and symptom appraisal and to promote appropriate symptom responses in patients with HF across all ages.

Chapter three was a cross-sectional exploratory study examining 611 rural patients' reasons for delay in seeking care for worsening HF symptoms. A total of 85.4% of patients reported at least one reason for delay. The most common reasons cited for delay were symptom-related and included symptoms seemed vague or came on too gradually, not sure of symptoms, symptoms didn't seem to be serious enough, and

symptoms were different from the last episode. Patients with higher levels of depressive symptoms were more likely to cite non-symptom related reasons (i.e., embarrassment about calling for help, problems with transportation, and financial concerns) for delay in seeking care compared to those without depressive symptoms. Patients with anxiety not only cited non-symptom related reasons (i.e., didn't want to second guess their doctors, embarrassed about calling for help, transportation issues, and financial concerns) but also reported symptom-related reasons (i.e., symptoms were vague, being unsure about their symptoms, symptoms didn't seem to be serious enough, symptoms were different from last time) for delay in seeking care as compared to those without anxiety. Findings from multiple regression demonstrated that both depressive symptoms and anxiety were positively associated with the number of reasons for a delay in seeking care. Patients with greater depressive symptoms and anxiety had a greater number of reasons for delay in seeking medical care.

Chapter four was a prospective, correlational, and predictive study that identified factors predicting care-seeking delay and examined the impact of care-seeking delay on subsequent cardiac rehospitalization or death among 153 patients hospitalized with an exacerbation of HF. The median delay time from patient perception of worsening HF to subsequent hospital admission was 134 hours [interquartile range, 49-364 hours]. Results of non-linear regression showed that worse New York Heart Association (NYHA) functional status (NYHA class III/IV), worse depressive symptoms, better HF knowledge, and lower perceived somatic awareness were predictors of care-seeking delay. Cox proportional hazards regression revealed that patients who delayed longer (more than 134 hours) had a 1.96-fold higher risk of experiencing cardiac events

compared to those who delayed shorter (less than 134 hours), demonstrating that care-seeking delay in patients with worsening HF symptoms was significantly associated with an increased risk of rehospitalization and mortality after hospital discharge.

Chapter five was a cross-sectional correlational study that determined (1) the relationship of perceived control to HF symptom status, and (2) the associations of perceived control to HF self-care, and of HF self-care to HF symptom status among 115 patients with HF. Findings demonstrated that perceived control was an independent predictor of symptom status after controlling for covariates (i.e., age, gender, NYHA functional class, comorbidity burden, and depressive symptoms). That is, patients with lower perceived control had worse symptom status. Perceived control was predictive of self-care and self-care was predictive of symptom status after controlling for covariates, indicating that higher levels of perceived control were associated with better self-care and better self-care was associated with better symptom status.

6.3 Impact of Dissertation on the State of the Science

The results of this dissertation provide a more complete understanding of patients' responses to worsening HF symptoms and factors that contribute to delay in seeking medical care by: (1) identifying that symptom perceptions, evaluations, and responses were inappropriate among patients with HF across all ages; (2) identifying rural patients' reasons for delay in seeking medical care and determining that delay in seeking medical care was impacted by depressive symptoms and anxiety; and (3) determining factors (i.e., functional status depressive symptoms, HF knowledge, and perceived somatic awareness) that influenced delay in seeking medical care. Furthermore, findings from this dissertation demonstrate that prompt care-seeking for worsening HF symptoms decreased

the risk of rehospitalization and mortality after hospital discharge. Moreover, greater perceived control and better HF self-care improved HF symptom distress. Accordingly, this dissertation has advanced the state of the science by providing clinicians and researchers with valuable information about the importance of prompt responses to worsening HF symptoms, symptom appraisal abilities, timely care-seeking, mental health, HF self-care, and outcomes in patients with HF.

6.4 Recommendations for Nursing Practice and Research

Symptom perception in patients with HF plays an important role in recognizing a new symptom or symptom changes.[6,7] However, the perception of early signs or symptoms of HF exacerbations was problematic in patients with HF. Many patients misattributed HF symptoms and were unable to identify symptoms as being related to HF, demonstrating the need to improve HF patients' symptom appraisal skills. Patients also responded to their worsening HF symptoms inappropriately by taking inactive approaches when they perceived high symptom distress. These findings suggest that healthcare providers must discuss with patients, and may also include informal caregivers if available, symptom management including how to recognize and identify escalating HF symptoms. They also need to teach patients the appropriate responses to different levels of HF symptom severity, and emphasize the necessity to seek emergency care when patients have severe exacerbations of HF symptoms. Further, interventions to improve symptom perceptions, symptom evaluations, and symptom responses should be developed and tested in patients with HF.

Individuals living in rural areas often face different barriers to care-seeking from those of their urban counterparts.[8,9] Therefore, interventions to promote timely care-

seeking in rural patients need to consider rural residents' unique needs (i.e., ability to perceive, seek, reach, pay, and engage) and challenges in healthcare (i.e., approachability, acceptability, availability and accommodations, affordability, and appropriateness).[10] Findings from chapter three indicate that depressive symptoms and anxiety not only were related to rural patients' specific reasons for delay but also were a precipitating factor for increasing the number of reasons for delay in seeking medical attention. As such, efforts in the prevention, screening, treatment, consultation, and intervention of mental disorders among rural patients with HF should be a priority.

Chapter four confirmed the findings of chapter two and chapter three that worse somatic awareness and higher levels of depressive symptoms were associated with increased delay time in seeking medical care. Worse functional status and greater HF knowledge were also found to be a significant predictor of delay in seeking medical care. Findings in the literature about the association of NYHA functional class with delay in seeking care were inconsistent. Some researchers found that patients with worse functional status (NYHA III/IV) had a longer delay[11,12] and others found that those with better functional status (NYHA II) were more likely to delay longer,[13,14] indicating a need to further investigate and understand patients with different levels of NYHA functional status in their decisions about care-seeking. Consistent with the existing literature,[11] a greater degree of HF knowledge was associated with delay in seeking medical care, reflecting that individuals who have greater knowledge in HF do not necessarily render timely care-seeking decisions. Self-care management in HF aims at increasing patients' abilities in recognizing escalating HF symptoms quickly, evaluating any changes in HF symptoms, and reporting them promptly as necessary.[15] Based on these, interventions

focusing on enhancing self-care management may be more effective than increasing HF knowledge in the promotion of timely care-seeking for worsening HF symptoms.

Perceived control is foundational to most counseling and self-care interventions.[16] Adequate self-care in HF has been suggested to improve symptom distress.[17] The main findings in chapter five show that perceived control was associated with HF symptom status, perceived control was associated with HF self-care, and self-care was associated with HF symptom status. The role of self-care served to connect the dots between perceived control and symptom status in this study. Although our findings are consistent with theories of perceived control in which better perceived control improved self-care and thus resulted in improvement in symptom status,[16,18] future research is suggested to examine the moderating or mediating influence of self-care on the relationship between perceived control and symptom status. After confirming these relationships, a psycho-educational intervention targeting optimal self-management of symptoms should be tested to determine if it may improve self-care and symptom status.

6.5 Limitations

Participants in each of the studies conducted in this dissertation were mostly white and as such generalizability is limited to this population although it is characteristic of the area from which subjects were drawn. Heart failure is also common in other races, particularly African Americans. Future research should include diverse samples to better understand patients' responses to worsening HF symptoms, abilities in performing self-care, and adherence to recommendations. Another limitation is that most studies of the dissertation were performed in Kentucky and thus geographical bias should be noted and findings of the studies should be interpreted with caution.

6.6 Conclusion and Future Research Plan

Appropriate responses and prompt care-seeking are essential in patients with acute exacerbations of HF symptoms. The results of this dissertation revealed that factors influencing appropriate responses and prompt care-seeking were multifactorial and individualized to each patient. Understanding patients' needs and difficulties are required to promote timely responses to worsening HF symptoms. Heart failure self-care and symptom management strategies in symptom recognition, symptom monitoring, symptom appraisals, and symptom responses are important skills required to reduce symptom distress and may prevent adverse HF events such as rehospitalization and mortality in this patient population. Subsequently, an effective intervention should be developed and tested to promote HF self-care and symptom management focused on a timely response to worsening HF symptoms to improve outcomes in patients with HF.

Copyright © Chin-Yen Lin 2020

APPENDICES

Appendix A: Self-check Plan for Heart Failure Management

Copyright permission obtained.

Appendix B: Copyright Permission

JOHN WILEY AND SONS LICENSE
TERMS AND CONDITIONS
Sep 22, 2020

This Agreement between Chin-Yen Lin ("You") and John Wiley and Sons ("John Wiley and Sons") consists of your license details and the terms and conditions provided by John Wiley and Sons and Copyright Clearance Center.

License Number	4913821225374
License date	Sep 21, 2020
Licensed Content Publisher	John Wiley and Sons
Licensed Content Publication	Journal of Advanced Nursing
Licensed Content Title	Advancing the science of symptom management
Licensed Content Author	Marylin Dodd, Susan Janson, Noreen Facione, et al
Licensed Content Date	Jul 7, 2008
Licensed Content Volume	33
Licensed Content Issue	5
Licensed Content Pages	9
Type of use	Dissertation/Thesis
Requestor type	University/Academic
Format	Print and electronic
Portion	Figure/table
Number of figures/tables	1
Will you be translating?	No
Title	Responses to Symptoms Among Patients with Heart Failure
Institution name	University of Kentucky
Expected presentation date	Nov 2020
Portions	Figure 1
Requestor Location	Ms. Chin-Yen Lin 2201 Regency Rd Suite 403 LEXINGTON, KY 40503 United States Attn: Chin-Yen Lin
Publisher Tax ID	EU826007151
Total	0.00 USD

Terms and Conditions

TERMS AND CONDITIONS

This copyrighted material is owned by or exclusively licensed to John Wiley & Sons, Inc. or one of its group companies (each a"Wiley Company") or handled on behalf of a society with which a Wiley Company has exclusive publishing rights in relation to a particular work (collectively "WILEY"). By clicking "accept" in connection with completing this licensing transaction, you agree that the following terms and conditions apply to this transaction (along with the billing and payment terms and conditions established by the Copyright Clearance Center Inc., ("CCC's Billing and Payment terms and conditions"), at the time that you opened your RightsLink account (these are available at any time at http://myaccount.copyright.com).

Terms and Conditions

- The materials you have requested permission to reproduce or reuse (the "Wiley Materials") are protected by copyright.

