

MAKING MEDICATION ADHERENCE DECISIONS: STORIES FROM OLDER  
ADULTS TAKING MEDICATIONS FOR CONGESTIVE HEART FAILURE

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## DEDICATION

To Aaron Meraz, my amazing husband, whose support and wisdom made it possible for me to complete this work. Your prayers and encouragement got me through. And to my children, Aaron and Sarah, thank you for your never-ending patience and love. I love you with all my heart.

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## ABSTRACT

REBECCA LYNN MERAZ

### MAKING MEDICATION ADHERENCE DECISIONS: STORIES FROM OLDER ADULTS TAKING MEDICATIONS FOR CONGESTIVE HEART FAILURE

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More than half of all CHF patients do not take medications as prescribed, resulting in substantial negative health outcomes. Research has shown that medication adherence may be more a consequence of individual decisions rather than the ability to follow prescribed regimens, yet very little is known about decision-making regarding adherence to medications for CHF. The purpose of this narrative inquiry study was to gain understanding and insight into older adults' decision-making experiences and perceptions in choosing to take or not to take medications for CHF in the community setting. Using purposive and snowball sampling, research flyers were placed in two churches, two senior community centers, three senior living communities, one indigent care clinic, and one cardiology office. The personal narratives of 11 adults aged 65 and older who took at least two daily medications for CHF were gathered using in-depth, semistructured interviews. The data in this study were organized and analyzed using Riessman's framework for narrative analysis. This study found that decision-making was a foundational and critical element of medication adherence to medications for CHF. This study suggests that medication nonadherence in older adults with CHF is primarily

attributed to intentional decisions, based on personal values, to deviate from the prescribed regimen. For some, making decisions not to adhere to a prescribed medication regimen was a one-time event, while for others it was a lifestyle. Although participants made decisions to take medications differently than prescribed, they did not perceive themselves to be nonadherent.

The findings brought to the forefront that decisions for adherence or nonadherence to medications for CHF are based on personal goals and values. Nurses have the potential to promote adherence to medications for CHF through providing care that is patient-centered and nonjudgmental. Since patients may not view their medication decisions as nonadherent, the nurse should ask pointed questions about medication-taking routines. More research is needed to understand the influence of physical values on medication nonadherence. Future research should also focus on ways nurses can support patients' decision-making to promote medication adherence in those taking medications for CHF.

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## CHAPTER I

### INTRODUCTION

Affecting over 5 million older Americans, congestive heart failure (CHF) is the most common chronic disease and reason for hospitalization among older adults (Hall, Levant, & DeFrances, 2012; Lloyd-Jones et al., 2010; Rattinger et al., 2012). CHF, also called heart failure (HF), is an incurable clinical condition commonly managed with long-term medication use. Although these medications are effective treatments, their full benefits are often not attained because many community-dwelling older adults do not take their CHF medications as recommended (Brown & Bussell, 2011). Despite efforts to ensure that patients take their medications as prescribed, individuals have choices about when or whether to take a dose of medication. Daily, older adults select one option over another and make decisions regarding issues of medication adherence. While most would agree that choosing to take a medication is a purposeful action, nonadherence in medication-taking is also thought to be primarily intentional, involving deliberate decisions to adjust medication use (Gadkari & McHorney, 2012; Johnson, 2002; Laba, Brien, & Jan, 2012; Wroe, 2002). When a drug is regularly used, individual decision-making becomes a critical variable in treatment effectiveness and health outcomes (Ivers, McGrath, Purdy, Hennigar, & Campbell, 2000; Wroe, 2002). Decision-making is essential to the medication-taking process and thus is an important area for nursing study in this population.

## **Focus of the Inquiry**

Throughout reports regarding medication adherence, adherence to medications is suboptimal for community-dwelling adults with chronic cardiovascular disease (Albert, 2008; Bouvy, Heerdink, Urquhart, Grobbee, Hoe, & Leufkens, 2003; Ho, Bryson, & Rumsfeld, 2009; Oosterom-Cole et al., 2013; Riegel et al., 2012). It is broadly estimated that one-half of all cardiac patients do not take their medications as prescribed resulting in poor health outcomes (Bouvy et al. 2003; Brown & Bussell, 2010; Dalem, Krass, & Aslani, 2012; Hope, Wu, Tu, Young, & Murray, 2004). In one large seminal study with 1,291 CHF patients, the self-reported nonadherence rate was 66% (Kravitz et al., 1993). Another seminal study of 7,247 patients with CHF, found that only 10% were adherent to medication therapy after 1 year (Monane, Bohn, Gurwitz, Glynn, & Avorn, 1994). Recent estimates suggest that 40% to 60% of all adults with CHF are nonadherent to their medications, indicating little progress has been made in improving medication adherence (Molloy, O'Carroll, Witham, & McMurdo, 2012; Riegel et al., 2012; Wu, Moser, Lennie, & Burkhart, 2008).

Although management of CHF may include diet modification, weight loss, or implantable cardiac devices, effective management of CHF symptoms is largely dependent upon pharmacological therapy. Subsequently, poor medication adherence is associated with negative health outcomes among patients with CHF. The consequences of nonadherence to CHF medications include increased morbidity and mortality, more frequent hospital visits, increased healthcare costs, and lower quality of life (Cutler &

Everett, 2010; Heidenreich et al., 2013; Ho et al., 2009; Van Camp, Rompaey, & Elseviers, 2013). Nonadherence to medications has also been shown to be the number one predictor of CHF-related hospitalizations (Esposito, Bagchi, Verdier, Bencio, & Kim, 2009; Fitzgerald et al., 2011; Ghali, Kadakia, Cooper, & Ferlinz, 1988; Michalsen, Konig, & Thimme, 1998; Riegel & Knafl, 2014). Accordingly, the lower the adherence to CHF medications, the higher the use and cost of healthcare. In light of the fact that the population is aging and the prevalence of CHF is projected to increase, medication nonadherence may possibly become a problem of striking magnitude (Agency for Healthcare Research and Quality [AHRQ], 2011; Heidenreich et al., 2013).

Despite an abundance of published research exploring factors associated with medication adherence, there is a paucity of effective, clinically useful interventions to promote medication adherence for the CHF patient. To date, several interventions aimed at increasing medication adherence to cardiovascular medications have been tested in controlled trials but none have proven to be consistently effective. Of all the tested interventions, research suggests that patient education about CHF self-management had the most positive influence on self-care behaviors. However, education alone was not effective in preventing medication nonadherence (Molloy et al., 2012). From the literature, it appears that more research in developing medication adherence interventions in patients with CHF is warranted.

Of the few published studies regarding decision-making in the CHF patient, the majority are in the context of self-care (Dickson, Tkacs, & Riegel, 2007; Hicks & Holm

2003; Jaarsma, Abu-Saad, Dracup, & Halfens, 2000). Self-care is defined as a series of decisions that lead to actions to effectively manage CHF symptoms (Moser & Watkins, 2008). Medication adherence is briefly mentioned as a self-care activity, yet there is gap in the literature explaining how patients with CHF make decisions specific to taking medications. Decision-making about medication adherence should be examined separate from the concept of self-care for the following three reasons: (1) the relationship between clinical outcomes and medication adherence is clearly defined in the existing research, (2) adherence to medications is a different behavioral phenomenon than other aspects of self-care (daily weight, diet changes, smoking cessation), and (3) future intervention strategies for medication adherence are likely to be different from other self-care adherence interventions.

Adherence to medications in the community setting is vital to the welfare of the older adult with CHF. While causes of poor medication adherence in the patient with CHF are dynamic and complex (Ho et al., 2009; van Dalem, Krass, & Aslani, 2012), a gap in the literature exists concerning the way in which older adults with CHF make decisions to take or not to take medications. Since a gap in the literature exists concerning the way in which older adults with CHF make decisions to take or not to take medications, new and deeper insights from the patient perspective are needed to gain a full understanding of how those with CHF experience the medication-taking process. A better understanding about how older adults with CHF make decisions about whether to take or not to take prescribed medications is needed to give providers insight into their

role in improving medication adherence, inform the development of evidence-based interventions to improve medication management, and improve health outcomes.

### **Statement of the Purpose**

The purpose of this qualitative study was to gain understanding and insight into patients' decision-making processes, experiences, and perceptions in choosing to take or not to take medications for CHF in the community setting. The central question of this study was: What are patients' storied decisions about choosing to take medications for CHF? The specific aims of the study were: (a) to identify the role of decision-making in medication adherence, (b) to elicit descriptions regarding how individuals make decisions regarding medication adherence, and (c) to describe how individuals comprehend medication adherence and nonadherence.

### **Researcher's Relationship to the Topic and Assumptions**

Within the context of this study, I felt that it is important to discuss how I became interested in medication adherence in older adults with CHF. Although I do not have CHF, I have greater than 20 years of experience providing nursing care to older adults with CHF. As a cardiovascular intensive care nurse and a research nurse in the cardiac catheterization lab, I witnessed the negative health outcomes of poor adherence to CHF medications. In my role as a cardiovascular clinical research nurse, I monitored CHF patients taking investigational medications. Despite aggressive teaching and the distribution of medication reminder devices, study participants would choose to take investigational medications differently than prescribed or to stop taking them all together.

Regrettably, even if study participants took the investigational medication as prescribed, it was not an indicator that they were adherent to all other routinely prescribed CHF medications. For example, it was not uncommon for study participants to be seen in the emergency department for fluid volume overload due to not taking diuretics as prescribed. After many years of working with CHF patients I have empathy for the physiological, psychological, pharmacological, and social complexities associated with managing this chronic condition. It is in this context that I have developed an interest in understanding how patients make choices to take or not to take prescribed CHF medications.

My personal experience and research findings from the literature led to the following assumptions pertinent to this study:

- Older adults with CHF have a story to tell about how they make medication-taking decisions and are willing to share this story with the researcher.
- Although unintentional nonadherence exists, patients make intentional decisions to deviate from their prescribed CHF medication regimen.
- Daily, patients follow a decision-making process about whether to take or not to take a CHF medication.
- To make medication-taking decisions, patients rely heavily on personal experiences and preferences rather than standardized teaching and knowledge.

## **Theoretical Framework**

A descriptive theoretical framework used to explain how people make decisions in real-world contexts is the Naturalistic Decision-Making Model [NDM] (Lipshitz, Klein, Orasanu, & Salas, 2001; Moser & Watkins, 2008; Pierce & Hicks, 2001; Riegel, Dickson, & Topaz, 2013; Riegel et al., 2009). According to the NDM, real world decisions typically involve changing conditions, uncertainty, ambiguity, missing information, time stress, risk, and ill-defined or shifting goals (Riegel et al., 2013). The NDM is presented as a blend of intuition and rational decision-making theory. The NDM asserts that while a task may be understood to have benefits and be easily performed, people may deviate from the rational choice based upon emotions, intuition, and personal values (Lipshitz et al., 2001).

Assumptions of the NMD include the following (Lipshitz et al., 2001; MacNeal, 1997; Riegel et al., 2013):

- Decisions are complex and dynamic.
- Decisions are purposeful and intentional.
- People do not always adhere to algorithms, policies, rules, or prescriptions.
- Decisions lead to actions that have consequences.
- Decisions develop in situational contexts.
- Decisions are preceded by uncertainty.
- Decisions are influenced by past, present, and future experiences.
- To make a decision, an option must be feasible.

