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Heart Failure Self-Management

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HEART FAILURE SELF-MANAGEMENT

by

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ABSTRACT
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Heart failure is a chronic health problem. Heart failure is costly for society, resulting in high morbidity and mortality which accounts for large public spending on this disease. Heart failure (HF) management is complex and requires coordination between patients, families, and their health team members. Self-management (SM) of HF is an important component of chronic disease management and, when done well, aids in preventing HF exacerbations and unnecessary hospitalizations. There are gaps in nursing knowledge of as to which strategies best account for successful outcomes of SM in HF and which patient attributes help contribute to better SM. To clarify these gaps, this dissertation tested concepts of the Individual and Family Self-Management Theory (Rayan & Sawin, 2009). This dissertation also examined association of the complexity of conditions, self-regulation and self-efficacy with self-management behavior in a population of patients with heart failure from a large Midwestern hospital. This was a cross-sectional correlational study. Complexity of conditions was not associated with heart failure behavior, and self-regulation and self-efficacy predicted some but not all self-management behaviors and there was no mediation among the variables. This study contributed to the accumulated knowledge of heart failure self-management and when seeking explanations for the study findings, underlined challenges of HF self-management.

To my family for endless support

and understanding

during these long 4 years of scholarly pursuit

and to my College of Nursing professors

for guiding me and teaching how to become a scholar

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CHAPTER 1

INTRODUCTION

According to Gray, Grove, and Sutherland (2017) "research is a major force in the nursing profession that is used to change practice, education, and health policy" (p. 479). The goal of research is to move nursing science forward, to advance evidence based practice, and ultimately improve patient care and well-being. Americans are living longer while having many chronic illnesses (Meleis, 2018). Cardiovascular nursing focuses on improving care and quality of life for patients with both acute and chronic cardiovascular disorders; including heart failure (HF). Heart failure is costly to society, because of high patient morbidity and mortality, and a reduced quality of life. Nurses caring for such patients must address their complex management needs. The incidence of heart failure is on the rise, with a prediction that the prevalence of HF will increase 46% from 2012 to 2030 (Mozaffarian et al., 2016).

Due to a rapidly aging population and improved survival from acute cardiac events, HF now affects nearly 6.5 million people in the United States and contributing to more than 68,000 deaths a year (Benjamin et al., 2017). One in five people die within one year of diagnosis from HF syndrome. It has been estimated that HF affects 10 per 1000 individuals after 65 years of age, and 1 in 5 will develop it after 40 years of age (Whitaker-Brown, Woods, Cornelius, Southard, & Gulati, 2017). There are 870,000 new cases of HF annually, and by 2030, more than 8 million adults in the US will have a diagnosis of HF (Whitaker-Brown et al., 2017). Although survival has improved, the absolute mortality rates for HF remain approximately 50% within 5 years of diagnosis (Benjamin et al., 2017). Heart failure is the primary diagnosis in greater than one million hospitalizations annually. Patients hospitalized for HF are at high risk for all-cause rehospitalization, with a 30-day readmission rates of 23% (Bergethon et al., 2016). The total cost

of HF care in the United States exceeds $30 billion annually, with over half of these costs spent on hospitalizations (Benjamin et. al., 2017). Mozaffarian et al. (2016) predict that by 2030, the total cost of HF will increase almost 127% to $69.7 billion from 2012. This is equivalent to $244 for every U.S. adult. Thus because of expectations of both increasing costs and prevalence for HF with possibilities for achieving effects on clinical and patient reported outcomes, researchers need to expand scientific knowledge about heart failure.

Pathophysiology of Heart Failure

Anatomy of the Heart

The heart is shaped roughly like a cone and consists of four muscular chambers. The right and left ventricles are the main pumping chambers. The less muscular right and left atria deliver blood to their respective ventricles (Lilly, 2016). Opening into the right atrium are the superior and inferior venae cavae and the coronary sinus. The venae cavae return deoxygenated blood from the systemic venous circulation into the right atrium, whereas the coronary sinus carries venous return from the coronary arteries. The tricuspid valve is located on the floor of the atrium and opens into the right ventricle. The right ventricle is roughly triangular in shape and when contracting, it propels the blood into the pulmonary artery via the pulmonic valve (Lilly, 2016). Entering the posterior half of the left atrium are the four pulmonary veins, which bring the oxygenated blood from the lungs. The mitral valve opens into the left ventricle through the inferior wall of the left atrium (Lilly, 2016). The cavity of the left ventricle is cone shaped and longer than that of the right ventricle. In a healthy adult heart, the wall thickness is 9 to 11 mm, roughly three times that of the right ventricle. The aortic valve separates the left ventricle from the aorta (Lilly, 2016). The heart muscle is supplied with oxygen and nutrients by the right

coronary and left coronary arteries, which originate from the root of the aorta just above the aortic valve cusps. The left main artery bifurcates into the circumflex artery and left anterior descending arteries. The impulse-conducting system is composed of specialized cells that both initiate the heartbeat and electrically coordinate contractions of the heart chambers. This system includes the sinoatrial node, atrioventricular node, bundle of *His*, right and left bundle branches, and the Purkinje fibers. The heart is innervated by both parasympathetic and sympathetic afferent and efferent nerves (Lilly, 2016).

Heart Physiology

The heart normally accepts blood at low filling pressures during diastole and then propels it forward at higher pressures in systole (Lilly, 2016). In a healthy person, cardiac output is matched to the body's total metabolic need. Cardiac output (CO) is equal to the product of stroke volume (SV, the volume of blood ejected with each contraction) and the heart rate (HR): CO=SV x HR (Lilly, 2016). The three major determinants of stroke volume are preload, afterload, and myocardial contractility (Lilly, 2016). The concept of preload in the heart was described by physiologists Frank and Starling. In 1895, Frank had reported that the greater the initial LV volume, the more rapid the rate of rise, the greater the peak pressure reached, and the faster the rate of relaxation (Mann et al., 2015). In 1918, Starling proposed that the larger the volume of the heart, the greater the energy of its contraction and the amount of chemical change at each contraction (Mann, Zipes, Libby, Bonow, and Braunwald, 2015). These complementary findings of Frank and Starling are often combined into the Frank-Starling law. The law states that within physiologic limits, the more a normal ventricle is distended (i.e., filled with blood) during diastole, the greater the volume that is ejected during the next systolic contraction (Lilly, 2016). Afterload in the normal heart reflects the resistance that the ventricle must overcome to empty its

contents. It is defined as the ventricular wall stress that develops during systolic ejection. Cardiac contractility is a myocardial force of blood ejection for a given set of preload and afterload conditions (Lilly, 2016).

Heart Failure

Heart failure is a complex clinical syndrome that results from any structural or functional impairment of ventricular filling or ejection of blood (Yancy et al., 2013). Heart failure is present when the heart is unable to pump blood forward at a sufficient rate to meet the metabolic demands of the body or is able to do so only if cardiac filling pressures are abnormally high (Yancy et al., 2013). Heart failure results in a clinical syndrome of fatigue, shortness of breath, and volume overload. Chronic heart failure results from a wide variety of cardiovascular causes. The etiologies can be grouped into those that (1) impair ventricular contractility, (2) increase afterload, or (3) impair ventricular relaxation and filling (preload). Heart failure that results from an abnormality of ventricular emptying (due to impaired contractility or greatly excessive afterload) is termed *systolic dysfunction*, whereas heart failure caused by abnormalities of diastolic relaxation or ventricular filling (preload) is termed *diastolic dysfunction* (Lilly, 2016). These physiologic principles can be applied to both right-sided and left-sided heart failure. Most of the heart failure science is devoted to left ventricular dysfunction. There is much overlap, with many patients demonstrating both systolic and diastolic abnormalities. As a result, it is common to categorize heart failure patients into two general categories based on the left ventricular ejection fraction (EF); a measure of cardiac performance: (1) **heart failure with reduced EF HF*r*EF** (i.e., primarily systolic dysfunction) and (2) **heart failure with preserved EF HF*p*EF** (i.e., primarily diastolic dysfunction). In the United States, approximately one half of patients with heart failure fall into each of these categories (Lilly, 2016).

Left ventricular ejection fraction (LVEF) or EF is a very important concept in HF. Mathematically, it is LV stroke volume divided by the end-diastolic volume (EDV) (Fuster, Harrington, Narula, & Eapen, 2017). EF is considered fundamental in the classification of patients with HF because of differing patient prognosis and response to therapies and because most clinical trials select patients based on EF (Yancy et a., 2013). Distinction between HFpEF and HFrEF is also important because therapies that have a proven mortality and morbidity benefit in patients with HFrEF do not appear to be effective in patients with HFpEF (Fuster, Harrington, Narula, & Eapen, 2017). HF with reduced EF is defined as the clinical diagnosis of HF with EF less or equal to 40%. There are differing EF cut-off criteria for HFpEF. HF with preserved EF has been sometimes classified as EF >40%, >45%, >50%, and more or equal 55%. Some scientists believe that patients with an EF in the range of 40% to 50% represent an intermediate group (Yancy et al., 2013).

Heart Failure with Reduced Left Ventricular Ejection Fraction

The decrease in cardiac output in heart failure activates a series of compensatory mechanisms that cushion the fall in cardiac output and help preserve sufficient blood pressure to perfuse vital organs (Mann, Zipes, Libby, Bonow, and Braunwald, 2015). These compensations include (1) preload augmentation with increased stroke volume via the Frank–Starling mechanism, (2) neurohormonal alterations, and (3) the development of ventricular hypertrophy and remodeling (Mann et al., 2015). However, eventually these compensations become maladaptive, contributing to adverse ventricular remodeling and progressive deterioration of ventricular function. Lilly (2016) states that heart failure caused by impaired left ventricular contractile function causes diminished ventricular performance. Consequently, at a given preload, stroke volume is decreased compared with normal (Lilly, 2016). The reduced stroke

volume results in incomplete chamber emptying, so that the volume of blood that accumulates in the ventricle during diastole is higher than normal. This increased stretch on the myofibers, acting via the Frank–Starling mechanism, induces a greater stroke volume on subsequent contraction, which helps to empty the enlarged left ventricle and preserve forward cardiac output (Lilly, 2016). This beneficial compensatory mechanism has its limits, however. In the case of severe heart failure with marked depression of contractility, marked elevation of the EDV (end diastolic volume) and pressure (which is transmitted backward to the left atrium, pulmonary veins, and capillaries) pulmonary congestion and edema may occur (Lilly, 2016). Several important neurohormonal compensatory mechanisms are activated in heart failure in response to the decreased cardiac output (Lilly, 2016). Three of the most important involve (1) the adrenergic nervous system (adrenergic nervous system and a withdrawal of parasympathetic tone, Mann et al., 2015), (2) the renin–angiotensin–aldosterone system (angiotensinogen → angiotensin I → angiotensin II → Norepinephrine, constriction, aldosterone), and (3) increased production of antidiuretic hormone (ADH) (sodium reabsorption, blunting response to ANP and BNP) (Lilly, 2016). In part, these mechanisms serve to increase systemic vascular resistance, which helps to maintain arterial perfusion to vital organs in the setting of a reduced cardiac output. However, adverse consequences of these activations include an increase in afterload from excessive vasoconstriction (which may then impede cardiac output) and excess fluid retention, which contributes to peripheral edema and pulmonary congestion (Lilly, 2016).

In contrast to the adverse consequences of the neurohormonal alterations, the natriuretic peptides are natural "beneficial" hormones secreted in heart failure in response to increased intracardiac pressures (Lilly, 2016). The best studied of these are atrial natriuretic peptide (ANP) and B-type natriuretic peptide (BNP). ANP is stored in atrial cells and is released in response to

atrial distention. BNP is not detected in normal hearts but is produced when ventricular myocardium is subjected to hemodynamic stress (Lilly, 2016). Clinical studies have shown a close relationship between serum BNP levels and the severity of heart failure. They result in excretion of sodium and water, vasodilatation, inhibition of renin secretion, and antagonism of the effects of angiotensin II on aldosterone and vasopressin levels (Lilly, 2016). Although these effects are beneficial to patients with heart failure, they are usually not sufficient to fully counteract the vasoconstriction and volume-retaining effects of the other activated hormonal systems (Lilly, 2016).

In addition to neurohormonal activation, Mann et al. (2015) have suggested LV remodeling is another process of HF progression. The term left ventricular (LV) remodeling describes the changes in mass, volume, shape, and composition observed in the left ventricle in response to the mechanical wall stress and strain and systemic neurohormonal activation (Mann and Felker, 2016). Changes in the biology of the failing myocyte and the failing myocardium result in progressive LV dilation and LV dysfunction that occur during cardiac remodeling (Mann et al., 2015). "The remodeled heart is not only larger but also more spherical in shape, causing increase in wall stress of the left ventricle, creating mechanical burden to the heart due to afterload mismatch further contributing to a decrease in cardiac output" (Mann et al., 2015, p. 363). Although initially adaptive, when sustained, remodeling can contribute to the development and progression of HF (Fuster et al., 2017).

Heart failure with preserved left ventricular ejection fraction

Patients who exhibit heart failure with preserved EF frequently demonstrate abnormalities of ventricular diastolic function: impaired early diastolic relaxation, increased stiffness of the ventricular wall, or both (Lilly, 2016). Patients with diastolic dysfunction often manifest signs of

vascular congestion because the elevated diastolic pressure is transmitted backward to the pulmonary and systemic veins. HF with preserved EF (HFpEF) is increasing in prevalence and is associated with poor outcomes (Mann & Felker, 2016). Additionally, the pathophysiologic mechanisms of HFpEF are not completely understood, which has contributed to the lack of specific therapeutic strategies to treat HFpEF. While the prognosis for patients with HF with reduced EF (HFrEF) or systolic HF has improved substantially over the past decades due to modern HF pharmacological therapy, similar pharmacologic agents yielded neutral results in HFpEF patients (Mann & Felker, 2016). Angiotensin-converting enzyme inhibitors, angiotensin receptor blockers, aldosterone antagonists, and β-blockers are ineffective in HFpEF, though there was a reduction in hospitalization in trials with candesartan and spironolactone (Mann and Felker, 2016). Mann, Zipes, Libby, Bonow, and Braunwald (2015) note that patients with preserved EF are older and more likely to be female; however, HFpEF occurs in both men and women throughout the 5th to the 9th decades of life. The most common disease leading to HFpEF is hypertension, which is present in more than 85% of patients, and ischemic heart disease is much less common in HFrEF (Mann et al.). Patients with HFpEF have a higher prevalence of hypertension, chronic obstructive pulmonary disease, atrial fibrillation, obesity, metabolic syndrome, diabetes mellitus, sleep apnea, and pulmonary hypertension (Mann et al., 2015).

Clinical HF symptoms of exercise intolerance, impaired peak oxygen consumption, and norepinephrine levels are similar between HFpEF and HFrEF patients, despite differences in EF. B-type natriuretic peptide (BNP) levels are elevated in both conditions, although they are elevated to a greater extent in HFrEF (Mann & Felker, 2016). HFpEF demonstrates an increasing prevalence, and currently approximately 50% of HF patients present with this type of

HF. Especially in HFpEF, pathophysiologic mechanisms and diagnostic and therapeutic strategies remain uncertain, and this is reflected in the lack of improvement of prognosis in HFpEF. Acute decompensated heart failure (ADHF) is a frequent outcome in patients with heart failure no matter the EF, and may require urgent treatment in the hospital, emergency department, or outpatient office setting (Mann & Felker, 2016). Some patients with HFrEF develop refractory heart failure despite medical management, and many patients with HFpEF develop acute decompensated HF.

Classification of Heart Failure

Several classifications have been created to describe heart failure to increase uniformity in diagnosis and treatment (Fuster, Harrington, Narula, and Eapen, 2017). The New York Heart Association (NYHA) functional classification was first introduced in 1928, and still prevails due to its ease of use and clinical relevance. Currently approved therapies are grounded in this classification, as it was used to select patients for a majority of randomized clinical trials in heart failure. Patients with NYHA class I have no symptoms attributable to heart disease; those in NYHA classes II, III, or IV have mild, moderate, or severe symptoms, respectively (Fuster et al., 2017). The American College of Cardiology and the American Heart Association introduced another classification based on the heart failure staging approach, which emphasizes the importance of development and evolution of disease. These stages are progressive and related to prognosis, and interventions can vary based on stage, including modifying risk factors (stage A), treating structural heart disease (stage B), or reducing morbidity and mortality (stages C and D) (Fuster et al., 2017).

Problem of Concern: Defining Self-Management in Heart Failure

Ditewig, Blok, Havers, and van Veenendaal (2010) describe self-management as follows:

> Self-management refers to the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition, to affect the cognitive behavioral and emotional responses necessary to maintain a satisfactory quality of life, so a dynamic and continuous process of self-regulation is established. (p. 297).

Another similar definition of self-management is maintaining (e.g. daily medication taking), monitoring (e.g. checking weight), and managing (e.g. responding to symptoms) symptoms to promote and maintain health (Xu et al., 2018). Self-management is a key pillar of the National Prevention Strategy for empowering Americans to achieve better health and wellness (Ory, Smith, Ahn, Jiang, Lorig, & Whitelaw, 2014). Chronic disease self-management initiatives are now widely recognized as an effective complement to improve health indicators and quality of life while reducing overall health-related complications and associated costs (Ory et al., 2014). The Institute of Medicine urges the use of proven self-management interventions such as the systematic provision of education by health care providers to strengthen patients' skills and confidence in managing their health problems, and includes regular assessment of progress and problems, goal setting, and problem-solving support (Ory, et al., 2014).

The diagnosis of HF necessitates that patients and families develop self-management skills and adopt lifestyle changes that facilitate controlling symptoms and slowing the progression of the disorder (Rasmusson, Flattery, & Baas, 2015). SM teaches recognizing symptoms of worsening HF, monitoring weight, restricting dietary salt, exercising, adhering to medications, and implementing plans for what to do in the event of an HF exacerbation (Baker et

al., 2011). The aim of these efforts is to improve patient's quality of life and increase their survival time. There is evidence that SM education improves knowledge, self-monitoring, time to hospitalization, and length of stay in a hospital in patients with HF (Yancy et al., 2013). Nursing researchers recognize the beneficial value of self-management in helping HF patients achieve more positive outcomes as demonstrated by significant research on this topic.

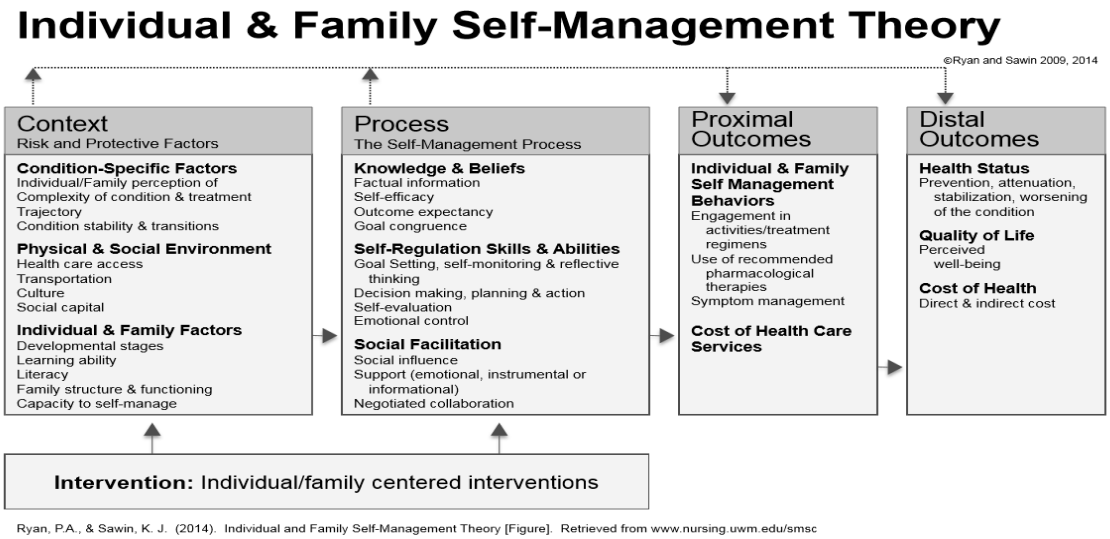
Purpose of the Study

This study investigates the relationship between heart failure self-management behavior and the characteristics of patients who engage in such self-management behavior. It further tests concepts from within the IFSMT to better understand relationships between select context, process and outcome variables in a population of patients with heart failure.

Theoretical Framework

The Individual and Family Self-Management Theory (IFSMT) (Ryan & Sawin, 2009) provides clinicians with a framework for assessing and applying a theory-based approach to care for persons with chronic illness and in need of self-management.

Figure 1. The Individual and Family Self-Management Theory



The IFSMT envisions SM as a process whereby both individuals and families employ knowledge and beliefs, self-regulation skills and abilities, and social facilitation to attain proximal (e.g., SM behaviors and health care services costs) and distal outcomes (health status, quality of life and cost of health) (Ryan & Sawin, 2009). The process of SM occurs within the context of risk and protective factors of the specific health condition, the physical and social environment and various individual and family factors (Verchota & Sawin, 2016).

There are important assumptions within the IFSMT. Each is introduced with examples in HF; persons pursue behaviors for reasons meaningful to them, as these reasons may or may not be directly related to modifying their health status. For example, a patient with HF may choose to focus on his family and professional life rather than attend medical care.

Factors which influence human behaviors include personal preferences, culture, social norms, and family rules and boundaries. For example, a first-generation immigrant with heart failure may prefer to follow up with a primary care provider who speaks his language and who

understands the patient's customs rather than go to an English-speaking heart specialist. Also, many herbal supplements are taken by ethnic patients and may not be communicated to the healthcare team.

An individual's and family's ability and motivation to engage in SM are influenced by many contextual factors. The patient with heart failure requires access to a HF specialist, and in rural areas this access may be difficult and depend on transportation to larger and farther hospital clinics. Individual and family perceptions of resources impact participation in SM behaviors. For example, new medications for heart failure such as Entresto are very costly and can be a significant financial burden for a family budget.

SM is a dynamic and repetitive process commanding time, repetition, and reflection. For patients with HF, SM education starts at the time of initial diagnosis. SM is explained at each visit, and with each visit the health care team, together with patients and families tries to reflect on patients' progress. However, the disease is insidious and hard to control and getting back on track to maintain euvolemia and well-being requires many efforts.

Social facilitation greatly influences engagement in SM behaviors and attainment of outcomes. The most effective interventions increase engagement in SM behaviors and lead to achievement of outcomes which are personal and family centered (Ryan & Sawin, 2009). For example, many patients with heart failure bring to appointments family members who help with self-management. Asking the patients and family members about their HF goals, should be performed at each SM visit.

The concepts of adherence, alliance, and compliance are not synonymous with SM because they contradict the notion that the primary responsibility and control lie within the individual or family. For example, in heart failure, dietary limitations are numerous, and the

patient is supposed to take at least 4-5 pills several times a day, all having potential side effects. Considering these limitations, the patient's SM goals can be quite different from expectations of the HF healthcare team. Individuals and families' engagement in health behaviors may or may not involve collaboration with healthcare providers. The HF patient who has been stable may choose not to follow up with healthcare team. Due to many side-effects of HF medications, the patient may stop taking them.

SM involves complex behaviors and the IFSMT supplies the foundation for expanding our understanding of SM (Ryan & Sawin, 2009). Not only is the IFSMT a comprehensive and logically formulated framework with distinct concepts and easily interpretable constructs, it is adaptable and has been used by many nursing student researchers as part of their dissertation. The theory is congruent with the four major nursing metaparadigms of environment, health, nurse, and person (Ryan & Sawin, 2009). IFSMT as a self-management framework can provide direction that will allow formulation of the research question related to heart failure.

Research Question

Based on the concepts derived from Individual and Family Self-Management Theory and applying the theory to HF, the following research question is proposed: what are the associations of the contextual factor of complexity of condition, SM processes of self-efficacy and self-regulation with self-management behaviors in patients with heart failure?

And the specific research questions are:

1. Does the complexity of condition predict heart failure SM behaviors?
2. Does self-regulation predict heart failure SM behaviors?
3. Does self-efficacy predict heart failure SM behaviors?
4. Do self-regulation and self-efficacy mediate the effect of complexity of condition on

heart failure SM behaviors?

Hypotheses

Complexity of condition, self-regulation, and self-efficacy predict self-management behaviors in a patient population with New York Heart Association (NYHA) functional class II-III HF. Self-efficacy and self-regulation are hypothesized to be mediators between the complexity of condition and heart failure SM behaviors.

Operational Definition of Concepts

Self-Regulation

Bandura (1986) defined self-regulation as a process whereby individuals control and direct their behaviors toward desired goals, as well as develop functional patterns of thinking and acting to attain new behaviors. Bandura (1991) described self-regulation as monitoring of "health-related behavior and the social and cognitive conditions under which one engages in it; adoption of goals to guide one's efforts and strategies for realizing them; and self-reactive influences that include enlistment of motivating incentives and social supports to sustain healthful practices" (p. 246). Leventhal, Brissette, and Leventhal (2003) proposed the Model of Theory of Self-Regulation and described patients' coping behavior as a common-sense reaction to their cognitive and emotional perceptions and interpretations of a specific threat, such as an illness.

According to Fleury (1998) self-regulation is volitional aspect of behavior change through selective processing of information, behavior monitoring, judging of individual performance, and self-evaluation. Self-regulatory behavioral changes occur in accordance with

personal goals, especially when goals are in conflict, or potentially lead to rewards.

Ryan and Sawin (2009) further developed self-regulation as a process used to change health behavior. "It includes activities such as goal-setting, self-monitoring and reflective thinking; decision-making, planning for and engaging in specific behaviors, self-evaluation, and management of physical, emotional, and cognitive responses associated with health behavior changes" (Sawin & Ryan, 2009, p.223).