- You are hereby granted a personal, non-exclusive, non-sublicensable (on a stand-alone basis), non-transferable, worldwide, limited license to reproduce the Wiley Materials for the purpose specified in the licensing process. This license, **and any CONTENT (PDF or image file) purchased as part of your order,** is for a one-time use only and limited to any maximum distribution number specified in the license. The first instance of republication or reuse granted by this license must be completed within two years of the date of the grant of this license (although copies prepared before the end date may be distributed thereafter). The Wiley Materials shall not be used in any other manner or for any other purpose, beyond what is granted in the license. Permission is granted subject to an appropriate acknowledgment given to the author, title of the material/book/journal and the publisher. You shall also duplicate the copyright notice that appears in the Wiley publication in your use of the Wiley Material. Permission is also granted on the understanding that nowhere in the text is a previously published source acknowledged for all or part of this Wiley Material. Any third party content is expressly excluded from this permission.

- With respect to the Wiley Materials, all rights are reserved. Except as expressly granted by the terms of the license, no part of the Wiley Materials may be copied, modified, adapted (except for minor reformatting required by the new Publication), translated, reproduced, transferred or distributed, in any form or by any means, and no derivative works may be made based on the Wiley Materials without the prior permission of the respective copyright owner.**For STM Signatory Publishers clearing permission under the terms of the STM Permissions Guidelines only, the terms of the license are extended to include subsequent editions and for editions in other languages, provided such editions are for the work as a whole in situ and does not involve the separate exploitation of the permitted figures**

or extracts, You may not alter, remove or suppress in any manner any copyright, trademark or other notices displayed by the Wiley Materials. You may not license, rent, sell, loan, lease, pledge, offer as security, transfer or assign the Wiley Materials on a stand-alone basis, or any of the rights granted to you hereunder to any other person.

- The Wiley Materials and all of the intellectual property rights therein shall at all times remain the exclusive property of John Wiley & Sons Inc, the Wiley Companies, or their respective licensors, and your interest therein is only that of having possession of and the right to reproduce the Wiley Materials pursuant to Section 2 herein during the continuance of this Agreement. You agree that you own no right, title or interest in or to the Wiley Materials or any of the intellectual property rights therein. You shall have no rights hereunder other than the license as provided for above in Section 2. No right, license or interest to any trademark, trade name, service mark or other branding ("Marks") of WILEY or its licensors is granted hereunder, and you agree that you shall not assert any such right, license or interest with respect thereto

- NEITHER WILEY NOR ITS LICENSORS MAKES ANY WARRANTY OR REPRESENTATION OF ANY KIND TO YOU OR ANY THIRD PARTY, EXPRESS, IMPLIED OR STATUTORY, WITH RESPECT TO THE MATERIALS OR THE ACCURACY OF ANY INFORMATION CONTAINED IN THE MATERIALS, INCLUDING, WITHOUT LIMITATION, ANY IMPLIED WARRANTY OF MERCHANTABILITY, ACCURACY, SATISFACTORY QUALITY, FITNESS FOR A PARTICULAR PURPOSE, USABILITY, INTEGRATION OR NON-INFRINGEMENT AND ALL SUCH WARRANTIES ARE HEREBY EXCLUDED BY WILEY AND ITS LICENSORS AND WAIVED BY YOU.

- WILEY shall have the right to terminate this Agreement immediately upon breach of this Agreement by you.

- You shall indemnify, defend and hold harmless WILEY, its Licensors and their respective directors, officers, agents and employees, from and against any actual or threatened claims, demands, causes of action or proceedings arising from any breach of this Agreement by you.

- IN NO EVENT SHALL WILEY OR ITS LICENSORS BE LIABLE TO YOU OR ANY OTHER PARTY OR ANY OTHER PERSON OR ENTITY FOR ANY SPECIAL, CONSEQUENTIAL, INCIDENTAL, INDIRECT, EXEMPLARY OR PUNITIVE DAMAGES, HOWEVER CAUSED, ARISING OUT OF OR IN CONNECTION WITH THE DOWNLOADING, PROVISIONING, VIEWING OR USE OF THE MATERIALS REGARDLESS OF THE FORM OF ACTION, WHETHER FOR BREACH OF CONTRACT, BREACH OF WARRANTY, TORT, NEGLIGENCE, INFRINGEMENT OR OTHERWISE (INCLUDING, WITHOUT LIMITATION, DAMAGES BASED ON LOSS OF PROFITS, DATA, FILES, USE, BUSINESS OPPORTUNITY OR CLAIMS OF THIRD PARTIES),

AND WHETHER OR NOT THE PARTY HAS BEEN ADVISED OF THE POSSIBILITY OF SUCH DAMAGES. THIS LIMITATION SHALL APPLY NOTWITHSTANDING ANY FAILURE OF ESSENTIAL PURPOSE OF ANY LIMITED REMEDY PROVIDED HEREIN.

- Should any provision of this Agreement be held by a court of competent jurisdiction to be illegal, invalid, or unenforceable, that provision shall be deemed amended to achieve as nearly as possible the same economic effect as the original provision, and the legality, validity and enforceability of the remaining provisions of this Agreement shall not be affected or impaired thereby.

- The failure of either party to enforce any term or condition of this Agreement shall not constitute a waiver of either party's right to enforce each and every term and condition of this Agreement. No breach under this agreement shall be deemed waived or excused by either party unless such waiver or consent is in writing signed by the party granting such waiver or consent. The waiver by or consent of a party to a breach of any provision of this Agreement shall not operate or be construed as a waiver of or consent to any other or subsequent breach by such other party.

- This Agreement may not be assigned (including by operation of law or otherwise) by you without WILEY's prior written consent.

- Any fee required for this permission shall be non-refundable after thirty (30) days from receipt by the CCC.

- These terms and conditions together with CCC's Billing and Payment terms and conditions (which are incorporated herein) form the entire agreement between you and WILEY concerning this licensing transaction and (in the absence of fraud) supersedes all prior agreements and representations of the parties, oral or written. This Agreement may not be amended except in writing signed by both parties. This Agreement shall be binding upon and inure to the benefit of the parties' successors, legal representatives, and authorized assigns.

- In the event of any conflict between your obligations established by these terms and conditions and those established by CCC's Billing and Payment terms and conditions, these terms and conditions shall prevail.

- WILEY expressly reserves all rights not specifically granted in the combination of (i) the license details provided by you and accepted in the course of this licensing transaction, (ii) these terms and conditions and (iii) CCC's Billing and Payment terms and conditions.

- This Agreement will be void if the Type of Use, Format, Circulation, or Requestor Type was misrepresented during the licensing process.

- This Agreement shall be governed by and construed in accordance with the laws of the State of New York, USA, without regards to such state's conflict of law rules.

Any legal action, suit or proceeding arising out of or relating to these Terms and Conditions or the breach thereof shall be instituted in a court of competent jurisdiction in New York County in the State of New York in the United States of America and each party hereby consents and submits to the personal jurisdiction of such court, waives any objection to venue in such court and consents to service of process by registered or certified mail, return receipt requested, at the last known address of such party.

WILEY OPEN ACCESS TERMS AND CONDITIONS

Wiley Publishes Open Access Articles in fully Open Access Journals and in Subscription journals offering Online Open. Although most of the fully Open Access journals publish open access articles under the terms of the Creative Commons Attribution (CC BY) License only, the subscription journals and a few of the Open Access Journals offer a choice of Creative Commons Licenses. The license type is clearly identified on the article.

The Creative Commons Attribution License

The Creative Commons Attribution License (CC-BY) allows users to copy, distribute and transmit an article, adapt the article and make commercial use of the article. The CC-BY license permits commercial and non-

Creative Commons Attribution Non-Commercial License

The Creative Commons Attribution Non-Commercial (CC-BY-NC) License permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.(see below)

Creative Commons Attribution-Non-Commercial-NoDerivs License

The Creative Commons Attribution Non-Commercial-NoDerivs License (CC-BY-NC-ND) permits use, distribution and reproduction in any medium, provided the original work is properly cited, is not used for commercial purposes and no modifications or adaptations are made. (see below)

Use by commercial "for-profit" organizations

Use of Wiley Open Access articles for commercial, promotional, or marketing purposes requires further explicit permission from Wiley and will be subject to a fee.

Further details can be found on Wiley Online Library
http://olabout.wiley.com/WileyCDA/Section/id-410895.html

Other Terms and Conditions:

v1.10 Last updated September 2015

Questions? customercare@copyright.com or +1-855-239-3415 (toll free in the US) or +1-978-646-2777.

REFERENCES

Chapter One

1. Ponikowski P, Anker SD, AlHabib KF, et al. Heart failure: preventing disease and death worldwide. *ESC Heart Fail.* 2014;1(1):4-25.
2. Virani SS, Alonso A, Benjamin EJ, et al. Heart Disease and Stroke Statistics-2020 Update: A Report From the American Heart Association. *Circulation.* 2020;141(9):e139-e596.
3. Lloyd-Jones DM, Larson MG, Leip EP, et al. Lifetime risk for developing congestive heart failure: the Framingham Heart Study. *Circulation.* 2002;106(24):3068-3072.
4. Heidenreich PA, Albert NM, Allen LA, et al. Forecasting the impact of heart failure in the United States: a policy statement from the American Heart Association. *Circ Heart Fail.* 2013;6(3):606-619.
5. Lesman-Leegte I, Jaarsma T, Coyne JC, Hillege HL, Van Veldhuisen DJ, Sanderman R. Quality of life and depressive symptoms in the elderly: a comparison between patients with heart failure and age- and gender-matched community controls. *J Card Fail.* 2009;15(1):17-23.
6. Aranda JM, Jr., Johnson JW, Conti JB. Current trends in heart failure readmission rates: analysis of Medicare data. *Clin Cardiol.* 2009;32(1):47-52.
7. Suter LG, Li SX, Grady JN, et al. National patterns of risk-standardized mortality and readmission after hospitalization for acute myocardial infarction, heart failure, and pneumonia: update on publicly reported outcomes measures based on the 2013 release. *J Gen Intern Med.* 2014;29(10):1333-1340.
8. Jackson SL, Tong X, King RJ, Loustalot F, Hong Y, Ritchey MD. National Burden of Heart Failure Events in the United States, 2006 to 2014. *Circ Heart Fail.* 2018;11(12):e004873.
9. Gerber Y, Weston SA, Redfield MM, et al. A contemporary appraisal of the heart failure epidemic in Olmsted County, Minnesota, 2000 to 2010. *JAMA Intern Med.* 2015;175(6):996-1004.
10. Arnett DK, Goodman RA, Halperin JL, Anderson JL, Parekh AK, Zoghbi WA. AHA/ACC/HHS strategies to enhance application of clinical practice guidelines in patients with cardiovascular disease and comorbid conditions: from the American Heart Association, American College of Cardiology, and US Department of Health and Human Services. *Circulation.* 2014;130(18):1662-1667.
11. Saczynski JS, Go AS, Magid DJ, et al. Patterns of comorbidity in older adults with heart failure: the Cardiovascular Research Network PRESERVE study. *J Am Geriatr Soc.* 2013;61(1):26-33.
12. Chamberlain AM, St Sauver JL, Gerber Y, et al. Multimorbidity in heart failure: a community perspective. *Am J Med.* 2015;128(1):38-45.
13. Wong CY, Chaudhry SI, Desai MM, Krumholz HM. Trends in comorbidity, disability, and polypharmacy in heart failure. *Am J Med.* 2011;124(2):136-143.