The basic principles of the NDM focus on the situation, setting, subject, and practicality of an option (Moon, 2002). What distinguishes the NDM from other decision theories is *situation awareness* (Moon, 2002). Situation awareness is defined as the perception of significant factors in the setting, the understanding of their meaning, and the mental simulation of the future for each option (Riegel et al., 2013). The NDM stresses that decision-making is context and situation bound. Human decisions are not made in controlled and predictable settings. Rather, human decisions are made in uncertain, every-day, real-life situations. Lipshitz and Strauss (1997) found that decision-makers cope with uncertainty by recalling past experiences to quickly categorize situations, form patterns that make sense of the situation, mentally simulate the outcome of each option, and weigh the pros and cons of each option. For an option to be considered it must be practical and feasible. Because people often make decisions based on what is important to them, evaluation of the decision lies in how it aligns with personal values and goals (Benson & Britten, 2002; Jaarsma et al., 2000; Riegel et al., 2013).

According to Mertz and Anfara (2006), theoretical frameworks direct all aspects of the research process including the research question, the aim of the study, and whether the research approach is quantitative or qualitative. Since the NDM describes decision-making as cognitive human action that takes place in real-world settings, a qualitative research approach was used to capture the subjective nature of medication decision-making. Decision-making cannot happen outside the context of the unique lives of

humans and develops in situational contexts, leading to actions that have consequences (MacNeal, 1997). Framing the study with a theoretical framework, ensures that the methodology, the data, and the analysis is consistent with the theory (Mertz & Anfara, 2006). The NMD concepts and constructs were used to guide participant sample selection, formulate interview questions, conduct data analysis, and explain the findings.

### **Significance to Nursing**

In October 2013, the National Council on Patient Information and Education (NCPIE) issued a nationwide call to action for an increased focus on poor medication adherence in patients with chronic conditions (National Council on Patient Information and Education [NCPIE], 2013). According to NCPIE, everyone in the healthcare environment, from the patient to the nurse, has a significant role to play in improving patient medication adherence (NCPIE, 2013). Nurses' continuous and visible presence with patients places them in the unique position to assist patients with issues of medication adherence. In order to effectively promote adherence to CHF medications, however, nurses need a clearer understanding of how patients make decisions whether to take to not to take medications.

In the current healthcare environment, nurses play an increasingly prominent role in promoting patient self-management. Nurses often have the responsibility of facilitating the learning needs of patients and evaluating their goal attainment. Moreover, nurses are familiar with the frustrations caused by treatment failure, poor health outcomes, and poor medication adherence (Kalogianni, 2012). By engaging in qualitative research, nurse

researchers can query patients about their medication-taking decisions, leading to evidence that can be used in nursing practice to improve CHF medication adherence.

What is learned in this study may contribute to filling an identified gap in knowledge regarding how patients make medication adherence decisions. This information can be used to inform the development of interventions aimed at increasing medication adherence. Knowledge about how older adults experience the medication-taking process can be used to facilitate anticipatory education and strengthen the preparation of patients for potential issues of medication nonadherence. This information may also be used to inform the development of assessment and screening tools that are needed to determine if there is cause for concern regarding medication adherence. Additionally, knowledge gained from the perspective of the community-dwelling older adult with CHF may be used to develop a model or framework for promoting medication adherence in those taking CHF medications, which may be transferable to older adults with other chronic conditions.

Knowledge gained from this study as it pertains to best practice in caring for patients with CHF, can be incorporated into nursing school curricula and shared with nursing students as they prepare for the clinical arena. What is learned from this study may also be included in continuing nursing education programs for practicing nurses. Participants in this study may benefit from being given a platform to share their “voice” regarding their everyday experiences. Affirming the voices and lives of participants has the potential for self-acknowledgement, self-awareness, and empowerment.

## **Context of the Study**

In order to fully appreciate the stories of patients taking CHF medications, one must first be familiar with the context in which these patients make medication-taking decisions. The subsequent discussion includes the following content areas pertinent to patients taking CHF medications: (a) CHF as a chronic illness, (b) pharmacological treatment of CHF, and (c) community dwelling older adults.

### **CHF as a Chronic Illness**

Chronic CHF is an abnormal clinical condition involving a progressive weakening of the heart muscle, impairing the ventricles from pumping blood effectively (Lewis, Dirksen, Heitkemper, Bucher, & Camera, 2011). The ventricular dysfunction associated with CHF results in reduced cardiac output, insufficient tissue perfusion, and signs of fluid retention (e.g., peripheral edema, shortness of breath) (Lehne, 2010). Consequently, patients suffer from reduced exercise tolerance, diminished quality of life, and shortened life expectancy.

Precipitating causes of CHF are other cardiovascular diseases, particularly coronary artery disease, long-standing hypertension, and myocardial infarction. Other comorbidities, such as diabetes, pulmonary disease, and obesity, can also contribute to the development of CHF (Lewis et al., 2011). Thus, those with CHF often suffer from more than one chronic illness.

The risk for CHF dramatically increases with advancing age. Of the 5 million Americans currently living with CHF, approximately 3.7 million are age 60 and older

(Emory Healthcare, 2014; Go et al., 2013). It is estimated that 10 in every 1000 older adults over the age of 65 years is diagnosed with CHF, making it the most common diagnosis in hospital patients age 65 and older (Go et al., 2013). Among those with CHF, more than half die within 5 years of diagnosis (Go et al., 2013). Projections indicate that the prevalence of CHF will increase 46% by 2030, resulting in more than 8 million people living with CHF (Go et al., 2013).

CHF is a disabling lifelong condition marked with progressively incapacitating symptoms. As the heart muscle begins to fail as a pump, vital organs and tissues, such as the kidneys, are not adequately perfused with oxygenated blood. The consequences include decreased urine production, leading to fluid overload in the circulatory system and lungs. Other clinical manifestations of chronic CHF include fatigue, dyspnea, cardiac arrhythmias, edema, and chest pain. CHF is incurable and requires long-term self-care, thus managing CHF symptoms out of the hospital setting is a priority of care (Lewis et al., 2011).

### **Pharmacological Treatment of CHF**

Medications play an important role in the management of CHF. Those suffering from CHF live with a substantial symptom burden, requiring multiple daily medications for life. Current CHF pharmacological guidelines stress the combination of several drug classes. Some commonly prescribed medications include anticoagulants, diuretics, angiotensin converting enzyme (ACE) inhibitors, calcium channel blockers, beta-blockers, angiotensin receptor blockers (ARB), vasodilators, and inotropic agents. The

prescribed medication regimen may be complex, with each medication having its own daily dosing schedule.

While medications play an important role in the management of patients with CHF, there are additional treatment modalities that are often offered in conjunction with medications. These may include devices such as implantable cardioverter defibrillators (ICDs) or left ventricular assist devices (LVADs). Weight loss, establishing an exercise program, limiting salt intake, smoking cessation, and controlling hypertension, high cholesterol, and diabetes may also be part of the treatment program for CHF. The aims of medication therapy are to improve symptoms, slow the progression of CHF, improve quality of life, and prolong survival (Lewis et al., 2011). CHF is largely managed by individuals in their own homes and any decisions to heed or reject medication recommendations occurs in this non-clinical environment (Fenwick, Chaboyer, & St. John, 2012).

### **Community Dwelling Older Adults**

Older adults are those aged 65 years and older, according to numerous federal and health agencies, such as the Federal Interagency Forum on Aging-Related Statistics (2012), the Administration on Aging [AoA] (2013), and the American Heart Association (Go et al., 2013). To establish the context of this study, it is important to understand the physical, cognitive, and social characteristics of the 65 and older age group.

**Physical characteristics of older adults.** The physical changes associated with aging are highly individual. Chronological age may not be a good indicator of biologic

age, nevertheless the majority of older adults experience normal age-related physical changes (Ferrini & Ferrini, 2013). As adults reach age 65, a number of physical changes contribute to a decline in health. The most common disabilities in community-dwelling older adults include hearing impairment, declining vision, and activity limitations (Ferrini & Ferrini, 2013).

Hearing impairment among older adults is often not severe, yet it is prevalent. The incidence of hearing loss increases with age where by the age of 75, nearly half of all older adults will experience some level of hearing deficit (Ferrini & Ferrini, 2013). Those with a hearing problem may exhibit the following behaviors: complain that others are not speaking clearly or loudly enough, ask others to repeat words, or get easily confused. The inability to hear could contribute to a breakdown in communication in social situations in that older adults may not admit to providers that they did not adequately hear all that was said during an office visit. Age-related visual changes are universal in older adults with reduced visual acuity being the most significant change that accompanies aging. Visual changes among older adults include problems with reading speed, seeing in dim light, reading small print, and locating objects. Once detected, the amount of time it takes to respond to environmental features is typically slower in older adults.

The proportion of older adults with activity limitations increases with age (AoA, 2013). Some functional limitations may be relatively minor but others significantly limit activities of daily living (ADLs) and instrumental activities of daily living (IADLs).

ADLs are routine self-care activities that include bathing, dressing, eating, and functional mobility. IADLs are activities that are important for living independently, such as shopping, managing finances, using communication devices, and managing medications. According to the AoA (2013), 28% of community dwelling older adults reported difficulty with one or more ADL and an additional 12% reported difficulty one or more IADLs. Gait and balance disorders are the most commonly reported disability in community dwelling older adults, with almost one quarter reporting ambulatory difficulty (AoA, 2013).

**Cognitive characteristics of older adults.** While there is a decline in some cognitive functions with advancing age, studies show large variability in cognition in older adults. The interrelated components of cognition include perception, attention, thinking, reasoning, executive function, memory, and motivation (Ferrini & Ferrini, 2013). Cognitive conditions such as dementia and Alzheimer's are not a normal part of aging and account for a small percentage of cognitive decline in older adults (Herbert, Weuve, Scherr, & Evans, 2013; Lewis et al., 2011). The rate at which information is learned or processed can be slower among community-dwelling older adults; however, daily occupational and social functioning is not impaired. Most aspects of language remain strong along with creativity, wisdom, and experience-based problem solving.

**Social and economic characteristics of older adults.** While many older adults begin to experience some physical limitations, only a small percentage (3.5%) live in institutional settings such as nursing homes. The majority (85%) live in the community

setting with their spouse or alone (Federal Interagency Forum on Aging-Related Statistics [Forum], 2012). Over the years, the median household income for older adults has shown a positive trend. The proportion of older adults living in poverty has declined and the proportion of those in the high income group has increased (Forum, 2012). There has also been a gradual rise in work force participation. Although some older adults work out of economic necessity, others report they are attracted by the social contact, intellectual stimulation, or sense of worth that work often provides (Forum, 2012).

On the average, older adults consume more healthcare and prescription medications than any other age group. The federal government pays a significant portion of the medical bills of older adults age 65 and older through the Medicare program. Almost all (93%) of community dwelling older adults are covered by Medicare (AoA, 2013). Medicare Part D, a voluntary outpatient prescription drug benefit program, provides some financial assistance for purchasing medications. According to most recent estimates, the majority of older adults (60%) enroll in Medicare Part D, while 30% have drug costs paid for by Medicaid, employer coverage, or supplementary insurance. The remaining 10% of the Medicare population lack credible drug coverage (Centers for Medicare and Medicaid Services, 2013).

Today's population of older adults is increasingly more educated. More than 80% of the older population have completed high school and almost a quarter have earned a bachelor's degree or higher (Forum, 2012). The majority of older adults are active in the community, with church membership being the most common institutional affiliation.