The concept of self-regulation has been used in heart failure research, but in few studies. De Smedt et al. (2012) used a theoretical Model of Self-Regulation to assess the role of beliefs and coping strategies concerning medications and adverse drug events perceptions. Cherrington, Lawson, and Clark (2006) used the model of self-regulation to explore beliefs of heart failure patients with left ventricular systolic dysfunction about their disease.

Complexity of Condition

The concept of complexity of condition is operationalized only in Ryan and Sawin's (2009) work. It is defined as "physiological, structural, or functional characteristics of the condition that impact the amount, type and critical nature of behaviors needed to manage the condition" (Ryan and Sawin, p. 225). As such this concept has not been used in heart failure studies. Grey, Knafl, and McCorkle (2006) describe a similar concept of severity of condition and define it by disease prognosis from the view of the healthcare professionals or disease burden from the view of the patients and their families. The other similar concept (which is widely used in heart failure research) is multimorbidity. Pefoyo et al., (2015) define multimorbidity as the coexistence of two or more chronic conditions. Chamberlain et al. (2015) concluded that among a sample of heart failure patients, nearly 86% had 2 or more of 16

identifiable chronic conditions as evidence of multimorbidity. Riegel, Dickson, and Faulkner (2016) state that in heart failure populations multimorbidity, or living with more than one condition, poses physical limitations and increases the need for support and financial resources which consume time and energy.

Self-Efficacy

Bandura was the first to describe the concept of self-efficacy and defined it as a person's perception of his or her ability to perform a specific behavior - "people's beliefs about their capabilities to exercise control over own level of functioning and over events that affect their lives (p.257, 1991). Ryan and Sawin (2009) defined self-efficacy as a "behavior specific concept, which refers to the degree of confidence one has in his/her ability to successfully engage in a behavior under normal and stressful situations" (p.225).

DiClemente, Salazar, and Crosby (2011) put a similar definition of self-efficacy as one's confidence in one's ability to take action or to change a health-related behavior; a task-specific self-perception of one's personal ability. Riegel, Jaarsma, and Stromberg (2012) define self-efficacy as "the confidence that one has in the ability to perform a specific action and to persist in performing that action despite barriers" (p.201).

The concept of self-efficacy is used widely in nursing heart failure research. Chen et al. (2013) explored relationships among health literacy and HF knowledge, self-efficacy, and adherence to self-care and reported that adequate health literacy was associated with greater HF knowledge but not self-efficacy or adherence to self-care expectations over time. Gary (2006) reported positive results in her study to evaluate exercise self-efficacy in older women with stable New York Heart Association Functional Class II – III heart failure who were enrolled in a

12-week exercise and education program. Casida, Wu, Harden, Carie, and Chern (2015) designed an instrument to measure caregivers' self-efficacy for adherence to the complex home-care regimen of heart failure patients with a left ventricular assist device (LVAD). Riegel, Dickson, Garcia, Masterson Creber, and Streur (2017) reported a study of motivational interviewing to build self-efficacy in self-care behaviors in chronically ill adults with HF.

Significance: Self-Management, Definition and Discussion

Ryan and Sawin (2009) define self-management as one's control and responsibility for management of chronic conditions or healthy behaviors by purposefully engaging in performance of learned behaviors. Self-management is a specific process, affected by specific programs or interventions, and results in particular outcomes. The authors distinguish the concept of self-management from the concept of self-care. In their view self-care is comprised of daily living and engaging in health behaviors without collaboration from healthcare professionals. However, in literature these two concepts are often used interchangeably especially in medical literature.

Riegel, Jaarsma, and Stromberg (2012) proposed a middle-range Theory of Self-Care of Chronic Illness. In their definition, self-care is a process of maintaining health via health promoting practices related to the management of illness through healthcare professionals' help and interventions. Engaging in self-care makes the patient an active participant in the management of their illness. They further divide self-care concept into 3 other sub-concepts: self-care maintenance, self-care monitoring, and self-care management. Self-care maintenance is defined as behaviors used by chronically ill patients in order to maintain their physical and emotional stability. Such behaviors can be self-directed or reflect mutually agreed upon recommendations from healthcare providers. Self-care monitoring refers to the process of

observing oneself for changes in signs and symptoms and is a link between self-care maintenance and self-care management. Self-care management is defined as the response to signs and symptoms as they occur.

Comparing Ryan and Sawin to Riegel et al. concepts and definitions, according to Ryan and Sawin, self-management concept is more complex than self-care, and self-care abilities are part of self-management process. From Riegel's explanations, self-care process is more complex concept than self-management, and self-care management is a part of self-care. Both concepts require involvement from healthcare professionals. Ryan and Sawin and Riegel and colleagues recognize the concepts' similarity. The national guidelines for managing heart failure include both self-care and self-management. Yancy et al (2013) propose that patients with HF should receive specific education to facilitate HF *self-care*, which is recommendation Class I, level of evidence B. However, in the most recent American College of Cardiology's national guidelines for management of heart failure with reduced ejection fraction (Yancy et al., 2017), the authors call for *self-management* interventions, which were associated with lower mortality and fewer hospital readmissions. This study is focused on self-management as it is described by Sawin and Ryan with the realization that much of the written research interchangeably uses both concepts as synonymous.

While most of the researchers focus on the positive aspects of SM, there are those having alternative opinions about self-management. Bovenkamp and Dwarswaard (2017) state that it is a “neoliberal agenda” to shift responsibility towards individuals with the goal of reducing public medical expenditures. Such a shift in responsibility has important implications. For example, while giving patients the opportunity to become engaged in SM, it also implies that the patients are to “blame” when they do not live up to ideal standards of SM and fail to self-manage

properly (Bovenkamp & Dwarswaard, 2017). The authors continue this debate stating that shifting focus on individual obligations disregards the social context, which determines when and how patients start to self-manage their chronic illness (Bovenkamp & Dwarswaard, 2017). The way SM responsibilities are imposed on individuals can lead to patient abandonment and inequality. Secondly, despite the emphasis on self-management and the creation of numerous interventions to support it, power relations remain firmly in place of healthcare professionals. This limits patient who want and have the capacity to SM (Bovenkamp and Dwarswaard, 2017). The authors made a point that the preference should be given to patient's autonomy and the desire to make American healthcare less paternalistic.

The IFSMT guides the researchers in this debate by stating that SM is not equal to adherence and compliance and the primary responsibility for SM lies with individuals and families. Patients engaging in self-management behavior may or may not cooperate with healthcare professionals (Ryan & Sawin, 2009).

Gardetto (2011) states that the science of self-management in HF care is still evolving. There are many challenges around complexity of HF self-management. HF requires substantial resources, commitments and lifestyle changes. The disease places a tremendous strain on patients, families, communities, and the health care system itself because there is no cure, except heart transplant which is limited in appropriateness, affordability, and availability. Adding to this burden are longer life expectancies and increasing numbers of people with HF living with other comorbidities. For patients living with HF, their day-to-day symptom burdens can vary depending upon the stage of their illness. These symptoms are insidious, and an illness trajectory is unpredictable. Nursing scholars should not be discouraged by these challenges.

Gaps in Understanding SM in Heart Failure

"Extensive scientific work has been done to increase our understanding in whom self-management is problematic and in whom self-management interventions are most effective (Bos-Touwen, Jonkman, Westland, Schuurmans, Rutten, de Wit, & Trappenburg, 2015, p. 231). However, there remain gaps in nursing knowledge around SM. At times, current "best practice" is not working for some people with heart failure, despite intensive education; certain patients fail to successfully manage their heart failure. Consequences of the inability to self-manage HF at home include being readmitted to acute care facilities due to exacerbation of symptoms, such as dyspnea, edema, and fatigue. Successful SM does not fully prevent but can reduce the risk for hospital readmission in patients with heart failure and improve overall health (Ahmad et al., 2018). Identifying factors associated with increased or decreased self-management behaviors in a population of patients with HF will fill an important gap in our understanding of additional ways to help people with HF to self-manage their disease. Exploring characteristics of people who self-manage poorly will help to identify a subset of people who may require more intensive or different types of interventions to foster self-management. Examining attributes, facilitators or barriers, which are associated with successful self-management behavior can inform the design of future specific components of SM interventions. Well-designed strategies grounded in theory and employing modern-day evidence are essential in improving patient outcomes such as risk of readmissions, mortality, SM abilities, knowledge, and quality of life (Boyd & Peters, 2014).

Structure to Dissertation

This dissertation is composed of five chapters and three articles prepared for publication, integrated into those chapters. Chapter One provides an introduction to the problem and the

dissertation. Chapter Two consists of a review of the literature, including IFSMT, together with a manuscript of a heart failure self-management integrative literature review. The focus of Chapter Three is a methodology utilized for the study. Chapter Four presents the results of the entire research study and includes a manuscript of the entire study. Finally, Chapter Five presents a synthesis of the preceding chapters in this dissertation and manuscripts and suggest implications for research, policy, education and practice. It also includes a third manuscript for nurse practitioners around practice issues regarding treating patients with chronic diseases, as HF is one of the chronic conditions, and applying theoretical framework.

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CHAPTER 2

REVIEW OF THE LITERATURE

INTRODUCTION

"Scholarship in a discipline refers to the degree to which its mission is defined and based on rigorous and credible research" (Meleis, 2018, p.8). A vital component in the process of scholarship is an extensive, comprehensive, and integrative literature review to define concepts or identify the existing evidence (Meleis, 2018). A literature review is an evaluation and synthesis of present-day knowledge about a topic for research or for use in clinical practice, education, administration, and other areas of nursing (Oermann & Hays, 2015). There are several purposes for reviewing the literature. The first is to define what is already known about a topic. The second is to pinpoint where the gaps are in knowledge (Oermann & Hays, 2015).

The purpose of this literature review is to examine the state of the science of self-management (SM) behavior as related to heart failure (HF), to integrate the literature about HF self-management by providing descriptions of empirical research studies related to HF SM, and to identify possible gaps in nursing knowledge. This chapter also includes a manuscript at the end - Heart Failure Self-Management, Integrative Literature Review.

Prevalence and Significance of HF

Heart failure (HF) is a growing public health problem. Epidemiologically, HF is a common chronic medical condition with an annual incidence in the U.S of approximately 915,000 cases per year. Care relating to HF is responsible for approximately 1.75 million office visits and more than 0.5 million emergency department visits annually (Neubauer, Gray, & Hemann, 2018). David, Howard, Dalton, and Britting (2018) state that all-cause unplanned readmissions cost Medicare $26 billion per year. Among these, heart failure (HF) exacerbation is

the cause of nearly 80,000 unplanned hospital readmissions each year. HF is also Medicare's greatest expenditure category with annual cost of HF at $31 billion. Although only 14% of Medicare beneficiaries are diagnosed with HF, they account for 43% of Medicare spending (David et al., 2018). Therefore, readmission of patients with HF is costly and places a marked burden on the resources of the health care system and on the patients and families who struggle with the disease.

HF management is complex and requires coordination between patients, families, and their health team members to overcome barriers and improve the transition to the outpatient environment. Self-management of HF is an important component of chronic disease management and, when done well, aids in preventing HF exacerbations and unnecessary hospitalizations. Patients with HF suffer from acute and chronic HF-related symptoms such as dyspnea, fatigue, weakness, edema, and depression. These symptoms limit activities of daily living (ADL) and impair quality of life (QOL). Lee and Riegel (2017) remark that SM improves QOL and HF outcomes. Patients are encouraged to maintain their health by using effective self-management techniques in their daily lives without the direct aid of health care professionals. A key element of self-management is regular HF symptom monitoring, which can decrease the risk of an exacerbation of HF symptoms and prevent hospital readmissions (Lee & Riegel, 2017).

Shively et al. (2013) define self-management as an active cognitive process undertaken by a patient to maintain health or manage illness and disease. Jaarsma et al. (2013) state that patients with heart failure need to cope with a lifelong regimen that involves more than simply medication taking. By self-managing lifestyle changes, patients learn how to deal with the consequences of this chronic illness. Nursing researchers recognized importance of HF self-management. There are number of studies devoted to this topic.

Literature Review

The literature review for this study was conducted by a computer-assisted search of multiple databases, in particular CINAHL, PubMed, and Google Scholar. The area of the science central to the study is the science of self-management, with a focus on cardiovascular nursing and care of patients with HF.

The author searched, using the terms *self-management* and *self-care*, combined with *heart failure*, for full text articles in nursing and medical peer - reviewed journals. The terms *self-management* and *self-care* are frequently used interchangeably. The search yielded 32 articles; most of them are primary studies, comprised of experimental, cross-sectional, mixed methods, and qualitative studies. Systemic reviews, integrative literature reviews, meta-synthesis of qualitative studies, and a secondary analysis of previous original research data were also included.

SM Interventions and Patient Outcomes

Many examined randomized controlled studies focused on improving patient outcomes via HF self-management interventions. When the outcome of the study was increased self-management behaviors, most interventions were successful. These heart failure SM interventions centered on patients' education about the disease, daily weight, blood pressure monitoring, and self-medication.

Tawalbeh (2018) reported that cardiac education program on Self-Care Behaviors (SCB) showed that knowledge of heart failure and SCBs, including management, maintenance, and confidence, were significantly improved at 1 and 3 months after the program implementation. Positive outcomes of HF self-management were reported by Otsu and Moriyama (2012). Their educational HF SM program was effective in sustaining self-management skills and activities up

to 24 months. The outcomes that the authors looked were compliance with a sodium-restricted diet, compliance with medications, compliance with activities or exercise, and the self-monitoring of weight and deterioration in the symptoms of HF. RCT conducted by Shively et al. (2013) concluded that tailored heart failure SM intervention among patients at high risk for readmission for HF increased engagement in SM behavior.

Shao, Chang, Edwards, Shyu, and Chen, (2013) conducted a randomized controlled trial (RCT) to determine the effectiveness of a self-management intervention on self-efficacy for salt and fluid control, HF-related self-management behaviors and symptoms, and health service use in older outpatients with HF in Taiwan. The participants in the study had a low baseline level of self-management behavior. Their conclusion was that the SM intervention was effective in improving the self-efficacy of Taiwanese HF patients for controlling salt and fluid intake, and for self-management behavior and in decreasing HF symptom distress, but not in reducing health service use. Tung et al. (2013) reported that as the result of their SM intervention, participants in the experimental group achieved better self-maintenance and self-management and QOL up to 2 months' post intervention. Boyne, Vrijhoef Spreeuwenberg, De Weerd, Kragten, and Gorgels (2014) used telehealth as intervention and reported that their intervention improved knowledge of HF, self-care abilities, along with adherence to daily weight, fluid intake, physical activity, and medications.

The outcomes of self-management on lowering hospitalizations have mixed evidence. Lee et al. (2017) conducted a study to define clinical events in groups of patients who engaged in self-management behavior well, who had poor self-management behavior and symptoms recognition, and the group of asymptomatic patients. Their conclusion was that subjects who had higher self-management behavior and knowledge had less clinical events than those with poor

behavior and knowledge or asymptomatic patients. Similarly, Lee, Moser, Lennie, and Riegel (2011) compared the risk of all-cause mortality, hospitalization or emergency room admission among HF patients who practiced above average self-management, those who practiced below average self-care management, and those who were symptom-free. They concluded that persons who were more engaged in HF self-care management had a 56% reduction in the risk of all-cause mortality, hospitalization or emergency room admission than persons who were less engaged. Persons with HF who were more engaged in self-management had an event risk nearly equivalent to those who were symptom-free, despite being a group with more comorbidity. Symptomatic HF patients who practiced above average self-management also had an event-free survival benefit similar to that of symptom-free HF patients.

De Souza et al. (2014) reported that because of post-discharge, nurse-led SM intervention, HF knowledge and HF self-care were significantly increased in the intervention group during follow-up visits. In addition, the composite endpoint of a first HF-related visit to the emergency department, hospital readmission, or all-cause death was decreased in the interventional group. Jonkman et al. (2016) reported protective effects of self-management interventions on time to the combined end point of HF-related hospitalization or all cause death, HF-related hospitalization alone, and HF-QOL.

Al-Sutari and Ahmad (2015) conducted a quazi-experimental study and reported that their SM educational program for HF patients decreased the frequency of emergency room visits and increased self-care behaviors, but did not decrease hospitalizations frequencies or mortality. Kato et al. (2016) reported that their HF self-management program delivered by a multidisciplinary team before discharge from the hospital showed mild reduction in HF hospitalization and cardiac death but no differences in HF self-care behavior. Ditewig et al.

(2010) conducted systematic review of 19 randomized controlled trials and reported that in HF patient effectiveness of self-management interventions showed a positive effect, although not always significant, on the reduction of numbers of all-cause hospital readmissions, decrease in mortality and increase in QOL.

On the other hand, Cockayne, Pattenden, Worthy, Richardson, and Lewin (2014) reported that their HF self-management program produced no difference in HF admission/readmission to the hospital. Boyde, Peters, New, Hwang, Ha, and Korczyk (2017) conducted an RCT with inconclusive findings, their educational intervention reduced all-cause unplanned hospital readmissions for this cohort of patients with HF. However, there were no group differences in knowledge and self-care scores, so the proximal outcomes were not achieved, but there was a difference in distal outcomes of hospital readmissions. Dewalt et al. (2012) conducted an RCT to define if self-care training can reduce hospitalization for heart failure (HF), and to determine if more intensive intervention benefited vulnerable patients, including those with low literacy. Their conclusion was the incidence of all-cause hospitalization and death did not differ between intensive intervention and single session groups. Smeulders et al. (2010) conducted an RCT to assess the effects of the chronic disease SM program on psychosocial attributes, self-care behavior and cardiac specific QOL. The study did not produce significant effect at 6 months or 12 months and concluded that achieving long-term behavioral change in SM of HF patients may be challenging, as patients constantly needed to adapt to an illness with progressive deterioration. Finally, Dracup et al. (2014) conducted an RCT to determine the impact of 2 different intensity levels of HF educational intervention on the composite endpoint of HF rehospitalization and cardiac death in patients with heart failure (HF) who live in rural areas. Patients were followed for two years. They reported that although a face-

to-face education intervention increased SM behavior and decreased cardiac death in 2 groups, the intervention did not significantly decrease the combined end-point of cardiac death and hospitalization for HF.

These studies show that SM interventions are important for patients' outcomes and are aimed at improving the outcomes. However, there is a gap in nursing knowledge in what constitutes effective SM interventions in patients with HF. Nursing researchers need a greater understanding why SM interventions are successful or not. Can there be specific patient attributes that make these well-intentioned interventions ineffective? Why despite healthcare professionals' best efforts to improve self-management behavior, frequently patients are unable to self-manage HF at home, and what are the consequences? Non-interventional studies explore these issues.

Consequences of Inability to Self-Manage Heart Failure

The main consequence of inability to SM heart failure at home for patients and for the healthcare systems is increased hospital admissions and readmissions, increasing cost of healthcare. Yancy et al. (2013) state that hospital readmissions significantly contribute to the economic burden, with evidence that 30–50 % of patients are readmitted within six months. Contributing factors include patients' inability to perform self-management behavioral activities as well as failure to adhere to their medical regimen, suggesting that at least some of these admissions are preventable. Per Boyde and Peters (2014) for patients living with HF, "the day-to-day symptom burden can vary depending upon the stage of their illness. These symptoms are insidious, with an illness trajectory that is unpredictable" (p.314). Ditewig et al. (2010) notes:

> Being diagnosed with heart failure (HF) not only has a major impact on the person's quality of life, also usage of health care facilities is challenged. Noncompliance with

> prescribed medical treatment and diet regimen, shortage of knowledge about deterioration of signs and symptoms and lack of professional intensive follow-up in HF patients often result in frequent, preventable and emergency visits. (p. 297).

Many nursing scholars looked at breakdown in self-management, and tried to explain it. Xu et al. (2018) conducted a mixed-methods cross-sectional study to explore association of self-care decision making with rehospitalization within 30 days of discharge along with the delays in seeking medical assistance. The inability to SM in this study results in a rehospitalization due to delayed decision making. Although the relationship between HF self-care and 30-day rehospitalization was not statistically significant, participants who had high self-care scores, with high ability to SM, and were not hospitalized within 30 days, exhibited a clear pattern of behavior characterized by being proactive in seeking outpatient medical attention from healthcare providers. Depressive symptoms predicted 30 days rehospitalizations. Similarly, Navidian Yaghoubinia, Ganjali, and Khoshsimaee (2015) reported that self-care behavior education had lower effect on the depressed patients with heart failure. Stewart et al. (2016) reported that multimorbidities contributed to inability of HF self-management the most. The authors postulated that due to poor self-management, patients face adverse events and hospitalizations. The consequences of inability to self-manage HF, were not only poor QOL and readmissions, but also hospitalization itself and its complications, "including delirium, iatrogenic illness, infections, deconditioning, sarcopenia, and increased falls risk" (Stewart et al., 2016, p. 6).

The focus of many nursing researchers is to address characteristics of the hospitalized HF patients in order to determine which of these characteristics are most predictive of their inability to SM and hospitalizations. Britz and Dunn (2010) reported that patients with heart failure who

demonstrated decreased self-management abilities, such as medication compliance, following a low-sodium diet, maintaining fluid restrictions, weighing themselves daily, and identifying the early warning symptoms of worsening heart failure, had frequent hospitalizations and decreased quality of life. The authors reported that self-care confidence and perceived better health were found to be significantly related to improved quality of life in hospitalized patients. One of the conclusions was that by developing a greater sense of confidence in their own abilities to self-manage their disease, many patients were able to avoid an acute onset of heart failure and prevent hospital readmissions. In their study gender and age predicted self-care behavior. Contrary findings were presented by Riegel, Dickson, Kuhn, Page, and Worrall-Carter (2010). Their mixed-methods study revealed that there were no consistent gender-specific differences in self-care abilities to manage HF at home. Tsai, Wang, Lee, Tsai, and Chen (2015) explored the determinants of self-care (SC) decision-making in hospitalized patients with HF in Taiwan. Their findings suggested a very poor self-care status among the participants of this study. Age, gender and comorbidity did not predict SC. No gender difference in SM went along with Riegel et al. (2010) findings. Tsai and coauthors found that participants with greater admission frequency had better SC scores and HF knowledge, meaning that patients acquired their ability to self-manage while hospitalized. They suggested that low levels of self-care engagement might therefore result in more frequent hospitalizations and early comprehensive patient education to help patients engage in better self-care is needed to prevent patients from merely learning how to perform self-care from repeated admissions. Riegel et al. (2018) in their mixed-methods research also showed that self-care is poor in persons with HF and even most SC savvy patients were not able to avoid a HF hospitalization, concurring with Tsai et al. (2015) findings.

Jaarsma et al. (2013) compared self-care HF behaviors between patients in 15 different

countries and remarked that most self-care behaviors are poor and can be improved in HF patients. There was wide variability in HF self-care across countries, but regardless of country there was markedly poor adherence to most self-care behaviors. Across all samples, there was high self-care in medication taking, a consistently low level of self-care in exercise and regular weight monitoring and there were large variations in adherence to salt restriction. Adherence to a low salt diet could have been related to differences in national HF guidelines, local food policies, available resources, and individual responses to suggested dietary changes.

Spaling, Currie, Strachan, Harkness, and Clark (2015) conducted systematic review of qualitative studies of self-care in HF patients. One of their conclusions was that patient knowledge of the domains of heart failure self-care remains low (as in Jaarsma et al., 2013, Tsai et al., 2015), particularly with respect to medication, diet, fluid management and timely help-seeking. According to the authors, merely providing patients with more sophisticated knowledge of HF is unlikely to improve HF self-care, and will not increase SM ability. Components of these interventions need to provide SM education more relevant and adaptive to each patient personal context (Spaling et al., 2015). Strachan, Currie, Harkness, Spaling, and Clark (2014) conducted qualitative meta-synthesis to look at contextual factors that influence engagement in self-care, and should be integrated into the promotion of self-care. These contextual factors included caregivers, social networks and social support, place, finances and financial capacity, work and occupation, and HF support groups and programs.

Lee and Riegel (2017) looked at symptom perception as a domain within HF self-care. One of the precursors of inability to HF SM is poor symptom recognition. Per their review most HF patients have difficulty recognizing an exacerbation of symptoms. Poor symptom recognition as part of self-care was a reason for delaying care. Barriers such as lack of support, limited

finances, poor access to health care, and fear of hospitalization impeded better self-care strategies and resulted in HF exacerbation. They reported that factors affecting self-care and inability of symptom recognition included age, comorbidity, living with others, educational status, uncertainty, acute symptom duration, gradual symptom progression, NYHA (New York Heart Association) class, and the total number of previous hospitalizations. Similarly, Athilingam, Jenkins, Zumpano, and Labrador (2018) reported that patients find the obligation of self-care surveillance overwhelming. The most common reasons for not seeking early treatment included: symptom uncertainty and patients' perception that early symptoms are not intense enough to warrant action or seek care.

Bos-Touwen et al. (2015) conducted a systematic review of studies examining tailored self-management interventions and patient characteristics associated with self-management abilities and success of interventions as building blocks for tailoring. The researchers noted that there were no clear descriptions within the studies how these interventions were tailored. Their conclusion was that improved self-management ability contributed to better HF-related outcomes and reduction in hospitalizations and mortality. Interventions aimed at supporting patients in increasing SM have shown to be successful, however, not in all patients. Certain patient characteristics associated with self-management capabilities do not influence the effectiveness of a given intervention (such as age, gender, ethnicity, disease severity, number of comorbidities) while other characteristics (such as low income, literacy, education, baseline self-management capacity) in fact are indicators of patients with a high likelihood for success. These findings validate Yancy et al. (2013) statement that patient characteristics may be important predictors of SM and hospitalizations.