14. Sharma A, Zhao X, Hammill BG, et al. Trends in Noncardiovascular Comorbidities Among Patients Hospitalized for Heart Failure: Insights From the Get With The Guidelines-Heart Failure Registry. *Circ Heart Fail.* 2018;11(6):e004646.
15. Johansson P, van der Wal M, van Veldhuisen DJ, Jaarsma T. Association between prehospital delay and subsequent clinical course in patients with/hospitalized for heart failure. *J Card Fail.* 2012;18(3):202-207.
16. Wong YW, Fonarow GC, Mi X, et al. Early intravenous heart failure therapy and outcomes among older patients hospitalized for acute decompensated heart failure: findings from the Acute Decompensated Heart Failure Registry Emergency Module (ADHERE-EM). *Am Heart J.* 2013;166(2):349-356.
17. American Heart Association. Managing Heart Failure Symptoms. https://www.heart.org/en/health-topics/heart-failure/warning-signs-of-heart-failure/managing-heart-failure-symptoms. Published May 31, 2017. Accessed August 31, 2020.
18. Sethares KA, Sosa ME, Fisher P, Riegel B. Factors associated with delay in seeking care for acute decompensated heart failure. *J Cardiovasc Nurs.* 2014;29(5):429-438.
19. Friedman MM, Quinn JR. Heart failure patients' time, symptoms, and actions before a hospital admission. *J Cardiovasc Nurs.* 2008;23(6):506-512.
20. Goldberg RJ, Goldberg JH, Pruell S, et al. Delays in seeking medical care in hospitalized patients with decompensated heart failure. *Am J Med.* 2008;121(3):212-218.
21. Jurgens CY. Somatic awareness, uncertainty, and delay in care-seeking in acute heart failure. *Res Nurs Health.* 2006;29(2):74-86.
22. Gallagher R, Sullivan A, Hales S, Gillies G, Burke R, Tofler G. Symptom patterns, duration and responses in newly diagnosed patients with heart failure. *Int J Nurs Pract.* 2012;18(2):133-139.
23. Okada A, Tsuchihashi-Makaya M, Kang J, Aoki Y, Fukawa M, Matsuoka S. Symptom Perception, Evaluation, Response to Symptom, and Delayed Care Seeking in Patients With Acute Heart Failure: An Observational Study. *J Cardiovasc Nurs.* 2019;34(1):36-43.
24. Johansson P, Nieuwenhuis M, Lesman-Leegte I, van Veldhuisen DJ, Jaarsma T. Depression and the delay between symptom onset and hospitalization in heart failure patients. *Eur J Heart Fail.* 2011;13(2):214-219.
25. Nieuwenhuis MM, Jaarsma T, van Veldhuisen DJ, van der Wal MH. Factors associated with patient delay in seeking care after worsening symptoms in heart failure patients. *J Card Fail.* 2011;17(8):657-663.
26. Friedman MM. Older adults' symptoms and their duration before hospitalization for heart failure. *Heart & Lung.* 1997;26(3):169-176.
27. Darling C, Saczynski JS, McManus DD, Lessard D, Spencer FA, Goldberg RJ. Delayed hospital presentation in acute decompensated heart failure: clinical and patient reported factors. *Heart Lung.* 2013;42(4):281-286.
28. Jurgens CY, Hoke L, Byrnes J, Riegel B. Why do elders delay responding to heart failure symptoms? *Nurs Res.* 2009;58(4):274-282.
29. Murman DL. The Impact of Age on Cognition. *Semin Hear.* 2015;36(3):111-121.

30. Riegel B, Dickson VV, Cameron J, et al. Symptom recognition in elders with heart failure. *J Nurs Scholarsh.* 2010;42(1):92-100.
31. Dodson JA, Truong TT, Towle VR, Kerins G, Chaudhry SI. Cognitive impairment in older adults with heart failure: prevalence, documentation, and impact on outcomes. *Am J Med.* 2013;126(2):120-126.
32. Lee CS, Gelow JM, Bidwell JT, et al. Blunted responses to heart failure symptoms in adults with mild cognitive dysfunction. *J Cardiovasc Nurs.* 2013;28(6):534-540.
33. Evangelista LS, Dracup K, Doering LV. Racial differences in treatment-seeking delays among heart failure patients. *J Card Fail.* 2002;8(6):381-386.
34. Graven LJ, Grant JS. Social support and self-care behaviors in individuals with heart failure: an integrative review. *Int J Nurs Stud.* 2014;51(2):320-333.
35. Sebern M, Riegel B. Contributions of supportive relationships to heart failure self-care. *European Journal of Cardiovascular Nursing.* 2009;8(2):97-104.
36. Horowitz CR, Rein SB, Leventhal H. A story of maladies, misconceptions and mishaps: effective management of heart failure. *Soc Sci Med.* 2004;58(3):631-643.
37. Patel H, Shafazand M, Schaufelberger M, Ekman I. Reasons for seeking acute care in chronic heart failure. *Eur J Heart Fail.* 2007;9(6-7):702-708.
38. Evangelista LS, Dracup K, Doering LV. Treatment-seeking delays in heart failure patients. *J Heart Lung Transplant.* 2000;19(10):932-938.
39. Levesque JF, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *Int J Equity Health.* 2013;12:18.
40. Goins RT, Williams KA, Carter MW, Spencer M, Solovieva T. Perceived barriers to health care access among rural older adults: a qualitative study. *J Rural Health.* 2005;21(3):206-213.
41. United States Department of Agriculture Economic Research Service. Rural Transportation At A Glance (Agriculture Information Bulletin No. 795). https://www.ers.usda.gov/webdocs/publications/42593/30150_aib795_lowres_002.pdf?v=3390.6. Published January 12, 2005. Accessed September 6, 2020.
42. Chan L, Hart LG, Goodman DC. Geographic access to health care for rural Medicare beneficiaries. *J Rural Health.* 2006;22(2):140-146.
43. Wu JR, Lee KS, Dekker RD, et al. Prehospital Delay, Precipitants of Admission, and Length of Stay in Patients With Exacerbation of Heart Failure. *Am J Crit Care.* 2016;26(1):62-69.
44. Cameron L, Leventhal EA, Leventhal H. Symptom representations and affect as determinants of care seeking in a community-dwelling, adult sample population. *Health psychology.* 1993;12(3):171.
45. Jurgens CY, Fain JA, Riegel B. Psychometric testing of the heart failure somatic awareness scale. *J Cardiovasc Nurs.* 2006;21(2):95-102.
46. Altice NF, Madigan EA. Factors associated with delayed care-seeking in hospitalized patients with heart failure. *Heart Lung.* 2012;41(3):244-254.
47. Xu J, Gallo JJ, Wenzel J, et al. Heart Failure Rehospitalization and Delayed Decision Making: The Impact of Self-care and Depression. *J Cardiovasc Nurs.* 2018;33(1):30-39.

48. Schiff GD, Fung S, Speroff T, McNutt RA. Decompensated heart failure: symptoms, patterns of onset, and contributing factors. *Am J Med.* 2003;114(8):625-630.
49. Lowey SE, Norton SA, Quinn JR, Quill TE. A Place to Get Worse: Perspectives on Avoiding Hospitalization from Patients with End-Stage Cardiopulmonary Disease. *J Hosp Palliat Nurs.* 2014;16(6):338-345.
50. Ivynian SE, Ferguson C, Newton PJ, DiGiacomo M. Factors influencing care-seeking delay or avoidance of heart failure management: A mixed-methods study. *Int J Nurs Stud.* 2020;108:103603.
51. Tsay SL, Chao YF. Effects of perceived self-efficacy and functional status on depression in patients with chronic heart failure. *J Nurs Res.* 2002;10(4):271-278.
52. Turvey CL, Klein DM, Pies CJ, Arndt S. Attitudes about impairment and depression in elders suffering from chronic heart failure. *Int J Psychiatry Med.* 2003;33(2):117-132.
53. Yu DS, Lee DT, Woo J, Thompson DR. Correlates of psychological distress in elderly patients with congestive heart failure. *J Psychosom Res.* 2004;57(6):573-581.
54. Johnson EM, Coles ME. Failure and delay in treatment-seeking across anxiety disorders. *Community Ment Health J.* 2013;49(6):668-674.
55. Burnett RE, Blumenthal JA, Mark DB, Leimberger JD, Califf RM. Distinguishing between early and late responders to symptoms of acute myocardial infarction. *The American journal of cardiology.* 1995;75(15):1019-1022.
56. Levy H, Janke A. Health Literacy and Access to Care. *J Health Commun.* 2016;21 Suppl 1:43-50.
57. Tsuchihashi-Makaya M, Matsuoka S. Abstract 19227: Impact of Health Literacy on the Length of Delay in Seeking Care After Worsening of Symptoms in Patients With Heart Failure. *Circulation.* 2013;128(suppl_22):A19227-A19227.
58. van der Wal MH, Jaarsma T, van Veldhuisen DJ. Non-compliance in patients with heart failure; how can we manage it? *European journal of heart failure.* 2005;7(1):5-17.
59. Riegel B, Dickson VV. A situation-specific theory of heart failure self-care. *J Cardiovasc Nurs.* 2008;23(3):190-196.
60. Lee CS, Gelow JM, Mudd JO, et al. Profiles of self-care management versus consulting behaviors in adults with heart failure. *Eur J Cardiovasc Nurs.* 2015;14(1):63-72.
61. Moser DK, Watkins JF. Conceptualizing self-care in heart failure: a life course model of patient characteristics. *J Cardiovasc Nurs.* 2008;23(3):205-218; quiz 219-220.
62. Riegel B, Dickson VV, Faulkner KM. The Situation-Specific Theory of Heart Failure Self-Care: Revised and Updated. *J Cardiovasc Nurs.* 2016;31(3):226-235.
63. Jonkman NH, Westland H, Groenwold RH, et al. Do Self-Management Interventions Work in Patients With Heart Failure? An Individual Patient Data Meta-Analysis. *Circulation.* 2016;133(12):1189-1198.
64. McAlister FA, Stewart S, Ferrua S, McMurray JJ. Multidisciplinary strategies for the management of heart failure patients at high risk for admission: a systematic review of randomized trials. *J Am Coll Cardiol.* 2004;44(4):810-819.