Older adults are far more likely than younger adults to attend church, with 71% reporting active church attendance (Barna Group, 2011).

### **Methodology**

This study used a qualitative research methodology, more specifically a narrative approach. Adhering to Riessman's (1993, 2008) understanding of narrative as stories that are topic specific and positioned in a world of experience, this study employed a narrative inquiry framework. Narrative research has postmodern and constructionist strands, providing a structure for rendering knowledge from everyday experiences as told through ordinary storytelling (Riessman, 2008). Utilizing a narrative inquiry approach, the researcher examined individuals' words as data to uncover the perceived truths of how older adults with CHF made decisions to take or not to take medications. This research method was selected to capture the human experience of medication adherence decision-making from the perspective of those who enact it. Face-to-face interviews were used to gather stories about how community-dwelling older adults with CHF made decisions regarding medication adherence. Data were analyzed using Riessman's guidelines for narrative analysis, specifically because they employ both thematic and structural analysis (Riessman, 1993, 2008).

### **Chapter Summary**

This chapter presented an introduction to the problem, identified the focus of the inquiry, stated the purpose of the study, and described the theoretical framework. This chapter also presented the context and methodology of the study. The previous literature

clearly indicated incomplete knowledge about the way in which older adults with CHF make decisions to take or not to take medications. Patients' decisions about choosing to heed or reject medication recommendations for CHF was examined by directly interviewing older community-dwelling adults. In order to better understand medication adherence decision-making in this population, the NDM theoretical framework was utilized. It is hoped that knowledge gained from this study will: (a) lead to evidence that can be used in nursing practice to improve CHF medication adherence, (b) be used to inform the development of interventions aimed at increasing medication adherence, (c) be used to inform the development of assessment and screening tools that are needed to determine if there is cause for concern regarding medication adherence, and (d) contribute to development of a model or framework for promoting medication adherence in those taking CHF medications.

CHAPTER II  
LITERARY CONTEXT

**Statement of the Problem**

Although medications are effective treatments for CHF, they do not work if patients decide not to take them. More than half of all CHF patients do not take medications as prescribed, resulting in substantial negative health outcomes. Research has shown that medication adherence may be more a consequence of individual decisions rather than the ability to follow prescribed regimens (Hicks & Holm, 2003), yet very little is known about decision-making regarding adherence to CHF medications. There is little explanation in the literature about how a patient goes about evaluating recommended medication alternatives and the strategies they use to make a choice. Numerous studies have sought to understand medication nonadherence by measuring medication rates or examining reasons for medication nonadherence, but none have studied the process of medication decision-making among those with CHF.

Investigations involving medication adherence decisions among older adults with CHF have primarily been oriented to the area of CHF self-care or self-management. Thus, existing decision-making models fail to capture the everyday, real-life decisions that patients with CHF make regarding medication adherence and only explain a small portion of adherence behaviors. Despite being fundamental to the medication-taking process, patient decision-making is an underappreciated component of medication

adherence. Understanding patient decision-making may hold the key to improving explanatory and predictive models of CHF medication-taking behaviors. But first, a better understanding of how patients make CHF medication adherence decisions was needed.

### **Definition of Medication Adherence**

Over time, a number of terms have been developed to describe the complex series of behaviors that are implied in the term adherence. According to the World Health Organization [WHO] (2003), medication adherence refers to the extent to which patient behavior aligns with agreed upon recommendations from a healthcare provider. The term adherence emphasizes the patient's voluntary and collaborative participation in constructing a mutually acceptable therapeutic plan to improve health outcomes (Gould & Mitty, 2010; Ho et al., 2009). Adherence also implies the ability of the patient to make his or her own informed decisions about his or her medication regimen. The term compliance, on the other hand, has paternalistic associations of obedience and emphasizes the correctness of patient behaviors in following the rules (Ekman et al., 2006; Gould & Mitty, 2010; Jimmy & Jose, 2011; Riles, Jain, & Fendrick, 2014). Not following a prescribed medication regimen typically results in the patient being labeled as noncompliant. In recent publications, the term adherence is preferred (Cohen, 2009; DiMatteo, 2004). Because the term adherence emphasizes that patients have the choice to take or persist in taking medications as prescribed, the term adherence is intended to be nonjudgmental and is viewed as a concept to be measured (Cohen, 2009).

There are several types of medication nonadherence. The first is an issue of non-fulfillment of the prescribed medication, where the provider writes a prescription but the prescription is never filled or initiated (Jimmy & Jose, 2011). The second type of nonadherence is non-persistence, deciding to stop taking a medication after starting it despite medical advice. A third type is non-conforming (Jimmy & Jose, 2011). This type of nonadherence includes a variety of ways in which medications are not taken as recommended, ranging from skipping doses to taking medications at incorrect times, to even adjusting the medication dose. Adherence is generally reported as the percentage of prescribed doses that are actually taken or taken at the prescribed time (Riegel et al., 2009). Patients may be selectively adherent in that adherence to one medication does not necessarily predict adherence to other medications in the same patient (Granger et al., 2005).

### **Prevalence of Nonadherence in CHF Patients**

Patient nonadherence to medications is common, yet it is difficult to draw valid conclusions about medication adherence rates in patients who take CHF medications. The literature reports wide variations in medication adherence rates in those taking CHF medications. Estimates range from 10% to 99%, with most studies citing rates of approximately 40% to 70% (Bouvy et al., 2003; Knafl & Riegel, 2014; Kongkaew, Sakunrag, & Jianmongkol, 2012; Kravtiz et al., 1993; Molloy et al., 2012; Moser, Doering & Chung, 2005; Moser & Watkins, 2008; Riegel et al., 2009; van der Wal, Jaarsma, & van Veldhuisen, 2005; Wu, Moser, Lennie & Burkhart, 2008). Variations in

adherence rates have been attributed to a number of factors including differences in study population, failure to include any operational definition of medication adherence in the study (Butler et al., 2004), as well as inconsistency in adherence measurement methods (Oosterom-Calo et al., 2013). Regardless of methodological differences, in CHF, investigators have shown that medication adherence is suboptimal.

Multiple clinical trials have evaluated patient nonadherence to the medication digoxin, a highly potent and effective treatment for CHF. A recent systematic review and meta-analysis of prospective observational studies of nonadherence with digoxin in older patients with CHF, encompassing 1,841 patients, found the median prevalence nonadherence rate with prescribed digoxin in outpatients was 43.1% [interquartile range [IQR] 29-48%] (Kongkaew et al., 2012). The investigators attributed the wide range of digoxin nonadherence to differences in nonadherence measurement. The majority of the studies used serum digoxin concentrations (SDC), while others used pill count, patient interviews, or a combination of interview and SDC. Differences in the SDC cut-off points for nonadherence was also a factor.

An earlier systematic literature review from 1988 to June 2003 described similar nonadherence rates to CHF medications (van der Wal et al., 2005). Of the 10 studies with a patient mean age of 65 years or older, the average nonadherence rate to CHF medications was almost 30%, yet the rates varied greatly between studies. For example, Monane, Bohn, Gurwitz, Glynn, and Avorn (1994) reported that of 7,247 older CHF patients, only 10%, were fully adherent to digoxin within a year. A large proportion of

patients substituted other medications and/or took less medication than expected.

Adherence was measured by tracking the number of prescriptions filled in a 12 month period and calculating the number of days no CHF medication was available to the patient. In contrast, when 128 patients with CHF were interviewed, 99% reported taking their medications as prescribed (Schwartz & Elman, 2003). Widely varying rates (1% to 90%) of nonadherence were reported, depending upon the method used to measure adherence and the sample studied (Oosterom-Calo et al., 2013; van der Wal et al., 2005).

A study by Newby et al. (2006), not included in the above reviews, is important to note for its large sample size. Using the Duke Databank for Cardiovascular Disease for the years 1995 to 2002, the annual prevalence and consistency of self-reported use of angiotensin-converting enzyme (ACE) inhibitors was assessed in 8,914 patients with CHF. At the end of the study, rates of self-reported medication use of an ACE inhibitor among patients with CHF was 51%; consistent use was only 39%. Compared to those without evidence of CHF, those with CHF were less likely to consistently use CHF medications (Newby et al., 2006). Butler et al. (2004), who monitored the pharmacy records of nearly 1,000 patients with CHF for 1 year after hospital discharge, reported that only 80% of patients with a prescription for an ACE inhibitor at discharge filled the prescription during the 30 days after discharge. Over time the adherence rate declined sharply in that at one year only 66% of the study participants were current ACE inhibitor users.

In summary, medication adherence rates to CHF medications is poor. Over the past two decades, there has been very little improvement in medication adherence rates among patients with CHF. Despite heterogeneity in adherence measurement and variations in study samples, there is compelling data to suggest that nonadherence to medications prescribed for CHF is a significant issue.

### **Intentional and Unintentional Adherence**

Several investigators have demonstrated that in older adults, nonadherence can occur in two forms: intentional and unintentional (Gadkari & McHorney, 2012; Henriques, Costa, & Cabrita, 2012; Jaarsma et al., 2000; Johnson, 2002; Lindquist et al., 2012; Unni & Farris, 2011; Wroe, 2002). Unintentional nonadherence is described as forgetfulness and carelessness in taking medications (Unni & Farris, 2011).

Unintentional nonadherence might be associated with demographics, unplanned changes in routine, limitations in capacity (i.e., cognitive changes), or unavailable resources. All of which may prevent patients from following through with taking medications as recommended (Jimmy & Jose, 2011; Johnson, 2002; Wroe, 2002). Intentional nonadherence is a purposeful action to miss or alter medication doses to suit one's need. Intentional nonadherence arises from deliberate decisions on the part of patients to forego prescribed medications (Unni & Farris, 2011; Wroe, 2002). Although patients can, and often do, exhibit both types of nonadherence behaviors (Scotto, 2005), many researchers agree that medication nonadherence among patients with chronic conditions is primarily intentional (Cholowski & Cantwell, 2007; Gadkari & McHorney, 2012; Henriques et al.,

2012; Jimmy & Jose, 2011; Johnson, 2002; Riegel & Carlson, 2002; Wroe, 2002). As a chronic condition, it is possible that a considerable number of those with CHF make purposeful decisions to disregard medication recommendations.

Since an individual can make an intentional decision either to take or not to take medicines at any given time point, the medication-taking process is not devoid of decision-making (Scotto, 2005). When authors wrote about decision-making in regard to medication adherence, motivation and intention to take medicines was described as essential to adhering to prescribed medication regimes (Cohen, 2009; Enriquez, Lackey, O'Connor, & McKinsey, 2004; Jaarsma et al., 2000; Schüz, Marx et al., 2011; Thorne, Paterson, & Russell, 2003). Data also indicated that long-term medication adherence is positively associated with patient motivation or intention to begin and persist a medication regimen (Cholowski & Cantwell, 2007; McHorney, Zhang, Stump, & Zhao, 2012; Thorne et al., 2003). Research over the past two decades has consistently shown that intentional nonadherence is strongly associated with internal drivers such as, patients' beliefs, attitudes, emotions, and expectations (Allen et al., 2012; Chia, Schlenk, & Dunbar-Jacob, 2006; Cottrell, Denaro, & Emmerton, 2013; Ekman et al., 2006; Goff, Mazor, Meterko, Dodd, & Sabin, 2008; Jeon, Kraus, Jowsey, & Glasgow, 2010; McHorney & Gadkari, 2010). Patient beliefs about prescribed medications is thought to have such a strong influence upon medication-taking behaviors that some have suggested that unintentional nonadherence may not exist in the purest form. One study by Gadkari and McHorney (2012) found no evidence that unintentional medication nonadherence

was random or accidental and both unintentional and intentional medication nonadherence were influenced by patients' beliefs about the medications. Patients that reported a low perceived need for medications were almost two-times more likely to report being careless and forgetful with medications.