Finally, Wu, Reilly, Holland, Higgins, Clark, and Dunbar (2017) explored how health

literacy levels of patients with HF and their family members influence HF knowledge and self-care abilities. They concluded that in order to improve HF patients' self-care, health care providers should assess patients' and family members' (FMs) health literacy levels, then provide comprehensible and tailored education to both patients and FMs, and especially target the group with highest risk when both patients and family members have low health literacy. This finding agrees with Bos-Touwen et al. (2015) findings that low-literacy is one of the indicators of patients with a high likelihood for success of SM interventions.

The literature review shows that heart failure self-management is complex. Evidence is mixed and there are gaps in nursing knowledge of what constitutes effective strategies for successful outcomes of SM in HF. Many but certainly not all the experimental studies or secondary analysis studies confirm that education about self-management and therapeutic interventions for heart failure SM work in improving patient outcomes, such as increasing HF SM behavior and patients' well-being, preventing worsening of HF symptoms, and reducing risk of hospitalizations. There are still gaps in nursing knowledge as considerable variations in SM intervention components, mode of delivery, and dose hamper answering which interventions improve HF outcomes. The worsening of heart failure symptoms and hospitalizations are the main consequences of inability to manage HF at home for patients with HF and healthcare systems. When SM interventions do not work in preventing hospitalizations and HF readmissions, researchers look at the reasons and gaps in nursing knowledge trying to explain the phenomenon. Several studies show that symptom recognition among HF patients is poor and the patients fail to engage in self-management behavior and there is a gap in nursing knowledge of how to improve HF symptoms recognition so the patients apply SM abilities to counteract those symptoms. The primary goal of HF self-management is to improve patients' outcomes such as

quality of life, reduce the frequency of HF exacerbation, and extend survival. Addressing these challenges, several researchers suggested that use of a tailored approach is more effective. The suggestion was to tailor to patient attributes. Many of these studies showed contradictory findings what contextual conditions should be incorporated in tailored interventions. Some studies reported that the age and sex of the participants influenced SM skills, while others refuted this suggestion. Several studies confirmed that the patients with lower SM abilities benefited from these programs the most. The complexity of SM in HF is especially underscored in both qualitative and mixed-methods studies which place emphasis on patients' efforts to improve their skills. Overall the literature review showed that "extensive scientific work has been done to increase our understanding in whom self-management is problematic and in whom self-management interventions are most effective (Bos-Touwen, 2015, p. 231). Jonkman et al. (2016) remarks that specific types of interventions might work better for specific subgroups of patients. The question what works for whom- deserves attention in subsequent research. There is conflicting evidence regarding which contextual factors are best associated with successful self-management behaviors and which patient characteristics clearly impede successful HF self-management behavior. Addressing a gap of nursing knowledge in patient attributes of HF self-management behavior has important implications and is the focus of this PhD study.

Summary

This chapter summarizes literature devoted to heart failure self-management. It divides findings in two subtopics SM interventions and patient outcomes and consequences of inability to self-manage heart failure. It highlights gaps in nursing knowledge and proposes directions for the study. It also includes the second manuscript - Heart Failure Self-Management, Integrative Literature Review.

Table 2. 1

Evidence Table

Author Year Country	**Research Question or Hypothesis**	**1. Design 2. Sample**	**Measures**	**Analyses Used**	**Findings Level of evidence**	**Strength/ Limitations**
Al-Sutari and Ahmad (2015), Jordan	To assess effectiveness of educational program on self-care behaviors and health outcomes	Quasi-experimental 144 patients	Charlson Comorbidity Index SCHFI	Independent samples t test and chi-square, Fisher's exact test	Lowered frequency of emergency room visits and increased self-care behaviors, but did not lower frequencies of hospitalizations or mortality B	+ first interventional study in Jordan measuring HF SM - short duration of the study, single site
Athilingam, Jenkins, Zumpano, and Labrador (2018), USA	To test the proof of concept of a mobile application in improving SC management of patients with HF	Qualitative study - a field study strategy with purposeful sampling, 125 subjects - patients with HF, physicians, nurses, paramedics, pharmacists, social	A standardized, open-ended, in-person interview	Constant comparative analysis	There is a need in further testing of adjunct device in home health setting to improve self-management and enhance communication with providers, and ultimately reduce readmissions; HF patients find the obligation of SC surveillance	+ qualitative study focusing on perspective of multiple healthcare players and the patients - it is not easy to figure out what the research is exactly about

		workers, telemedicine and hospital administrators, insurance companies, vice presidents of telehealth companies, and other health care team members			overwhelming. C	
Bos-Touwen et al. (2015), Netherlands	To synthesize the literature on current use of tailoring in SM interventions and patient characteristics associated with SM capacity and success of interventions, as building blocks for tailoring.	Integrative literature review (though the authors called it IPD meta-analysis) of RCTs. 28 studies	Focus of the research was on tailored interventions, no instruments were listed	No statistics described	Certain patient characteristics that are associated with poor self-management capacity (age, gender, ethnicity, disease severity, number of comorbidities) do not influence effectiveness of a given intervention and other characteristics (low: income, literacy, education, baseline self-management capacity) are indicators of patients with a high likelihood	+ underlines complexity of tailoring SM interventions - low level of evidence, this is not a true meta-analysis; does not even lists study limitations

					for success. The degree to which interventions are explicitly tailored is marginal. C	
Boyde, Peters, New, Hwang, Ha, and Korczyk (2017), Australia	To determine the effectiveness of a multimedia educational intervention for patients with heart failure in reducing unplanned hospital readmissions, SC abilities, HF knowledge	RCT, single center hospital 200 patients	Dutch Heart Failure Knowledge Scale (DHFKS) and SCHFI	Multiple statistics: Pearson's chi squared (categorical data) and student's *t*-tests (numerical data) Kolmogorov–Smirnov test. Mann–Whitney *U* test and the Friedman test post-hoc analysis using Wilcoxon signed-rank tests with a Bonferroni correction	Contradictory findings: educational intervention reduced all-cause unplanned hospital readmissions but there were no group differences in knowledge and self-care scores A	+ longitudinal study – 12 months follow up; methodologicall y done well - single center – hard to generalize, the study never elaborated on the quality of their education's DVD

Boyne, Vrijhoef Spreeuwenberg, De Weerd, Kragten, and Gorgels (2014) Netherlands	to analyze the effects of telemonitoring on disease specific knowledge, SE, self-care and adherence	RCT outpatients from 3 hospitals	the Dutch Heart Failure Knowledge Scale; European Heart Failure Self-Care Behavior Scale; Barnason Efficacy Expectation Scale assessed self-efficacy; the Heart Failure Compliance Scale	Multiple statistics: Student t-test and Mann-Whitney U test; generalized estimating equations analysis	improved knowledge of HF, self-care abilities, and adherence with daily weights and fluid intake, physical activities, and medication adherence A	+multi-site, large enrollment - attrition
Britz and Dunn (2010), USA	to determine if there were specific self-care deficits among patients with heart failure at the time of discharge	Cross-sectional, descriptive study 30 hospitalized HF patients	Minnesota Living with Heart Failure questionnaires SCHFI	Bivariate correlations	SC confidence and perceived better health were significantly related to improved QOL; females had higher total SC scores than males C	+conceptual framework - small sample size
Cockayne et al., (2014), UK	To examine effectiveness of behavioral SM manual on readmissions/admissions	RCT, 260 symptomatic HF patients	The Minnesota Living with Heart Failure (MLHF), EQ5D;	ANCOVA; a repeated measures multilevel regression	SM program produced no difference in HF	+ reveals important evidence that SM interventions not always work

	, QOL, SM, caregiver's QOL		European heart-failure self-care behavior scale and the Hospital, Anxiety and Depression Scale (HAD)	model	admission/readmissio n to the hospital, or QOL, or SM A	- intervention and control groups were skewed in size
De Souza et al. (2014), Brazil	To evaluate the clinical efficacy of a nurse-based SM strategy involving home visits and telephone reinforcement after HF admission	RCT 252 HF patients	European Heart Failure Self Care Behavior Scale; unspecified 14-item questionnaire about HF	Multiple statistics: Student's t tests, Mann-Whitney U tests, Fisher's exact tests, or Pearson $\chi 2$. Kaplan–Meier survival curves	HF knowledge and HF self-care were significantly increased; the composite endpoint of a first HF-related visit to the ED, hospital readmission, or all-cause death was decreased A	- question about statistical significance of findings, combined point was statistically significant, but not each of points independently +implications to cost effectiveness of their interventions
Dewalt et al. (2012), USA	to compare the effects of two different amounts of self-care training on the incidence of all-cause hospitalization and death incidence of HF-related hospitalizations and	Multi-site RCT 605 HF outpatients	Short-Test of Functional Health Literacy in Adults Heart Failure Symptom Scale	Multiple statistics: a Wald test Hazard ratios, Confidence Intervals	The incidence of all-cause hospitalization and death did not differ between intensive intervention and single session groups.	+ multi-site, longitudinal for 12 mo - attrition, statistics not well described

	HFQOL				A	
Ditewig et al. (2010), Netherlands	To examine the effectiveness of self-management interventions compared to usual care on mortality, all-cause hospital readmissions, chronic heart failure hospitalization rate and quality of life in patients with chronic heart failure	A systematic review of 19 RCT over 4,000 patients	Studies were assessed for: methodological quality; effect of SM on mortality; all cause hospital readmission; CHF hospitalization rate; on QoL	No statistics use, but statistics used in 19 RCTs were analyzed	effectiveness of SM interventions in CHF patients shows a + effect, although not always significant, on the reduction of all-cause hospital readmitted patients and due to CHF, decrease in mortality and increasing QOL. B	+ good analysis, shows methodological shortcomings of many studies, gives expertise in CHF SM research - no control over what data have been collected, and how.
Dracup et al. (2014), USA	To determine the impact of an SM educational intervention on the composite end point of HF rehospitalization and cardiac death in rural patients	RCT, multi-site 661 outpatients	Mini-Cog test, clock-drawing test; Charlson Comorbidity Index; HF Knowledge Scale; the Short Test of Functional Health Literacy in Adults; European HF Self-Care Behavior Scale	$\chi 2$ or 1-way ANOVA; intent-to-treat strategy; a linear mixed-models' analysis; Cox proportional hazards estimates of the survival curves; The Wald	Although a face-to-face education intervention increased SM behaviors and decreased cardiac death in 2 groups, the intervention did not significantly decrease the combined end-point of cardiac death and hospitalization for HF. A	+ well designed multi-center longitudinal RTC +2 year follow up + rural population -complicated design, generalizability to urban population

				statistic for survival		
Jaarsma et al. (2013), multi-country study	To describe self-care behaviors of patients from 15 countries across three continents	A secondary analysis of data on HF self-care pooled from 22 samples of HF patients across 15 countries, 5964 HF patients	SCHFI; European HF SC Behavioral Scale	Descriptive statistics	SC behaviors are sub-optimal in heart failure patients and need to be improved worldwide. B-C	+ large data sets, comparing HF SC internationally on a large scale - secondary data, have no control over the collected data
Jonkman et al. (2016), multiple countries	To evaluate the effectiveness of SM interventions on HF-related QoL or generic QoL, HF-related or all-cause hospitalization, and all-cause mortality and to identify subgroups of patients with HF who respond differently to such interventions	Meta-analysis 20 RCTs, representing 5624 patients in total	HF-QoL generic QoL	HR with Cox proportional-hazard models	Protective effects of self-management interventions on time to the combined end point of HF-related hospitalization or all cause death, HF-related hospitalization alone, and HF-QOL A	+ analysis of large data sets - takes time and effort; potential for confounding variables
Kato et al. (2016), Japan	To evaluate the effectiveness of a pilot SC HF program before hospital discharge	Pilot RCT 38 hospitalized HF patients	European Heart Failure Self-Care Behavior Scale	Multiple statistics: Student's t-test	HF self-management program delivered by multidisciplinary team before discharge from	+ article is very well and logically written and easy to

	combined outcomes	Japanese HF knowledge scale	Japanese HF knowledge scale	or the Mann–Whitney U-test the chi-square test or Fisher's exact test; Kaplan–Meier survival curve analysis; Cox proportional-hazard model	the hospital showed mild reduction in HF hospitalization and cardiac death but there were no differences in HF self-care behavior. B	follow-up; longitudinal 2 yrs follow-up - pilot study, small patient sample
Lee and Riegel (2017), USA	To describe the research conducted on HF symptom perception to further understanding of this new concept	Integrative literature review; 21 studies	None listed	None listed	Use of a symptom diary improved HF self-care, symptom distress and functional class, and decreased mortality, hospital stay, and medical costs. Poor symptoms recognition as part of self-care was a reason for delaying care. Barriers such as lack of support, limited finances, poor access to health care, and fear	+ conceptual framework; quantitative and qualitative studies included - low level of evidence, no instruments listed or how studies were assessed methodologicall y

					of hospitalization impeded good self-care strategies and resulted in HF exacerbation. C	
Lee et al. (2018), USA	To identify patterns of self-care behaviors in HF patients and their association with clinical events.	Secondary analysis of prospective, non-experimental, cohort study, 459 community dwelling adults – convenience sample	SCHFI European Heart Failure Self-care Behavior scale, Charlson Comorbidity Index, Minnesota Living with Heart Failure Questionnaire	F-statistics from analysis of variance, $\chi 2$, and K-Wallis tests Cox proportional hazards modeling	Subjects who had higher self-management behavior had less clinical events than those with poor SM behavior or asymptomatic patients. C	+ large sample size, nursing implications for practice - Non-experimental design, convenience sample, complicated design so hard to follow explanations, no explicit theoretical framework
Lee, Moser, Lennie, and Riegel (2011)	To describe the significance of HF self-care management in estimating the risks of all-cause mortality, hospitalizations, or emergency-room admissions.	A secondary analysis 195 patients pulled from prior 3 studies	Charlson comorbidity index Duke Activity Status Index Medical Outcomes Study specific adherence scale	Multiple statistics: Student's t tests, Mann-Whitney U tests, Fisher's exact tests, or Pearson	Persons more engaged in HF self-care management had a 56% reduction in the risk of all-cause mortality, hospitalization or emergency room admission than	- in secondary analysis, no control over study population or study design + analysis of large data sets, allows to explore effectiveness of

			SCHFI	$\chi 2$ Hierarchical Cox proportional hazards modeling	persons who were less engaged. Symptomatic HF patients who practice above average self-management had an event-free survival benefit similar to that of symptom-free HF patients. A	SM; reducing the time and cost of doing research
Navidian et al. (2015), Iran	to evaluate the effect of SC training on depressed and non-depressed hospitalized HF patients; the negative effects of depression on the level of learning SC behaviors	Quasi-experimental study -Non-Randomized Between-Group Design; purposive sampling 70 hospitalized pts	Beck Depression Inventory; Self-Care Behaviors Questionnaire	independent-samples and paired-sample t tests, Chi square, ANCOVA	SC behavior education had lower effects on the depressed patients with heart failure B	+ purpose of the trial depression in HF patients - no control group, comparison between depressed and non-depressed pts
Otsu and Moriyama (2012), Japan	What is the effect of HF SM program on medical costs and deterioration of outpatients with CHF	RCT, convenience sample	MacNew- QOL questionnaire	Repeated two-way ANOVA	Program was effective up to 24 months. A	+ measured objective markers and clinical indicators of CHF as outcomes

						- convenience sample
Riegel et al., 2018, USA	To explore symptom perception in patients with chronic HF.	a longitudinal sequential explanatory mixed methods Qual>quan 36 outpatients, adults	intrathoracic impedance by Optivol® Heart Failure Somatic Perception Scale; 7-item Multidimensional Fatigue Inventory A semi-structured interview Barratt Simplified Measure of Social Status Iowa Gambling Task Patient Health Questionnaire SCHFI	Quan: latent case analysis; descriptive statistics Qual: content thematic analysis; Within-case analysis triangulation	mismatch between symptoms and hemodynamics in a subset of patients, especially in younger age most SC savvy patients were not able to avoid a HF hospitalization	+ triangulation, done well methodologically -high dropout rate -no theoretical framework, sample is from one clinic – generalizability is limited.
Riegel, Dickson, Kuhn,	To describe HF self-care in men and women and to identify gender-specific barriers and facilitators	A cross-sectional, comparative mixed methods study	Charlson Comorbidity Index; SCHFI; Multidimensional Scale of	Qual: within-case analysis; within-in case and across-case	No consistent gender-specific differences in self-care practices C	+ theoretical framework, triangulation used - sample size

Page, and Worrall-Carter (2010), Australia	influencing HF self-care	Qual>quan; 27 adults (8 women) with HF	Perceived Social Support; 9-item Patient Health Questionnaire; Brief Symptom Inventory (BSI)	analysis; Quan: no statistics described integration of Both: with triangulation Semi-structured interviews;		skewed 8 women and 19 men, no statistics for quantitative arm is described
Riegel, Vaughan - Dickson, Goldberg, and Deatrick (2007)	To describe and understand how expertise in HF self-care develops	A mixed-methods (Qual > quant) design, 29 outpatients	Charlson comorbidity Index; SCHFI; Probed Memory Recall Test; Digit Symbol Substitution Test; Epworth Sleepiness Scale; McMaster Family Assessment Device; Patient Health Questionnaire PHQ-9	Quant: within-case analysis Qual: ANOVA and chi-square. Mixed – triangulation.	SC is poor in hospitalized persons with HF C	+ well done methodologicall y - no theoretical framework, sample is from one clinic – generalizability is limited.
Shao, Chang, Edwards, Shyu, and Chen,	Effect of SM intervention on SE for salt and fluid control and	RCT HF outpatients in 2 clinics	Self- Efficacy for Salt and Fluid Control scale;	repeated-measures ANOVA	SM intervention was effective in improving the SE of	- short duration – 3 months +multi-site study

(2013) Taiwan	HF SM and health services use		HF SM behavior scale; HF symptoms distress scale	Mann-Whitney U test	HF patients for controlling salt and fluid intake, and SM behavior and in decreasing HF symptom distress, but not in reducing health service use B	
Shively et al. (2013), USA	What is the efficacy of a SM patient activation intervention on SC management, hospitalizations, and ED visits in patients with HF	RCT, convenience sample, single-site VA hospital, 84 pts	Patient activation measure; SCHFI, Medical outcomes study specific adherence scale	ANOVA	Participants in the intervention group had increased SM behavior and fewer hospitalizations A or B	+ used tailored interventions - complicated design, hard to follow conclusions, convenience sample, attrition
Smeulders et al. (2010), Netherlands	To assess the effects of the CDSMP on psychosocial attributes, self-care behavior and QOL among HF patients	RCT, multi-site 317 outpatients	General Self-Efficacy Scale, Cardiac Self-Efficacy Questionnaire; a mastery scale; The Coping with Symptoms Scale; European Heart Failure Self-Care Behavior Scale; RAND 36-item	Chi-square tests, Mann–Whitney U-tests and t-tests for independent samples mixed-effects; mixed linear regression models	The effects of the program were limited and did not last over time A	+theoretical framework, large multi-site - intervention group was much larger than control group

			Health Survey; Kansas City Cardiomyopathy Questionnaire; Hospital Anxiety and Depression Scale	intention-to-treat principle		
Spaling, Currie, Strachan, Harkness, and Clark (2015), UK and Canada	To generate patient-focused recommendations to enhance support of heart failure self-care by examining patients' experiences, perspectives and self-care behaviors.	Systematic review and qualitative interpretive synthesis of 37 qualitative studies, 1343 patients	Critical Appraisal Skills Program (CASP) Qualitative Appraisal Too	A multi-stage analytic process	Patients' knowledge of the domains of HF SC remains low; attempts to manage HF were based on how patients 'felt' rather than clinical indicators of worsening symptoms. C	+ large data, underlined patients' complexity of HF SC; - since it is a review of previously collected data, no control how the data was collected
Stewart et al. (2016)	To provide a comprehensive LR of the most common conditions requiring concurrent management in patients with HF. 2. To articulate a framework for improving HF health outcomes; 194 papers	Literature review of what conditions most affect HF and framework to improve outcomes in HF	None	none	Multimorbidity in HF is common C	+ formulates new framework, argues for complexity if HF -Non-experimental design, low level of evidence

Strachan, Currie, Harkness, Spaling, and Clark, A. M. (2014), UK and Canada	To identify the main contextual factors and processes that influence patients' self-care of heart failure (HF).	Qualitative meta-synthesis; **4**5 qualitative studies; 1,398 patients; 180 caregivers, and 63 health professionals	Critical Appraisal Skills Programme (CASP) qualitative appraisal tool	A 4-stage process of qualitative studies synthesis by Noblit and Hare.	Caregivers; social networks and social support; place; finances and financial capacity; work and occupation; and HF support groups and programs influenced HF SC in the studies C	+ large data set, - data depends on quality of the studies
Tawalbeh (2018) Jordan	What is the effect of cardiac education program on Self-Care Behaviors	Quasi-experimental pre-test/post-test convenience sample 127 pts	Dutch HF Scale, SCHFI, knowledge scale	Repeated-measures ANOVA	Education program helps improve knowledge and self-care among patients with heart failure; A	+nursing implications - convenience sampling, self-questionnaires, short time for follow up
Tsai, Wang, Lee, Tsai, and Chen (2015), Taiwan	To explore the important determinants of self-care decision-making in inpatients with heart failure.	A cross-sectional correlational research design; non-probability sampling - 71 inpatients	the Dutch Heart Failure Knowledge Scale; SCHFI	t-tests and ANOVA	Poor HF knowledge and improper performance of SC in patients; HF knowledge, having a spouse and admission frequency were shown to be important	+ easy to follow findings; - theoretical framework

					determinants of self-care confidence C	
Tung et al (2013), Taiwan	To test the effectiveness of SM intervention in HF patients and examine the relationship between self-care ability and quality of life.	Quasi-experimental design, convenience sample	Demographics questionnaire, SCHFI, Minnesota Living with HF Questionnaire	The generalized estimating equations (GEEs) model, Mann-Whitney U test	Intervention group - better self-maintenance and SM and QOL up to 2 months' post intervention B	+ well conducted study, has nursing implications - convenience sample, short duration – 2 mo
Wu, Reilly, Holland, Higgins, Clark, and Dunbar (2017), USA	To explore how health literacy levels of patients with HF and their FMs influence HF knowledge and SC behaviors	A secondary data analysis of previous RCT, 170 patient–FM pairs	The Rapid Estimate of Adult Literacy in Medicine; the Atlanta Heart Failure Knowledge Test; Morisky Medication Adherence Scale; 24-hr urinary sodium	Multiple statistics: Independent t tests, Mann–Whitney nonparametric tests; Spearman's correlation, and chi-square tests of independence; ANOVA; Multivariate linear regression	In order to improve HF patients' SC, HC providers should assess patients' and family members' health literacy levels, provide understandable and tailored education to both patients and FMs, and especially target the group with highest risk when both patients and family members have low health literacy. C	+one of the few studies that explores SC management in both patients and caregivers at the same time - the data was collected 10 yrs ago; the measure of medication adherence was by self-report, may not be reliable

Xu et al. (2018), USA	To explore the association of self-care decision making variables with (1) rehospitalization within 30 days of discharge and (2) delay in seeking medical assistance (delayed decision making)	A cross-sectional, explanatory sequential mixed methods design Qual>quan surveyed 127 hospitalized HF patients and interviewed 15	Mini-Cog test Dutch HF Knowledge Scale; Short-form Test of Functional Health Literacy; Center for Epidemiologic Studies-101; Decision Regret scale; SCHFI; Charleston Comorbidity Index Medical Outcomes Study (MOS) Social Support Scale-Short Version	t tests or Fisher exact; Backward stepwise logistic regression qualitative, descriptive analysis; congruence between the quantitative findings and qualitative data put in matrix	Patients with high depressive symptoms were more likely to delay going to the hospital and be rehospitalized within 30 days of their last hospitalization; Patients with high self-care contacted outpatient healthcare professionals for advice when symptoms worsened and were less likely to be rehospitalized within 30 days. C	+ theoretical framework -small survey sample may have increased the likelihood of a type 1 error - attrition, incomplete medical charts surveys

Abbreviations: ANOVA – analysis of variance, CHF – congestive heart failure, ED -emergency department; HF – heart failure, IPD – individual patient data, QoL - quality of life, Quant – quantitative, Qual – qualitative, Pts – patients, RCT – randomized controlled trial, SC – self-care, SCHFI self-care heart failure index, SM- self-management, VA veteran administration

Manuscript One: Heart Failure Self-Management, Integrative Literature Review

Background: Heart failure (HF) is a growing public health problem. Self-management (SM) of heart failure aids in preventing HF exacerbation and risk of hospitalizations. Extensive scholarly work has been done to increase our understanding in whom self-management is problematic and in whom SM interventions are most effective but the gaps exist.

Purpose. The purpose of this literature review is to integrate literature about HF self-management and to identify gaps in nursing knowledge around HF self-management.

Conclusions. A computer-assisted literature search was conducted by using CINAHL, PubMed, and Google Scholar. The terms used for search were *self-management, self-care*, and *heart failure*, in full-text English language articles in peer reviewed journals with a 10-year time limit since the date of publication. The search yielded thirty-two articles, comprised of experimental, cross-sectional, mixed methods, qualitative studies, meta-synthesis of qualitative studies, and integrative literature reviews. SM interventions are aimed at improving patient outcomes and are successful in increasing HF SM behavior. However, the outcomes of SM on lowering hospitalizations have mixed evidence. There is a gap in nursing knowledge of how to improve HF symptom recognition. A knowledge gap exists what contextual conditions should be incorporated in tailored SM interventions and which contextual factors are associated with successful SM behavior.