65. Jovicic A, Holroyd-Leduc JM, Straus SE. Effects of self-management intervention on health outcomes of patients with heart failure: a systematic review of randomized controlled trials. *BMC Cardiovasc Disord.* 2006;6:43.
66. Yu DS, Thompson DR, Lee DT. Disease management programmes for older people with heart failure: crucial characteristics which improve post-discharge outcomes. *Eur Heart J.* 2006;27(5):596-612.
67. Auld JP, Mudd JO, Gelow JM, Hiatt SO, Lee CS. Self-care Moderates the Relationship Between Symptoms and Health-Related Quality of Life in Heart Failure. *J Cardiovasc Nurs.* 2018;33(3):217-224.
68. Buck HG, Lee CS, Moser DK, et al. Relationship between self-care and health-related quality of life in older adults with moderate to advanced heart failure. *J Cardiovasc Nurs.* 2012;27(1):8-15.
69. Seto E, Leonard KJ, Cafazzo JA, Masino C, Barnsley J, Ross HJ. Self-care and quality of life of heart failure patients at a multidisciplinary heart function clinic. *J Cardiovasc Nurs.* 2011;26(5):377-385.
70. Wang SP, Lin LC, Lee CM, Wu SC. Effectiveness of a self-care program in improving symptom distress and quality of life in congestive heart failure patients: a preliminary study. *J Nurs Res.* 2011;19(4):257-266.
71. Oosterom-Calo R, van Ballegooijen AJ, Terwee CB, et al. Determinants of heart failure self-care: a systematic literature review. *Heart Fail Rev.* 2012;17(3):367-385.
72. Sayers SL, Riegel B, Pawlowski S, Coyne JC, Samaha FF. Social support and self-care of patients with heart failure. *Ann Behav Med.* 2008;35(1):70-79.
73. Gallagher R, Luttik ML, Jaarsma T. Social support and self-care in heart failure. *J Cardiovasc Nurs.* 2011;26(6):439-445.
74. Schnell-Hoehn KN, Naimark BJ, Tate RB. Determinants of self-care behaviors in community-dwelling patients with heart failure. *J Cardiovasc Nurs.* 2009;24(1):40-47.
75. Pelle AJ, Schiffer AA, Smith OR, Widdershoven JW, Denollet J. Inadequate consultation behavior modulates the relationship between type D personality and impaired health status in chronic heart failure. *Int J Cardiol.* 2010;142(1):65-71.
76. Schiffer AA, Denollet J, Widdershoven JW, Hendriks EH, Smith OR. Failure to consult for symptoms of heart failure in patients with a type-D personality. *Heart.* 2007;93(7):814-818.
77. Holzapfel N, Lowe B, Wild B, et al. Self-care and depression in patients with chronic heart failure. *Heart Lung.* 2009;38(5):392-397.
78. Biddle MJ, Moser DK, Pelter MM, Robinson S, Dracup K. Predictors of Adherence to Self-Care in Rural Patients With Heart Failure. *J Rural Health.* 2020;36(1):120-129.
79. Cameron J, Worrall-Carter L, Riegel B, Lo SK, Stewart S. Testing a model of patient characteristics, psychologic status, and cognitive function as predictors of self-care in persons with chronic heart failure. *Heart Lung.* 2009;38(5):410-418.
80. Chen AM, Yehle KS, Albert NM, et al. Relationships between health literacy and heart failure knowledge, self-efficacy, and self-care adherence. *Res Social Adm Pharm.* 2014;10(2):378-386.

81. Cene CW, Haymore LB, Dolan-Soto D, et al. Self-care confidence mediates the relationship between perceived social support and self-care maintenance in adults with heart failure. *J Card Fail.* 2013;19(3):202-210.
82. Salyer J, Schubert CM, Chiaranai C. Supportive relationships, self-care confidence, and heart failure self-care. *J Cardiovasc Nurs.* 2012;27(5):384-393.
83. Hwang B, Moser DK, Dracup K. Knowledge is insufficient for self-care among heart failure patients with psychological distress. *Health Psychol.* 2014;33(7):588-596.
84. Evangelista LS, Shinnick MA. What do we know about adherence and self-care? *J Cardiovasc Nurs.* 2008;23(3):250-257.
85. Dodd M, Janson S, Facione N, et al. Advancing the science of symptom management. *J Adv Nurs.* 2001;33(5):668-676.
86. Larson PJ, Carrieri-Kohlman V, Dodd MJ, et al. A model for symptom management. The University of California, San Francisco School of Nursing Symptom Management Faculty Group. *Image J Nurs Sch.* 1994;26(4):272-276.
87. Dracup K, Moser DK, Pelter MM, et al. Randomized, controlled trial to improve self-care in patients with heart failure living in rural areas. *Circulation.* 2014;130(3):256-264.
88. Probst JC, Laditka SB, Moore CG, Harun N, Powell MP, Baxley EG. Rural-urban differences in depression prevalence: implications for family medicine. *Fam Med.* 2006;38(9):653-660.
89. Remes O, Brayne C, van der Linde R, Lafortune L. A systematic review of reviews on the prevalence of anxiety disorders in adult populations. *Brain Behav.* 2016;6(7):e00497.
90. Lennie TA, Moser DK, Biddle MJ, et al. Nutrition intervention to decrease symptoms in patients with advanced heart failure. *Res Nurs Health.* 2013;36(2):120-145.
91. Riegel B, Moser DK, Anker SD, et al. State of the science: promoting self-care in persons with heart failure: a scientific statement from the American Heart Association. *Circulation.* 2009;120(12):1141-1163.

Chapter Two

1. Pfuntner A, Wier L, Stocks C. Most frequent conditions in US hospitals, 2011. HCUP Statistical Brief #162. Agency for Healthcare Research and Quality. https://www.hcup-us.ahrq.gov/reports/statbriefs/sb162.jsp. Published September 2013. Accessed June 10, 2020.
2. Blecker S, Paul M, Taksler G, Ogedegbe G, Katz S. Heart failure-associated hospitalizations in the United States. *J Am Coll Cardiol.* 2013;61(12):1259-1267.
3. Heidenreich PA, Albert NM, Allen LA, et al. Forecasting the impact of heart failure in the United States: a policy statement from the American Heart Association. *Circ Heart Fail.* 2013;6(3):606-619.
4. Jones NR, Roalfe AK, Adoki I, Hobbs FDR, Taylor CJ. Survival of patients with chronic heart failure in the community: a systematic review and meta-analysis. *Eur J Heart Fail.* 2019;21(11):1306-1325.

5. Heo S, Lennie TA, Okoli C, Moser DK. Quality of life in patients with heart failure: ask the patients. *Heart Lung.* 2009;38(2):100-108.
6. Blinderman CD, Homel P, Billings JA, Portenoy RK, Tennstedt SL. Symptom distress and quality of life in patients with advanced congestive heart failure. *J Pain Symptom Manage.* 2008;35(6):594-603.
7. Rodriguez-Artalejo F, Guallar-Castillon P, Pascual CR, et al. Health-related quality of life as a predictor of hospital readmission and death among patients with heart failure. *Arch Intern Med.* 2005;165(11):1274-1279.
8. Larson P, Carrieri-Kohlman V, Dodd M, et al. A model for symptom management. *Image J Nurs Sch.* 1994;26(4):272-276.
9. Riegel B, Barbaranelli C, Carlson B, et al. Psychometric Testing of the Revised Self-Care of Heart Failure Index. *J Cardiovasc Nurs.* 2019;34(2):183-192.
10. Alpert CM, Smith MA, Hummel SL, Hummel EK. Symptom burden in heart failure: assessment, impact on outcomes, and management. *Heart Fail Rev.* 2017;22(1):25-39.
11. Lee CS, Bidwell JT, Paturzo M, et al. Patterns of self-care and clinical events in a cohort of adults with heart failure: 1 year follow-up. *Heart Lung.* 2018;47(1):40-46.
12. Khalsa SS, Rudrauf D, Tranel D. Interoceptive awareness declines with age. *Psychophysiology.* 2009;46(6):1130-1136.
13. Petersen RC. Mild cognitive impairment: current research and clinical implications. *Semin Neurol.* 2007;27(1):22-31.
14. Riegel B, Dickson VV, Cameron J, et al. Symptom recognition in elders with heart failure. *J Nurs Scholarsh.* 2010;42(1):92-100.
15. Battaglia S, Sandrini MC, Catalano F, et al. Effects of aging on sensation of dyspnea and health-related quality of life in elderly asthmatics. *Aging Clin Exp Res.* 2005;17(4):287-292.
16. Dodson JA, Truong TT, Towle VR, Kerins G, Chaudhry SI. Cognitive impairment in older adults with heart failure: prevalence, documentation, and impact on outcomes. *Am J Med.* 2013;126(2):120-126.
17. Lee CS, Gelow JM, Bidwell JT, et al. Blunted responses to heart failure symptoms in adults with mild cognitive dysfunction. *J Cardiovasc Nurs.* 2013;28(6):534-540.
18. Harkness K, Heckman GA, Akhtar-Danesh N, Demers C, Gunn E, McKelvie RS. Cognitive function and self-care management in older patients with heart failure. *Eur J Cardiovasc Nurs.* 2014;13(3):277-284.
19. Jurgens CY, Hoke L, Byrnes J, Riegel B. Why do elders delay responding to heart failure symptoms? *Nurs Res.* 2009;58(4):274-282.
20. Dodd M, Janson S, Facione N, et al. Advancing the science of symptom management. *J Adv Nurs.* 2001;33(5):668-676.
21. Bennett JA, Riegel B, Bittner V, Nichols J. Validity and reliability of the NYHA classes for measuring research outcomes in patients with cardiac disease. *Heart & Lung.* 2002;31(4):262-270.
22. Jurgens CY, Fain JA, Riegel B. Psychometric testing of the heart failure somatic awareness scale. *J Cardiovasc Nurs.* 2006;21(2):95-102.