Within qualitative reports, it is common to hear patients report a conscious and deliberate decision to forget, miss, or delay a dose (Henriques et al., 2012; McHorney & Gadkari, 2010; Moser et al., 2012; Riegel & Carlson, 2002; Riegel et al., 2013). Many patients report that they know they should take their medications and they understand how, but they choose to act differently (Cohen, 2009; Jaarsma et al., 2000). It is clear from the literature that decision-making is a foundational and critical element of medication adherence. Yet, understanding of patient decision-making as it appears in medication nonadherence is poorly understood.

### **Medication Adherence Decision-Making Theories**

A single theoretical approach to understanding decision-making for medication adherence is largely missing in the literature. Investigations regarding medication adherence decision-making either report no particular underlying theoretical perspective for the research or report drawing from a variety of behavioral and cognitive theoretical frameworks. Of the investigations that reported a theoretical perspective, four basic decision-making tenets for medication adherence emerged. The following discussion will introduce the theoretical models as applied to medication adherence decision-making

investigations: (a) rational action approach, (b) reasoned action approach, (c) self-regulatory approach, and (d) naturalistic decision-making approach.

### **Tenet 1: Rational Action Approach**

In this model, the risks of taking a medication are weighed against the benefits, making a cost-benefit ratio (Benson & Britten, 2002; Cohen, 2009; Wroe, 2002). Driven by past experiences, perceived benefits, and a desire to avoid negative consequences with their prescribed treatment, patients conduct a value proposition for each medication (Benson & Britten, 2002). This model insists that when equipped with all the facts, a patient will weigh the pros and cons for each medication and reach a concordant decision. Theories like the Health Belief (HBM) model fall into the category of rational choice (Gehlert & Browne, 2011). Following a rational action approach, interventions to improve medication adherence focus on patient education as key to influencing medication-taking decisions. Central to this theoretical framework, when faced with several courses of actions, patients tend to choose the option that is most beneficial for them.

One investigation to support medication decision-making as a rational action is by Laba, Brien, and Jan (2012). Based on the rational action approach, Laba and colleagues (2012) sought to understand the medication-taking decisions that underpin intentional medication nonadherence. After surveying 161 community-dwelling adults, the investigators found that the respondents' derived their medication-taking decisions from a deliberate process of weighing medication risks and benefits. In the decision-making

process, medication harms were more influential on the decision-making process than the medication benefits. At the end of the study, the researchers concluded that medication adherence decision-making was subject to rational choice (Laba et al., 2012).

The findings extended the previous findings of Benson and Britten (2002) who also found that patients weigh their reservations about taking medications against potential personal benefits. After interviewing 38 patients with prescriptions for antihypertensives, the investigators determined that when patients perceived the benefits to outweigh the risks to taking the drug, they were more likely to adhere to the prescribed regimen. The researchers also concluded that although the medication risks and benefits were similar for each patient, patients weigh facts differently to make a decision that is personally rational (Benson & Britten, 2002).

For some, assumptions about the concept of decision-making tend to derive from conventional understandings of decision-making as a rational process, influenced by expected consequences of the decision (Benson & Britten, 2002; Laba et al., 2012; Lipshitz et al., 2001; Noone, 2002). Although perhaps ideal, this rational approach has been criticized as a poor description of why individuals choose not to take medications as prescribed even when medication adherence is the most logically sound alternative for optimizing health outcomes and reaching clinical goals. In addition, some argue that the rational approach is a poor description of decisions made by those in the real world, where information is lacking, situations and choices are ambiguous, and decisions need to be made quickly (Riegel et al., 2013). Other researchers believe rational action theories

fail to take into account emotions, constraints, and other noncognitive determinants of human behavior (Fishbein, 2008). Opponents suggest that after weighing the costs, patients know what to do and what they should do but will still choose to act differently (Horowitz, Rein, & Leventhal, 2004; Ivers et al., 2000; Jaarsma et al., 2000; Johnson, 2002; Lipshitz et al., 2001; Paterson, Russell, & Thorne, 2001; Wroe, 2002). In the literature, there is significant questioning of the rationality of patient decision-making in medication-taking practices and no clear evidence to suggest that adherence to CHF medications is fully captured in rational action theoretical models.

## **Tenet 2: Reasoned Action Approach**

The reasoned action approach evolved in response to decision-making tenets that failed to recognize cognitive, psychological, and social variables that influence human behavior (Cohen, 2009; Fishbein, 2008). A reasoned action approach assumes that people's beliefs and perceptions about performing a behavior will automatically influence their intentions and motivations (Fishbein, 2008). Accordingly, a reasoned action approach describes intention or motivation to perform behaviors as the immediate predictor or determinant of medication adherence decisions (Johnson, 2002). Focusing on the reasons people do not take their medications as prescribed, the reasoned action approach gives attention to patients' beliefs, attitudes, intentions, social norms, and ideas about self-efficacy. Theories like The Transtheoretical Model of Behavior Change and Planned Behavior fall into a reasoned action framework (Glanz, Burke, & Rimer, 2011; Redding, Rossi, Rossi, Velicer, & Prochaska, 2000; Taylor et al., 2007). Following a

reasoned action approach, interventions to improve medication adherence should address patients' beliefs and motivations.

An early investigation to support the tenet of medication adherence decision-making as a reasoned action was conducted by Donovan and Blake (1992). According to the investigators, 54 rheumatology patients received copious amounts of medication advice and education, but nonadherence rates varied widely where some took extra doses, some took fewer doses, and some changed the dosing times. To the investigators, this indicated that patients were thinking about their medication-taking. It was not just a matter of obeying the instructions or not; patients were active and deliberate in their nonadherence. The respondents did not forget or misunderstand the teaching or the prescription itself, but instead chose to ignore medication recommendations. The findings suggested that an apparently irrational act of nonadherence (from the doctor's point of view) may be a very reasoned action when seen from the patient's point of view. Building upon these findings, a number of subsequent studies report intention, self-efficacy, and beliefs to be significant factors in predicting medication adherence, supporting the idea that medication adherence decision-making is a reasoned action (Cholowski & Cantwell, 2007; Ekman et al., 2006; Horowitz et al., 2004; Jaarsma et al., 2000; Johnson, Driskell, Johnson, Prochaska et al., 2006; Johnson, Driskell, Johnson, Dymont et al., 2006; Unni & Farris, 2011).

Although a reasoned action theoretical framework has been important in understanding the role of patients' motivations in medication nonadherence decisions, the

model is not without limitations. One significant limitation is the model assumes that once a person has intent to perform a behavior, they will engage in the behavior. Critics of the reasoned action approach point out that a person thinking about taking their medications can have intent to take them, but may or may not actually follow through with that intent. A person also may not be free to act on that intention due to circumstances beyond their control (Scotto, 2005). It can be argued that intention, which is central to the reasoned approach, may be too far removed to be good a predictor of actual medication adherence behaviors (Glanz et al., 2011). Another concern voiced by critics is that the model's theoretical constructs do not account for the role of emotions (i.e., fear or sadness) or past experiences in patients' decisions about medication adherence. Lastly, the model assumes decision-making is linear with formed behavioral patterns and does not consider that decisions are contextual and can change over time (Riegel et al., 2013).

### **Tenet 3: Self-Regulatory Approach**

The self-regulatory approach provides a role for emotions and self-regulation in health behavior decisions. This approach assumes that people are innately self-regulating problem solvers that are motivated to avoid and treat illness (Cameron & Leventhal, 2003; Munro, Lewin, Swart, & Volmink, 2007). According to this approach, patients adapt their medication-taking behaviors to fear of potential health threats. Medication-taking decisions are informed by teaching, past experiences, emotions, beliefs about the

illness and medication, and symptoms. Within the self-regulatory approach is Lenenthal's Common-Sense Model of Health and Illness Self-Regulation Theory.

An investigation to support medication decision-making as a self-regulatory action is by De Smedt et al. (2012). Using the Self-Regulation Model, the investigators sought to explain how medication beliefs and perceptions influence coping behaviors. After surveying 250 CHF patients who had experienced a past adverse drug event, the investigators found that perceptions of potential adverse events and major consequences to daily life motivated the majority of the respondents to seek health information (32%) and social support (60%). Only 7% of those surveyed reported reacting to the fear of an adverse drug event by becoming nonadherent to their medications. Consistent with the self-regulatory model, the investigators found that among those who had experienced an adverse drug event, the majority were motivated to exhibit positive health behaviors.

While fear of consequences has been shown to influence decisions and behaviors, some complain that the self-regulation approach may be too idealistic (de Riddler & de Wit, 2006). Opponents suggest that factors other than fear of negative repercussions have a significant impact on health decisions. Thus, promoting medication adherence is not as simple as convincing a person of potential illness (Hale, Treharne, & Kitas, 2007). In addition, the self-regulation approach revolves around the individual and does not allow for predictions about the role and interaction of family, friends, and caregivers (Hale et al., 2007). Lastly, some argue that the emotional component of the self-regulation approach is not amenable to investigational analysis using an instrument (Pitts,

2002). Although this approach highlights the role of emotions in medication decision-making, it may not be effective in explaining the full scope of the medication-taking process.

#### **Tenet 4: Naturalistic Decision-Making Approach**

The naturalistic decision-making approach provides a theoretical perspective for explaining how people make decisions in the real world, involving changing conditions, uncertainty, ambiguity, missing information, time stress, and risks (Riegel et al., 2013). Rather than an analytic decision-making approach, naturalistic decision-making is intuitive. Naturalistic decision makers do not use critical thinking or formal problem solving methods to make medication adherence decisions, instead they use practical approaches like comparing a medication-taking option to other possible options to make predictions about what will work in a particular situation. Decisions depend heavily on past experience, which provides a repertoire of patterns that suggest expected outcomes (Moser et al., 2012). This model assumes that when faced with uncertainty, patients make medication adherence decisions based on the situation and the information available at the moment (Riegel et al., 2009). Decisions about medication adherence are modified according to personal goals, situation characteristics, and new experiences (Riegel et al., 2013).

Recent research conducted by Riegel, Dickson, and Topaz (2013) generated findings to support CHF self-care as a naturalistic action. After qualitatively analyzing interview data of 36 adults with CHF, the investigators found that patients experience

uncertainty in CHF self-care which prompts a naturalistic decision-making process. Consistent with the premises of a naturalistic decision-making approach, patients' self-care decisions were influenced by the situation, past experience, and personal goals. This study contributes to a growing body of evidence that adherence decisions rely heavily on knowledge founded by personal experience within the context of patients' unique lives. The naturalistic model has been the basis for multiple investigations directed at understanding the decision-making process in the patient with CHF (Albert et al., 2014; Allen et al., 2012; Dickson et al., 2007; Moser et al., 2012; Riegel et al., 2009; Riegel, Dickson, Goldberg, & Deatrck, 2007; Thorne et al., 2003). These studies have shown good support for the validity and utility of the model.