Clinical Implications. The literature review shows that heart failure SM is complex. Addressing a gap of nursing knowledge in patient attributes of HF self-management behavior has important implications for future nursing research as it can inform success of nursing interventions.

Key Words: heart failure, self-management, self-care, gaps in nursing knowledge

"What's New?"

- This literature review summarizes HF self-management evidence, including both quantitative and qualitative research, and examines gaps in nursing knowledge.
- This literature review combines evidence for both concepts of self-care and self-management in heart failure
- SM interventions do not always prevent HF hospitalizations; and there is inconsistent evidence which patient characteristics impede successful HF self-management behavior. These gaps should guide future nursing research.

Prevalence and Significance

Heart failure (HF) is a growing public health problem. Epidemiologically, HF is a common chronic medical condition with an annual incidence of approximately 915,000 cases per year. Annual care relating to HF is responsible for approximately 1.75 million office visits and more than 0.5 million emergency department visits (Neubauer, Gray, and Hemann, 2018). David, Howard, Dalton, and Britting (2018) state that all-cause unplanned readmissions cost Medicare $26 billion per year. Among these, heart failure (HF) exacerbation is the cause of nearly 80,000 unplanned hospital readmissions each year. HF is also Medicare's leading healthcare expenditure amounting to $31 billion annually. Although only 14% of Medicare beneficiaries are diagnosed with HF, they account for 43% of Medicare spending (David et al., 2018).

Literature Review

The literature review for this study was conducted by computer-assisted search of

multiple databases including the Cumulative Index to Nursing and Allied Health (CINAHL), PubMed, and Google Scholar. The area of the science central to the study is the science of self-management, with a focus on cardiovascular nursing and care for patients diagnosed with HF. The literature search was limited to studies reported during the time frame of years 2007 through 2018. The articles selected were published in English, were peer reviewed, and included adult participants.

The author searched, using terms *self-management, self-care*, combined with *heart failure*, for full text articles in nursing and medical peer reviewed journals. The terms *self-management* and *self-care* are frequently used interchangeably. The initial search using *self-management* and *self-care* displayed 103 articles. When the heart failure term was applied, the number of articles was reduced to 54. Out of those, 32 articles were most pertinent to the topic of investigation.

Literature Search Results

The identified articles that were appropriate to include in the literature review are listed in Table 2.1. There were 17 experimental, 2 cross-sectional, 3 mixed methods, 1 qualitative study, 1 systematic review and 1 meta-synthesis of qualitative studies, 3 integrative literature reviews, and 3 secondary analyses of previous original research data were also included. Initial analysis of the included studies is organized into 2 main sub-concepts of outcomes of HF self-management interventions and characteristics of patients who engaged in HF self-management.

SM Interventions and Patients Outcomes

Many randomized controlled studies focus on improving patients' outcomes with HF self-management interventions. When the outcome of the study is self-management behaviors,

most interventions are successful. These heart failure SM interventions center on patients' education about the disease, daily weight, blood pressure monitoring, and self-medication.

Tawalbeh (2018) reported that a cardiac education program focused on Self-Care Behaviors (SCB) showed that knowledge of heart failure and SCBs including management, maintenance, and confidence were significantly improved at 1 and 3 months after the program application. Positive outcomes of HF self-management reported by Otsu and Moriyama (2012). Their educational HF SM program was effective in sustaining self-management skills and activities up to 24 months. The outcomes that the authors investigated were compliance with a sodium-restricted diet, with medicine administration, compliance with exercise, self-monitoring of weight and deterioration in the symptoms of HF. Randomized controlled trial (RCT) conducted by Shively et al. (2013) concluded that tailored heart failure SM intervention among patients with chronic HF increased patients' engagement in SM behavior and decreased hospitalizations. Shao, Chang, Edwards, Shyu, and Chen, (2013) conducted a randomized controlled trial to determine the effectiveness of a self-management intervention on self-efficacy for salt and fluid control, HF-related self-management behaviors and symptoms, and health service use in older outpatients with HF in Taiwan. Their conclusion was that the SM intervention was effective in improving the self-efficacy of Taiwanese HF patients for controlling salt and fluid intake, and self-management behavior and in decreasing HF symptom distress, but not in reducing health service use. The participants in the study had a low baseline level of self-management behavior. Tung et al. (2013) reported that as the result of their SM intervention, participants in the experimental group achieved better self-maintenance and self-management and QOL up to 2 months' post intervention. Boyne, Vrijhoef Spreeuwenberg, De Weerd, Kragten, and Gorgels (2014) used telehealth as intervention and reported that their

intervention improved knowledge of HF, self-care abilities, and adherence to daily weight monitoring, fluid intake, physical activity, and medications.

Studies which focus on outcomes of self-management interventions on lowering hospitalizations achieved mixed results. Lee et al. (2018) conducted a study to define clinical events in patients who engaged in self-management behavior vs patients who had poor self-management behavior and symptom recognition, and a third group of asymptomatic patients. Their conclusion was that subjects who had higher self-management behavior had fewer clinical events compared to those with poor SM behavior or group of asymptomatic patients. Similarly, Lee, Moser, Lennie, and Riegel (2011) compared the risk of all-cause mortality, hospitalization or emergency room admission among HF patients who practiced above average self-management, those who practiced below average self-care management, and those who were symptom-free. They concluded that persons more engaged in HF self-care management had a 56% reduction in the risk of all-cause mortality, hospitalization or emergency room admission than persons who were less engaged. Persons with HF who were more engaged in self-management had an event risk nearly equivalent to those who were symptom-free, despite being a group with more comorbidity. Symptomatic HF patients who practiced above average self-management had an event-free survival benefit similar to that of symptom-free HF patients.

De Souza et al. (2014) reported that because of post-discharge, nurse-led SM intervention, HF knowledge and HF self-care were significantly increased in the intervention group during follow-up visits. In addition, the composite endpoint of a first HF-related visit to the emergency department, hospital readmission, or all-cause death was decreased in the intervention group. Jonkman et al. (2016) reported protective effects of self-management interventions on time to the combined end point of HF-related hospitalization or all cause death,

HF-related hospitalization alone, and HF-QOL.

Al-Sutari and Ahmad (2015) reported that their SM educational program for HF patients lowered the frequency of emergency room visits and increased self-care behaviors, but it did not lower frequencies of hospitalizations or patient mortality. Kato et al. (2016) reported that their HF self-management program delivered by multidisciplinary team before discharge from the hospital showed mild reduction in HF hospitalization and cardiac death with no differences in HF self-care behavior. Ditewig et al. (2010) conducted a systematic review of 19 RCTs and reported that the effectiveness of self-management interventions in patients with HF had a positive though not always significant effect on the reduction of all-cause hospital readmitssions and due to HF, decrease in mortality and an increase in QOL.

On the other hand, Cockayne, Pattenden, Worthy, Richardson, and Lewin (2014) reported their self-management program produced no differences in HF admissions and readmissions to the hospital. Boyde, Peters, New, Hwang, Ha, and Korczyk (2017) conducted RCT with inconclusive findings. Their educational intervention reduced all-cause unplanned hospital readmissions for patients with HF, but produced no group differences in knowledge and self-care scores. Thus, in this study proximal outcomes were not achieved, however there was a difference in distal outcomes of hospital readmissions. Dewalt et al. (2012) conducted an RCT to define the impact of self-care training on reduction of hospitalizations for heart failure patients, and whether or not more intensive intervention benefited vulnerable patients, including those with low literacy. Their conclusion was the incidence of all-cause hospitalization and death did not differ between intensive intervention and single session groups. Smeulders et al. (2010) conducted an RCT to assess the effects of a chronic disease SM program on psychosocial attributes, self-care behaviors and cardiac specific QOL. The study showed no significant effect

at either 6 or 12 months and concluded that achieving long-term behavioral change in SM of HF patients may be challenging (as patients constantly needed to adapt to a condition which deteriorates progressively). Finally, Dracup et al. (2014) conducted an RCT to determine the impact of two different intensity levels of HF educational interventions on the composite endpoint of HF rehospitalizations and cardiac death in patients with heart failure (HF) who live in rural areas. Study patients were followed for two years. The authors reported that although a face-to-face education increased SM behaviors and decreased cardiac death in 2 intervention groups, the intervention did not significantly decrease the combined end-point of cardiac death and hospitalization for HF.

These studies show that SM interventions are aimed at improving HF outcomes. Despite a plethora of nursing experimental research in self-management, the outcomes sought are frequently different, measured differently, thus they are hard to compare. There is a gap in nursing knowledge as what constitutes the most effective SM intervention for patients with HF. Nursing researchers need a greater understanding of why SM interventions are successful or not. Are there specific patient attributes that make these well-intentioned interventions ineffective? Why, despite healthcare professionals' best efforts to improve self-management behaviors, do patients demonstrate inability to self-manage HF at home; and what are the consequences? Non-interventional studies explore these issues.

Self-Management and Patients Characteristics

The consequences of the inability to SM heart failure at home for patients and for the healthcare system is increased hospital admissions and readmissions and increased cost of healthcare. Per Yancy et al. (2013) hospital HF readmissions significantly contribute to the economic burden, with evidence that 30–50 % of patients are readmitted within six months.

Contributing factors include patients' difficulty to perform self-management behavioral activities as well as failure to adhere to their medical regimen, suggesting that at least some of these readmissions are preventable.

Many nursing scholars looked at breakdown in HF self-management, and attempted to explain it. Xu et al. (2018) conducted a mixed-methods cross-sectional study to explore association of self-care decision making to rehospitalization within 30 days of discharge and delays in seeking medical assistance. Although the relationship between HF self-care and 30-day rehospitalization was not statistically significant, participants who had high self-care scores, high capability to SM, and were not hospitalized within 30 days, demonstrated different behavior and were proactive in seeking outpatient medical attention from healthcare providers. Depressive symptoms predicted 30 days rehospitalizations. Similarly, Navidian Yaghoubinia, Ganjali, and Khoshsimaee (2015) reported that self-care behavior education had lower effects on the depressed patients with heart failure. Stewart et al. (2016) reported that multimorbidity contributed to the inability of HF self-management the most. The authors reflected that due to poor self-management, patients face adverse events and hospitalizations.

The focus of many nursing researchers is to address characteristics of the hospitalized HF patients, and see which self-management skills can best predict patients' inabilities to SM and hospitalizations. Britz and Dunn (2010) reported that patients with HF who demonstrated decreased self-management abilities in area of medication compliance, following a low-sodium diet, maintaining fluid restrictions, weighing themselves daily, and identifying the early warning symptoms of worsening heart failure, had frequent hospitalizations and a decreased quality of life. The authors reported that self-care confidence and perceived better health were found to be significantly related to improved quality of life in hospitalized patients. One of the conclusions

was that by developing a greater sense of confidence in their own abilities to self-manage their disease, many patients will be able to avoid an acute onset of heart failure and prevent hospital readmissions. In their study gender and age predicted self-care behaviors. Contrary findings were presented by Riegel, Dickson, Kuhn, Page, and Worrall-Carter (2010). Their mixed-methods study revealed that there were no consistent gender-specific differences in self-care abilities to manage HF at home. Tsai, Wang, Lee, Tsai, and Chen (2015) explored the determinants of self-care (SC) decision-making in hospitalized patients with HF in Taiwan. Their findings suggested a very poor self-care status among the participants of this study. Age, gender and comorbidity did not predict SC. No gender differences in SM went along with Riegel et al. (2010) findings. Tsai and coauthors found that participants who had more frequent admissions, had better SC scores and HF knowledge, meaning that patients acquired ability to self-manage while hospitalized. They suggested that low self-care engagement might therefore result in frequent hospitalizations and early comprehensive patient education to help patients better engage in self-care is needed to prevent patients from merely learning how to perform self-care from repeated admissions. Riegel et al. (2018) also observed that self-care is poor in persons with HF and that even the most self-care knowledgeable patients were not always able to avoid a HF hospitalization, concurring with Tsai et al. (2015) findings.

Jaarsma et al. (2013) compared patient's self-care HF behaviors from 15 different countries and noted that most self-care behaviors are poor and can be improved in HF patients. Across countries there was wide variability in HF self-care, but regardless of country selected there was notably poor adherence to most self-care behaviors. Across all samples, there was high self-care in medication taking, a consistently low level of self-care in exercise and regular weight monitoring and there were large variations in adherence to salt restriction. Adherence to

a low salt diet could have been related to difference in national HF guidelines, local food policies, available resources, and individual responses to suggested dietary changes.

Spaling, Currie, Strachan, Harkness, and Clark (2015) conducted a systematic review of qualitative studies of self-care in HF patients. One of their conclusions was that patients' knowledge of the domains of heart failure self-care remains low (as in Jaarsma et al., 2013, Tsai et al., 2015), particularly with respect to medications, diet, fluid management and timely help-seeking. According to the authors, merely providing patients with more sophisticated knowledge of HF is unlikely to improve HF self-care, and will not increase SM ability. Components of these interventions need to provide SM education more relevant and adaptive to the personal context of each patient (Spaling et al., 2015). Strachan, Currie, Harkness, Spaling, and Clark (2014) conducted a qualitative meta-synthesis to examine contextual factors that influence engagement in self-care, and should be integrated into the promotion of self-care. They were: caregivers, social networks and social support, place, finances and financial capacity, work and occupation, and HF support groups and programs.

Lee and Riegel (2017) examined symptom perceptions as a domain of HF self-care. One of the consequences of inability to SM of HF is poor symptom recognition. Per their review most HF patients had difficulty recognizing an exacerbation of symptoms. Poor symptoms recognition as part of self-care was a reason for delaying care. Barriers such as lack of support, limited finances, poor access to health care, and fear of hospitalization impeded good self-care strategies and resulted in HF exacerbation. The authors reported that factors affecting self-care and inability of symptom recognition included age, comorbidity, living with others, educational status, uncertainty, acute symptom duration, gradual symptom progression, NYHA (New York Heart Association) class, and the total number of previous hospitalizations. Similarly,

Athilingam, Jenkins, Zumpano, and Labrador (2018) reported that patients found the obligation of self-care surveillance overwhelming. The most common reasons for not seeking early treatment included: symptom uncertainty and patients' perception that early symptoms were not intense enough that warranted action or seeking care.

Bos-Touwen and colleagues (2015) conducted systematic review of studies incorporating tailoring into self-management interventions and patient characteristics associated with self-management abilities and success of interventions. Their conclusion was that improved self-management ability contributed to better HF-related outcomes and reduction in hospitalizations and mortality. Interventions aimed at supporting patients in increasing these competences have shown to be successful, however, not in all patients. Certain patient characteristics associated with poor self-management ability did not influence effectiveness of a given intervention (i.e., age, gender, ethnicity, disease severity, number of comorbidities) and that other characteristics (low: income, literacy, education, baseline self-management capacity) in fact were indicators of patients with a high likelihood for success. These findings validated Yancy's et al. (2013) HF guideline statement that patient characteristics may be important predictors of SM and hospitalization.

Finally, Wu, Reilly, Holland, Higgins, Clark, and Dunbar (2017) explored how health literacy levels of patients with HF and their family members (FM) influenced HF knowledge and self-care abilities. They concluded that in order to improve HF patients' self-care, health care providers should assess patients' and family members' health literacy levels, provide understandable and tailored education to both patients and FMs, and should selectively target groups at highest risk when both patients and family members have low health literacy. Wu et al. (2017) findings concur with Bos-Touwen et al. (2015) findings that low-literacy is one of the

indicators of patients with a high likelihood for success with SM interventions.

Discussion

The literature review shows that patient heart failure self-management is complex. Evidence is mixed. There are gaps in nursing knowledge as to what constitutes effective strategies for successful outcomes of SM in HF. Frequently there is a lack of detailed descriptions of the active components driving the intervention (Herber et al., 2018). Many but certainly not all the experimental studies confirmed that education about self-management and therapeutic interventions for heart failure SM work to improve patient outcomes, such as increasing HF SM behavior and patients' well-being, preventing worsening of HF symptoms, and reducing risk of hospitalizations. There are still gaps in nursing knowledge as substantial variations in SM intervention components, mode of delivery, and dose restrict answering what interventions improve HF outcomes. Worsening of heart failure symptoms and hospitalizations are the consequences of inability to manage HF at home for patients with HF and healthcare systems. When SM interventions do not work in preventing hospitalizations and HF readmissions, researchers examine the reasons and gaps in nursing knowledge trying to explain the phenomenon. Several studies (Lee & Riegel, 2017; Lee et al., 2017, Athilingam et al, 2018) show that symptom recognition among HF patients is limited and the patients fail to engage in self-management behavior and there is a gap in nursing knowledge of how to improve HF symptom recognition so the patients apply SM abilities to counteract those symptoms. The primary goal of HF self-management is to improve patients' outcomes such as quality of life, reduce the frequency of HF exacerbations, and extend survival. Addressing these challenges, several researchers suggested using a tailored approach is more effective. The suggestion was to tailor to patient attributes. However, many studies did not specify how the tailoring was done

(Bos-Touwen, 2015). Many of these studies showed contradictory findings what contextual conditions should be incorporated in tailored interventions as some studies reported that age and sex of the participants influenced SM skills, and some refuted this suggestion. Several studies (Bos-Touwen, 2015, Wu et al., 2017) confirmed that the patients with lower SM abilities benefited from these programs the most. The challenges and complexity of SM in HF are especially prominent in qualitative and mixed-methods studies emphasizing patients' efforts to improve their skills.

Integrative literature review demonstrates that only few studies (5 out of 32) used explicit theoretical models, which could have strengthened the research. Overall, the literature review showed that "extensive scientific work has been done to increase our understanding in whom self-management is problematic and in whom self-management interventions are most effective" (Bos-Touwen, 2015, p. 231). Jonkman et al. (2016) remark that specific types of interventions might work better for specific subgroups of patients. The question what works for whom, deserves attention in subsequent research. There is conflicting evidence concerning which contextual factors associated with successful self-management behavior and which patients' characteristics clearly impede successful HF self-management behavior. Addressing a gap in nursing knowledge in patient attributes of HF self-management behavior has important future nursing implications. Using a theoretical framework is essential to future nursing research.

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CHAPTER 3

METHODS

INTRODUCTION

This research is aimed at improving care delivered to people with heart failure. The primary purpose of the study is to advance nursing science by examining the gaps in understanding the attributes of patients with heart failure when they self-manage their disease. This chapter includes a description of the study design, target population, sample size, setting, procedure, eligibility criteria, and measurement tools. Additionally, this chapter includes the human subjects' protection plan, a description of data analysis plan, study safety checks, and potential study limitations.

Research Gap

Overall the literature review, described in chapter 2, suggests that determining contextual factors associated with successful self-management behavior in a population of patients with HF will fill an important gap in nursing understanding of additional ways to help people with HF to self-manage their complex chronic disease (Bos-Touwen et al., 2015, Strachan, Currie, Harkness, Spaling, and Clark, 2014). Despite recommendations of SM, engagement in SM remains low (Young, Barnason, & Kupzyk, 2016). SM is complex behaviors, which are influenced by various factors (Young et al., 2016). Addressing nursing knowledge gaps in patient attributes of HF self-management behavior has important implications and is the focus of this study.

Research Question

Based on a literature review and the concepts derived from the Individual and Family

Self-Management Theory (IFSMT, Ryan, & Sawin, 2009) and applying this theory to HF, the following research question is proposed: what are the associations of the contextual factor of complexity of condition, the SM processes of self-efficacy and self-regulation with self-management behaviors in patients with heart failure?

And the specific research questions are:

1. Does the complexity of condition predict heart failure SM behaviors?
2. Does self-regulation predict heart failure SM behaviors?
3. Does self-efficacy predict heart failure SM behaviors?
4. Do self-regulation and self-efficacy mediate effect of complexity of condition on heart failure SM behaviors?

Hypotheses

Complexity of condition, self-regulation, and self-efficacy predict self-management behaviors in a patient population with New York Heart Association (NYHA) functional class II-III HF. The hypothesis for this study uses the IFSMT as a theoretical framework, and variables are derived from the theory. Ryan and Sawin proposed that testing the theory will improve its clarity and provide an increased awareness as to which concepts mediate and moderate SM.

Self-efficacy and self-regulation are hypothesized to be mediators between complexity of condition and SM behaviors.

Study Design

A descriptive cross-sectional correlational study is used. Hulley, Cummings, Browner, Grady, and Newman, (2013) state that a descriptive study examines the distributions of predictors and outcomes in a population. In a cross-sectional study, the researcher collects all of

the measurements on the single occasion or within a short period of time and draws a sample from the population and looks at the distributions of variables within that sample. "Cross-sectional designs are well suited to the goal of describing variables and their distribution patterns" (Hulley et al., 2013, p. 85). A major advantage of cross-sectional studies is that there is no waiting for the outcome to occur. This makes them fast and inexpensive, and avoids the problem of loss to follow-up.

Sample

The target population for this study is patients with congestive heart failure with preserved or reduced ejection fraction, and who are being seen by providers in cardiology clinic in a large Midwestern hospital. The sample being used is a convenience sample of community dwelling adults in an outpatient cardiology clinic.

Inclusion criteria are individuals older than 18, diagnosed with HF with preserved or reduced left ventricular ejection fraction, having NYHA class II-III heart failure symptoms, who speak and understand English. Study exclusion criteria are individuals with HF having NYHA class I or IV symptoms and patients not understanding the English language. Individuals with Class IV NYHA heart failure symptoms are acutely symptomatic and require intense medical intervention. And individuals with class I NYHA HF are considered to be asymptomatic.

A power analysis was used to determine the sample size needed to protect against Type II error. Using an alpha of 0.05 and a power of 0.80, the estimated sample size is 73 patients.

Variables and Measurement Instruments

In quantitative studies, rigor is determined through an evaluation of the reliability and validity of the tools or instruments utilized in the study. Per Hulley et al. (2013) cross-sectional

studies are used for examining associations, although the choice of which variables to label as predictors and which as outcomes is dependent on the hypotheses. Therefore, for this study the predictor variables are complexity of conditions, self-regulation, and self-efficacy, and the outcome variable is HF self-management. Both self-efficacy and self-regulation however can also be mediating variables. A mediating variable is a variable, which is an intermediate link in the relationship between other variables (Grey, Grove, & Sutherland, 2013). All instruments described below are presented in Appendix A.

The variable **complexity of condition** is measured by the Charlson Comorbidity Index (CCI) (Charlson, Szatrowski, Peterson, & Gold, 1994). The Charlson Comorbidity Index is the most extensively studied comorbidity index for predicting mortality (De Groot, Beckerman, Lankhorst, & Bouter, 2003). It is available for use without permission. The CCI was developed and validated as a measure of 1-year mortality risk and the burden of disease. Comorbidities are weighted from 1 to 6 for mortality risk and disease severity, and then summed to form the total CCI score. A higher Charlson comorbidity score indicates an increased severity of a condition. Conditions with a weight of 1 include: myocardial infarction, congestive heart failure, peripheral vascular disease, cerebrovascular disease, dementia, chronic pulmonary disease, connective tissue disease, ulcer disease, mild liver disease and diabetes. Conditions with a weight of 2 include: hemiplegia, moderate or severe renal disease, diabetes with end organ damage and any malignancy. Moderate or severe liver disease (e.g., cirrhosis with ascites) is given a weight of 3 and metastatic solid tumor or AIDS received a weight of 6 (Charlson et al.,1994). Charlson Comorbidity Index scores of 5 have been associated with a 1-year mortality of 85% (Roffman, Buchanan, & Allison, 2016). This index has substantial validity and reliability testing supporting its use, and will yield ordinal level data. It is not a self-reported questionnaire but a tool

completed by a research nurse from the abstracting of a patient's medical record**.**

Four out of six comparisons with other indices of comorbidity yielded correlation coefficients exceeding 0.40, supporting concurrent validity (De Groot et al., 2003). Traditional construct validity using the known groups method is rarely tested in comorbidity indices (Roffman, Buchanan, & Allison, 2016). Criterion validity (which encompasses concurrent and predictive validity) has been demonstrated for the CCI through comparison to other comorbidity indices and prediction of outcomes (Roffman, Buchanan, & Allison, 2016). Predictive validity was confirmed by finding many significant relationships of the Charlson index with various criterion outcomes, such as mortality, disability, readmissions and length of stay. Test-retest reliability was good with intraclass correlation coefficients of 0.92 ($p < 0.0001$) (Roffman, Buchanan, & Allison, 2016), and inter-rater reliability was moderate to good of 0.74 to 0.945 (De Groot et al.).

The variable **self-regulation** is measured by the Index of Self-Regulation (ISR) (Fleury, 1998). It is available for use without permission via the UWM Self-Management Center web-site. The Index of Self-Regulation (ISR) is a nine-item scale designed to measure individuals' level of self-regulation. Items are formatted using a 5-point Likert scale ranging from 1 - "Strongly Disagree" to 5 - "Strongly Agree". Higher scores are indicative of a higher amount of the concept being measured. Since this study is interested in the concept of self-regulation in patients with HF, the ISR has an appropriate conceptual fit. The tool has substantial validity and reliability testing supporting use, and yields ordinal level data (Yeom, Choi, Beleya, and Fleury, 2011). According to Fleury (1998) three subscales demonstrated internal consistency ranging from 0.73- 0.76. Cronbach's alpha of the whole instrument is 0.87, demonstrating a high reliability of the ISR. Test–retest reliability coefficients of the ISR was 0.73. Content validity

was estimated through panel ratings. Both criteria related and construct validity of the ISR demonstrated correlation 0.20-0.47 and were moderate (Fleury, 1998).