23. Moser DK, McKinley S, Dracup K, Chung ML. Gender differences in reasons patients delay in seeking treatment for acute myocardial infarction symptoms. *Patient Educ Couns.* 2005;56(1):45-54.
24. Friedman MM, Quinn JR. Heart failure patients' time, symptoms, and actions before a hospital admission. *J Cardiovasc Nurs.* 2008;23(6):506-512.
25. Burnett RE, Blumenthal JA, Mark DB, Leimberger JD, Califf RM. Distinguishing between early and late responders to symptoms of acute myocardial infarction. *Am J Cardiol.* 1995;75(15):1019-1022.
26. Dracup K, Moser DK. Beyond sociodemographics: factors influencing the decision to seek treatment for symptoms of acute myocardial infarction. *Heart Lung.* 1997;26(4):253-262.
27. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today.* 2004;24(2):105-112.
28. Riegel B, Dickson VV, Faulkner KM. The Situation-Specific Theory of Heart Failure Self-Care: Revised and Updated. *J Cardiovasc Nurs.* 2016;31(3):226-235.
29. Hajduk AM, Kiefe CI, Person SD, Gore JG, Saczynski JS. Cognitive change in heart failure: a systematic review. *Circ Cardiovasc Qual Outcomes.* 2013;6(4):451-460.
30. Patel H, Shafazand M, Schaufelberger M, Ekman I. Reasons for seeking acute care in chronic heart failure. *Eur J Heart Fail.* 2007;9(6-7):702-708.
31. Friedman MM. Older adults' symptoms and their duration before hospitalization for heart failure. *Heart & Lung.* 1997;26(3):169-176.
32. Jurgens CY. Somatic awareness, uncertainty, and delay in care-seeking in acute heart failure. *Res Nurs Health.* 2006;29(2):74-86.
33. Lewis EF, Coles TM, Lewis S, et al. Development, psychometric evaluation, and initial feasibility assessment of a symptom tracker for use by patients with heart failure (HFaST). *J Patient Rep Outcomes.* 2019;3(1):26.
34. Eastwood CA, Travis L, Morgenstern TT, Donaho EK. Weight and symptom diary for self-monitoring in heart failure clinic patients. *J Cardiovasc Nurs.* 2007;22(5):382-389.
35. Bauce K, Fahs DB, Batten J, Whittemore R. Videoconferencing for Management of Heart Failure: An Integrative Review. *J Gerontol Nurs.* 2018;44(4):45-52.
36. Hedemalm A, Schaufelberger M, Ekman I. Symptom recognition and health care seeking among immigrants and native Swedish patients with heart failure. *BMC Nurs.* 2008;7:9.
37. Zambroski CH, Moser DK, Bhat G, Ziegler C. Impact of symptom prevalence and symptom burden on quality of life in patients with heart failure. *Eur J Cardiovasc Nurs.* 2005;4(3):198-206.
38. Sethares KA, Sosa ME, Fisher P, Riegel B. Factors associated with delay in seeking care for acute decompensated heart failure. *J Cardiovasc Nurs.* 2014;29(5):429-438.
39. American Heart Association. Managing Heart Failure Symptoms. https://www.heart.org/en/health-topics/heart-failure/warning-signs-of-heart-failure/managing-heart-failure-symptoms. Published May 31, 2017. Accessed July 14, 2020.

40. Gravely-Witte S, Jurgens CY, Tamim H, Grace SL. Length of delay in seeking medical care by patients with heart failure symptoms and the role of symptom-related factors: a narrative review. *Eur J Heart Fail.* 2010;12(10):1122-1129.
41. Ambepitiya G, Roberts M, Ranjadayalan K, Tallis R. Silent exertional myocardial ischemia in the elderly: a quantitative analysis of anginal perceptual threshold and the influence of autonomic function. *J Am Geriatr Soc.* 1994;42(7):732-737.
42. Rittger H, Rieber J, Breithardt OA, et al. Influence of age on pain perception in acute myocardial ischemia: a possible cause for delayed treatment in elderly patients. *Int J Cardiol.* 2011;149(1):63-67.
43. Jurgens CY, Hoke L, Byrnes J, Riegel B. Why do elders delay responding to heart failure symptoms? *Nursing research.* 2009;58(4):274-282.
44. Schiff GD, Fung S, Speroff T, McNutt RA. Decompensated heart failure: symptoms, patterns of onset, and contributing factors. *Am J Med.* 2003;114(8):625-630.

Chapter Three

1. Verdejo HE, Ferreccio C, Castro PF. Heart failure in rural communities. *Heart Fail Clin.* 2015;11(4):515-522.
2. Chan L, Hart LG, Goodman DC. Geographic access to health care for rural Medicare beneficiaries. *J Rural Health.* 2006;22(2):140-146.
3. Gamble JM, Eurich DT, Ezekowitz JA, Kaul P, Quan H, McAlister FA. Patterns of care and outcomes differ for urban versus rural patients with newly diagnosed heart failure, even in a universal healthcare system. *Circ Heart Fail.* 2011;4(3):317-323.
4. Teng TH, Katzenellenbogen JM, Hung J, et al. Rural-urban differentials in 30-day and 1-year mortality following first-ever heart failure hospitalisation in Western Australia: a population-based study using data linkage. *BMJ Open.* 2014;4(5):e004724.
5. Gravely-Witte S, Jurgens CY, Tamim H, Grace SL. Length of delay in seeking medical care by patients with heart failure symptoms and the role of symptom-related factors: a narrative review. *Eur J Heart Fail.* 2010;12(10):1122-1129.
6. American Heart Association. Managing Heart Failure Symptoms. https://www.heart.org/en/health-topics/heart-failure/warning-signs-of-heart-failure/managing-heart-failure-symptoms. Published May 31, 2017. Accessed May 5, 2020.
7. Jurgens CY, Hoke L, Byrnes J, Riegel B. Why do elders delay responding to heart failure symptoms? *Nurs Res.* 2009;58(4):274-282.
8. Friedman MM, Quinn JR. Heart failure patients' time, symptoms, and actions before a hospital admission. *J Cardiovasc Nurs.* 2008;23(6):506-512.
9. Schiff GD, Fung S, Speroff T, McNutt RA. Decompensated heart failure: symptoms, patterns of onset, and contributing factors. *Am J Med.* 2003;114(8):625-630.
10. Jurgens CY. Somatic awareness, uncertainty, and delay in care-seeking in acute heart failure. *Res Nurs Health.* 2006;29(2):74-86.

11. Goldberg RJ, Goldberg JH, Pruell S, et al. Delays in seeking medical care in hospitalized patients with decompensated heart failure. *Am J Med.* 2008;121(3):212-218.
12. Johansson P, Nieuwenhuis M, Lesman-Leegte I, van Veldhuisen DJ, Jaarsma T. Depression and the delay between symptom onset and hospitalization in heart failure patients. *Eur J Heart Fail.* 2011;13(2):214-219.
13. Nieuwenhuis MM, Jaarsma T, van Veldhuisen DJ, van der Wal MH. Factors associated with patient delay in seeking care after worsening symptoms in heart failure patients. *J Card Fail.* 2011;17(8):657-663.
14. Sethares KA, Sosa ME, Fisher P, Riegel B. Factors associated with delay in seeking care for acute decompensated heart failure. *J Cardiovasc Nurs.* 2014;29(5):429-438.
15. Probst JC, Laditka SB, Moore CG, Harun N, Powell MP, Baxley EG. Rural-urban differences in depression prevalence: implications for family medicine. *Fam Med.* 2006;38(9):653-660.
16. Dwyer-Lindgren L, Mackenbach JP, van Lenthe FJ, Mokdad AH. Self-reported general health, physical distress, mental distress, and activity limitation by US county, 1995-2012. *Popul Health Metr.* 2017;15:16.
17. Rutledge T, Reis VA, Linke SE, Greenberg BH, Mills PJ. Depression in heart failure a meta-analytic review of prevalence, intervention effects, and associations with clinical outcomes. *J Am Coll Cardiol.* 2006;48(8):1527-1537.
18. Evans DL, Charney DS, Lewis L, et al. Mood disorders in the medically ill: scientific review and recommendations. *Biol Psychiatry.* 2005;58(3):175-189.
19. Lesman-Leegte I, van Veldhuisen DJ, Hillege HL, Moser D, Sanderman R, Jaarsma T. Depressive symptoms and outcomes in patients with heart failure: data from the COACH study. *Eur J Heart Fail.* 2009;11(12):1202-1207.
20. Johnson TJ, Basu S, Pisani BA, et al. Depression predicts repeated heart failure hospitalizations. *J Card Fail.* 2012;18(3):246-252.
21. Volz A, Schmid JP, Zwahlen M, Kohls S, Saner H, Barth J. Predictors of readmission and health related quality of life in patients with chronic heart failure: a comparison of different psychosocial aspects. *J Behav Med.* 2011;34(1):13-22.
22. Johansson P, van der Wal M, van Veldhuisen DJ, Jaarsma T. Association between prehospital delay and subsequent clinical course in patients with/hospitalized for heart failure. *J card fail.* 2012;18(3):202-207.
23. Lee CS, Moser DK, Lennie TA, Riegel B. Event-free survival in adults with heart failure who engage in self-care management. *Heart Lung.* 2011;40(1):12-20.
24. Blinderman CD, Homel P, Billings JA, Portenoy RK, Tennstedt SL. Symptom distress and quality of life in patients with advanced congestive heart failure. *J Pain Symptom Manage.* 2008;35(6):594-603.
25. Benjamin EJ, Muntner P, Bittencourt MS. Heart disease and stroke statistics-2019 update: a report from the American Heart Association. *Circulation.* 2019;139(10):e56-e528.
26. Xu J, Gallo JJ, Wenzel J, et al. Heart failure rehospitalization and delayed decision making: the impact of self-care and depression. *J Cardiovasc Nurs.* 2018;33(1):30-39.