Since coping with uncertainty is foundational to the naturalistic approach and the unpredictable nature of CHF conveys high levels of uncertainty for most patients, naturalistic decision-making may help to explain the different degrees of medication adherence in a single patient (Allen et al., 2012). The major drawback of this approach, however, is it has received limited attention in investigations aimed specifically at understanding medication adherence behaviors. Of the publications found in the literature, all were investigating CHF self-care. While medication-taking is a component of self-care, application of this model to understanding medication adherence decision-making is still largely unknown.

### **Decision-Making for Medication Adherence to CHF Medications**

There are a limited number of studies about the process patients use in making medication management decisions. Of the few published studies regarding decision-making in the CHF patient, medication adherence is not the primary focus of the inquiry, rather medication adherence decision-making is presented as an aspect of CHF self-management or self-care (Allen et al., 2012; Dickson, Buck, & Riegel, 2013; Dickson et al., 2007; Hicks & Holm, 2003; Horowitz et al., 2004; Jaarsma et al., 2000; Jeon et al., 2010; Riegel & Carlson, 2002; Riegel et al., 2013; Scotto, 2005; Siabani, Leeder, & Davidson, 2013). In the literature, self-care in the CHF patient is commonly defined as a series of behavioral decisions and choices that maintain physiologic stability (Riegel & Dickson, 2008). Self-care behaviors include monitoring and interpreting symptoms, daily weights, dietary adherence, fluid restriction, alcohol restriction, exercise, medication adherence, and preventative behaviors (Riegel et al., 2009). Self-care maintenance also involves deciding to respond to CHF symptoms and adhering to the plan of care (Dickson et al., 2013). In each study, medication adherence is briefly described as a self-care activity but the study findings are in the generalized area of CHF self-care and fail to explain how patients make CHF medication-taking decisions. Research specific to decision-making for adherence to CHF medications could not be found.

A number of closely related studies have investigated the subjective experiences of medication decision-making among those with a chronic illness, such as rheumatoid

arthritis (RA), hypertension, diabetes, acquired immunodeficiency syndrome (AIDS), multiple sclerosis (MS), and osteoporosis (Audulv, Norbergh, Asplund, & Hornsten, 2009; Benson & Britten, 2002; Donovan & Blake, 1992; Elstad, Carpenter, Devellis, & Blalock, 2012; Enriquez et al., 2004; Fenwick, Chaboyer, & St. John, 2012; Henriques et al., 2012; Ivers et al., 2000; Laba et al., 2012; Pattenden, Watt, Lewin, & Stanford, 2002; Reach et al., 2011; Sale et al., 2011; Salt & Peden, 2011; Thorne et al., 2003). Appraisal of investigations describing medication decision-making among those with other chronic illnesses may be useful to this review in that both those with CHF and those with other chronic conditions make everyday medication-taking decisions in relation to incurable conditions and perpetual symptoms. With the exception of a few selected diagnoses such as AIDS and MS, much of the decision-making research in those with chronic illness also involves older adults. Lastly, compared to the available investigations in the CHF population, the available investigations among with those with chronic illnesses are more specific to how patients make decisions about whether or not to take a medication.

According to Moser and Watkins (2008), not engaging in effective self-care is manifested in CHF patients as nonadherence to recommended treatment plans. Thus, failure to engage in self-care activities may also point to decisions for medication nonadherence. Although self-care behaviors are not synonymous with medication adherence behaviors (Riegel et al., 2009; Riegel et al., 2013), research regarding CHF self-care may offer insight into decision-making processes regarding CHF medication adherence. Similarly, appraising investigations regarding medication decision-making in

those with chronic illness may assist in identifying themes that can be applied to future research in the CHF population. The forthcoming discussion will present what is known about medication decision-making in the context of CHF self-care and among those with chronic illness.

### **Medication Decision-Making Defined**

Analysis of the literature showed medication decision-making to be associated with the terms choice, alternatives, and options (Laba et al., 2012; Pierce & Hicks, 2001; Riegel et al., 2013). The most common definition of decision-making in the healthcare literature is the selection or rejection of a course of action (Hicks & Holm, 2003; Johnson, 2002; Lipshitz & Strauss, 1997; MacNeal, 1997; Noone, 2002; Riegel et al., 2013). Audulv, Norbergh, Asplund, and Hörnsten (2009) understand decision-making to be an “ongoing inner negotiation between different incompatible perspectives” (p. 283). Others present medication decision-making as making rational choices (Laba et al., 2012; Paterson et al., 2001) or choosing reasonable options (Donovan & Blake, 1992). Still others describe medication decision-making as mentally simulating the future outcome for each option based on past and present situations and choosing the best course of action (Riegel et al., 2013). According to the existing literature, attributes of medication decisions are: (a) deliberate and intentional choices between two or more alternatives, (b) developed in a situational context, (c) committed by a person to potential action, (d) expected to accomplish a specific goal, and (e) interwoven with individual perceptions.

The existing literature informs us that medication decision-making is an everyday, complex, cognitive, perceptual, and affective process that is multidimensional and often inaccessible to direct observation (Elstad et al., 2012; Pierce & Hicks, 2001). As an active cognitive process, the decision-maker needs the ability to learn, perceive, interpret, reason, and respond to make a good choice (Dickson et al., 2007). Decision-making cannot happen outside the context of the unique lives of patients and develops in situational contexts, leading to actions that have consequences (MacNeal, 1997; Riegel et al., 2013; Thorne et al., 2003). From the literature analyzed, medication decision-making is a coping mechanism that is stimulated by uncertainty or competing goals. Since individuals perceive and interpret situations differently (Pierce & Hicks, 2001; Riegel et al., 2013; Riegel et al., 2009), medication decision-making is a subjective process of adapting and modifying the decision to suit the situation (Fenwick et al., 2012; Lipshitz et al., 2001; Riegel et al., 2013).

Patients make health decisions in the context of making predictions about the future (Thorne et al., 2003). Medication decisions were labeled as time dependent in that choices can only be made about potential actions. One cannot make a decision to take a medication dose yesterday. Similarly, decisions about medications are based on information that is available and considered relevant in the moment (Riegel et al., 2013).

Decisions about medications and the trajectory of illness or symptoms arise in the social and environmental context within which life with illness is lived (Thorne et al., 2003). Patients make decisions in a way that makes sense to them personally (Allen et

al., 2012; Benson & Britten, 2002), guided by their understanding of the situation or experience (Pierce & Hicks, 2001; Riegel et al., 2013). The processes by which individuals make decisions are impacted by consequences, social controls (obligations, rules, standards, instructions, culture, expectations); illness characteristics (sleepiness, pain, depression, anxiety, confusion); and personal variables (beliefs, skills, values, emotions, age, gender, past experiences) (Allen et al., 2012; Ivers et al., 2000; MacNeal, 1997; Noone, 2002; Pierce & Hicks, 2001; Riegel et al., 2009; Scotto, 2005). When presented with several options, contextual factors and social influences establish the condition for medication making decisions and shape decisional responses (Horowitz et al., 2004). Chronic illnesses, such as CHF, are managed by individuals in their own homes and any decisions to heed or reject medication recommendations happens in this non-clinical environment.

Although decision-making is a profoundly individual process, medication decisions can be influenced by others (arguments, suggestions, invitations, and teaching). Medication decision-making can be a cooperative process with persons offering support and a new perspective (Fenwick et al., 2012; Jaarsma et al., 2000; Jeon et al., 2010; MacNeal, 1997; Riegel & Carlson, 2002; Riegel et al., 2009; Salt & Peden, 2011; Scotto, 2005; Thorne et al., 2003); however, tensions can arise from trying to balance decisions against the approval of others (Fenwick et al., 2012).

## **The Decision-Making Process**

Authors consistently presented medication decision-making as an intentional, complex and dynamic process (Thorne et al., 2003). However, no single, clearly defined process for making medication decisions was evident in the literature. From the available published investigations regarding the process used to come to a medication or CHF self-care decision, five concepts emerged. The five concepts are: (a) stimulus recognition, (b) appraisal of the options, (c) formulation of a plan, (d) feasibility, and (e) consequences.

**Stimulus recognition.** Medication decision-making, as discussed by multiple authors, requires a stimulus to trigger the process (Ivers et al., 2000; Noone, 2002). Fundamental to making a decision is recognition of a situation that requires action (MacNeal, 1997; Riegel et al., 2013; Thorne et al., 2003). Numerous investigations demonstrated that perception of disease, illness, or symptoms is needed to prompt a medication-taking decision (Fenwick et al., 2012; Hicks & Holm, 2003; Johnson, 2002; Riegel et al., 2013; Siabani et al., 2013; Sale et al., 2011; Salt & Peden, 2011). In one investigation exploring the process used by CHF patients to make self-care decisions, *situation awareness*, the recognition and interpretation of a symptom, was found to initiate the decision-making process (Riegel et al., 2013). Given that CHF patients frequently suffer from multiple comorbid conditions, multiple narrative accounts revealed that patients are frequently faced with differentiating the source of symptoms (Dickson et al., 2013; Riegel et al., 2009). Much of the literature suggests that symptom recognition

and situation awareness is critical to the medication decision-making process in the CHF patient (Allen et al., 2012; Dickson et al., 2007; Riegel et al., 2013; Riegel et al., 2009).

Uncertainty was also identified as a direct stimulus to medication decision-making (Lipshitz et al., 2001; Lipshitz & Strauss, 1997; Moser & Watkins, 2008; Pierce & Hicks, 2001; Riegel et al., 2013). In particular, uncertainty of the need for a medication, the benefits or effectiveness of medication, and the safety of medication were most commonly discussed (Allen et al., 2012; Benson & Britten, 2002; Cohen, 2009; Gadkari & McHorney, 2012; Haverhals et al., 2011; Johnson, 2002; Wroe, 2002). Uncertainty is subjective in that even in identical situations, different individuals may experience different doubts and make different decisions (Lipshitz & Strauss, 1997).

**Appraisal of the options.** The concept *appraisal of the options* was easily recognized in the literature. Paramount to decision-making are options from which to choose. Individuals must know the alternatives within a given situation in order to make a decision (Allen et al., 2012; MacNeal, 1997; Pierce & Hicks, 2001). Well documented in the literature was an appraisal process where individuals compare medication decision alternatives against a standard such as a goal, belief, value, past experience, or pattern (Allen et al., 2012; Henriques et al., 2012; Ivers et al., 2000; Johnson, 2002; Lipshitz et al., 2001; Noone, 2002; Pattenden et al., 2002; Riegel & Carlson, 2002; Riegel et al., 2013). Several investigators describe patients performing a risk-benefit analysis of medications based on criteria important to them and trying to strike a balance (Audulv et al., 2009; Benson & Britten, 2002; Donovan & Blake, 1992; Elstad et al., 2012; Enriquez

et al., 2004; Sale et al., 2011). Many times, patients recognize the side effects of medications, but consider the benefits to outweigh the risks (Henriques et al., 2012; Laba et al., 2012). Other times, the fear of possible adverse effects outweighed their perceived needs for the medication (Donovan & Blake, 1992; Laba et al., 2012).