The variable **self-efficacy** is measured by the Self-Efficacy for Managing Chronic Disease (Standford Patient Education Center, 2018). The Self-Efficacy for Managing Chronic Disease 6-Item Scale was developed by the Patient Education Research Center of Stanford University, California, in 1980s, where it was widely used for evaluation of the effect of the self-management of patients with chronic diseases (Wang, Lang, Xuan, Li, & Zhang, 2017). It is available for use without permission. The Short-form CDSES contains six items namely "general disease management" and "symptom management" as these are common across many chronic diseases (Chow & Wong, 2014). For each of the questions, patients choose a score corresponding to the confidence that they can do the tasks regularly at the present time. Items are scored on a 10-point scale, with a higher score indicating better self-management efficacy. The composite score for the scale is the mean of the six items (Lorig, Sobel, Ritter Laurent, & Hobbs, 2001). Since we are interested in the concept of self-efficacy in patients with HF, this tool has an appropriate conceptual fit. The instrument yields ordinal level data. The scale is particularly valuable for use among patients with chronic illness (Chow & Wong, 2014). The Cronbach's alpha coefficient was 0.96 indicating a high internal consistency. Chow and Wong reported substantial content and construct validity of the instrument.

The last variable is **self-management behavior.** It is measured by the SCHFI (Self-Care Heart Failure Index) score (Riegel et al, 2009). It is available for use without permission and it is offered in several languages. This instrument uses a 22 items self-reported questionnaire to assess self-management behaviors in patients with HF. It is a quantitative, ordinal, self-reported, performance-rating scale. Each 3 sub-scales are standardized to a total possible score

of 100 for ease of interpretation. It is designed for a specific population of patients with HF (Riegel, Lee, Dickson, & Carlson, 2009). The Self-Care Maintenance scale has 10 items. It has answers ranging from 1- Never or Rarely to 4- Always or Daily. The SC Management Scale has 6 items, and is scored only if a patient reports shortness of breath or edema. It is a scale with answers from 1 – Not likely to 4 – Very likely, with two questions offering responses from 0 to 4. The third subscale, the SC Confidence scale has 6 items. It is a scale with answers ranging from 1- Not Confident to 4 – Extremely Confident. Higher scores are indicative of a higher amount of the concept being measured. The authors reported Chronbach's alpha for the 3 subscales: for the self-care maintenance it was 0.553, for the self-care management it was 0.597, and for the self-care confidence was 0.827. The SCHFI was tested and has substantial concurrent, construct and convergent validity (Riegel, et al.).

Human Subjects Protection Plan

The study was submitted and approved by two institutional review boards (IRB) – a Midwestern medical school and a large Midwestern University IRBs. The study team consists of a cardiologist, an advanced heart failure physician as a primary investigator, and a Nurse Practitioner at the general outpatient cardiology clinic, as a sub-investigator. Another sub-investigator on the team is a Nursing Professor from a large Midwestern University. The research team also includes six cardiology nurse practitioners, along with three cardiovascular medicine department research nurses. All research team members have Collaborative Institutional Training Initiative (CITI) current certification and extensive human subjects' research experience. The sub-investigator Nurse Practitioner trained other nurse practitioners and research nurses regarding the study protocol, recruitment, and consenting. The Nurse Practitioner or research nurse consents the patient. The process of informed consent is

performed without rush and each patient i given enough time to read through the consent. The patients receive a copy of the consent form with phone numbers of study staff to call back. The patients are informed that if they change their mind, concerning study participation, they have an opportunity to withdraw, and their questionnaires will be destroyed.

The Process of Informed Consent

A copy of the consent form is included in Appendix B. The study staff presents information about the study in the simple language that is easy to understand. The recruiter informs the patient that this study seeks to learn about the characteristics of patients with heart failure in the cardiology clinic. The proposed study does not benefit the patients but helps cardiology providers learn more about how patients self-manage their congestive heart failure and their HF symptoms. Heart failure is a chronic disease. The study staff recognizes that it is not easy for the patients to live with the disease, take many medications, and control the symptoms. Some patients may have difficulties with HF and some may not. This study examines the differences. If doctors and nurses can understand these characteristics of the patients with HF, they can design future education for patients with heart failure better and more efficient. The recruiter explains to each prospective patient that regardless of study participation no part of the patient's medical care changes. They will continue to be seen by their cardiology providers as usual, no matter what the answer is. It is up to the patient to say yes or no. This is a minimal risk study. The study team minimizes main risk to their privacy by protecting their personal information. The patients are offered a small monetary reward – a $5 gift certificate for participation.

Recruitment Plan

The main person leading this study is the cardiology nurse practitioner. She provided submission of required documents to the relevant IRB along with the amendments. She recruited the patients for the study and entered the data into a secure database. Approval for the study was obtained not only from the IRB, but also from the hospital research regulatory body. The study received a grant from Harriet H. Werley Doctoral Student Nursing Research Scholarship Fund.

Recruitment of patients occurred during their routine visits with the cardiology nurse practitioner or with the advanced heart failure physicians. After the nurse practitioner verified the patient eligibility, she approached potential patients for study participation during their visit. Persons who signed the consent form were given questionnaires to complete on site, which took them approximately 15 minutes. Upon completion, they were offered $5 gift certificate. A signed copy of each patient's consent form was e-mailed to regulatory hospital body. The nurse practitioner checked questionnaires for completion. Patients were asked to provide responses for any missing data. Questionnaires were scored by the NP with data entered into the electronic secure database. The patients filled in the Index of Self-Regulation, the Short-form Chronic Disease Self-Efficacy Scales and the SCHFI questionnaires. The Charlson Comorbidity index was completed by the Nurse Practitioner based on patient's health history from the medical records. The medical school statistician performed original power analysis, and helped with statistical analysis using Stata software.

Safety Checks

Each patient was assigned a unique patient identifier that had no meaning external to the study database. The following demographics were collected: age, gender, race, type of heart

failure, the pro B-Type natriuretic peptide values, presence of social support, presence of atrial fibrillation, presence of coronary bypass or valve surgeries, history of stroke and renal disease. The scores for all the questionnaires, Charlson comorbidity index scores, were also recorded in the same database.

Study databases which contained personal identifiers were maintained on secure servers accessible only to authorized members of the research team, each of whom has a user ID and password. Any database fields which contained personal identifiers were deleted prior to sharing the data. To ensure data accuracy, before the analysis, the research staff checked the data for correctness. As an additional safeguard, the frequency distributions of all variables were checked before proceeding with the analysis. Loss of the database was prevented by regular backups and by archiving copies of key versions of the database for future use.

Quality control of data management included oversight of the accuracy and integrity of collecting, entering, editing, and analyzing the data. The statistical team and research staff worked together to make decisions about any needed modifications and kept a log by tracing the history and rationale for modifications.

Data Analysis Plan

Data analysis was conducted using the Stata Version 13 software. Initially, the distributions of each variable were analyzed using frequency distributions, means, and standard deviations. Transformations were used in the presence of skewed distributions. Descriptive statistics were used to describe and summarize sample characteristics. Continuous variables, including complexity of condition, self-regulation, self-efficacy and SCHFI, were described using the mean and standard deviation.

To test the first hypothesis linear regression analysis was performed to determine the

relative contribution of variables in predicting Self-Care Heart Failure Index score. According to Kovach (2016) by using linear regression, the study is more feasible, powerful to find significant (with smaller sample size when including the most significant variables into the model). Such analysis is more parsimonious, which is desired for advancing students' knowledge in doing research.

In the second hypothesis, it was predicted that self-efficacy and self-regulation were mediators between complexity of condition and SM behaviors. Mediating variables are intermediate variables that are links between independent and dependent variables (Gray, Grove, & Sutherland, 2017). Mediating variables are used to understand the process by which two variables are related (MacKinnon, 2011). There are four steps in establishing mediation (Kenny, 2018). Step one is to show that the causal variable, the complexity of condition, is correlated with the outcome, SM behaviors, to indicate that there is an effect to be mediated. Step two is to show that causal variable, complexity of condition, is correlated with the mediators – self-regulation and self-efficacy. Step three is to show that the mediators, self-regulation and self-efficacy, affect the outcome variable SM behaviors. Step four is to establish if self-regulation and self-efficacy completely or partially mediate self-management behaviors. If one or more of the first three steps show non-significant relationships, researchers usually conclude that mediation is not possible or likely (Kenny, 2018). One reason for testing mediation is trying to understand the mechanism through which the causal variable affects the outcome (Kenny, 2018).

Limitations

There are several limitations to this study. The study design is not experimental but cross-sectional. Cross-sectional design yields weaker evidence for causality (Hulley et al., 2013). The study uses self-administered questionnaires. Using self-administered questionnaires

can result in poor or subjective recollection results, which is a form of bias, which threatens internal validity of the study.

The study uses a convenience sample of community dwelling adults in a cardiology clinic at a large Midwest hospital. Convenience sampling violates the random sampling assumption and can threaten study external validity, i.e. research findings are subject to selection bias due to nonrandom selection. Also, this study uses a small sample size and it may have been underpowered due to a small sample size. Generalizations should be done with caution.

Summary

This chapter described methodology of the research, instruments, and limitations. It provided detailed description of human subjects' protection plan, recruitment and data analysis plan, safety checks, and study limitations.

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CHAPTER 4

Study Results

The purpose of this study was to test the concepts of the Individual and Family Self-Management Theory (IFSMT, Ryan & Sawin, 2009) in a sample of patients with heart failure (HF) and to test two hypotheses about predictions and mediations of the concepts and heart failure self-management (SM) behavior. The rationale for this is that this theory was never used in heart failure research. The selected concepts were: complexity of condition, self-regulation, self-efficacy, and self-management behaviors. Based on a literature review and the concepts derived from the Individual and Family Self-Management Theory (Ryan, & Sawin, 2009) and applying the theory to HF, the following two hypotheses were proposed:

The complexity of condition, self-regulation, and self-efficacy will predict self-management behaviors in a sample of patients in New York Heart Association NYHA functional class II-III HF. Self-efficacy and self-regulation are hypothesized to be mediators between complexity of condition and SM behaviors. It was expected that complexity of condition, self-regulation, and self-efficacy would predict self-management behaviors (HF maintenance, HF management, and HF confidence), and that self-efficacy and self-regulation would mediate the effect of complexity of condition on SM behaviors.

Description of Sample and Descriptive Analysis of Demographic Data

The study sample consisted of 73 community-dwelling adults who are outpatients in a single cardiovascular clinic at a large Midwestern academic hospital. Descriptive statistics were used to describe the sample. The mean age of the patients was 65 years. Females comprised 49% of the sample, and 51% were males. The majority of the participants were Caucasian; others

were African American, Latino, and Asian. The full sample characteristics are shown in Table 4.1.

Table 4. 1

Characteristics of the Sample

Sample Demographics	Mean and SD	Frequencies (%)
Age, Mean ± SD	65.21 ± 11.91	
Gender		
Female		36 (49.32)
Male		37 (50.68)
Race		
White		51 (69.86)
African American		19 (26.03)
Hispanic		2 (2.74)
Asian		1 (1.37)
Social Support		
No		5 (6.94)
Yes		67 (93.06)
ProBNP Value	5104.97 ± 12160.78	
ProBNP Elevation		
Normal		9 (13.24)
High		59 (86.76)
LVEF		
HF preserved		42 (57.53)
HF reduced		31 (42.5)
NYHA		
Class II		34 (46.58)
Class III		39 (53.42)
HF Stage		
B		28 (38.36)
C		45 (61.64)

Number of meds	15.29 ± 6.09	
Years of education	13.05 ± 2.89	
Freq of hospitalizations	2.71 ± 2.47	
Substance Abuse		
Smoking		
None		33 (45.21)
Former Smoker		36 (49.32)
Present Smoker		4 (5.48)
Alcohol		
None		42 (57.53)
Alcohol		31 (42.47)
Drugs		
None		70 (95.89)
Drugs		3 (4.11)
Prior CABG		
No		61 (83.56)
Yes		12 (16.44)
Prior Stroke		
No		67 (91.78)
Yes		6 (8.22)
Atrial Fibrillation		
No		45 (61.64)
Yes		28 (38.36)
Renal Disease		
No		27 (36.99)
Yes		46 (63.01)

The majority of the patients had renal disease, showing that in heart failure patients, cardio-renal syndrome is a common occurrence. Mean pro-BNP (B-type natriuretic peptide) value was high, and most of the patients had high pro-BNP. About one-third of the patients had

atrial fibrillation; atrial fibrillation can add to the symptoms of heart failure. Since this study assessed self-management behavior, it was important to collect data about the incidence of prior stroke and previous heart surgeries. Having a stroke or being on cardiopulmonary bypass could affect memory and understanding of self-management. In this sample, only 8% of the patients had a history of prior stroke, and 16% of the patients had prior cardiovascular surgery with the use of cardiopulmonary bypass.

Describing independent variables, the mean value of the Charlson comorbidity index was 2.88 (±1.62), with the highest possible score 31; self-regulation mean score was 37.45 (±6.169), with the highest possible score 45; and self-efficacy mean value was 6.89 (±2.076), with the highest possible score of 10.

Outcome, or dependent, variable self-management behavior was measured by the Self-Care Heart Failure Index (SCHFI) 6.2 version. Riegel, Lee, Dickson, and Carlson (2009) recommended that the three scales (self-care maintenance—scale A, management—scale B, and confidence—scale C) be used separately. The authors noted that self-care management scores (scale B) remain suitable only in persons who have been symptomatic, such as having trouble breathing or ankle swelling; otherwise asymptomatic persons' answers were not scored and not included in the analysis.

A cut-point of ≥70 on each SCHFI scale indicated self-care adequacy. Study population scores were: SCHFI Maintenance Score (A) 68.99 (±16.62); SCHFI Management Score (B) 61.05 (±15.747); SCHFI Confidence Score C 72.20 (±18.05). This means that study patients had low self-management abilities, as only the confidence scores were adequate. This coincides with Dos Santos et al. (2015), Cocchieri et al. (205), Jaarsma et al. (2013), and Tsai, Wang, Lee, Tsai, and Chen (2015) that frequently in patients with heart failure, self-care behaviors are poor.

On the maintenance A scale, out of 73 patients, 34s, or 47% had adequate scores ≥ 70. Study patients' management B scale scores were the lowest. The patients were supposed to answer this part of questionnaire only if they acknowledged having trouble breathing or had experienced ankle swelling in the past month. Otherwise, Riegel et al. (2009) recommended ignoring the B scale responses, since those patients are considered to be asymptomatic. In this study, out of 73 patients, 16 patients (21%) stated that they were asymptomatic. There were two possible explanations. One is that these patients were indeed less symptomatic—NYHA class I rather than class II (when ordinary physical activities produce shortness of breath), even though providers assessed their heart failure symptoms as NYHA class II—more symptomatic. The second explanation was that patients had poor symptom recognition, and they were sicker than they recognized. Out of those 57 patients who reported that they had symptoms, 17 patients, or 30%, had adequate scores of 70 and above.

On the confidence C scale, out of 73 patients, 41 (55%) had adequate scores. This was the highest scored scale in this study sample and showed that patients were confident in their self-management behavior. When these scores were compared to the scores from other studies, the following trends were noted. Overall the proportions of patients with appropriate self-care (scores ≥70 points) in this study were 47%, 30%, and 55%, respectively, for maintenance, management, and confidence scales, which were higher than in other studies (Table 4.2).

Table 4. 2

Comparison of HF Behaviors, % of Patients with Scores ≥70

Variable	**This study (2019), USA**	**Dos Santos et al. (2015) Brazil**	**Cocchieri et al. (2015), Italy**	**Tsai et al, 2015, Taiwan**
SCHFI Maintenance	**47%**	6.9%	14.5%	8.5%

Score (A)				
SCHFI Management Score (B) *for 57 symptomatic patients*	**30%**	14.7%	24.4%	7%
SCHFI Confidence Score (C)	**55%**	19%	21.2%	9.9%

For example, a study from Brazil (Dos Santos, Dos Santos, Da Conceição, & De Almeida Lopes Monteiro da Cruz, 2015) reported the proportions of patients with appropriate self-care (scores ≥70 points) were much lower: maintenance—6.9%, management—14.7%, and confidence—19%. In the Italian study, Cocchieri et al. (2015) stated that the percentage of HF participants with adequate self-care (scores ≥ 70) was 14.5% for self-care maintenance, 24.4% for self-care management, and 21.2% for self-care confidence.

A Taiwanese study by Tsai, Wang, Lee, Tsai, and Chen (2015) reported the percentage of adequate self-care scores to be 8.5% for SC maintenance, 7% for management scale, and 9.9% for confidence scale. Similar higher proportions of patients with adequate self-care were reported in an American study by Cené et al. (2013), which listed 52% for adequate SC maintenance, 32% for adequate SC management, and 33% adequate confidence. The higher scores in this study should be interpreted cautiously, however, since the study used convenience and nonrandom sample, so there was a possibility of cultural differences in this study compared to other international studies.

Statistical Analysis of Research Question

A power analysis was used to determine the sample size needed to achieve the power of 0.80 assuming two-tailed tests, an effect size of 2.1 and a Type I error rate equal to 0.05. The

estimated sample size was 73 patients. There were 74 patients enrolled; one was withdrawn from the study, as the patient did not answer any of the questionnaires. Stata Version 13 statistical software was used for all analyses. Separate simple and multiple linear regressions were run for each outcome variable (SCHFI maintenance scale A, management scale B, confidence scale C), with the independent variable complexity of condition unadjusted and then adjusted for self-regulation and self-efficacy.

To test the second hypothesis about mediator variables, the plan was to run the Preacher-Hayes method for mediation analysis. After running the regression, complexity of condition did not have a statistically significant effect on any of the three outcomes. Since there was no association between complexity of condition and SM behaviors, mediation by self-regulation and self-efficacy was not possible, and it was not necessary to test the mediational hypotheses. Self-regulation and self-efficacy were independently associated with each of the outcomes.

Outcome Variable SCHFI Scale A—Maintenance

As shown in Table 4.3, only self-efficacy significantly predicted the A scale of maintenance behavior. The A scale of maintenance behavior increased 2.39 units for each unit of increase in self-efficacy, adjusted for self-regulation and complexity of condition. Complexity of condition and self-regulation did not significantly predict the A scale maintenance Self-Care Heart Failure behavior scores.

Table 4. 3

Linear Regression Results

	SCHFI Maintenance Score (A)		SCHFI Management Score (B)		SCHFI Confidence Score (C)	

	Unadjusted Coef (95% CI)	Adjusted Coef (95% CI)	Unadjusted Coef (95% CI)	Adjusted Coef (95% CI)	Unadjusted Coef (95% CI)	Adjusted Coef (95% CI)
Charlson Index	0.64 (-1.78,3.05)	0.55 (-1.76,2.85)	1.69 (-.80,4.17)	1.55 (-.83,3.94)	1.64 (-.97,4.24)	1.43 (-0.55,3.42)
Self-regulation		0.20 (-0.49,0.89)		**0.78 (0.04,1.52)**		**0.68 (0.08,1.27)**
Self-efficacy		**2.39 (0.32,4.46)**		0.91 (-.31,3.12)		**4.47 (2.69,6.24)**
***p = < 0.05**						
	SCHFI Maintenance Score (A)		SCHFI Management Score (B)		SCHFI Confidence Score (C)	
	P-value	P-value	P-value	P-value	P-value	P-value
Charlson Index	0.601	0.639	0.179	0.198	0.214	0.153
Self-regulation		0.565		**0.039**		**0.026**
Self-efficacy		**0.024**		0.417		**0.000**

Outcome Variable SCHFI Scale B—Management

Only self-regulation significantly predicted management B behavior. The B scale of management behavior increased by 0.78 units for each unit increase in self-regulation, adjusted for complexity of condition and self-efficacy. Complexity of condition or self-efficacy were not significant predictors of B—management scores.

Outcome variable SCHFI scale C—Confidence

Both self-regulation and self-efficacy significantly predicted the C scale of confidence behavior. The C scale of confidence behavior increased 0.68 units for each unit of increase in self-regulation, adjusted for self-efficacy and complexity of condition. The C scale of confidence behavior increased 4.47 units for each unit of increase in self-efficacy, adjusted for self-regulation and complexity of condition. And this was a large unit increase compared to self-regulation. Complexity of condition did not predict C confidence scale.

Findings

Based on the results, the first hypothesis was partially supported: complexity of condition

(measured by Charlson Comorbidity Index) did not predict self-management behavior. Self-efficacy significantly predicted maintenance (A) and confidence (C) behavior, and self-regulation significantly predicted management (B) and confidence (C scale) behavior.

Since the relationship between complexity of condition and SM behaviors was not statistically significant, self-efficacy and self-regulation cannot be mediators between complexity of condition and SM behaviors. Therefore, the second hypothesis was not supported.

Discussion

To our knowledge, this is one of the first studies to test concepts of the Individual and Family Self-Management Theory (Ryan & Sawin, 2009) in a sample of persons with heart failure. The independent and dependent variables were all derived from the theory.

Complexity of Condition. This study showed that complexity of condition, as measured by the Charlson Comorbidity Index, did not predict self-management behaviors. This is contrary to the findings of Dickson, Buck, and Riegel, (2013), who reported that comorbidity contributed to the inability of HF self-management when the level of comorbidity was moderate or high. However, it was consistent with the findings of Tsai, Wang, Lee, Tsai, and Chen (2015) and Dos Santos et al. (2015), who reported that comorbidity did not predict SM.

The possible explanation of this finding is that the patients did not have high complexity of condition as measured by Charlson comorbidity scores. A higher Charlson comorbidity score indicates increased severity of condition and potential mortality. All of the study patients had a score of at least 1 for heart failure. The Charlson Comorbidity Index classifies comorbidity scores as low (scores 1-2), moderate (3-4), and high (≥5) (Dos Santos, 2015) or in numbers: 1-2 score correlates to 26% mortality in 1 year, 3-4 correlates to 52% of mortality in 1 year, and ≥5 –

85% mortality in one year (Charlson, Pompei, Ales, & MacKenzie, 1987). The mean value of the Charlson Comorbidity Index for this study population was 2.88 (±1.62)—low, and this may potentially explain the study findings, no statistically significant prediction of heart failure SM behavior.

Self-Regulation. Ryan and Sawin (2009) defined self-regulation as a process—such as goal-setting, reflective thinking, and decision-making—used to change health behavior. In De Smedt et al. (2012), study self-regulation predicted self-management behavior, such as coping and dealing with adverse events of heart failure. It was hypothesized that self-regulation predicted all 3 behaviors—maintenance, management, and confidence, —but the results revealed that self-regulation predicted only two out of three behaviors: patients' heart failure management (scale B) and confidence (scale C) in the ability to perform heart failure self-care behavior. There was no statistical significance in predicting maintenance (scale A) behaviors.

The *maintenance* scale (A) centers on *symptom monitoring and treatment adherence*. The *management* scale (B) measures the *ability of the patient to recognize symptoms* and assesses *decision making in response to symptoms*. The *confidence* scale C assesses one's level of confidence in carrying out heart failure self- management behaviors. In this study, the *higher self-regulation,* or volitional, process to change health behavior was associated with better heart failure *symptoms recognition* and *active decision-making processes undertaken in response to symptoms* and *higher confidence* in carrying SM.

In this study, *self-regulation* did not predict heart failure *symptom monitoring and treatment adherence,* such as checking daily weights, exercising, keeping appointments and remembering to take medications. One possible explanation is that study patients were more focused on changing their health behavior to achieve good symptom recognition, and were

confident in these abilities, but did not focus on adherence to treatment. The answer might be found in the IFSMT. Ryan and Sawin (2009) noted that patients may pursue behaviors for personally meaningful reasons that may or may not be directly related to improving their health status. The primary responsibility and control lie with the individual, and sometimes adherence does not align with self-management (Ryan & Sawinm 2009). That is why it is important to let the theory guide nursing practice.

Self-Efficacy. In this study, self-efficacy was associated with maintenance (maintaining physiologic stability and treatment adherence, scale A) and confidence behavior (scale C) but not management behavior (symptoms recognition and acting upon those symptoms, scale B).

Self-efficacy is the degree of certainty one has in his/her ability to successfully carry a health behavior (Ryan & Sawin, 2009). Our instrument of self-efficacy assessed confidence in managing chronic disease in general, and we expected that self-efficacy in chronic disease predicts the confidence of managing heart failure behaviors as well as HF maintenance and management. However, in this study, self-efficacy predicated only two out of three behaviors. Riegel, Lee, and Dickson (2011) noted that for patients with heart failure, *self-care maintenance* includes taking multiple medications, following a low-salt diet, staying physically active, and monitoring weight and edema. Compared with maintenance behavior, *self-care management* behaviors are more difficult and challenging to accomplish. This type of behavior involves the recognition of early signs or symptoms of heart failure and acting upon these symptoms.

In this case, being generally confident, i.e., *self-efficacious*, was not enough to master *early HF symptoms recognition*. In this study, 21 percent of the patients considered themselves asymptomatic, even though healthcare professionals assessed them to be more symptomatic. They were *confident* that they were stable and *followed the treatment* and *self-efficacious in HF*.

However, objectively the patients had more symptoms than they realized. And this could be a reason why *self-efficacy* was not associated with *self-care management* behavior or HF symptoms recognition behavior.

Mediating Variables

In the second hypothesis, it was predicted that self-efficacy and self-regulation were mediators between complexity of condition and SM behaviors. Mediating variables are used to understand the process by which two variables are related (MacKinnon, 2011). It was hypothesized that two independent variables—self-efficacy, and self-regulation, —mediated the effect of complexity of condition (causal variable) on the outcome variable: self-management behavior. A linear regression found that complexity of condition did not have a statistically significant effect on any of the three self-management behaviors.

Based on the *p*-value approach, the conclusion was that there was no effect of complexity of condition on SM behaviors, which means the mediation of self-regulation and self-efficacy is not possible. The main predictor has to be significant to start exploring mediation (Kenny, 2018). When the main effect is non-significant, the literature suggests that no mediation effect can change that (MacKinnon, Fairchild, & Fritz, 2007). The second hypothesis was not supported. Self-efficacy and self-regulation did not mediate the complexity of condition and self-management behaviors. Testing the IFSMT, it was important to look at whether study independent variables mediated the dependent variable and each other.