27. Wu JR, Lee KS, Dekker RD, et al. Prehospital Delay, Precipitants of Admission, and Length of Stay in Patients With Exacerbation of Heart Failure. *Am J Crit Care.* 2016;26(1):62-69.
28. Dracup K, Moser DK, Pelter MM, et al. Randomized, controlled trial to improve self-care in patients with heart failure living in rural areas. *Circulation.* 2014;130(3):256-264.
29. Steenland NK, Auman CM, Patel PM, et al. Development of a rapid screening instrument for mild cognitive impairment and undiagnosed dementia. *J Alzheimers Dis.* 2008;15(3):419-427.
30. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med.* 2001;16(9):606-613.
31. Kroenke K, Spitzer RL. The PHQ-9: a new depression diagnostic and severity measure. *Psychiatric annals.* 2002;32(9):509-515.
32. Hammash MH, Hall LA, Lennie TA, et al. Psychometrics of the PHQ-9 as a measure of depressive symptoms in patients with heart failure. *European Journal of Cardiovascular Nursing.* 2013;12(5):446-453.
33. Derogatis LR. *Brief Symptom Inventory: Administration, scoring, and procedures manual.* National Computer Systems (NCS); 1993.
34. Derogatis LR, Melisaratos N. The brief symptom inventory: an introductory report. *Psychological medicine.* 1983;13(03):595-605.
35. Khalil AA, Hall LA, Moser DK, Lennie TA, Frazier SK. The psychometric properties of the Brief Symptom Inventory depression and anxiety subscales in patients with heart failure and with or without renal dysfunction. *Arch Psychiatr Nurs.* 2011;25(6):419-429.
36. *Criteria Committee of the New York Heart Association. Nomenclature and criteria for diagnosis of diseases of the heart and great vessels.* 7th ed. Boston: Little & Brown; 1973.
37. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis.* 1987;40(5):373-383.
38. Caldwell MA, Peters KJ, Dracup KA. A simplified education program improves knowledge, self-care behavior, and disease severity in heart failure patients in rural settings. *Am Heart J.* 2005;150(5):983.
39. Baker DW, Williams MV, Parker RM, Gazmararian JA, Nurss J. Development of a brief test to measure functional health literacy. *Patient Educ Couns.* 1999;38(1):33-42.
40. Leventhal H, Brissette I, Leventhal EA. *The Common-Sense Model of Self-Regulation of Health and Illness: The Self-Regulation of Health and Illness Behaviour.* London: Routledge Taylor & Francis Group; 2003.
41. Doblyte S, Jimenez-Mejias E. Understanding help-seeking behavior in depression: a qualitative synthesis of patients' experiences. *Qual Health Res.* 2017;27(1):100-113.
42. Patel H, Shafazand M, Schaufelberger M, Ekman I. Reasons for seeking acute care in chronic heart failure. *Eur J Heart Fail.* 2007;9(6-7):702-708.

43. Zhang P, Tao G, Anderson LA. Differences in access to health care services among adults in rural America by rural classification categories and age. *Australian Journal of Rural Health.* 2003;11(2):64-72.
44. Pathman DE, Ricketts TC, 3rd, Konrad TR. How adults' access to outpatient physician services relates to the local supply of primary care physicians in the rural southeast. *Health Serv Res.* 2006;41(1):79-102.
45. White MM, Howie-Esquivel J, Caldwell MA. Improving heart failure symptom recognition: a diary analysis. *J Cardiovasc Nurs.* 2010;25(1):7-12.
46. Lee KS, Lennie TA, Dunbar SB, et al. The association between regular symptom monitoring and self-care management in patients with heart failure. *J Cardiovasc Nurs.* 2015;30(2):145-151.
47. Mudd-Martin G, Biddle MJ, Chung ML, et al. Rural Appalachian perspectives on heart health: social ecological contexts. *Am J Health Behav.* 2014;38(1):134-143.
48. Zahnd WE, Scaife SL, Francis ML. Health literacy skills in rural and urban populations. *Am J Health Behav.* 2009;33(5):550-557.
49. Darling C, Saczynski JS, McManus DD, Lessard D, Spencer FA, Goldberg RJ. Delayed hospital presentation in acute decompensated heart failure: clinical and patient reported factors. *Heart Lung.* 2013;42(4):281-286.
50. Goins RT, Williams KA, Carter MW, Spencer M, Solovieva T. Perceived barriers to health care access among rural older adults: a qualitative study. *J Rural Health.* 2005;21(3):206-213.
51. Weinhold I, Gurtner S. Understanding shortages of sufficient health care in rural areas. *Health Policy.* 2014;118(2):201-214.
52. Housing Assistance Council. Race and Ethnicity in Rural America. http://www.ruralhome.org/storage/research_notes/rrn-race-and-ethnicity-web.pdf. Published April 2012. Accessed July 18, 2020.

Chapter Four

1. Virani SS, Alonso A, Benjamin EJ, et al. Heart Disease and Stroke Statistics-2020 Update: A Report From the American Heart Association. *Circulation.* 2020;141(9):e139-e596.
2. Glynn P, Lloyd-Jones DM, Feinstein MJ, Carnethon M, Khan SS. Disparities in Cardiovascular Mortality Related to Heart Failure in the United States. *J Am Coll Cardiol.* 2019;73(18):2354-2355.
3. Bytyci I, Bajraktari G. Mortality in heart failure patients. *Anatol J Cardiol.* 2015;15(1):63-68.
4. Sidney S, Go AS, Jaffe MG, Solomon MD, Ambrosy AP, Rana JS. Association Between Aging of the US Population and Heart Disease Mortality From 2011 to 2017. *JAMA cardiology.* 2019.
5. Loehr LR, Rosamond WD, Chang PP, Folsom AR, Chambless LE. Heart failure incidence and survival (from the Atherosclerosis Risk in Communities study). *Am J Cardiol.* 2008;101(7):1016-1022.
6. O'Connor CM, Miller AB, Blair JE, et al. Causes of death and rehospitalization in patients hospitalized with worsening heart failure and reduced left ventricular ejection fraction: results from Efficacy of Vasopressin Antagonism in Heart Failure

Outcome Study with Tolvaptan (EVEREST) program. *Am Heart J.* 2010;159(5):841-849 e841.
7. Gheorghiade M, Vaduganathan M, Fonarow GC, Bonow RO. Rehospitalization for heart failure: problems and perspectives. *J Am Coll Cardiol.* 2013;61(4):391-403.
8. Reynolds K, Butler MG, Kimes TM, Rosales AG, Chan W, Nichols GA. Relation of Acute Heart Failure Hospital Length of Stay to Subsequent Readmission and All-Cause Mortality. *Am J Cardiol.* 2015;116(3):400-405.
9. Goldberg RJ, Goldberg JH, Pruell S, et al. Delays in seeking medical care in hospitalized patients with decompensated heart failure. *Am J Med.* 2008;121(3):212-218.
10. Johansson P, van der Wal M, van Veldhuisen DJ, Jaarsma T. Association between prehospital delay and subsequent clinical course in patients with/hospitalized for heart failure. *Journal of cardiac failure.* 2012;18(3):202-207.
11. Nieuwenhuis MM, Jaarsma T, van Veldhuisen DJ, van der Wal MH. Factors associated with patient delay in seeking care after worsening symptoms in heart failure patients. *J Card Fail.* 2011;17(8):657-663.
12. Evangelista LS, Dracup K, Doering LV. Treatment-seeking delays in heart failure patients. *J Heart Lung Transplant.* 2000;19(10):932-938.
13. Johansson P, Nieuwenhuis M, Lesman-Leegte I, van Veldhuisen DJ, Jaarsma T. Depression and the delay between symptom onset and hospitalization in heart failure patients. *European journal of heart failure.* 2011;13(2):214-219.
14. Xu J, Gallo JJ, Wenzel J, et al. Heart Failure Rehospitalization and Delayed Decision Making: The Impact of Self-care and Depression. *J Cardiovasc Nurs.* 2018;33(1):30-39.
15. Maisel AS, Peacock WF, McMullin N, et al. Timing of immunoreactive B-type natriuretic peptide levels and treatment delay in acute decompensated heart failure: an ADHERE (Acute Decompensated Heart Failure National Registry) analysis. *J Am Coll Cardiol.* 2008;52(7):534-540.
16. Peacock WFt, Fonarow GC, Emerman CL, et al. Impact of early initiation of intravenous therapy for acute decompensated heart failure on outcomes in ADHERE. *Cardiology.* 2007;107(1):44-51.
17. Wong YW, Fonarow GC, Mi X, et al. Early intravenous heart failure therapy and outcomes among older patients hospitalized for acute decompensated heart failure: findings from the Acute Decompensated Heart Failure Registry Emergency Module (ADHERE-EM). *Am Heart J.* 2013;166(2):349-356.
18. Sethares KA, Sosa ME, Fisher P, Riegel B. Factors associated with delay in seeking care for acute decompensated heart failure. *J Cardiovasc Nurs.* 2014;29(5):429-438.
19. Bennett JA, Riegel B, Bittner V, Nichols J. Validity and reliability of the NYHA classes for measuring research outcomes in patients with cardiac disease. *Heart Lung.* 2002;31(4):262-270.
20. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis.* 1987;40(5):373-383.
21. Charlson M, Szatrowski TP, Peterson J, Gold J. Validation of a combined comorbidity index. *J Clin Epidemiol.* 1994;47(11):1245-1251.

22. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med.* 2001;16(9):606-613.
23. Derogatis LR, Melisaratos N. The Brief Symptom Inventory: an introductory report. *Psychol Med.* 1983;13(3):595-605.
24. Khalil AA, Hall LA, Moser DK, Lennie TA, Frazier SK. The psychometric properties of the Brief Symptom Inventory depression and anxiety subscales in patients with heart failure and with or without renal dysfunction. *Arch Psychiatr Nurs.* 2011;25(6):419-429.
25. Zimet GD, Powell SS, Farley GK, Werkman S, Berkoff KA. Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. *J Pers Assess.* 1990;55(3-4):610-617.
26. Shumaker SC, Frazier SK, Moser DK, Chung ML. Psychometric Properties of the Multidimensional Scale of Perceived Social Support in Patients With Heart Failure. *J Nurs Meas.* 2017;25(1):90-102.
27. van der Wal MH, Jaarsma T, Moser DK, van Veldhuisen DJ. Development and testing of the Dutch Heart Failure Knowledge Scale. *Eur J Cardiovasc Nurs.* 2005;4(4):273-277.
28. Jurgens CY, Fain JA, Riegel B. Psychometric testing of the heart failure somatic awareness scale. *J Cardiovasc Nurs.* 2006;21(2):95-102.
29. Vellone E, Riegel B, Cocchieri A, et al. Psychometric testing of the Self-Care of Heart Failure Index Version 6.2. *Res Nurs Health.* 2013;36(5):500-511.
30. Riegel B, Lee CS, Dickson VV, Carlson B. An update on the self-care of heart failure index. *J Cardiovasc Nurs.* 2009;24(6):485-497.
31. Sherbourne CD, Hays RD, Ordway L, DiMatteo MR, Kravitz RL. Antecedents of adherence to medical recommendations: results from the Medical Outcomes Study. *J Behav Med.* 1992;15(5):447-468.
32. Hays RD, Kravitz RL, Mazel RM, et al. The impact of patient adherence on health outcomes for patients with chronic disease in the Medical Outcomes Study. *J Behav Med.* 1994;17(4):347-360.
33. Jurgens CY, Lee CS, Riegel B. Psychometric Analysis of the Heart Failure Somatic Perception Scale as a Measure of Patient Symptom Perception. *J Cardiovasc Nurs.* 2017;32(2):140-147.
34. Tsuyuki RT, McKelvie RS, Arnold JM, et al. Acute precipitants of congestive heart failure exacerbations. *Arch Intern Med.* 2001;161(19):2337-2342.
35. Patel H, Shafazand M, Schaufelberger M, Ekman I. Reasons for seeking acute care in chronic heart failure. *Eur J Heart Fail.* 2007;9(6-7):702-708.
36. Schiff GD, Fung S, Speroff T, McNutt RA. Decompensated heart failure: symptoms, patterns of onset, and contributing factors. *Am J Med.* 2003;114(8):625-630.
37. Lowey SE, Norton SA, Quinn JR, Quill TE. A Place to Get Worse: Perspectives on Avoiding Hospitalization from Patients with End-Stage Cardiopulmonary Disease. *J Hosp Palliat Nurs.* 2014;16(6):338-345.
38. Wu JR, Lee KS, Dekker RD, et al. Prehospital Delay, Precipitants of Admission, and Length of Stay in Patients With Exacerbation of Heart Failure. *Am J Crit Care.* 2016;26(1):62-69.