The literature supports that individuals select a course of action that most closely corresponds with desired goals (desired consequences) and lifestyle values (Donovan & Blake, 1992; Enriquez et al., 2004; Hicks & Holm, 2003; MacNeal, 1997; Riegel et al., 2013). New goals may surface as one experiences consequences of actions (MacNeal, 1997; Scotto, 2005). Several authors described values as beliefs about the worth, utility, and attractiveness of each outcome and formed by life experiences (Pierce & Hicks, 2001; Riegel et al., 2013; Johnson, 2002). Prior to making a decision, potential courses of actions were balanced against priorities in life-values such as spontaneity, fun, pleasure, comfort, and freedom (Enriquez et al., 2004; Jaarsma et al., 2000; Salt & Peden, 2011; Thorne et al., 2003). Authors frequently detailed patients' conscious decisions to ignore or violate medication rules to make room for values and personal beliefs (Donovan & Blake, 1992; Goff et al., 2008; Henriques et al., 2012; Ivers et al., 2000; Johnson, 2002; Paterson et al., 2001; Pierce & Hicks, 2001; Riegel & Carlson, 2002; Riegel et al., 2013; Thorne et al., 2003).

The literature consistently described knowledge seeking as part of the appraisal of options (Enriquez et al., 2004; Johnson, 2002; Riegel & Carlson, 2002; Siabani et al., 2013; Stravropoulou, 2011; Thorne et al., 2003). In evaluating medication options,

patients often desired more information before making a decision (Donovan & Blake, 1992; Salt & Peden, 2011). Unfortunately, patients very often experienced conflicting or incompatible advice (Auduly et al., 2009; Donovan & Blake, 1992; Elstad et al., 2012). Receiving similar information from multiple sources such as healthcare providers, written materials, and friends reinforced beliefs in the accuracy of the information. (Elstad et al., 2012; Goff, et al., 2008; Haverhals et al., 2011; Hicks & Holm, 2003; Pierce & Hicks, 2001; Salt & Peden, 2011). Information developed from a combination of learned knowledge and past experiences, influenced an individual's ability to detect symptoms, understand the severity of the symptoms, and decide upon an action (Cohen, 2009; MacNeal, 1997; Riegel et al., 2013; Salt & Peden, 2011; Thorne et al., 2003). Relying on past experiences with a similar problem, individuals mentally simulated consequences to decide upon an action (Elstad et al., 2012; Ivers et al., 2000; Pierce & Hicks, 2001; Reach et al., 2011; Riegel et al., 2013; Thorne et al., 2003; Wroe, 2002).

**Formulation of a plan.** Much of the literature points to experience as a key factor for helping individuals to recognize and interpret their circumstances, mentally simulate a plan, and decide on a medication-taking action (Henriques et al., 2012; Ivers et al., 2000; Riegel et al., 2013, Thorne et al., 2003). For example, a patient taking CHF medications was quoted as saying, “now I know...I can tell before they even listen to my lungs...if there's gonna be fluid...so I take another diuretic” (Riegel et al., 2013, p. 95). Although experience influences the decision-making process, Riegel and colleagues (2013) found

that similar past experiences did not lead necessarily to the same decision among different individuals or even in the same individual.

In the absence of past experiences, individuals experimented with different medication options. This was frequently referred to as trial and error decision-making (Donovan & Blake, 1992; Elstad et al., 2012; Ivers et al., 2000; Salt & Peden, 2011; Thorne et al., 2003). Study participants with chronic illness reported that intentionally defying recommended medication dosages and times helped them to define treatment boundaries and the consequences of their decisions (Donovan & Blake, 1992; Thorne et al., 2003). Evaluating the consequences, often times, was based on a creative combination of personal theories and standardized criteria (Henriques et al., 2012; Thorne et al., 2003). Individuals frequently realigned their decision-making according to feedback from outcomes, enabling them to have times of calculated cheating in their medication management (Henriques et al., 2012; Ivers et al., 2000; Pierce & Hicks, 2001; Thorne et al., 2003). With time, many patients integrate medication-taking practices into their daily lives, forming decision habits and patterns that made sense for their lives and particular symptom responses (Henriques et al., 2012; Ivers et al., 2000; Scotto, 2005; Thorne et al., 2003).

**Feasibility.** The literature indicated that determining the feasibility of an option is an antecedent to decision-making. Options deemed ideal but cannot be implemented are without value (Horowitz et al., 2004; Lipshitz et al., 2001). Of particular importance is the high probability on being able to carry out a selected option (MacNeal, 1997; Scotto,

2005). Research has shown that health literacy, cost, physical limitation, emotional limitation (depression, trust, and beliefs), task difficulty, and self-efficacy have an effect of medication adherence decisions (Auduly et al., 2009; Dickson et al., 2013; Enriquez et al., 2004; Henriques et al., 2012; Hicks & Holm, 2003; Horowitz et al., 2004; Riegel & Carlson, 2002; Scotto, 2005; Wu, Moser, Lennie, Peden et al., 2008). Several investigators found that self-efficacy shaped how individuals made self-care decisions in that individuals most often made decisions to adhere to behaviors they felt they could actually carry out (Auduly et al., 2009; Dickson et al., 2013; Jaarsma et al., 2000). This supports the notion that the practicality of taking medications has significant impact on decisions for adherence (Auduly et al., 2009; Benson & Britten, 2002; Cohen, 2009; Gadkari & McHorney, 2012; Goff et al., 2008; Hicks & Holm 2003; Ivers et al., 2000; Johnson, 2002; Laba et al., 2012; Jaarsma et al., 2000; Riegel & Carlson, 2002; Wroe, 2002). The feasibility of an option may vary in degrees of intensity per individualized situation. Once an option is deemed feasible, motivation and intention of the person to follow a medication-taking decision seems to be essential (Auduly et al., 2009; Enriquez et al., 2004; Henriques et al., 2012; Matlock, Nowels, & Bekelman, 2010; Salt & Peden, 2011; Thorne et al., 2003).

**Consequences.** Consequences are the outcomes of the decision-making process (Rogers & Knafl, 2000). From a broad perspective, consequences of the decision-making process are acceptance of an action, rejection of an action, no action, and an error (Lipshitz et al., 2001; MacNeal, 1997; Noone, 2002). Consequences that are specific to

decision-making in the context of medication adherence were behaviors of adherence and nonadherence to prescribed medication regimens (Hicks & Holm, 2003; Ivers et al., 2000; Pierce & Hicks, 2001; Riegel & Carlson, 2002; Salt & Peden, 2011). Many authors discussed medication adherence as integral to self-care, thus a consequence of decision-making about medications was described as effective or ineffective self-care (Auduly et al., 2009; Dickson & Riegel, 2013; Paterson et al., 2001; Riegel & Carlson, 2002; Riegel et al., 2013; Salt & Peden, 2011; Scotto, 2005; Thorne et al., 2003). Individuals frequently looked to health responses for feedback regarding their selected course of action (Johnson, 2002; Noone, 2002; Riegel et al., 2013; Thorne et al., 2003). In a study by Riegel, Dickson, and Topaz (2013), patients with CHF responded that they knew a decision had been correct when symptoms were alleviated or prevented. Subsequently, individuals established patterns and routines for consistent medication decision-making based on consequences of a decision (Enriquez et al., 2004; Johnson, 2002; Pierce & Hicks, 2001; Scotto, 2005). Several authors termed these established patterns “rules of thumb” (Elstad et al., 2012, p. 5; Thorne et al., 2003, p. 1350).

Although not as prevalent in the literature, consequences of the decision-making process include errors in choices or no decision, a stalemate. A lack of understanding by the decision maker caused some to not recognize the symptoms they were experiencing and make no decision (Horowitz et al., 2004; Jaarsma et al., 2000) and caused others to make mistakes in decision-making (Pierce & Hicks, 2001; Riegel et al., 2013; Riegel et al., 2009). Initially, they were pleased with their decision but when bad things happened

they experienced regret and believed the medication decision was a mistake (Pierce & Hicks, 2001). It is evident from the literature that the burden of proof of an error in decision-making comes in hindsight (Lipshitz et al., 2001).

### **Decision Influences that Affect CHF Medication-Taking**

A copious amount of research exists regarding reasons for medication nonadherence. Patients' attempts at medication adherence fail for a number of reasons, but decision-making seems to be the critical point at which many reasons accumulate (Moser & Watkins, 2008). Prevalent in the literature is the concept that medication adherence decision-making is influenced by factors both internal and external to patients. Internal factors are described as motivations, feelings, perceptions, and understandings and external factors are typically associated with patients' environments or individual demographics (Henriques et al., 2012; Riegel & Carlson, 2002). This section will present internal and external factors that have been shown to influence medication adherence decision-making.

#### **Internal Factors**

**Beliefs, attitudes, and motivation.** A preponderance of authors described the influence of patient beliefs and attitudes on decisions about whether or not to take a medication. There is evidence to support that patient belief in the efficacy of the medication is a predictor of decisions for CHF medication adherence (Cholowski & Cantwell, 2007; DiMatteo, Lepper, & Croghan, 2000; Gadkari & McHorney, 2012; Henriques et al., 2012; Hicks & Holm, 2003; Horne & Weinman, 1998; Riegel et al.,

2007; Schüz, Marx et al., 2011; Schüz, Wurm et al., 2011; Scotto, 2005). Ekman et al. (2006) found a high adherence rate (86.6%) in those that reported belief that the heart medication would make them feel better. The stronger the belief in the benefits of the medication, the stronger the adherence (Cholowski & Cantwell, 2007). A recent study by Percival, Cottrell, and Jayasinghe (2012) suggests that patients with a strong belief in the necessity of the CHF medication have significantly higher self-reported adherence compared to patients with strong concerns (21.5 vs. 18.0,  $p= 0.006$ ). When uncertainty about a medication is high, patients tend to pessimistically evaluate the perceived need for a medication, resulting in careless and inconsistent medication-taking (McHorney et al., 2012; Unni & Farris, 2011). The literature suggests beliefs about a medication is a powerful predictor of medication adherence, and therefore a major influence on decisions to take or not to take a medication.

Many authors found that when patients had confidence and trust in care providers they were more likely to adhere to recommended medication regimens (Jeon et al., 2010; Salt & Peden, 2011), while wavering trust in healthcare providers was reported as negatively influencing decisions about whether or not to take medications (Elstad et al., 2012; Goff et al., 2008; Sale et al., 2011). Allen and colleagues (2012) advocated trust in the prescriber as the basis for patients' decision-making processes about their CHF management. Investigations have shown that the strength of the patient-provider relationship positively correlates with medication adherence (Riles et al., 2014). After interviewing seven women and nine men with CHF, Wu, Moser, Lennie, Peden et al.

(2008) found that positive relational connections and trust in a health provider enhanced treatment adherence. Some researchers suggest that difficulty accessing providers is a barrier to medication adherence (Horowitz et al, 2004). Oosterom-Calo et al. (2013), however, found that more contact with healthcare professionals was not correlated with improved rates of medication adherence. Thus, it can be reasoned that patient perceptions about the relationship with the prescriber is more influential on patients' medication-taking decisions than the actual number of patient-provider encounters.

A number of authors describe the importance of motivations and individual goals in the patient medication decision-making process. Goals were defined as desired consequences regarding the medication (Hicks & Holm, 2003; MacNeal, 1997; Riegel et al., 2013). Motivation of the patient to follow medication recommendations seems to be essential to medication adherence (Henriques et al., 2012). The level of motivation is dependent upon how a person perceives their CHF symptoms, their current situation, and the effects of the medication. It was common in the literature for patients to report a decreased motivation to take CHF medications when they were uncertain about the need for the medication, the risks of the medication, or had a conflict with personal goals or values (Allen et al., 2012; Bissonnette, 2008; Elstad et al., 2012; Fenwick et al., 2012; Riegel & Carlson, 2002; Riegel et al., 2013; Sale et al., 2011; Schüz, Marx et al., 2011; Schüz, Wurm et al., 2011; Thorne et al., 2003; Wu et al., 2008b). Patients reported that unresolved uncertainties stimulated complex emotions and made decisions regarding medication adherence difficult (Allen et al., 2012).