Limitations

There are several limitations to this study. The design for the study is not experimental but cross-sectional. Cross-sectional designs yield weaker evidence for causality (Hulley et al.,

2013). Further, the study used self-administered questionnaires. Using self-administered questionnaires can result in poor or subjective recollection results, which is a form of bias that threatens the internal validity of the study.

The study uses a convenience sample of community-dwelling adults in a cardiology clinic at a large Midwest hospital. Convenience sampling violates the random sampling assumption and can threaten study external validity, i.e., research findings are subject to selection bias due to nonrandom selection. Also, the study uses a small sample size, and due to the small sample size, it was underpowered.

Conclusion

In conclusion, this study suggests that complexity of condition, or comorbidity, and the process of volitional decision making, or self-regulation, and self-efficacy were only partially associated with self-management behaviors, because not all associations were statistically significant. The results of the study are only suggestive due to the small sample size, and they need to be replicated in the larger trial. This study suggests the need for more research, with a random and larger sample to strengthen the outcomes.

Though the study is underpowered, it is still valuable because it is the first study to test IFSMT in heart failure. Further, it is one of the few studies to examine the effects of the individuals' characteristics on their own self-management behaviors. The patients' self-management scores were adequate only for confidence scores in managing heart failure, but when compared to other studies, the patients' scores were higher, possibly meaning that this study patient population is savvier in self-management behavior. Smeulders et al. (2010) noted that achieving long-term behavioral change in SM of HF patients may be challenging, as patients

constantly need to adapt to a condition that progressively deteriorates. Future nursing interventions should take into account the above findings and continue to explore the benefits and barriers of self-management skills and abilities among patients with heart failure.

Summary

This chapter describes the results of the study and the statistical analyses used. It presents data in the tables for review. It contains detailed discussions regarding the findings and how they relate to the literature review. This chapter provides an explanation of why the proposed hypotheses were supported or not. It presents the limitations of the study, and it provides a second manuscript.

Manuscript Two

Heart Failure Self-Management Cross-sectional Study: Testing the Individual and Family Self-Management Theory

Background: Heart failure (HF) is a growing public health problem, as it is the primary diagnosis in greater than one million hospitalizations annually. Self-management (SM) of HF is an important component of chronic disease management and, when done well, aids in preventing HF exacerbations and unnecessary hospitalizations. The Individual and Family Self-Management Theory (IFSMT) provides clinicians with a framework for applying a theory-based approach to care for persons with chronic illness in order to engage them in self-management.

Objectives: This study investigates the relationship between heart failure self-management behavior and the characteristics of patients who engage in HF self-management behavior. It also tests the concepts of the IFSMT to better understand relationships among three factors: complexity of condition, self-regulation, and self-efficacy on SM behaviors in a population of patients with heart failure.

Methods: A descriptive cross-sectional correlational study is used. Seventy-three patients from a cardiology clinic with both HF preserved and reduced ejection fraction were enrolled.

Results: Complexity of condition did not predict self-management behavior. Self-efficacy predicted maintenance and confidence behavior, and self-regulation predicted management and confidence behavior. Self-efficacy and self-regulation were not mediators between complexity of condition and SM behaviors. The patients' self-management scores were adequate only for confidence scores in managing heart failure.

Conclusions: This is a first study to test IFSMT in heart failure. It is one of the few studies to

examine the effects of the individuals' characteristics on their own self-management behaviors. Implications for research and practice are described.

As stated above, heart failure (HF) is a growing public health problem. Care relating to HF is responsible for approximately 1.75 million office visits and more than 0.5 million emergency department visits annually (Neubauer, Gray, & Hemann, 2018). It has been estimated that HF affects 10 in 1000 individuals after 65 years of age (Whitaker-Brown, Woods, Cornelius, Southard, & Gulati, 2017). Although survival has improved, the absolute mortality rates for HF remain approximately 50% within 5 years of diagnosis (Benjamin et al., 2017). Heart failure is the primary diagnosis in greater than one million hospitalizations annually. Patients hospitalized for HF are at high risk for all-cause re-hospitalization, with a 30-day readmission rate of 23% (Bergethon et al., 2016). By 2030, the total cost of HF will increase almost 127% to $69.7 billion from 2012 (Mozaffarian et al., 2016). Readmission of patients with HF is costly and places a marked burden on the resources of the health care system and on the patients and families who struggle with the disease.

HF management is complex and requires coordination between patients, families, and their health team members. Self-management of HF is an important component of chronic disease management and, when done well, aids in preventing HF exacerbations and unnecessary hospitalizations. Patients with HF suffer from acute and chronic HF-related symptoms such as dyspnea, fatigue, weakness, edema, and depression. These symptoms limit activities of daily living and impair quality of life (QOL). SM improves QOL and HF outcomes (Lee & Riegel, 2017). Patients are encouraged to maintain their health by using effective self-management techniques in their daily lives without the direct aid of health care professionals.

A key element of self-management is regular HF symptom monitoring, which can

decrease the risk of an exacerbation of HF symptoms and prevent hospital readmissions (Lee & Riegel, 2017). SM teaches recognizing symptoms of worsening HF, monitoring weight, restricting dietary salt, exercising, adhering to medications, and implementing plans for what to do in the event of an HF exacerbation (Baker et al., 2011). There is evidence that SM education improves knowledge, self-monitoring, time to hospitalization, and days in the hospital in patients with HF (Yancy et al., 2013).

Theoretical Framework

Self-management is defined as one's control of and responsibility for the management of chronic conditions or healthy behaviors by purposefully engaging in the performance of learned behaviors (Ryan & Sawin, 2009). The authors distinguish the concept of self-management from the concept of self-care in that self-care is comprised of daily living and engagement in health behaviors without collaboration with healthcare professionals. However, in the outside literature these two concepts are used interchangeably. The Individual and Family Self-Management Theory (IFSMT) provides clinicians with a framework for assessing and applying a theory-based approach to care for persons with chronic illness in order to engage them in self-management (Ryan & Sawin, 2009). The IFSMT envisions SM as a process by which individuals and families employ knowledge and beliefs, self-regulation skills and abilities, and social facilitation to attain proximal (e.g., SM behaviors and health care services costs) and distal outcomes (health status, quality of life, and cost of health) (Ryan & Sawin, 2009).

Factors in the *contextual dimension* influence individual and family engagement in the *process of SM* as well as directly impact *outcomes"* (Ryan & Sawin, 2009, p. 223). Interventions enhancing the individuals and families' *contextual factors* and *SM processes* result in more positive *proximal* and distal *outcomes*. One of the contextual dimensions is **complexity of**

condition and treatment. **Self-regulation, self-efficacy, and social facilitation** (such as social support) are parts of the SM process according to the model. "Interventions aimed at the context can reduce risk or foster conditions that support SM. Interventions aimed at the SM process can enhance knowledge and beliefs, increase an individual's use of self-regulation behaviors and foster social facilitation" (Ryan & Sawin, 2009, p. 224). *Complexity of condition* is defined as physiological, structural, or functional characteristics of the condition that impact the nature of behaviors needed to manage the condition (Ryan & Sawin, 2009). *Self-regulation* is a cognitive process, such as goal-setting, reflective thinking, and decision-making, used to change health behavior and manage responses associated with health behavior changes (Ryan & Sawin, 2009). *Self-efficacy* is the degree of confidence one has in the ability to successfully engage in a behavior under normal and stressful situations (Ryan & Sawin, 2009).

Literature Review

The literature review shows that heart failure self-management is complex (Boyde et al., 2017). Evidence is mixed, and there are gaps in nursing knowledge of what constitutes effective strategies for successful outcomes of SM in HF. Frequently there is a lack of detailed description of the active ingredients driving the intervention (Herber et al., 2018). Many, but certainly not all, of the experimental studies confirmed that education about self-management and therapeutic interventions for heart failure SM work in improving outcomes, such as increasing HF SM behavior and patients' well-being, preventing worsening of symptoms, and reducing the risk of hospitalizations. Tawalbeh (2018) reported positive outcomes of a cardiac education program on self-care behaviors. Tung et al. (2013) reported that as the result of their SM intervention, participants achieved better self-maintenance and self-management and QOL up to 2 months' post intervention.

The outcomes of self-management on lowering hospitalizations have mixed results. Lee et al. (2017) reported that subjects who had higher self-management knowledge had fewer clinical events than those with poor knowledge or asymptomatic patients. Al-Sutari and Ahmad (2015) reported that their SM educational program for HF patients lowered the frequency of emergency room visits and increased self-care behaviors, but it did not lower the frequency of hospitalizations or mortality. Cocayne (2014) reported that their self-management program produced no difference in HF admission/readmission to the hospital.

Further, there are still gaps in nursing knowledge, as substantial variations in SM intervention components, mode of delivery, and dose restrict answering the question of what interventions improve HF outcomes. Worsening of heart failure symptoms and hospitalizations are the consequences of the inability to manage HF at home for patients and healthcare systems. When SM interventions do not work in preventing hospitalizations, researchers look at the reasons and gaps in nursing knowledge to try to explain the phenomenon. Navidian Yaghoubinia, Ganjali, and Khoshsimaee (2015) reported that self-care behavior education had lower effects on the depressed patients with heart failure. Stewart et al. (2016) reported that multi-morbidity contributed to the inability of HF self-management the most.

Tsai, Wang, Lee, Tsai, and Chen (2015) noted that HF knowledge, having a spouse, and admission frequency predicted self-care (SC) decision-making in hospitalized patients with HF in Taiwan. Their findings suggested a very poor self-care status among the participants in this study. Lee and Riegel, 2017; Lee et al. (2017) and Athilingam et al. (2018) show that symptom recognition among HF patients is poor, and the patients fail to engage in self-management behavior. Lee and Riegel (2017) noted that factors affecting self-care and inability of symptoms recognition included age, comorbidity, living with others, educational status, acute symptom

duration, NYHA (New York Heart Association) class, and the total number of previous hospitalizations. Several researchers suggested using a tailored approach is more effective (Spaling, Currie, Strachan, Harkness, & Clark, 2015). However, many studies did not specify how the tailoring was done (Bos-Touwen, 2015).

Studies showed contradictory findings about which contextual conditions should be incorporated in tailored interventions. Some studies reported that the age and sex of the participants influenced SM skills (Britz & Dunn, 2010), while others refuted this suggestion (Bos-Touwen et al., 2015; Riegel et al., 2010). Bos-Touwen (2015), Tsai et al. (2015,) and Wu et al. (2017) confirmed that the patients with lower SM abilities benefited from these programs the most.

Complexity of SM in HF is especially underscored in both qualitative and mixed-methods studies which place emphasis on patients' efforts to improve their skills. Strachan, Currie, Harkness, Spaling, and Clark (2014) looked at contextual factors that influenced engagement in self-care, and reported that caregivers, social networks and social support, place, finances and financial capacity, work and occupation, and HF support groups and programs should be integrated into the promotion of self-care. Overall the literature review showed that "extensive scientific work has been done to increase our understanding in whom self-management is problematic and in whom self-management interventions are most effective" (Bos-Touwen, 2015, p. 231).

Specific types of interventions might work better for specific subgroups of patients (Jonkman et al., 2016). The question what works for whom deserves attention in subsequent research. There is conflicting evidence regarding which contextual factors are associated with successful self-management behavior and which patient characteristics clearly impede successful

HF self-management behavior. Addressing the gap in nursing knowledge in patient attributes of HF self-management behavior has important future nursing implications.

Research Gap

Overall the literature review suggested that determining contextual factors associated with successful self-management behavior in a population of patients with HF will fill an important gap in nursing's understanding of additional ways to help people with HF to self-manage their complex chronic disease (Bos-Touwen et al., 2015; Strachan, Currie, Harkness, Spaling, &Clark, 2014). Despite recommendations of SM, engagement in SM remains low (Young, Barnason, & Kupzyk, 2016). SM is a complex set of behaviors, which are influenced by various factors (Young et al., 2016). Addressing the nursing knowledge gap in patient attributes of HF self-management behavior has important implications and is the focus of this study.

Purpose of the Study

This study investigates the relationship between heart failure self-management behavior and the characteristics of patients who engage in HF self-management behavior. It further tests concepts of the IFSMT to better understand relationships between select context, process, and outcome variables in a population of patients with heart failure.

Research Question

Based on the concepts derived from Individual and Family Self-Management Theory and applying the theory to HF, the following research question is proposed: what are the associations of the contextual factor of complexity of condition, the SM processes of self-efficacy and self-regulation with self-management behaviors in patients with heart failure?

And the specific research questions are:

1. Does the complexity of condition predict heart failure SM behaviors?

2. Does self-regulation predict heart failure SM behaviors?

3. Does self-efficacy predict heart failure SM behaviors?

4. Do self-regulation and self-efficacy mediate the effect of complexity of condition on heart failure SM behaviors?

Hypotheses

Complexity of condition, self-regulation, and self-efficacy predict self-management behaviors in a patient population with New York Heart Association (NYHA) functional class II-III HF. Self-efficacy and self-regulation are hypothesized to be mediators between complexity of condition and heart failure SM behaviors.

A descriptive cross-sectional correlational study was conducted. For this study, the predictor variables were complexity of condition, self-regulation, and self-efficacy, and the outcome variable was HF self-management; however self-efficacy and self-regulation can be mediating variables.

Measurements

Complexity of condition was measured by the *Charlson Comorbidity Index (CCI)* (Charlson, Szatrowski, Peterson, & Gold, 1994). The CCI was developed as a measure of 1-year mortality risk and burden of disease. A higher Charlson comorbidity score indicated an increased severity of condition. Four out of six comparisons with other indices of comorbidity yielded correlation coefficients exceeding 0.40, supporting concurrent validity (De Groot et al., 2003). Test-retest reliability was good with intra-class correlation coefficients of 0.92 ($p < 0.0001$) (Roffman, Buchanan, & Allison, 2016), and inter-rater reliability was moderate to good of 0.74

to 0.945 (De Groot et al.).

Self-regulation was measured by the Index of Self-Regulation (ISR) (Fleury, 1998). Index of Self-Regulation (ISR) is a nine-item scale designed to measure an individual's level of self-regulation. Cronbach's alpha of the whole instrument is 0.87, demonstrating a high reliability of the ISR. Test–retest reliability coefficient of the ISR was 0.73. Criterion related and construct validity of ISR demonstrated correlation 0.20-0.47 and were moderate (Fleury, 1998).

Self-efficacy was measured by the Self-Efficacy for Managing Chronic Disease 6-Item Scale (Stanford Education Center, 2018). The instrument contained six items, including "general disease management" and "symptom management," as they were common across many chronic diseases (Chow & Wong, 2014). The Cronbach's alpha coefficient was 0.96, indicating high internal consistency. Chow and Wong reported substantial content and construct validity of the instrument.

Self-management behavior was measured by the SCHFI 6.2 version (Self-Care Heart Failure Index) score (Riegel et al., 2009). This was a 22-item self-report questionnaire to assess self-management behavior in patients with HF. It consisted of three sub-scales. The Self-Care (SC) maintenance scale had 10 items. The SC Management Scale had 6 items, and it was scored only if the patient reported shortness of breath or edema. The SC confidence had 6 items. A cut-point of ≥70 on each SCHFI scale indicated self-care adequacy. The 3 scales (SC maintenance—scale A, management—scale B, and confidence—scale C) were scored separately (Riegel, Lee, Dickson, & Carlson, 2009). Cronbach's alpha for SC maintenance was 0.553, for SC management was 0.597, and for SC confidence was 0.827. The instrument has substantial concurrent, construct, and convergent validity (Riegel et al.).

Sample

A power analysis was used to determine the sample size needed to achieve a power of 0.80 assuming two-tailed tests, an effect size of 2.1 and a Type I error rate equal to 0.05. The estimated sample size was 73 patients. There were 74 patients enrolled, and one was withdrawn from the study. The study sample consisted of outpatients in a single cardiovascular clinic at a large Midwestern academic hospital. The target population for this study was patients with congestive heart failure with preserved or reduced ejection fraction and who were seen by providers in cardiology clinic at that hospital. The sample used was a convenience sample of community-dwelling adults.

The inclusion criteria were individuals older than 18, diagnosed with HF with preserved or reduced left ventricular ejection fraction, having NYHA class II-III heart failure symptoms, and who spoke and understood English. The study was approved by two institutional review boards (IRBs), those of a Midwestern medical school and a large Midwestern university.

Results

Table 4. 4

Characteristics of the Sample

Sample Demographics	Results
Age, Mean ± SD	65.21 ± 11.91
Gender, Freq (%)	
Female	36 (49.32)
Male	37 (50.68)
Race, Freq (%)	

White	51 (69.86)
African American	19 (26.03)
Hispanic	2 (2.74)
Asian	1 (1.37)
Social Support, Freq (%)	
No	5 (6.94)
Yes	67 (93.06)
ProBNP Value, Mean ± SD	5104.97 ± 12160.78
ProBNP Elevation, Freq (%)	
Normal	9 (13.24)
High	59 (86.76)
LVEF, Freq (%)	
HF preserved	42 (57.53)
HF reduced	30 (41.10)
HR reduced	1 (1.37)
NYHA, Freq (%)	
Class II	34 (46.58)
Class III	39 (53.42)
HF Stage, Freq (%)	
B	28 (38.36)

C	45 (61.64)
Number of meds, Mean ± SD	15.29 ± 6.09
Years of education, Mean ± SD	13.05 ± 2.89
Freq of hospitalizations, Mean ± SD	2.71 ± 2.47
Substance Abuse	
Smoking, Freq (%)	
None	33 (45.21)
Former Smoker	36 (49.32)
Smoker	4 (5.48)
Alcohol, Freq (%)	
None	42 (57.53)
Alcohol	31 (42.47)
Drugs, Freq (%)	
None	70 (95.89)
Drugs	3 (4.11)
Prior CABG, Freq (%)	
No	61 (83.56)
Yes	12 (16.44)
Prior Stroke, Freq (%)	
No	67 (91.78)

Yes	6 (8.22)
Afib, Freq (%)	
No	45 (61.64)
Yes	28 (38.36)
Renal Disease, Freq (%)	
No	27 (36.99)
Yes	46 (63.01)

Descriptive statistics were used to describe the sample. As shown in Table 1, the mean age of the patients was 65 years. Females comprised 49% of the sample and 51% were males. The majority of the participants were Caucasian. Among enrolled patients, 43% were patients with heart failure (HF) with reduced left ventricular (LV) ejection fraction (EF less than 35%), and 57% of the patients had preserved LVEF. Mean pro-BNP value was high, 5104.97 (12160.78). The patients had had at least two hospitalizations or ED visits per year.

Table 4. 5

Scores for Independent Variables

Variable	**Mean**	**Possible range**
Charlson Index, Mean ± SD	2.88 ± 1.62	1- 31
Self-regulation	37.45 (±6.169)	9-45
Self-efficacy	6.89 (±2.076)	1-10

As shown in Table 4.6, study population scores were: SCHFI Maintenance Score (A) 68.99 (±16.62); SCHFI Management Score (B) 61.05 (±15.747); SCHFI Confidence Score C 72.20 (±18.05). Study patients had low self-management abilities, as only confidence scores were adequate (scores ≥70).

Table 4. 6

Heart Failure Management, Maintenance, and Confidence

Variable	**Mean (SD)**	**# patients with scores ≥70**	**% of patients with scores ≥70**
SCHFI Maintenance Score (A)	68.99 ± 16.62	34 patients	47%
SCHFI Management Score (B) *for 57 symptomatic patients*	61.05 ± 15.75	17 patients	30%
SCHFI Confidence Score (C)	72.20 ± 18.05	40 patients	55%

In maintenance A scale, out of 73 patients, 47% had adequate scores (scores ≥70). Study patients' management B scale scores were the lowest. The patients were supposed to answer this part of questionnaire only if they acknowledged having trouble breathing or ankle swelling in the past month; otherwise, asymptomatic persons' answers were not included in the analysis (Riegel et al., 2009). Out of 73 patients, 16 patients (21%) stated that they were asymptomatic. Out of those 57 patients who reported that they had symptoms, 17 patients or 30% had adequate scores of 70 and above. On the confidence C scale, out of 73 patients, 55% had adequate scores. This is the highest scored scale in this study sample, and shows that half of the patients were confident in their self-management behavior.

Statistical Analysis of Research Questions

Stata Version 13 statistical software was used for all analyses. Separate simple and multiple linear regressions were run for each outcome variable (SCHFI maintenance scale A, management scale B, confidence scale C), with complexity of condition unadjusted and then adjusted for self-regulation and self-efficacy. To test the second hypothesis about mediator variables, the plan was to run the Preacher-Hayes method for a mediation analysis. After running the regression, the complexity of condition factor did not have a statistically significant effect on any of the three outcomes. Therefore, the Preacher-Hayes mediation analysis was unnecessary, as there was no relationship between complexity of condition and SM behaviors, which meant mediation of self-regulation and self-efficacy was not possible. Self-regulation and self-efficacy were independently associated with each of the outcomes.

Table 4. 7

Linear Regression Results

	SCHFI Maintenance Score (A)		SCHFI Management Score (B)		SCHFI Confidence Score (C)	
	Unadjusted Coef (95% CI)	Adjusted Coef (95% CI)	Unadjusted Coef (95% CI)	Adjusted Coef (95% CI)	Unadjusted Coef (95% CI)	Adjusted Coef (95% CI)
Charlson Index	0.64 (-1.78,3.05)	0.55 (-1.76,2.85)	1.69 (-.80,4.17)	1.55 (-.83,3.94)	1.64 (-.97,4.24)	1.43 (-0.55,3.42)
Self-regulation		0.20 (-0.49,0.89)		**0.78 (0.04,1.52)**		**0.68 (0.08,1.27)**
Self-efficacy		**2.39 (0.32,4.46)**		0.91 (-.31,3.12)		**4.47 (2.69,6.24)**
***p = < 0.05**						
	SCHFI Maintenance Score (A)		SCHFI Management Score (B)		SCHFI Confidence Score (C)	

	P-value	P-value	P-value	P-value	P-value	P-value
Charlson Index	0.601	0.639	0.179	0.198	0.214	0.153
Self-regulation		0.565		**0.039**		**0.026**
Self-efficacy		**0.024**		0.417		**0.000**

Outcome Variable SCHFI Scale A—Maintenance. Only self-efficacy significantly predicted the A scale of maintenance behavior. Complexity of Condition and Self-Regulation did not significantly predict the A scale maintenance Self-Care Heart Failure behavior scores.

Outcome Variable SCHFI Scale B—Management. Only self-regulation significantly predicted management B behavior. Complexity of condition or self-efficacy were not significant predictors of B—management scores.

Outcome variable SCHFI scale C—Confidence. Both self-regulation and self-efficacy significantly predicted the C scale of confidence behavior. Complexity of condition does not predict the C confidence scale.

Based on the results, the first hypothesis was partially supported, that is, complexity of condition did not predict self-management behavior. Self-efficacy significantly predicted maintenance (A) and confidence (C) behavior, and self-regulation significantly predicted management (B) and confidence (C scale) behavior.

Since the relationship between complexity of condition and SM behaviors was not statistically significant, self-efficacy and self-regulation cannot be mediators between complexity of condition and SM behaviors. Therefore, the second hypothesis was not supported.

Discussion

To our knowledge, this is one of the first studies to test the concepts of the Individual and Family Self-Management Theory (Ryan & Sawin, 2009) in a sample of persons with heart failure. The variables were all derived from the theory. This study showed that complexity of condition measured by the Charlson Comorbidity Index did not predict self-management behaviors, which is contrary to the findings of Dickson, Buck, and Riegel, (2013), who reported that comorbidity contributed to the inability of HF self-management when the level of comorbidity was moderate or high. However, it was consistent with the findings of Tsai, Wang, Lee, Tsai, and Chen (2015) and Dos Santos et al. (2015), who reported that comorbidity did not predict SM.

The possible explanation of this finding is that our patients did not have high complexity of condition as measured by Charlson comorbidity scores. A higher Charlson comorbidity score indicates an increased severity of condition and potential mortality. The Charlson Comorbidity Index (CCI) classifies as low (scores 1-2), moderate (3-4), and high (≥5) (Dos Santos, 2015); in numbers, a 1-2 score correlates to 26% mortality in 1 year, 3-4 correlates to 52% of mortality in 1 year, and ≥5 – 85% to mortality (Charlson, Pompei, Ales, & MacKenzie, 1987). The mean value of the Charlson Comorbidity Index for this study population was 2.88 (±1.62)—low, and this may potentially explain the study findings, that is, no statistically significant prediction of heart failure SM behavior.

Self-Regulation. The results revealed that self-regulation predicted only two out of three behaviors: patients' heart failure management (B) and confidence (scale C) in the ability to perform heart failure self-care behavior. There was no statistical significance in predicting maintenance (scale A) behaviors. The *maintenance* scale (A) centers on *symptom monitoring and*

treatment adherence. The *management* scale (B) measures the *ability of the patient to recognize symptoms* and assesses *decision making in response to symptoms*. The *confidence* scale (C) assesses one's level of confidence in carrying out heart failure self- management behaviors.

In this study, the *higher self-regulation,* or volitional, process to change health behavior was associated with better heart failure *symptoms recognition, active decision-making processes undertaken in response to symptoms,* and *higher confidence* in carrying SM. In this study, *self-regulation* did not predict heart failure *symptom monitoring and treatment adherence*—such as checking weight daily, exercising, keeping appointments, and remembering to take medications. One possible explanation is that study patients were more focused on changing their health behavior to achieve good symptom recognition and were confident in these abilities, but they did not focus on adherence to treatment. The answer might be found in the IFSMT. Ryan and Sawin (2009) noted that patients may pursue behaviors for personally meaningful reasons that may or may not be directly related to improving their health status. The primary responsibility and control lie with the individual, and sometimes adherence does not align with self-management (Ryan & Sawin, 2009). That is why it is important to let the theory guide nursing practice.