39. Albert NM, Zeller R. Depressed patients understand heart failure prognosis but not how to control it. *Heart Lung.* 2009;38(5):382-391.
40. Allman E, Berry D, Nasir L. Depression and coping in heart failure patients: a review of the literature. *J Cardiovasc Nurs.* 2009;24(2):106-117.
41. Kato N, Kinugawa K, Seki S, et al. Quality of life as an independent predictor for cardiac events and death in patients with heart failure. *Circulation journal.* 2011:1104261209-1104261209.
42. Ghosh RK, Ball S, Prasad V, Gupta A. Depression in heart failure: Intricate relationship, pathophysiology and most updated evidence of interventions from recent clinical studies. *Int J Cardiol.* 2016;224:170-177.
43. Jurgens CY, Hoke L, Byrnes J, Riegel B. Why do elders delay responding to heart failure symptoms? *Nursing research.* 2009;58(4):274-282.
44. Dodd M, Janson S, Facione N, et al. Advancing the science of symptom management. *Journal of advanced nursing.* 2001;33(5):668-676.
45. Riegel B, Dickson VV, Cameron J, et al. Symptom recognition in elders with heart failure. *J Nurs Scholarsh.* 2010;42(1):92-100.
46. Jurgens CY. Somatic awareness, uncertainty, and delay in care-seeking in acute heart failure. *Res Nurs Health.* 2006;29(2):74-86.
47. Gallagher R, Sullivan A, Hales S, Gillies G, Burke R, Tofler G. Symptom patterns, duration and responses in newly diagnosed patients with heart failure. *Int J Nurs Pract.* 2012;18(2):133-139.
48. Darling C, Saczynski JS, McManus DD, Lessard D, Spencer FA, Goldberg RJ. Delayed hospital presentation in acute decompensated heart failure: clinical and patient reported factors. *Heart Lung.* 2013;42(4):281-286.
49. Altice NF, Madigan EA. Factors associated with delayed care-seeking in hospitalized patients with heart failure. *Heart Lung.* 2012;41(3):244-254.

Chapter Five

1. Jurgens CY, Hoke L, Byrnes J, Riegel B. Why do elders delay responding to heart failure symptoms? *Nursing research.* 2009;58(4):274-282.
2. Gallagher R, Sullivan A, Hales S, Gillies G, Burke R, Tofler G. Symptom patterns, duration and responses in newly diagnosed patients with heart failure. *Int J Nurs Pract.* 2012;18(2):133-139.
3. Albert N, Trochelman K, Li J, Lin S. Signs and symptoms of heart failure: are you asking the right questions? *Am J Crit Care.* 2010;19(5):443-452.
4. Friedman MM. Older adults' symptoms and their duration before hospitalization for heart failure. *Heart & Lung: The Journal of Acute and Critical Care.* 1997;26(3):169-176.
5. Zambroski CH, Moser DK, Bhat G, Ziegler C. Impact of symptom prevalence and symptom burden on quality of life in patients with heart failure. *European Journal of Cardiovascular Nursing.* 2005;4(3):198-206.
6. Song EK, Moser DK, Rayens MK, Lennie TA. Symptom clusters predict event-free survival in patients with heart failure. *J Cardiovasc Nurs.* 2010;25(4):284-291.

7. Ekman I, Cleland JG, Swedberg K, Charlesworth A, Metra M, Poole-Wilson PA. Symptoms in patients with heart failure are prognostic predictors: insights from COMET. *J Card Fail.* 2005;11(4):288-292.
8. Blinderman CD, Homel P, Billings JA, Portenoy RK, Tennstedt SL. Symptom distress and quality of life in patients with advanced congestive heart failure. *J Pain Symptom Manage.* 2008;35(6):594-603.
9. Bekelman DB, Havranek EP, Becker DM, et al. Symptoms, depression, and quality of life in patients with heart failure. *J Card Fail.* 2007;13(8):643-648.
10. Moser DK, Watkins JF. Conceptualizing self-care in heart failure: a life course model of patient characteristics. *J Cardiovasc Nurs.* 2008;23(3):205-218; quiz 219-220.
11. Hwang B, Moser DK, Dracup K. Knowledge is insufficient for self-care among heart failure patients with psychological distress. *Health Psychol.* 2014;33(7):588-596.
12. Heo S, Moser DK, Lennie TA, Riegel B, Chung ML. Gender differences in and factors related to self-care behaviors: a cross-sectional, correlational study of patients with heart failure. *Int J Nurs Stud.* 2008;45(12):1807-1815.
13. Moser DK, Dracup K. Psychosocial recovery from a cardiac event: the influence of perceived control. *Heart Lung.* 1995;24(4):273-280.
14. McKinley S, Fien M, Riegel B, et al. Complications after acute coronary syndrome are reduced by perceived control of cardiac illness. *J Adv Nurs.* 2012;68(10):2320-2330.
15. Dracup K, Westlake C, Erickson VS, Moser DK, Caldwell ML, Hamilton MA. Perceived control reduces emotional stress in patients with heart failure. *J Heart Lung Transplant.* 2003;22(1):90-93.
16. Calfee CS, Katz PP, Yelin EH, Iribarren C, Eisner MD. The influence of perceived control of asthma on health outcomes. *CHEST Journal.* 2006;130(5):1312-1318.
17. Heo S, Lennie TA, Pressler SJ, Dunbar SB, Chung ML, Moser DK. Factors associated with perceived control and the relationship to quality of life in patients with heart failure. *Eur J Cardiovasc Nurs.* 2015;14(2):137-144.
18. Banerjee T, Lee KS, Browning SR, et al. Limited association between perceived control and health-related quality of life in patients with heart failure. *The Journal of cardiovascular nursing.* 2014;29(3):227.
19. Jurgens CY, Moser DK, Armola R, et al. Symptom clusters of heart failure. *Res Nurs Health.* 2009;32(5):551-560.
20. Lee KS, Song EK, Lennie TA, et al. Symptom clusters in men and women with heart failure and their impact on cardiac event-free survival. *J Cardiovasc Nurs.* 2010;25(4):263-272.
21. Park J, Moser DK, Griffith K, Harring JR, Johantgen M. Exploring Symptom Clusters in People With Heart Failure. *Clin Nurs Res.* 2019;28(2):165-181.
22. Wallston KA, Wallston BS, Smith S, Dobbins CJ. Perceived control and health. *Current Psychology.* 1987;6(1):5-25.
23. Lennie TA, Moser DK, Biddle MJ, et al. Nutrition intervention to decrease symptoms in patients with advanced heart failure. *Res Nurs Health.* 2013;36(2):120-145.

24. Nasreddine ZS, Phillips NA, Bedirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc.* 2005;53(4):695-699.
25. Portenoy RK, Thaler HT, Kornblith AB, et al. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. *Eur J Cancer.* 1994;30A(9):1326-1336.
26. Zambroski C, Lennie T, Chung M, Heo S, Smoot T, Ziegler C. Use of the memorial symptom assessment scale-heart failure in heart failure patients. Paper presented at: Circulation2004.
27. Moser DK, Riegel B, McKinley S, et al. The Control Attitudes Scale-Revised: psychometric evaluation in three groups of patients with cardiac illness. *Nurs Res.* 2009;58(1):42-51.
28. Riegel B, Carlson B, Moser DK, Sebern M, Hicks FD, Roland V. Psychometric testing of the self-care of heart failure index. *J Card Fail.* 2004;10(4):350-360.
29. Riegel B, Dickson VV. A situation-specific theory of heart failure self-care. *J Cardiovasc Nurs.* 2008;23(3):190-196.
30. Riegel B, Lee CS, Dickson VV, Carlson B. An update on the self-care of heart failure index. *J Cardiovasc Nurs.* 2009;24(6):485-497.
31. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med.* 2001;16(9):606-613.
32. Hammash MH, Hall LA, Lennie TA, et al. Psychometrics of the PHQ-9 as a measure of depressive symptoms in patients with heart failure. *Eur J Cardiovasc Nurs.* 2013;12(5):446-453.
33. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis.* 1987;40(5):373-383.
34. Dickson VV, Buck H, Riegel B. Multiple comorbid conditions challenge heart failure self-care by decreasing self-efficacy. *Nursing Research.* 2013;62(1):2-9.
35. Charlson M, Szatrowski TP, Peterson J, Gold J. Validation of a combined comorbidity index. *J Clin Epidemiol.* 1994;47(11):1245-1251.
36. Hall SF, Groome PA, Streiner DL, Rochon PA. Interrater reliability of measurements of comorbid illness should be reported. *J Clin Epidemiol.* 2006;59(9):926-933.
37. Heart Failure Society of A, Lindenfeld J, Albert NM, et al. HFSA 2010 Comprehensive Heart Failure Practice Guideline. *J Card Fail.* 2010;16(6):e1-194.
38. Bennett JA, Riegel B, Bittner V, Nichols J. Validity and reliability of the NYHA classes for measuring research outcomes in patients with cardiac disease. *Heart Lung.* 2002;31(4):262-270.
39. Westlake C, Evangelista LS, Stromberg A, Ter-Galstanyan A, Vazirani S, Dracup K. Evaluation of a Web-based education and counseling pilot program for older heart failure patients. *Prog Cardiovasc Nurs.* 2007;22(1):20-26.
40. Evangelista LS, Liao S, Motie M, De Michelis N, Lombardo D. On-going palliative care enhances perceived control and patient activation and reduces symptom distress in patients with symptomatic heart failure: a pilot study. *Eur J Cardiovasc Nurs.* 2014;13(2):116-123.