Study participants consistently reported that their beliefs, motivations, and perceptions were developed from past experiences (Jeon et al., 2010; Moser & Watkins, 2008; Riegel et al., 2013; Thorne et al., 2003). Patients made judgments about the outcomes of their medication-taking decisions and formed opinions about which decisions were best for them. Since separating patients' beliefs and perceptions from everyday living is not possible, it can be reasoned that past experience is a key factor in medication adherence. Whether accurate or inaccurate, the consequences of past behaviors influence future medication-taking decisions.

**Comorbid conditions.** Virtually all patients with CHF suffer with other illnesses. It has been estimated that every two out of three patients with CHF have two or more non-cardiac comorbidities and greater than 25% have six or more concomitant diseases (Abete et al., 2013). It is generally thought that patients have difficulty interpreting and distinguishing the symptoms of each condition, interfering with their medication decision-making (Jeon et al., 2010; Knafl & Riegel, 2014; Moser et al., 2012; Riegel et al., 2009; Siabani et al., 2013). Additionally, the treatment of concomitant diseases contributes to polypharmacy and an already complex CHF medication regimen (Moser et al., 2012; Riegel et al., 2009). Several studies have investigated whether the number of comorbidities in patients with CHF is related to the degree of medication adherence. These studies, however, have generated conflicting results. Dickson, Buck, and Riegel (2013), in an investigation of 114 patients with CHF, reported a significant correlation between self-care (including medication-taking) and the number of co-morbid

conditions ( $r = -.253$ ;  $p = .03$ ). Those with two or more comorbid conditions scored significantly lower in self-care behaviors ( $F = 4.66$ ,  $df [1, 72]$ ,  $p = .034$ ). Several other published studies have generated data to support that adherence to CHF medications is lower in patients who have multiple comorbidities (Moser et al., 2012; Moser et al., 2005; Oosterom-Calo et al., 2013; Riles et al., 2014; Siabani et al., 2013; Wu et al., 2008b). Conversely, a large investigation with 7,599 patients with CHF, found no significant association ( $p = 0.003$ ) between the number of comorbid conditions and medication adherence rates (Granger et al., 2005). Although the presence of comorbid conditions may have some level of influence upon patients' decision-making process, there is no clear evidence to determine whether a relationship exists between the number of comorbid conditions and the extent of medication adherence in individuals with CHF.

**Depression.** Depression is the most common mood disturbance in patients with CHF. Ranging in prevalence from 13% to 77%, depending upon the method of diagnosis, depression is more prevalent in CHF patients than the general population (MacMahon & Lip, 2002; Moser & Watkins, 2008; Riegel et al, 2009). Numerous publications present depression as a barrier to medication adherence in cardiac patients (Allen et al., 2012; DiMatteo et al., 2000; Falk, Ekman, Anderson, Fu, & Granger, 2013; Marti et al, 2013, Moser et al., 2012; Riegel et al., 2009; Riegel & Carlson, 2002; van der Wal et al., 2005). The evidence from studies that investigated the relationship between depression and medication adherence, however, is inconsistent. One study by DiMatteo, Lepper, and Croghan (2000) concluded that compared to non-depressed patients, patients

exhibiting depression are three-times more likely to be nonadherent with treatment recommendations. In subsequent studies, however, no relationship between depression and CHF medication adherence was found (Hansen et al., 2009; Oosterom-Calo, 2013; Schweitzer, Head & Dwyer, 2007; Wu et al., 2008b). Namely, one study of 187 patients with CHF found a nonsignificant relationship between depression and medication adherence (Wu et al., 2008b). Even though depression has been associated with slowed information processing and substantial deficits in all domains of cognition (Allen et al., 2012; Riegel et al., 2009), it is unclear if there is a relationship between depression and decisions regarding CHF medication adherence.

**Impaired cognition.** Impaired cognition has been estimated to affect as many as 50% of community-dwelling CHF patients with higher levels of cognitive impairment seen in patients with more than one chronic medical condition (Bennett & Sauve, 2003; Moser & Watkins, 2008; Riegel et al., 2002; Riegel et al., 2009). Common cognitive deficits seen in CHF patients include problems with attention, concentration, memory, problem solving, and executive function (Moser & Watkins, 2008; Riegel et al., 2009). Often, the CHF patient with mild cognitive impairment can perform activities of daily living and live independently in the community setting (Moser & Watkins, 2008). In complex situations regarding uncertainties about CHF medications, cognitive dysfunction can impair reasoning abilities and make decision-making about medication-taking difficult. Ultimately, impaired cognition and has been shown to be associated with poor

cardiac treatment adherence, affecting medication adherence decision-making (Moser et al., 2012; Riegel et al., 2009; Schwarz & Elman, 2003; Siabani et al., 2013).

**Sleep disturbances.** Much of the literature points to the devastating effects of poor sleep on CHF self-care, including potential problems with treatment adherence (Riegel et al., 2009). An integrative literature review with reports from 2001 to 2011 found daytime sleepiness to be five times more prevalent in older patients with CHF compared to the general population (Falk et al., 2013). Patients with CHF have numerous reasons for poor sleep including disordered breathing, insomnia, nocturia, and medication side effects. Poor sleep has been associated with deficits in memory, executive function, and psychomotor speed. In one study describing how expertise in CHF self-care develops, those poor in CHF self-care had more daytime sleepiness and worse cognition, whereas those with better CHF self-care had less daytime sleepiness (Riegel, Dickson, Goldberg, & Deatrck, 2007). Since problems with sleep can accentuate and contribute to poor cognition, CHF patients with daytime sleepiness are more likely to have ineffective decision-making, giving rise to problems of medication adherence (Knafl & Riegel, 2014; Moser et al., 2012; Riegel et al., 2009; Riegel et al., 2011; Riegel et al., 2012).

**Poor health literacy.** The Institute of Medicine (2001) has identified health literacy, an individual's capacity to obtain, process, and understand health information for appropriate decision-making, as one of 20 priority areas for improving the health of individuals (Brach et al., 2012). In regards to medication-taking, health literacy involves

the ability to read and understand prescription medication information to effectively make health decisions (Riegel et al., 2009). Numerous authors describe how patients with CHF had low health literacy about their medications. Multiple investigations found that at least half of study participants could not name their CHF medications or why they were taking them (Ekman et al., 2006; Jaarsma et al., 2000; West, Lefler, & Franks, 2010). In a study with in-depth interviews with 22 CHF patients, Cline and colleagues (1999) reported that half of the patients ( $n=11$ ) could not recall the correct dose of the prescribed medication and 14 patients could not remember the correct time for taking the medication. It is also important to note that more than three-fourths of study participants ( $n= 18$ ) were stilling taking medication that had been discontinued by their physician. Despite efforts to give patients adequate medication information, health literacy was low among those taking CHF medications.

Not surprisingly, low health literacy has been attributed to poor medication adherence in much of the literature (Allen et al., 2012; Falk et al., 2013; Hope et al., 2004; Horowitz et al., 2004; Morrow et al., 2006; Morrow, Weiner, Steinley, Young, & Murray, 2007; Moser et al, 2005; Murray et al., 2009; Noureldin et al., 2012; Riegel & Carlson, 2002; Siabani et al., 2013). Published research data regarding the influence of health literacy on medication nonadherence, however, is inconsistent. A recent integrative review of 14 qualitative studies found the themes *insufficient knowledge* and *lack of knowledge* to be associated with reports of nonadherence to prescribed therapies (Jeon et al., 2010). On the contrary, Gallagher, Warwick, Chenoweth, Stein-Parbury, and

Milton-Willey (2011) found that those with low medication knowledge had the highest adherence rates. A literature review by Wu, Moser, Lennie, and Burkhart (2008) found no clear association between health literacy and medication nonadherence and another study by Riegel and Dickson (2008) found that patient level of knowledge had no significant effect on self-care behaviors. In summary, studies of health literacy conducted among patients with CHF show health literacy is poor, but the degree of influence health literacy has upon decisions for medication adherence is uncertain.

**Self-efficacy.** Much of the literature suggests that self-efficacy is an important predictor of medication adherence (Cholowski & Cantwell, 2007; Maeda, Shen, Schwarz, Farrell, & Mallon, 2013; Riegel & Dickson, 2008). It is thought that a patient's belief that they are able to manage their CHF medications influences decision-making by shaping perceptions of their problem, the treatment, and themselves (Dickson et al., 2013). Upon interviewing patients with CHF, researchers found that study participants easily reported knowing what to do to manage their CHF but did not know how to integrate this knowledge into their daily lives (Granger, Sandelowski et al., 2009). Research has suggested that a patient's lack of confidence is a barrier to successful management of CHF (Riegel & Carson, 2002) and higher levels of confidence are associated with skillful CHF management (Riegel et al., 2012). When patients were asked which CHF self-care practices they would implement in response to symptoms, respondents consistently selected those in which they had the most confidence (Dickson et al., 2013). Since feasibility and the ability to carry out an option is an important component of the

decision-making process, levels of self-efficacy may influence medication-taking decisions.

### **External Factors**

**Gender.** A number of studies have focused on gender and medication adherence, yet the degree to which this variable predicts nonadherence to CHF medications varies (Monane et al., 1994; Oosterom-Calo et al., 2013; Wu et al., 2008b; Wu, Moser, Lennie, & Burkhart, 2008). Some research shows that males are more likely than females to purposely disregard medication recommendations (Cholowski & Cantwell, 2007; Gallagher, Warwick, Chenoweth, Stein-Parbury, & Milton-Wildey, 2011). A large study of over 7,000 CHF patients, on the other hand, found women, particularly those under the age of 75, to be more nonadherent with CHF medications (Granger, Ekman et al., 2009). To date, the evidence regarding the influence of gender on medication adherence decision-making is conflicting and inconclusive.

**Cost.** The average annual cost of CHF medications is estimated to be as high as \$1,626 per person (Voigt et al., 2014). Those with severe CHF or multiple comorbidities have the highest medication costs (Albert, 2008). Although Medicare prescription benefits have made medications more accessible to many older adults, some still cite expense as a barrier to taking medications as prescribed (Baroletti & Dell'Orfano, 2010; Moser et al., 2012; Riles et al., 2014). In a study examining medication adherence in older women with heart disease, West, Lefler, and Franks (2010) found that the majority of the participants (71.9%) reported they had difficulty affording their medications and

had to give something up to buy their medications. Additionally, approximately one in five participants indicated that they had not filled needed medications because of costs. In another investigation, patients reported ignoring or deliberately forgetting to take a dose of medication due to the price (Henriques et al., 2012). Contrary to other findings, a large investigation regarding cost-related nonadherence in 3,071 older adults found that only 20% reported some form of cost-related nonadherence (Zivin, Ratliff, Heisler, Langa, & Piette, 2010). Other factors independent of costs, such as depression, were better predictors of medication nonadherence. Since health insurance may reduce out of pocket expenses for medications, it might be expected that those with some form of insurance coverage would have better adherence, yet Marti et al. (2013) found no association between insurance status and medication adherence rates. While it may be important to minimize medication costs, other factors may have a greater influence on medication-taking decisions.