Self-Efficacy. In this study, self-efficacy was associated with maintenance (maintaining physiologic stability and treatment adherence) and confidence behavior but not management behavior (symptoms recognition and acting upon those symptoms).

Self-efficacy is the degree of certainty one has in his/her ability to successfully carry a health behavior (Ryan & Sawin, 2009). Our instrument of self-efficacy assessed confidence in managing a chronic disease in general, and we expected that self-efficacy in chronic disease would predict the confidence of managing heart failure behaviors as well as HF maintenance and management. However, in this study, self-efficacy predicated only two out of three behaviors.

For patients with heart failure, *self-care maintenance* (scale A) includes taking multiple medications, following a low-salt diet, staying physically active, and monitoring of weight and edema (Riegel, Lee, & Dickson, 2011).

Compared with maintenance behaviors, *self-care management* behaviors (scale B) are more difficult and challenging to accomplish. This type of behavior involves the recognition of early signs or symptoms of heart failure and acting upon those symptoms. In this case being generally confident, i.e., *self-efficacious*, was not enough to master *early HF symptoms recognition*. In this study, 21% of the patients considered themselves asymptomatic, even though healthcare professionals assessed them to be more symptomatic. They were *confident* that they were stable and *followed the treatment* and *self-efficacious in HF*. However, objectively the patients had more symptoms than they realized. And this could be a reason why *self-efficacy* was not associated with *self-care management* behavior or HF symptoms recognition behavior.

Mediating Variables. In the second hypothesis, it was predicted that two independent variables, self-efficacy and self-regulation, mediated the effect of complexity of condition (causal variable) on the outcome variable—self-management behavior. After running a linear regression, complexity of condition did not have a statistically significant effect on any of the three self-management behaviors. Based on the *p* value approach, the conclusion was that there was no effect of complexity of condition on SM behaviors, which means mediation of self-regulation and self-efficacy is not possible. The main predictor has to be significant to start exploring mediation (Kenny, 2018). When the main effect is non-significant, the literature suggests that no mediation effect can change that (MacKinnon, Fairchild, & Fritz, 2007). The second hypothesis was not supported.

Limitations

There are several limitations to this study. The design for the study is not experimental but cross-sectional. Cross-sectional designs yield weaker evidence for causality (Hulley et al., 2013). In addition, the study uses self-administered questionnaires. Using self-administered questionnaires can result in poor or subjective recollection results, which is a form of bias, which threatens internal validity of the study.

The study uses a convenience sample of community-dwelling adults in a cardiology clinic at a large Midwest hospital. Convenience sampling violates the random sampling assumption and can threaten study external validity, i.e., research findings are subject to selection bias due to nonrandom selection. Also, the study uses a small sample size, and due to a small sample size, it was underpowered. The results of the study are only suggestive. This study findings have to be replicated in a larger and preferably random sample.

Conclusion

Though the study is underpowered, but it is still valuable because it is the first study to test the IFSMT in heart failure, and it is one of the few studies to examine the effects of the individuals' characteristics on their own self-management behaviors. In this study, contextual factors such as complexity of condition did not predict heart failure SM behavior, and process of self-management, such as self-regulation and self-efficacy, predicted only some but not all HF self-management behaviors. The patients' self-management scores were adequate only for confidence scores in managing heart failure, and low for maintenance and management behaviors.

Smeulders et al (2010) noted that achieving long-term behavioral change in SM of HF

patients may be challenging, as patients constantly need to adapt to a condition that deteriorates progressively. The future nursing interventions should take in account the above findings and continue to explore the benefits and barriers of self-management skills and abilities among patients with heart failure. The results of the study are only suggestive due to small sample size, and they need to be replicated in the larger trial. This study suggests the need for more research, with a random and larger sample to strengthen the outcomes.

Implications for Education and Practice

Many scholars argue that we need to do more in the area of self-management. The American Heart Association published a recent statement about the necessity for and benefits of self-care and self-management of chronic cardiovascular disease (Riegel et al., 2017). There is a need for SM of chronic disease to become a part of medical and nursing undergraduate and graduate curricula. Continuing nursing education should include self-management of chronic disease. Patients' SM education needs to be a higher priority for nurses and nursing leaders (Albert et al., 2015). There is a necessity to develop and employ SM initiatives and and to initiate SM quality improvement projects. The direction for future nursing practice, including self-management of heart failure, should be practice guided by theory. Theory can bring a framework for assessing the needs of patients and developing interventions to enhance patients' abilities to manage the daily care of themselves and their family members, and conserve their energy as well as their structural, personal, and social integrity (Ryan & Sawin, 2009).

Implications for Research

Collins et al. (2015) noted that attempts to assess and document self-management are often “thwarted by the lack of the necessary resources or time (p. 10).” There are challenges for

measuring self-management. In particular, clinicians are more focused on biomarkers and the biomedical control of chronic disease as a feature of success, where the patients may focus more on feelings of well-being and social interaction (Mudge, Kayes, & McPherson, 2015). Future nursing studies can focus on designing a new instrument for HF self-management surveillance to be a concise, valid, and time-effective tool—easily implemented during outpatient visits—to measure and document the progress of HF SM in electronic records. There is also a need for future research of cost-effectiveness analysis of value of SM programs in heart failure. Showing HF self-management cost-effectiveness will bring players endorsing SM interventions. [clarify]Many international studies have been published recently about heart failure self-management. Many of them use Self-Care Heart Failure Index scores. It may be beneficial to conduct a multinational study to measure HF behaviors in other countries and compare them to American patients' HF SM abilities. Ryan and Sawin (2009) state that robust theory offers numerous new opportunities for expanding knowledge related to SM. Nursing researchers can help identify theoretical concepts essential to engagement in SM behaviors (Ryan & Sawin, 2009). If nurses effectively promote SM at multiple levels, more people with chronic disease may actively self-manage (Riegel et al., 2017).

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CHAPTER 5

Synthesis

INTRODUCTION

This study investigates the relationship between heart failure self-management and the characteristics of patients who engage in HF self-management behavior. It also tests the concepts of the Individual and Family Self-Management Theory (IFSMT) to better understand relationships between select context, process, and outcome variables in a population of patients with heart failure. Two hypotheses were proposed, and the variables were derived from the theory.

Synthesis of the Study

This dissertation is composed of five chapters and three articles prepared for publication, integrated into those chapters. Chapter 1 provides an introduction to the problem and the dissertation. It highlights the pathophysiology of heart failure and initiates a discussion about heart failure self-management. It provides a description of the Individual and Family Self-Management Theory (IFSMT) as a framework guiding this study and a description of the concepts that were tested in this study. Chapter 2 consists of a review of the literature, including the IFSMT, together with a manuscript of a heart failure self-management integrative literature review. This chapter reviews 32 articles written in peer-reviewed journals in the last 10 years. The reviewed articles are divided in two broad topics: (1) SM interventions and patient outcomes, and (2) the consequences of the inability to self-manage HF. This chapter underlines the gaps in nursing knowledge in heart failure SM and provides direction for the study. The focus of Chapter 3 is the methodology utilized for the study. It provides description of the sample, variables, and instruments to measure variables. It describes the subjects' protection

plan, recruitment plan, study procedures, and data analysis. Chapter 4 presents the results of entire study. It describes statistical analyses and presents a discussion of the findings and study limitations; it also includes a manuscript of the entire study. [?]Finally, this dissertation concludes with Chapter 5 presenting a synthesis of the dissertation and manuscripts, and it proposes implications for research, policy, education, and practice. It includes a third manuscript about nurse practitioner practice issues regarding treating patients with chronic diseases and applying the theoretical framework.

Gaps in Nursing Knowledge

Several gaps in the nursing knowledge of heart failure SM were identified in Chapter 2. The literature review showed that there is a gap in what constitutes effective strategies for successful outcomes of SM in HF. There are gaps in nursing knowledge as considerable variations in SM intervention components, mode of delivery, and dose hamper answering what interventions improve HF outcomes. When SM interventions do not work in preventing hospitalizations and HF readmissions, researchers look at the reasons and gaps in knowledge to try to explain the phenomenon. Several studies show that symptom recognition among HF patients is poor, and the patients fail to engage in self-management behavior. There is a gap in nursing knowledge of how to improve HF symptom recognition so the patients apply SM abilities to counteract those symptoms.

The primary goal of HF self-management is to improve patients' outcomes such as quality of life, reduce the frequency of HF exacerbation, and extend survival. Addressing these challenges, several researchers have suggested that using a tailored approach is more effective. The suggestion was to tailor to patients' attributes. However, there is conflicting evidence regarding which contextual factors are associated with successful self-management behavior and

which patient characteristics clearly impede successful HF self-management behavior. Only six out of 32 articles in the literature review mentioned a theoretical framework; thus, the lack of a theoretical framework in nursing research and publications is one of the identified gaps.

This study investigated a gap in nursing knowledge in association of patients' attributes and HF self-management behavior; it also addressed the lack of a theoretical framework in nursing research. By doing so, it contributed to the accumulated knowledge of heart failure self-management and, when seeking explanations for the study findings, underlined the challenges of HF self-management. This study utilized the Individual and Family Self-Management Theory, which is applicable to heart failure self-management, making this study the first testing concepts of the theory in a population of patients with heart failure.

Brief Summary of Study Findings

The findings of the study were that the patients showed adequate scores only for self-management confidence in performing heart failure behavior, and lower for other self-management behaviors, such as maintenance—that is, symptom monitoring and treatment adherence, and management—the ability to recognize symptoms, and decision-making in response to symptoms. When looking at variables predictions, complexity of condition did not predict self-management behavior. Self-efficacy significantly predicted maintenance and confidence behavior. Self-regulation significantly predicted management and confidence behavior. There was no mediating effect of self-efficacy and self-regulation between complexity of condition and SM behaviors.

Synthesis of the Manuscripts

The first manuscript is proposed to be submitted to the *Journal of Cardiovascular*

Nursing and follows its guidelines for authors: *Heart Failure Self-Management, Integrative Literature Review.* The purpose of the manuscript was to perform a literature review to integrate the literature about HF self-management and to identify gaps in nursing knowledge about this topic. The innovative feature of this particular literature review was to combine both qualitative and quantitative research articles and combine evidence for the concepts of both self-care and self-management. The gaps in nursing knowledge were underlined: what constitutes effective strategies for successful outcomes of SM in HF; how to improve HF symptom recognition so the patients apply SM abilities to counteract symptoms; which contextual factors are associated with self-management behavior; and the lack of theoretical framework in nursing research. The last two gaps guided this study.

The second manuscript is proposed to be submitted to the *Journal of the American College of Cardiology* and follows its guidelines for authors: *Heart Failure Self-Management Crossectional Study, Testing the Individual and Family Self-Management Theory.* The purpose of the manuscript was to describe the findings of the study, to examine the effects of the individuals' characteristics on their self-management behaviors, and to explain the gaps in nursing knowledge as identified in the literature review. In particular, it identified a gap of nursing knowledge of the association of patients' characteristics and their SM behavior. By doing so, it provided a contribution to the nursing knowledge of heart failure self-management. It described testing the concepts of the IFSMT in a population of patients with heart failure patients. It showed the challenges and complexity of heart failure self-management. It provided implications for future research and practice.

One of the conclusions of the literature review and this study was the importance of a theoretical framework for guiding nursing research and practice. An argument can be made that

nursing practice, particularly nurse practitioners' practice, needs to rely on a theoretical base. To involve patients more in the self-management of any chronic illness, it is preferable that the nurse practitioner seek the guidance of a theoretical framework. The discussion in Chapter 1 about the importance of SM showed that there are different and not always positive views of HF self-management. The Individual and Family Self-Management Theory can help practitioners steer through the obstacles and demands to self-management.

To address this issue, the third manuscript was written: *Nurse Practitioners' Practice and the Individual and Family Self-Management Theory.* This manuscript explored the necessity of theory for nurse practitioner practice in dealing with chronic disease self-management in general, as heart failure is one of the most common and most difficult to control chronic diseases. The manuscript addressed the gap of lacking a theoretical framework in nursing research applicable to everyday practice. It is proposed to be submitted to the *Journal for Nurse Practitioners* and follows its guidelines.

Based on the findings and discussions in Chapters 1, 2, 3, and 4 and the manuscripts presented in this dissertation, the following implications for research, policies, education, and practice are proposed.

Implications for Research

The discussion of self-management in Chapter 1 about the state of the science and the literature review in Chapter 2 showed that even though some researchers view self-care and self-management as different concepts, in scholarly publications, these concepts are used interchangeably and both concepts are considered synonymous. In Chapter 1, there is a discussion about the similarity of both concepts. The authors of the IFSMT, Ryan and Sawin

(2009), and Riegel, the co-author of the Self-Care of Heart Failure Index and Self-Care of Chronic Illness theory, recognize the similarity of the concepts (Riegel, Jaarsma, & Stromberg, 2012; Riegel, Lee, Dickson, & Carlson, 2009). The state of the science shows that the national guidelines for managing heart failure include both self-care and self-management. Yancy et al. (2013) propose that patients with HF should receive specific education to facilitate HF *self-care*.

However, in the most recent American College of Cardiology national guideline for the management of heart failure with reduced ejection fraction (Yancy et al., 2017), the authors call for *self-management* interventions. The recent statement from the American Heart Association calls for *self-care* for the prevention and management of cardiovascular disease and stroke, and Dr. Riegel is one of the co-authors (Riegel et al., 2017). The self-care in this statement is defined according to her theory of Self-Care of Chronic Illness (Riegel, Jaarsma, & Stromberg, 2012). However, in the section for Heart Failure recommendations, the authors discuss *self-management* of HF, and the references include many articles of HF *self-management*. The national institutions, such as HealthyPeople.gov, call for the *self-management* of diabetes and hypertension, not *self-care* (HealthyPeople.gov, 2019). The Centers for Disease Control and Prevention calls for *self-management* education (CDC.gov, 2018).

There is a need for formal research to unify these concepts. The study may start with a concept analysis of Self-Care and Self-Management. Then a pilot qualitative study to assess nurses' understanding of both concepts in the area of cardiovascular disease should be designed. The next step is to devise a wider study to measure the view of health care professionals of both concepts. And based on this, the following step is to bring attention to wider health care professionals' communities and associations to put a statement in the national guidelines that these concepts are synonymous.

The literature review in Chapter 2 shows that many international studies have recently been published about heart failure self-management. In fact, among 32 articles in the literature review, 21 were international studies. And out of 32 reviewed studies, 13 used the Self-Care Heart Failure Index and seven were international studies. This indicates that this instrument is widely used in heart failure research in the U.S. and, especially, in other countries. Comparing Self-Care Heart Failure Index scores in the present study with the scores in studies from other countries, this study's patients had higher SCHFI scores (Table 4.4, Chapter 4). This study is small and underpowered; therefore, the results should be interpreted with caution.

However, the higher scores possibly mean that the patients in this study showed better HF SM abilities. One possible explanation is that American heart failure patients have better self-management abilities because of the efforts of health care providers in the U.S. to prevent readmissions for heart failure, which results in better SM behaviors than in other countries. The direction for future nursing study is to perform a large-scale international study measuring self-management behaviors among heart failure patients in different countries to see if, indeed, there is a trend of American patients being savvier in their HF SM behavior.

As mentioned above, the literature review in Chapter 2o shows that the Self-Care Heart Failure index is widely used in HF self-management research. However, this instrument is not used in everyday practice in heart failure clinics to assess patients' SM abilities. Consistent with the idea that "what gets measured gets done," there is a need for surveillance of SM (Brady et al., 2018). There are challenges with how to measure self-management, as clinicians are more focused on biomedical control of chronic disease as a feature of success, where patients may focus more on feelings of well-being and social interactions (Mudge, Kayes, & McPherson, 2015). In Chapters 2, 3, and 4, the description of the Self-Care Heart Failure Index instrument

and interpretation of study findings show that in HF, self-management includes multiple behaviors: signs and symptoms identification and management; seeking health advice; dietary sodium modification; fluid management; taking prescribed medications; physical exercise; and preventative behaviors (e.g., influenza vaccine).

Clinicians document the success of HF self-management by lower BNP levels, taking guided HF therapy medications, fewer ED visits or hospital admissions, and control of symptoms. For their part, patients appreciate collegial provider relationships, understandable directions for care, and participation in care decision-making (King, Johnson, Cramer, Purdy, & Huntley, 2018). Biomedical parameters of self-management are easier to measure and document compared to patients' satisfaction with care, mutual decision-making, and HF knowledge. Based on this study, filling in the Self-Care Heart Failure Index questionnaire by the research patients took 10-15 minutes. Also, it has a complicated formula for scoring each scale, which added another 15 minutes to finalize the scores (Riegel, 2009). Thus, this instrument is too lengthy to use during the patient's visit to document HF self-management progress.

Based on the literature review and state of the science and methodology in Chapter 1, 2, and 3, future nursing studies need to focus on designing a new instrument for HF self-management surveillance to be a concise and valid tool easily implemented during outpatient visits. The other option is to cooperate with Dr. Riegel and propose a study to design and test the psychometric properties of SCHFI-short version, which can be a six- or seven-question tool instead of 22, with more simplified scoring metrics. The shorter version HF self-management instrument can be used in everyday practice to measure the progression of self-management, and scores can be documented from visit to visit in vital signs charts in electronic medical records.

The literature review in Chapter 2 showed that there are gaps in nursing knowledge as

considerable variations in SM intervention components, mode of delivery, and dose hamper answering what interventions improve HF outcomes. The state of the science and discussion in Chapter 1 about the significance of HF self-management noted that self-management in the 2013 ACCF/AHA guideline for the management of heart failure has level of evidence B, because studies of heart failure SM have mixed results. HF self-management frequently is not a priority in hospital quality improvement projects (Rielgel et al., 2017). To secure the support of hospital nursing leaders and hospital administrators in bringing financial and people resources to support HF self-management interventions, there is a need for future research into a cost-effectiveness analysis of value of SM programs in heart failure. Showing HF self-management cost-effectiveness will help endorse SM interventions on the local and national level.

Implications for Policies

Based on the literature and state of the science in Chapters 2 and 1, many nursing self-management interventions were aimed at preventing heart failure readmissions. The Center for Medicaid and Medicare services (CMS) implemented the Federal Hospital Readmissions Reduction Program (HRRP) on October 1, 2012, to provide financial incentives or penalties for hospitals to reduce readmissions for heart failure, pneumonia, and myocardial infarction, with a downward adjustment of Medicare payment for hospitals with an "excess" of 30-day readmission rates (Pandey et al., 2016). As the result, health care professionals focus on ways to reduce the risk of heart failure readmissions. The self-management of heart failure aids in reducing the risk of readmissions. Therefore, nursing researchers focus on interventions to increase heart failure self-management abilities, as shown in literature review.

The literature review shows that there is a gap in nursing knowledge, however, as those interventions are not always successful in preventing readmissions. The literature often suggests

implications for future research in heart failure SM but seldom implications for policy change. There is a need for policies in place promoting self-management. According to HealthyPeople.gov, law and policy are among the most effective tools to improve health (2019). Also, changing policy requires an advocate. Nurse practitioners, due to their advanced roles, can become these advocates. On the hospital level, the first step in policy change should be to familiarize themselves with existing policies on heart failure self-management as well as who are the hospital administrators involved with quality improvement projects in HF readmission prevention programs.

The second step is to identify colleagues who are interested in helping with promoting heart failure self-management. The next step is to propose to hospital administrators a quality improvement project to perform patients' self-management education at the time of diagnosis with heart failure and at each visit and to require the documentation of education, built-in electronic health records. These measures are simple, and do not necessitate large expenditures. To promote these initiatives on the larger scale in the future, patients' heart failure SM education requires higher priority by the nurses and nursing leaders (Albert et al., 2015). The hospital administrators need to buy in to allocating financial and people resources to adequately develop and employ heart failure SM initiatives and to initiate further SM quality improvement projects. Inviting external speakers for nursing and medical grand rounds who are experts in heart failure self-management and self-management cost-effectiveness can help secure administrative support.

On the state level, the Wisconsin Nurses Association serves as the voice of professional nursing. As the only registered lobbyist for Wisconsin’s registered nurses, this organization influences Wisconsin nursing policies. Registered nurses and nurse practitioners who are experts

in self-management, including heart failure self-management, should be encouraged to join the organization in order to develop state policies regarding SM and to be actively involved in planning, advocacy, and implementation of chronic disease SM practices to transform the state healthcare system.

According to literature review and the state of science in the first two chapters, many of the scholars remark that we need to do more in the area of self-management. The American Heart Association published a statement about the necessity and benefits of self-care and self-management of chronic cardiovascular disease (Riegel et al., 2017). One possible step is to suggest that the National League of Nursing and American Nursing Credentialing Center offer national certifications in nursing self-management of chronic disease.

Next step is to be sure that self-management is part of the national health guidelines. Expanding the national guidelines to include chronic disease self-management can help change policies in the future, and the registered nurses and nurse practitioners who are experts in chronic disease self-management, including heart failure, should serve on the national committees that write these guidelines. The last national guideline for heart failure management was written in 2013 (Yancy et al., 2013). There is a necessity for heart failure guideline updates, and nurse researchers can bring their vast knowledge and experience in heart failure self-management to form new guidelines and plan new directions for HF self-management.

Implications for Education and Practice

Chapter 1e reviews the Individual and Family Self-Management Theory, which was written in 2009 with the goal of expanding our understanding of SM (Ryan & Sawin, 2009). Several years later, as the literature review shows, despite the large body of research, there are

multiple gaps in nursing knowledge about self-management, HF self-management included. One possible explanation is that we need to improve the education of nurses and physicians in chronic disease self-management The self-management of chronic disease has to become a part of nursing and medical undergraduate and graduate curricula. Continuing nursing and medical education should include self-management of chronic disease for providers who are in practice. The nurse practitioners and registered nurses who are experts in self-management of chronic illness, heart failure included, should design this nursing continuing education.

The literature review shows the complexity and challenges of heart failure self-management. Collins et al. (2015) noted that attempts to assess and document self-management are often "thwarted by the lack of the necessary resources or time (p. 10)." Chronic diseases are multifaceted and complex and require ongoing management. Riegel (2012) assesses 22 HF self-management behaviors. The American Heart Association advises that heart failure self-management consists of 28 different self-management behaviors, including disease control, symptom control, and prevention of deterioration (Riegel et al., 2017). In a 20-minute established patient visit, or a 40-minute new patient visit, the providers can only assess the symptom control and medication adherence as part of self-management.

Specialized heart failure clinics have large, multi-disciplinary teams with nurses who can follow up with a phone call to check other self-management needs, but this also requires patient engagement and a willingness to communicate. In general, cardiology clinic patients with heart failure, due to the frequency of their symptoms, often see the nurse practitioner, who may have limited nursing support and a very busy clinic schedule. The hospitals to prevent re-hospitalizations for heart failure within 30 days employ registered nurses who call the patient after hospital discharge and weekly within 30 days to encourage compliance and prevent fluid

overload. However, beyond these 30 days, the patient relies on his own knowledge of heart failure.

One of the practice solutions is to instruct the patients to call the clinic to talk to the clinic nurse prior to the visit, symptomatic or not, so the potential HF issues can be flagged right away. The purpose of research is to be applicable to practice and capture patients' outcomes. And when research shows the benefits of self-management, practice should be changed—even small steps can point us in the right directions. Patients are likely not aware that hospitals are penalized for frequent heart failure readmissions. The patients' goal is to feel better and to understand their treatment. Frank conversation with the patients can help bringing their engagement. There are outpatient infusion clinics, which can administer IV diuretics on a scheduled basis to control fluid overload in patients with diastolic heart failure. The goals of uptitrating neurohormonal therapy every 2 weeks can help recover low left ventricular ejection fraction in patients with systolic heart failure, as Chapter 1 states. Explaining a theoretical view of heart failure self-management to the patient, and explaining that the amount of medication, comorbidity, and social and family issues may all impact their care and providers understand that as well. [clarify]The providers' goal is to increase patients' self-regulation—their decision-making and confidence in their knowledge of the disease in order to manage the symptoms. This conversation may not be feasible in a 20-minute, established-patient visit, but it can be done in subsequent phone calls, or by seeing the patient more frequently in the clinic.

Ryan and Sawin (2009) state that robust theory offers numerous new opportunities for expanding knowledge related to SM. Nursing researchers help identify the theoretical concepts essential to engagement in SM behaviors (Ryan & Sawin, 2009). If nurses effectively promote SM at multiple levels, more people with chronic disease may actively self-manage. The direction

for future nursing practice, including the self-management of heart failure, should be practice guidance guided by the theory.

The discussion in Chapter 1 shows that even savvy patients can find the obligation of HF self-care surveillance overwhelming. Clinicians' recommendations do not always influence patients' engagement in SM of heart failure symptoms (Athilingam, Jenkins, Zumpano, & Labrador, 2018). Theory can offer a framework for assessing the needs of patients and developing interventions to enhance their abilities to manage the daily care of themselves and their family members, and conserve their energy as well as their structural, personal, and social integrity (Ryan & Sawin, 2009). Nursing theories, including the Individual and Family Self-Management Theory, are particularly concerned that American health care is frequently paternalistic, when the power remains with providers (Ryan & Sawin, 2009). The patient's autonomy is a center of nursing theories, and familiarizing themselves with nursing theoretical frameworks, as shown in the manuscript Three, helps nurses and nurse practitioners to build their practice focusing on the patients' needs in addition to biomedical parameters. Self-management is one of the means of engaging the patients in their health management, including self-management of heart failure.