41. Agren S, Berg S, Svedjeholm R, Stromberg A. Psychoeducational support to post cardiac surgery heart failure patients and their partners--a randomised pilot study. *Intensive Crit Care Nurs.* 2015;31(1):10-18.
42. Tsuchihashi-Makaya M, Matsuoka S, Ishida H, Saka M, Nakatsugawa E. Perceived Control Mediates Association Between Health Literacy and Self-Care Behavior in Heart Failure Patients. *Circulation.* 2017;136(suppl_1):A16236-A16236.
43. Jonkman NH, Westland H, Groenwold RH, et al. Do self-management interventions work in patients with heart failure? An individual patient data meta-analysis. *Circulation.* 2016;133(12):1189-1198.
44. Buck HG, Stromberg A, Chung ML, et al. A systematic review of heart failure dyadic self-care interventions focusing on intervention components, contexts, and outcomes. *Int J Nurs Stud.* 2018;77:232-242.
45. Gusick GM. The contribution of depression and spirituality to symptom burden in chronic heart failure. *Arch Psychiatr Nurs.* 2008;22(1):53-55.
46. Olajos-Clow J, Costello E, Lougheed MD. Perceived control and quality of life in asthma: impact of asthma education. *J Asthma.* 2005;42(9):751-756.

Chapter Six

1. Virani SS, Alonso A, Benjamin EJ, et al. Heart Disease and Stroke Statistics-2020 Update: A Report From the American Heart Association. *Circulation.* 2020;141(9):e139-e596.
2. Ponikowski P, Anker SD, AlHabib KF, et al. Heart failure: preventing disease and death worldwide. *ESC Heart Fail.* 2014;1(1):4-25.
3. Peacock WF, Emerman C, Costanzo MR, Diercks DB, Lopatin M, Fonarow GC. Early vasoactive drugs improve heart failure outcomes. *Congest Heart Fail.* 2009;15(6):256-264.
4. Maisel AS, Peacock WF, McMullin N, et al. Timing of immunoreactive B-type natriuretic peptide levels and treatment delay in acute decompensated heart failure: an ADHERE (Acute Decompensated Heart Failure National Registry) analysis. *J Am Coll Cardiol.* 2008;52(7):534-540.
5. Mueller C, Laule-Kilian K, Schindler C, et al. Cost-effectiveness of B-type natriuretic peptide testing in patients with acute dyspnea. *Arch Intern Med.* 2006;166(10):1081-1087.
6. Dodd M, Janson S, Facione N, et al. Advancing the science of symptom management. *J Adv Nurs.* 2001;33(5):668-676.
7. Riegel B, Dickson VV, Faulkner KM. The Situation-Specific Theory of Heart Failure Self-Care: Revised and Updated. *J Cardiovasc Nurs.* 2016;31(3):226-235.
8. Verdejo HE, Ferreccio C, Castro PF. Heart Failure in Rural Communities. *Heart Fail Clin.* 2015;11(4):515-522.
9. Chan L, Hart LG, Goodman DC. Geographic access to health care for rural Medicare beneficiaries. *J Rural Health.* 2006;22(2):140-146.
10. Levesque JF, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *Int J Equity Health.* 2013;12:18.

11. Nieuwenhuis MM, Jaarsma T, van Veldhuisen DJ, van der Wal MH. Factors associated with patient delay in seeking care after worsening symptoms in heart failure patients. *J Card Fail.* 2011;17(8):657-663.
12. Evangelista LS, Dracup K, Doering LV. Treatment-seeking delays in heart failure patients. *J Heart Lung Transplant.* 2000;19(10):932-938.
13. Johansson P, van der Wal M, van Veldhuisen DJ, Jaarsma T. Association between prehospital delay and subsequent clinical course in patients with/hospitalized for heart failure. *J Card Fail.* 2012;18(3):202-207.
14. Johansson P, Nieuwenhuis M, Lesman-Leegte I, van Veldhuisen DJ, Jaarsma T. Depression and the delay between symptom onset and hospitalization in heart failure patients. *Eur J Heart Fail.* 2011;13(2):214-219.
15. Riegel B, Dickson VV. A situation-specific theory of heart failure self-care. *J Cardiovasc Nurs.* 2008;23(3):190-196.
16. Moser DK, Watkins JF. Conceptualizing self-care in heart failure: a life course model of patient characteristics. *J Cardiovasc Nurs.* 2008;23(3):205-218; quiz 219-220.
17. Auld JP, Mudd JO, Gelow JM, Hiatt SO, Lee CS. Self-care Moderates the Relationship Between Symptoms and Health-Related Quality of Life in Heart Failure. *J Cardiovasc Nurs.* 2018;33(3):217-224.
18. Wallston KA, Wallston BS, Smith S, Dobbins CJ. Perceived control and health. *Current Psychology.* 1987;6(1):5-25.

Curriculum Vitae

Chin-Yen Lin

Education

Institution	Degree	Date Conferred	Field of Study
Chang Gung University of Science and Technology, Taoyuan City, Taiwan	ASN	2001, June	Nursing
Fu Jen Catholic University, New Taipei City, Taiwan	BSN	2004, January	Nursing
University of Kentucky, Lexington, KY	PhD	Estimated 2020	Nursing

Licensure

2014 - present	Commonwealth of Kentucky RN license # 1141984
2007 - 2010	New York State RN license # 596324
2001 - 2007	Taiwan RN license # 087562

Professional Experience

Dates	Institution and Location	Position
Aug. 2014 - present	University of Kentucky, Lexington, KY	Research Assistant
Mar. 2004 – Mar.2007	National Taiwan University Hospital, Taipei, Taiwan	Staff Nurse in Cardiovascular Surgical ICU
Oct. 2001 – Jan. 2004	Tian-Jii Obs & Gyn Clinic, New Taipei City, Taiwan	Staff Nurse

Honors and Awards

2020	Evelyn T. Daniels Scholarship, University of Kentucky, Kentucky
2019	Saha Awards for Cardiovascular Research and Education
2019	College of Nursing Millennium Fund, University of Kentucky, Kentucky
2018	Center for Clinical and Translational Science – College of Nursing Scholarship Showcase, 1st Place Podium Presentation, "*Perceived Control Predicts Symptom Frequency, Severity, and Burden in Patients with Heart Failure*" University of Kentucky, Kentucky
2018	Katherine Tenore-Girone Scholarship, University of Kentucky, Kentucky
2017	Katherine Tenore-Girone Scholarship, University of Kentucky, Kentucky
2016	Finalist in Nursing Research Award, The Annual Scientific Meeting of the Heart Failure Society of America, Orlando, Florida
2004	Presidential Award: an honor for top 5% students in class, Nursing Dept., Fu Jen Catholic University, Taiwan

Conference Presentations

Podium presentations

Lin, C.Y., Moser, D. K., & Lennie, T. A. *Perceived Control Predicts Symptom Frequency, Severity, and Burden in Patients with Heart Failure.* The University of Kentucky Center for Clinical and Translational Science. Lexington, KY. 4/13/2018

Lin, C.Y., Dracup, K., Biddle, M. J., & Moser, D. K. *Heart Failure Symptom Knowledge Improves Heart Failure Self-Care in Rural Patients with Heart Failure*. Heart Failure Society of America Annual Scientific Meeting, Orlando, FL. 9/18/2016

Poster presentations

Lin, C. Y., Hammash, M., Mudd-Martin, G., Biddle, M. J., & Moser, D. K. (2020). *Older and Younger Patients' Perceptions, Evaluations, and Responses to Worsening Heart Failure Symptoms.* American Heart Association Scientific Sessions, A Virtual Experience. 11/13/2020

Lin, C. Y., Hammash, M., Miller, J. L., Schrader, M., & Moser, D. K. (2019). *Delay in Seeking Medical Care for Worsening Heart Failure Symptoms: Predictors and Association with Cardiac Events.* American Heart Association Scientific Sessions, Philadelphia, PA. 11/17/2019

Lin, C.Y., Moser, D. K., & Lennie, T. A. *Perceived Control Independently Predicts Frequency, Severity, and Burden from Heart Failure Symptoms*. American Heart Association Scientific Sessions, Anaheim, CA. 11/14/2017

Lin, C.Y., Dracup, K., Pelter, M. M., Biddle, M. J., & Moser, D. K. *Why Don't Heart Failure Patients Respond to Worsening Symptoms?* American Heart Association Scientific Sessions, Orlando, FL. 11/09/2015

Publications

Journal articles - data based

1. **Lin, C. Y.,** Miller, J. L., Lennie, T. A., Biddle, M. J., Mudd-Martin, G., Hammash, M. H., & Moser, D. K. (2020). Perceived Control Predicts Symptom Status in Patients with Heart Failure. *Journal of Cardiovascular Nursing.* Advance online publication. DOI: 10.1097/JCN.0000000000000684

2. Hammash, M. H., Crawford, T., Shawler, C., Schrader, M., **Lin, C. Y.,** Shewekah, D., & Moser, D. K. (2017). Beyond Social support: Self-care confidence is the key for better treatment adherence in patients with chronic heart failure. *European Journal of Cardiovascular Nursing, 16*(7), 632-637. DOI: 10.1177/1474515117705939.

Manuscript in progress

1. **Lin, C. Y.**, Hammash, M., Mudd-Martin, G., Biddle, M. J., Dignan, M., & Moser, D. K. (2020). Older and Younger Patients' Perceptions, Evaluations, and Responses to Worsening Heart Failure Symptoms. [Manuscript in progress and submitted for publication on 09/20/2020.]

2. **Lin, C. Y.,** Dracup, K., Pelter, M. M., Biddle, M. J., & Moser, D. K. (2020). Association of Psychological Distress with Reasons for Delay in Seeking Medical Care in Rural Patients with Worsening Heart Failure Symptoms. [Manuscript in progress and submitted for publication on 07/22/2020.]

3. **Lin C.Y.,** Hammash, M., Miller, J. L., Schrader, M., Mudd-Martin, G., Biddle, M. J., & Moser, D. K. (2020). Delay in Seeking Medical Care for Worsening Heart Failure Symptoms: Predictors and Association with Cardiac Events. [Manuscript in progress and submitted for publication on 07/14/2020.]

Teaching

Year	Role	Course
Spring 2020	Teaching Assistant	NUR 779: Doctoral Seminar: Career Development (graduate-PhD)
Fall 2019	Teaching Assistant	NUR 794: Analysis, Interpretation, and Presentation of Quantitative Data (graduate-PhD)

Service

Reviewer Service

2020 - present	Manuscript reviewer, Journal of Cardiovascular Nursing

University of Kentucky College Level Service

2019 - present	Mentor, PhD student

Professional Memberships

2015 - present	Member, American Heart Association
2016 - present	Member, Kentucky Academy of Science
2016 - 2017	Member, Honor Society of Nursing, Sigma Theta Tau International