Conclusion

This study tested concepts of the Individual and Family Self-Management Theory in a population of patients with heart failure. This study is the first to test the IFSMT in the area of heart failure. The study was small and likely underpowered, and its findings need to be tested in the larger study. However even in a small study, the challenges of heart failure are evident. In this chapter, the findings of the study are summarized and three manuscripts are discussed. It provides a discussion of the future implications of heart failure self-management to nursing

policy and suggests future directions for heart failure SM research, education, and practice. This chapter includes with a last manuscript about nurse practitioners' practice and the importance of theoretical framework in self-management.

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Manuscript Three: Nurse Practitioners' Practice and the Individual and Family Self-Management Theory

Abstract

Nurse Practitioners (NP) treat patients with chronic illnesses. There is an assumption that the self-management of chronic illness carries benefits for controlling symptoms and preventing their exacerbation as well as preventing hospitalizations. However, self-management (SM) is not a straightforward process. There is a necessity to enrich nurse practitioners' (NP) practice with theoretical frameworks to ascertain whether self-management is "right" or "wrong." The Individual and Family Self-Management Theory helps guide NP practice. Using a theoretical framework is essential in future nursing research and practice to improve SM intervention in chronic illness.

According to Gray, Grove, and Sutherland (2017), "Research is a major force in the nursing profession that is used to change practice, education, and health policy" (p. 479). The goal of the research is to move nursing science forward, to advance evidence-based practice, and, ultimately, to improve patients' care and well-being. Americans are living longer but have many chronic illnesses (Meleis, 2018). Nursing focuses on improving care delivered to people with both acute and chronic disorders. Chronic illnesses are costly to society, leading to high patient morbidity and mortality, and reduced quality of life. Nurses caring for these patients must address the complex management needs of their illnesses.

The future for advancing nursing knowledge relies on the extent to which nurses are willing to commit to developing scientific frameworks to drive future research and practice (Meleis, 2018). The nature of nursing practice is affected by the role of advanced nursing

practitioners, who ask for a reassessment of the theories needed for their practice (Meleis, 2018).

Patients with acute exacerbations of chronic conditions see providers frequently, and many outpatient visits are used by patients with chronic diseases (Wallace et al., 2015). The utilization of nurse practitioners (NPs) allows the physician to treat a patient with a chronic condition and subsequently develop a plan of care. Then the NP manages disease intermittently and frequently until the patient sees the physician again in 6-12 months. Nurse practitioners are educated within a nursing framework that emphasizes health promotion, prevention of disease complications, disease treatment, and symptom alleviation in the care of the patient (Meleis, 2018).

Health care organizations prioritize improving performance and patient outcomes by focusing their attention on chronic disease management in an effort to prevent readmissions, decrease costs, and improve patients' quality of life (Kutzleb et al., 2015). Self-management (SM) is an additional path to prevent repeated emergency department visits and reduce the risk of hospitalizations. Chronic disease SM initiatives are now recognized as an effective method to improve patient health status and quality of life while aiding in the reduction of overall health-related complications and associated costs (Ory et al., 2014). The National Academy of Medicine (formerly the Institute of Medicine) urges the use of proven self-management interventions, such as the systematic provision of education by health care providers, to strengthen patient skills and confidence in the overall management of chronic illness. It includes regular assessment of progress and problems, goal-setting, and problem-solving support (Ory, et al., 2014).

In focusing on patients and families, NPs are successful in providing care to persons with chronic conditions because of their advocacy of patient self-management skills (Kutzleb et al., 2015). The goal is to provide SM teaching in combination with traditional patient education. NPs

teach how to identify and improve chronic health problems and develop confidence in new health behaviors. In the management of chronic disease, a partnership develops between the NP, patients, and family members. Patients who acquire SM skills undergo an overall change in behavior and are able to better define and control their symptoms. The NP applies advanced clinical judgment and expert clinical practice, and provides evidence-based care at an advanced level (Katzleb et al., 2015). The NP assesses the patient's understanding of disease processes and educates the patient regarding disease self-management, symptom exacerbation, medications, and possible dietary restrictions (Kutzleb et al., 2015). The goal is increasing patient engagement in chronic disease SM and adopting lifestyle changes that facilitate controlling symptoms and slowing the progression of the disorder (Rasmusson, Flattery, & Baas, 2015). There is evidence that SM education improves knowledge and self-monitoring, delays time to hospitalization, and reduces days in the hospital (Yancy et al., 2013).

Nursing scholars recognize the benefits of self-management in helping patients, and there is a significant body of research on this topic. The Nurse Practitioners' practice of self-management is enriched by applying theoretical frameworks. Nursing conceptual frameworks provide means to look at nursing in relation to patients' well-being, thereby assigning meaning to the practice (Meleis, 2018). Self-management has many facets. There is a dichotomy of views of healthcare providers and patients regarding SM. Without using a theoretical framework, providers can achieve only moderate success or even failure.

The premise of self-management is based on increasing patients' autonomy (Podlog & Brown, 2016). LeRoy et al. (2014) note that a clinician may advise a patient to take a medication or monitor blood pressure and weight on a daily basis, but it is the patient who has to integrate these activities into daily life. While providers know which behaviors and treatments lessen

morbidity and mortality, the patients know how those behaviors and treatments fit within their own life preferences. Clinicians hope that SM of chronic diseases helps patients self-manage in ways that will optimize their health and prevent hospitalizations, while the patients may see hospital admissions as a beneficial tuning up of their chronic condition (LeRoy et al., 2014).

Some scholars have a negative opinion about self-management. Bovenkamp and Dwarswaard (2017) state that there is a controversy about shifting responsibility to individuals with the goal of reducing public spending. Such a shift may give patients the opportunity to become engaged in SM, but it also implies that the patients are to blame when they cannot live up to the ideal and fail to self-manage properly (Bovenkamp & Dwarswaard, 2017). The focus on individual obligations disregards the social context, which determines whether and how patients start to self-manage (Bovenkamp & Dwarswaard, 2017). The way SM responsibilities are imposed on individuals can lead to patient abandonment and inequality (Bovenkamp & Dwarswaard, 2017). Despite the emphasis on self-management and the creation of numerous interventions to support it, power relations remain firmly in place with healthcare professionals. This may limit patients who want and have the capacity to SM (Bovenkamp and Dwarswaard, 2017). Providers must consider a patient's autonomy and the desire to make American healthcare less paternalistic (Bovenkamp and Dwarswaard, 2017).

In this debate, it is important to seek guidance through theory. One of the middle-range theories that addresses self-management is Ryan and Sawin's Individual and Family Self-Management theory. Ryan and Sawin (2009) define self-management as one's control over and responsibility for the management of chronic conditions or healthy behaviors by purposefully engaging in the performance of learned behaviors. The IFSMT envisions SM as a process by which individuals and families employ knowledge and beliefs, self-regulation skills and abilities,

and social facilitation to attain proximal (e.g., SM behaviors and health care services costs) and distal outcomes (health status, quality of life, and cost of health) (Ryan & Sawin, 2009). The process of SM occurs within the context of risk and the protective factors of the specific health condition, the physical and social environment, and various individual and family factors (Verchota & Sawin, 2016). "Factors in the contextual dimension influence individual and family engagement in the process of SM as well as directly impact outcomes" (Ryan & Sawin, 2009, p. 223). Interventions enhancing both the individual's and family's contextual factors and SM processes result in more positive outcomes.

Self-management seems like a straightforward process, but it is not. And wherever there is a debate about the benefits and ownership of "right" versus "wrong" SM, the theory should direct the practice. The need for a theoretical framework in NP practice is especially evident in SM work with patients with heart failure. Athilingam, Jenkins, Zumpano, and Labrador (2018) reported that even savvy patients find the obligation of HF self-care surveillance overwhelming. A clinician's recommendations do not always influence patient engagement in SM of heart failure symptoms.

The IFSMT guides the researchers in this debate by stating that SM is not always equal to adherence and compliance, and the primary responsibility for SM lies with individuals and families. Patients engaging in self-management behavior may or may not cooperate with healthcare professionals (Ryan & Sawin, 2009). Sometimes good healthcare intentions may have unintended consequences and make healthcare professionals, nurse practitioners included, question their abilities and methods. There are often hidden nuances that may impact outcomes. Interventions have to be supported by quality research, which refines existing knowledge that can be translated to practice (Ryan & Sawin, 2009). The Individual and Family Self-

Management Theory (IFSMT) (Ryan & Sawin, 2009) provides clinicians with a framework for assessing and applying a theory-based approach to care for persons with chronic illness in order to engage them in self-management.

Ryan and Sawin (2009) remark that while SM appears to offer significant promise, widespread agreement about what individual and family self-management actually is and how it can be developed is not fully understood and is the subject of scholarly dispute. Theory brings a framework for assessing the needs of patients and developing an intervention for enhancing patients' abilities to manage the daily care of themselves and their family members, and conserve their energy, and structural, personal, and social integrity (Ryan & Sawin, 2009).

The American Association of Colleges of Nursing (2018) states that scholarship informs clinical practice and healthcare delivery. Scientific inquiry engages and helps diverse populations and age groups, supplying the evidence to support culturally sensitive interventions to improve quality of life and enable self-management. Conceptual frameworks provide meaning to nursing. Using a theoretical framework is essential in future nursing research and practice. Nurse practitioners' practice is enriched by the theory and, especially, by the participation in research testing theoretical frameworks to improve SM interventions in chronic illness, including heart failure.

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Appendix A: Instruments

Charlson Comorbidity Index (Charlson et al., 1994)

Charlson Criteria Checklist

[Interviewer: Please underline information that is abstracted from the chart.]
1 point per event

MI:	One or more definite or probably infarcts (note if more than one) Hospitalized ECG and/or enzyme changes (not ECG changes only)	_____
CHF:	Those exertional or paroxysmal nocturnal dyspnea and who have Evidenced response symptomatically or on physical examination To Dig, diuretics, afterload reducing meds. Does not include those On meds by have had no symptomatic response and no evidence of Improvement of physical signs.	_____
PVD:	Intermittent claudication or who had a bypass for arterial insufficience; gangrene or acute arterial insufficiency, and those with an untreated thoace or abdominal aneurysm of 6 cm or more.	_____
CVD:	Hx of CVA with minor or no residual and TIA's	_____
Dementia:	Chronic cognitive deficit	_____
Chronic Lung Disease:	Mild—dyspneic with moderate activity without tx or those who are dyspneic only with attack	_____
	Mod—dyspneic with slight activity with/wo tx; those who are dyspneic with mod activity despite tx	
Connective tissue disease:	SLE, polymitositisis, mixed connective Tissue disease; polymalgia rheumatica; Mod-severe RA	_____
PUD:	Patients who have had required tx for ulcers disease, including Those who have bled from ulcers	_____
Mild Liver Disease:	Cirrhosis without portal HTN or chronic hepatitis	_____
Diabetes:	Mild—tx with insulin or oral hypoglycemics, but not diet alone	_____
	Mod—Previous hospitalization for DKA, hyperosmolar coma, control and those with juvenile onset or brittle diabetes	

2 points per event

Hemiplegia:	Dense hemiplegia or paraplegia, secondary to CVA or Other condition	_____
Diabetes—end organ damage:	Severe—retinopathy, neuropathy, Nephropathy	_____
Renal disease:	Mod—serum creatinine > 3 mg %	_____
	Severe—on dialysis, had a transplant and uremia	
Any tumor:	Solid tumors with no documented mets, but initially tx Within last 5 years, including breast, colon, lung, other Tumors	_____
Leukemia:	AML/CML; ALL/CLL	_____
Lymphoma:	Hodgkins, lymphosarcoma, Waldenstrom's macro-Globulinemia, myeloma, other lymphomas	_____

3 points per event

Liver disease:	Mod—cirrhosis, portal HTN but no hx of variceal bleeding	_____
	Severe—cirrhosis, portal HTN and a hx of variceal bleeding	_____

4 points per event

AIDS:	Definite or probably dx	_____
Metastatic solid cancer:	met solid tumors including breast, lung, colon, other tumors	_____
	Total Charlson	_____

Index of Self-Regulation (Fleury, 1998)

Subcode _____
Date _____

Index of Self-Regulation

Directions: On this page are statements that describe ways people feel about the way that they take care of themselves. Beside each statement is a scale that ranges from strongly agree (5) to strongly disagree (1). Please respond to each statement by first reading the statement, and then circling the response which best describes the extent to which you agree or disagree with the statement.

When answering each statement, think about any recent changes that you have made in the way that you take care of yourself, such as quitting smoking, going on a diet, or starting an exercise program. Please respond to each statement.

There are no right or wrong answers to the statements. Please take your time and make sure that you understand the statements. Your name will not appear on the questionnaire and all responses will be kept confidential.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1. I think of the benefits of changing the ways that I take care of myself.	1	2	3	4	5
2. I remind myself of the good that I am doing by changing the ways that I take care of myself.	1	2	3	4	5
3. I remind myself of the importance of changing the ways that I take care of myself.	1	2	3	4	5
4. I keep track of how I am doing in changing the ways that I take care of myself.	1	2	3	4	5
5. I watch for signs of progress as I change the ways that I take care of myself.	1	2	3	4	5
6. I monitor myself to see if I am meeting my goals.	1	2	3	4	5
7. I have learned new habits for the ways that I take care of myself.	1	2	3	4	5
8. I have learned to approach old situations in new ways.	1	2	3	4	5
9. I have learned to make changes that I can live with.	1	2	3	4	5

Self-Efficacy for Managing Chronic Disease 6-Item Scale (Stanford Patient Education Center, 2018)

STANFORD
PATIENT EDUCATION
RESEARCH CENTER

Self-Efficacy for Managing Chronic Disease 6-Item Scale

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

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

not at all confident 1 2 3 4 5 6 7 8 9 10 totally confident

2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

not at all confident 1 2 3 4 5 6 7 8 9 10 totally confident

3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

not at all confident 1 2 3 4 5 6 7 8 9 10 totally confident

4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

not at all confident 1 2 3 4 5 6 7 8 9 10 totally confident

5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?

not at all confident 1 2 3 4 5 6 7 8 9 10 totally confident

6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?

not at all confident 1 2 3 4 5 6 7 8 9 10 totally confident

Scoring

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the scale is the mean of the six items. If more than two items are missing, do not score the scale. Higher number indicates higher self-efficacy.

Characteristics

Tested on 605 subjects with chronic disease

No. of Items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
6	1-10	5.17	2.22	.91	NA

Source of Psychometric Data

Stanford/Garfield Kaiser Chronic Disease Dissemination Study. Psychometrics reported in: Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001,pp. 256-262.

Comments

This 6-item scale contains items taken from several SE scales developed for the Chronic Disease Self-Management study. We use this scale now, as it is much less burdensome for subjects. It covers several domains that are common across many chronic diseases, symptom control, role function, emotional functioning and communicating with physicians. For internet studies, we add radio buttons below each number. There are 2 ways to format these items. We use the format on this document, the other is shown on the web page. A 4-item version of this scale available in Spanish.

References

Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001,pp. 256-262.

This scale is free to use without permission

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Self-Care Heart Failure Index 6.2 (Riegel et al., 2009)

SELF-CARE OF HEART FAILURE INDEX v.6.2

All answers are confidential.

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

SECTION A:

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

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

SECTION B:

Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure.

In the past month, have you had trouble breathing or ankle swelling? Circle one.

0) No

1) Yes

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

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

J Cardiovasc Nurs. Author manuscript; available in PMC 2010 November 1.

Listed below are remedies that people with heart failure use. If you have trouble breathing or ankle swelling, how likely are you to try one of these remedies?

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

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

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

SECTION C:

In general, how confident are you that you can:

	Not Confident	Somewhat Confident	Very Confident	Extremely Confident
17. Keep yourself free of heart failure symptoms?	1	2	3	4
18. Follow the treatment advice you have been given?	1	2	3	4
19. Evaluate the importance of your symptoms?	1	2	3	4
20. Recognize changes in your health if they occur?	1	2	3	4
21. Do something that will relieve your symptoms?	1	2	3	4
22. Evaluate how well a remedy works?	1	2	3	4

Appendix B: Copy of Informed Consent

Medical College of Wisconsin and Froedtert Hospital

CONSENT TO PARTICIPATE IN RESEARCH

Name of Study Subject: _____

HF self-management

You are invited to take part in this research study. This form tells you why this research study is being done, what will happen in the research study, and possible risks and benefits to you. If there is anything you do not understand, please ask questions. Then you can decide if you want to join this study or not.

A1. INTRODUCTION – WHY ARE WE ASKING YOU ABOUT THIS STUDY?

You are invited to participate in this research study because you have been diagnosed with congestive heart failure and are eligible for our research study of patients with CHF A total of about 100 people are expected to participate in this study.

There are no financial conflicts of study personnel.

A2. DO I HAVE TO BE IN THIS STUDY?

You can decide whether to take part in this study or not. You are free to say yes or no. If you say no, your regular medical care will not change. Even if you join this study, you do not have to stay in it. You may stop at any time.

A3. WHY IS THIS RESEARCH STUDY BEING DONE?

The purpose of this study is to see what predicts self-management behavior in patients diagnosed with congestive heart failure. We expect patients with CHF to recognize their symptoms and

feel confident to manage CHF. However, some patients have difficult time to control their disease. We want to see if the other health conditions, patient's knowledge and confidence about CHF explains how people manage their congestive heart failure.

B1. WHAT WILL HAPPEN IF I TAKE PART IN THE STUDY?

Study staff will screen potential patients who are diagnosed with CHF. We will approach these patients to consent for the study. We will ask these patients to fill in 3 questionnaires about how they feel about their congestive heart failure symptoms. We will score the answers and will perform a statistical analysis to see how these answers correlate.

B2. HOW LONG WILL I BE IN THE STUDY?

You will perform study activities, filling in questionnaires for this research study, for 1 visit only.

- After your visit to the health facility is finished, we want to keep in touch with you to follow your health over time. We will telephone you / ask you to come in to the health facility once more if we need clarification of your answers.

B3. CAN I STOP BEING IN THE STUDY?

You may stop at any time. If you decide to leave the study, please let the study team know. The study investigator may stop your participation in the study at any time for any reason without your consent. He / she will tell you if this happens.

C1. WHAT RISKS OR PROBLEMS CAN I EXPECT FROM THE STUDY?

We watch everyone in the study for unexpected problems. **You need to tell the study doctor or a member of the study team immediately if you experience any problems or become too upset.**

⇒ **Questionnaires:** You may feel that some of the questions we ask are stressful or upsetting. If

you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately, however we would really like for you to finish answering all the questions in full.

Another risk may be loss of confidentiality. Every effort will be made to keep your study records confidential but we cannot guarantee it. Depending on the kind of information being collected, if your study information were accidentally seen, it might be used in a way that could embarrass you or affect your ability to get insurance. If you have questions, you can talk to the study director about whether this could apply to you.

C2. RISKS TO WOMEN WHO COULD BECOME PREGNANT

There is no risk to pregnant women to participate in this study.

C3. ARE THERE ANY BENEFITS TO TAKING PART IN THE STUDY?

This study will not help you, but we hope the information from this study will help us to provide better health services for patients with congestive heart failure.

D1. ARE THERE ANY COSTS TO BEING IN THE STUDY?

There are no costs to you for any of the visits or services you receive in this study. If you have questions regarding study costs, please contact research team at 414 805-6547.

D2. WILL I BE PAID FOR BEING IN THE STUDY?

You will be offered $5 gift certificate for participating in this study.

D3. WHAT OTHER CHOICES DO I HAVE?

You do not have to join this study. You are free to say yes or no.

⇒ Whether or not you join this study, your usual medical services will not change.

D4. WILL I BE GIVEN NEW INFORMATION ABOUT THE STUDY?

After the study has been completed, we will notify you of the results.

Nothing in this consent form affects any legal rights you may have nor does it release the investigator, the sponsor, the institution, or its agents from liability for negligence.

D6. WHO CAN ANSWER MY QUESTIONS ABOUT THE STUDY?

- If you have more questions about this study at any time, you can call 414 805-6547
- If you have questions about your rights as a study participant, want to report any problems or complaints, obtain information about the study, or offer input you can call Hospital Research Subject Advocate line at 414-955-8844.

E. PERMISSION TO COLLECT, USE AND SHARE HEALTH INFORMATION

E1. What health information will be collected and used for this study?

To be in this research study, the study team needs your permission to access, collect and use some of your health information. If you say no, you cannot be in the study. This information may come from questions we ask, forms we ask you to fill out, or your medical record, as described below. We will only collect and use information needed for the study.

The protected health information (PHI) originates from services you will or have received at one or more of the following locations: listed locations follow.

The health information we will collect and use for this study is:

Health information collected during this study, such as, questionnaires

⇨ Medical records dating from when you join this study until the study is over

E2. Who will see the health information collected for this study?

The only people allowed to handle your health information are those on the study team at the Hospital, those on the Institutional Review Board (IRB) and those who check on the research activities to make sure the hospital's rules are followed.

If the costs of any necessary emergency medical treatment in the event of a research-related injury are billed to your health insurance, your health information may need to be disclosed to the insurer for billing purposes.

We will not use your health information for a different study without your permission, or the permission of a hospital research review board (IRB). Once all personal identification is removed, the information might be used or released for other purposes without asking you. Results of the study may be presented in public talks or written articles, but no information will be presented that identifies you.

E3. What are the risks of sharing this health information?

One risk of taking part in a research study is that more people will handle your personal health information collected for this study. The study team will make every effort to protect the information and keep it confidential, but it is possible that an unauthorized person might see it. Depending on the kind of information being collected, it might be used in a way that could embarrass you or affect your ability to get insurance. If you have questions, you can talk to the study director about whether this could apply to you.

E4. How long will you keep the health information for this study?

If you sign this form, we plan to keep your information for 10 years after the research study ends in case, we need to check it again for this study.

E5. Can I cancel my permission to share this health information?

If you change your mind later and do not want us to collect or share your health information, you need to send a letter to research team at the address provided. The letter must say that you have changed your mind and do not want the researcher to collect and share your health information. At that time, we may decide that you cannot continue to be part of the study. We may still use the information we have already collected.

CONSENT TO PARTICIPATE IN THE STUDY

By signing my name below, I confirm the following:

- I have read (or had read to me) this entire consent document. All of my questions have been answered to my satisfaction.
- The study's purpose, procedures, risks and possible benefits have been explained to me.
- I agree to let the study team use and share the health information and other information gathered for this study.
- I voluntarily agree to participate in this research study. I agree to follow the study procedures as directed. I have been told that I can stop at any time.

IMPORTANT: You will receive a signed and dated copy of this consent form. Please keep it where you can find it easily. It will help you remember what we discussed today.

Subject's Name *please print*	**Subject's Signature**	**Date**

*** Name of person discussing/ obtaining consent** *please print*	**Signature of person discussing/obtaining consent**	**Date**

** A member of the study team trained and authorized by the Principal Investigator to act on her/his behalf in obtaining informed consent according to the protocol. In all research study protocols the Principal Investigator is responsible and accountable for the study.*

CURRICULUM VITAE

April 2019

Svetlana Zaharova, RN, MSN, FNP-BC

Advanced Practice Nurse Prescriber

Family Nurse Practitioner

Office Address: Medical College of Wisconsin
8701 Watertown Plank Rd
Milwaukee, WI 53226
Phone:(414) 805-6547, 955-7004
Fax: (414) 805-8778
Email: szaharov@mcw.edu

Education:

May 2015 – present. PhD in Nursing- **in process, 4th year student**
University of Wisconsin-Milwaukee, College of Nursing

May 2005 - Masters of Science in Nursing, Family Nurse Practitioner (MSN, FNP)
University of Wisconsin-Milwaukee, College of Nursing
GPA 3.9.

1997 Bachelors of Science in Nursing (BSN)
College of Nursing
University of Wisconsin-Milwaukee
Dean's honor list.

Experience:

May 2007 – present.
Cardiology Nurse Practitioner
Department of Medicine, Cardiovascular Division
Medical College of Wisconsin

Experience:

October 2005 –May 2007
Heart Transplant Nurse Practitioner
Department of Medicine, Cardiovascular Division
Medical College of Wisconsin

Experience:

July 2004 – September 2005
Research Nurse
Department of Medicine, Division of Pulmonary and Critical Care
Medical College of Wisconsin

2000 – 2004
Research nurse
Department of Medicine, Cardiovascular Division
Medical College of Wisconsin

1997-2000
Staff RN, Telemetry Unit
St. Mary's Hospital-Milwaukee

Research: Cardiac Rehabilitation in Cardiomyopathy Patients (Chart Review Study)
CHF Self-Management Study (Research Award, University of Wisconsin - Milwaukee) – ongoing
Research NP with Dr. Strande project of Micro RNA in diastolic dysfunction

Poster Presentations: Department of Medicine Research Retreat, UW- Milwaukee Student Research Symposium

Awards: Harriet H. Werley Doctoral Student Nursing Research Award
Department of Medicine Research Retreat: First Abstract Submission Recognition 2018
Sigma Theta Tau International Nursing Student Poster Award 2018, Sigma Theta Tau International Best Doctoral Student Award 2017

Certification: Certified as a Family Nurse Practitioner on 7/25/2005
Basic Life Support certified (BLS)
ACLS certified

Additional Responsibilities: Preceptor for nurse practitioner students

Leadership Opportunities: Advanced Practice Providers Onboarding Coordinator
Former member of the Medical College of Wisconsin (MCW) advanced practice ambulatory counsel; Member of the MCW advanced practice preceptors committee;
Member of a pilot program in cardiovascular medicine and Froedtert Hospital for CHF readmission prevention,

Professional Organizations: Member of Sigma Theta Tau Nursing International