**Polypharmacy and dosing complexity.** Because of advancements in the pharmacological treatment of patients with CHF and the frequent presence of comorbidities, medication regimens have become more complex (Moser & Watkins, 2008; van der Wal et al., 2005). Increases in the number and dosing frequency of CHF pills, has led to issues of polypharmacy (Albert, 2008; Henriques et al., 2012; Jeon et al., 2010; Knafl & Riegel, 2014; Riles et al., 2014; van der Wal et al., 2005). Polypharmacy, the chronic use of five or more medications, has been identified as a barrier to medication adherence among those taking CHF medications. In an investigation involving 202

participants with CHF, Riegel et al. (2012) found that those with two or more medication doses per day were more likely to have a steep decline in adherence over time. Notably, the researchers found that dosing frequency was identified as the only therapy-related predictor of CHF medication nonadherence. Since polypharmacy is related to CHF medication nonadherence and a large number of CHF patients have poor self-efficacy and cognitive function, polypharmacy may have some degree of influence upon decisions about medication-taking.

**Aging and physical impairments.** CHF is mainly a condition associated with aging (Moser & Watkins, 2008). A recent systematic review by Oosterom-Calo et al. (2013) found an equal number of studies showing age to be a determinant of medication adherence as those showing age to have no association with adherence. Of note, in those studies that showed correlations between age and medication adherence, older age was associated with better rates of adherence. With aging comes certain physical changes, such as seeing and hearing impairments. A decline in visual and hearing acuity affects reading medication bottles and hearing medication-taking instructions and might make decision-making difficult. Poor functional status, particularly fatigue and activity intolerance, is high among patients with CHF. One study demonstrated that patients with higher New York Heart Association (NYHA) classifications had lower adherence (Wu, Moser, Lennie, & Burkhart, 2008). Poor functional status affects patients' abilities to purchase prescriptions and properly complete tasks specific to the act of taking medications (Moser & Watkins, 2008). An investigation of adherence to self-care

instructions (including medication-taking) in 307 CHF patients, found adherence to be low but not associated to functional capacity (Marti et al., 2013). Aging and functional impairments may interfere with decision-making processes, yet how much these factors influence decisions about medication-taking is largely unknown. In summary, there is little evidence in the literature to support that age and the physical effects of aging have a significant impact medication adherence decisions.

**Forgetfulness.** Forgetfulness is commonly associated with medication nonadherence. Poor sleep, aging, and a plethora of other factors may contribute to poor attention and forgetfulness in older adults (Riegel et al., 2012). Investigations regarding CHF medication adherence acknowledge that forgetting to take a medication is common (Cholowskik & Cantwell, 2007; Doggrell, 2010; Wu, Moser, Lennie, & Burkhart, 2008). For example, Ekman et al. (2006) reported that 24% of patients described forgetting to take regular heart medication from 1 to 5 times per week. Forgetting to take a medication has been described as unintentional nonadherence (Jimmy & Jose, 2011; Wroe, 2002), yet some research suggests that there is some degree of intention in the forgetfulness. Gadkari and McHorney (2012), in a study that explores intentional and unintentional medication nonadherence among 24,017 adults with a chronic illness, reported that 62% of study participants forgot to take a medication and 23% were careless about taking a medication. In both the *forgot to take medications* group and the *being careless* group, high concern about the medication was shown to be a statistically significant predictor for the behaviors. The researchers suggest that the seemingly unintentional behavior of

forgetting to take a medication is not random. Although forgetfulness is a real phenomenon, there is evidence to suggest that chronically forgetting to take a medication may have some degree of intention and be related to patients' beliefs about a medication.

**Medication side effects.** Medication side effects are frequently referred to in the literature as barriers to medication adherence (Laba et al., 2012; Leventhal, Riegel, Carlson, & De Geest, 2005; McHorney & Gadkari, 2010; Mishra, Gioia, Childress, Barnet, & Webster, 2011; Oosterom-Calo et al., 2013; Schüz, Marx et al., 2011; Wu, Moser, Lennie, Peden et al., 2008). Patients that connected an adverse health outcome to a CHF medication were less likely to persist in taking the medication (Wu, Moser, Lennie, Peden et al., 2008). In a study with 32 older women with heart disease, 52.1% reported that side effects were bothersome and of those respondents 58.1% were less adherent to the medication therapy (West et al., 2010).

While there are known side effects to CHF medications, other research findings imply that patients' perceptions of medication side effects have a greater influence on decisions to adhere to a medication than actual side effects. In a double-blind, randomized, controlled clinical trial, Granger et al. (2005) compared the effects of the CHF medication candesartan (Atacand) with placebo in 7,599 patients with CHF. Study drug discontinuations that were not ordered by physicians arose equally in the candesartan and placebo groups (9% in both). The study concluded that medication nonadherence is not primarily driven by actions of the drug itself. According to the researchers, poor medication adherence was because of patient decision alone, based on

perceived side effects. Thus, the level of influence medication side effects have on medication decision-making is questionable.

**Education level.** Publications frequently cite low education levels as a factor in medication nonadherence; however, to date there is little empirical evidence that level of education is associated with degree of adherence to medications. A few studies have attempted to show a correlation between patient level of education and the rate of medication adherence (Wroe, 2002). The results have been conflicting, associating level of patient education with both increased and decreased rates of medication adherence (Hope et al., 2004; Marti et al., 2013; Moser & Watkins, 2008; Riles et al., 2014; Zhang & Balk, 2013). Since level of education is frequently collected about study participants, multiple studies looked at participant characteristics as potential predictors. No association between level of education and medication adherence was found (Evangelista, Berg, & Dracup, 2001; Knafl & Riegel, 2014; Oosterom-Calo et al., 2013; van der Wal et al., 2005; Wu et al., 2008a). Further research is needed to better describe the relationship between education level and medication adherence decisions.

**Race and ethnicity.** There are inconsistent findings on differences in medication adherence rates between races. In some studies, ethnic minorities, particularly the black race, were found to be less adherent compared to Caucasian ethnic majorities (Bagchi, Esposito, Kim, Verdier, & Bencio, 2007; Marti et al., 2013; Monane et al., 1994; Wu et al., 2008b; Wu et al., 2010). Zhang and Balk (2013) compared medication adherence among Medicare patients with CHF by race and ethnicity. At one year, adherence to at

least one heart failure drug was lowest for African Americans compared to Native Americans, Hispanics, Asians, and Whites, respectively. Overall, minorities were less likely to adhere to CHF medications than whites, suggesting that there are racial disparities in medication adherence. Among the studies that did not find significant relationships (Evangelista et al., 2001; Oosterom-Calo et al., 2013; Rodgers & Ruffin, 1998; van der Wal et al., 2005; Wu, Moser, Lennie, & Burkhart, 2008), there was little to no difference between races. One study of 561 CHF patients compared CHF medication adherence between Hispanics, whites, and blacks. All three ethnicities were similar in medication adherence rates, indicating no racial differences in medication adherence rates. Based on the available literature, it is difficult to draw a conclusion about the relationship between race and medication adherence decision-making.

**Social support.** Decisions regarding CHF medication adherence are made in the home by patients. Not surprisingly, high levels of social support have been associated with higher medication adherence (Moser & Dickson, 2008; Moser et al., 2012; Moser & Watkins, 2008; Riegel et al., 2009; Sayers, Riegel, Pawlowski, Coyne, & Samaha, 2008; Scotto, 2005; Simpson, Farris, Johnson, Tsuyuki, 2000; Wu, Moser, Lennie, Peden et al., 2008). Research findings, however, have been inconsistent. A prospective, intervention trial to study the effects of a multidisciplinary disease management program in CHF patients, found that living with another individual, such as a spouse or partner, had beneficial effects on CHF medication adherence (Rich, Gray, Beckham, Wittenberg, & Luther, 1996). Similarly, a medication adherence intervention trial by Scheurer and

colleagues (2012), discovered that practical social support was most consistently associated with greater medication adherence. The researchers concluded that medication adherence interventions that use family and friends may be more effective. In another study, decision-making that was shared between couples was positively correlated to CHF self-care and medication-taking (Sebern & Riegel, 2009). There is evidence to suggest that unmarried or unpartnered CHF patients are likely to have poor self-care and low medication adherence levels (Granger et al., 2005; Riegel et al., 2009; Sebern & Riegel, 2009; Wu, Moser, Lennie, & Burkhart, 2008; Wu et al., 2012). A study by Marti et al. (2013) in 308 CHF patients, however, failed to associate marital status with medication adherence rates. Although some research suggests that social support may have a positive influence on medication adherence, the level of influence social support has on decisions about medication-taking is unclear.

### **Measuring Problems of Medication Adherence**

According to the literature, there is no gold standard or one proven method of accurately measuring medication adherence. Rather, a myriad of methods have been used to assess issues of adherence in CHF patients. Since most researchers have not found it practical to measure patient's medication-taking behaviors in a controlled environment, adherence is primarily measured indirectly. Many studies have attempted to quantify medication adherence through patient self-reports, pill counts, pharmacy refill histories, patient diaries, medication bottle electronic monitoring systems (MEMS), serum medication levels, and patient outcomes (Butler et al., 2004; Ho et al., 2009;

Riegel & Knafl, 2014). Self-report alone or combined with another method are the most commonly used methods of measurement. The accuracy of measuring medication adherence by self-report has been questioned; however, each measurement approach has strengths and weaknesses and no one method has emerged as superior (McDonald-Misczak, Neupert, & Gutman, 2009; Williams, Amico, Bova, & Womack, 2013; Wu et al., 2008a).

In the literature, good medication adherence is most commonly defined as at least 80% of medications taken in 30 days, but the basis for this standard is unclear (Hansen et al., 2009; Riegel et al., 2009). In a study specific to CHF patients, Wu and colleagues (2008a) found that a medication adherence rate of 88% was associated with improved CHF outcomes and predicted better event-free survival. Although an adherence rate of at least 80% is the most common threshold to classify patients as adherent, it is likely that adherence levels greater than 80% are needed to produce optimal health outcomes in those with CHF.

### **Measuring Medication Decision-Making**

Since decision-making is an abstract and highly individualized process, it is not easily observed or measured. Within the literature, qualitative interviewing of decision-makers was the dominant method of measuring and understanding medication decision-making (Auduly et al., 2009; Benson & Britten, 2002; Dickson et al., 2013; Donovan & Blake, 1992; Elstad et al., 2012; Fenwick et al., 2012; Goff et al., 2008; Haverhals et al., 2011; Horowitz et al., 2004; Matlock et al., 2010; Riegel & Carlson, 2002; Riegel et al.,

2013; Salt & Peden, 2011; Scotto, 2005). In addition to patient interviews, Jaarsma, Abu-Saad, Dracup, and Halfens (2000) developed and administered a 19-item questionnaire named the Heart Failure Self-care Behaviour Scale to assess for barriers to self-care. Elstad, Carpenter, Devellis, and Blalock (2012) measured decision-making by presenting individuals with vignettes with conflicting medication information and recording their decision response. Laba, Brein, and Jan (2012) presented individuals with long-term medication scenarios and asked them to imagine what their preference would be. Thorne, Paterson, and Russell (2003) utilized think-aloud sessions during which participants audio recorded all decisions pertaining to any aspect of self-care decisions. The think-aloud sessions were followed by interviews to uncover the logic and context underpinning a decision. Other common methods of examining medication decision-making are measuring variables that influence the decision-making process such as beliefs about medications, health literacy, self-efficacy, and cognitive abilities (Hicks & Holm, 2003; Martin, Kripalani, & DuRapau, 2012; Schüz, Marx et al., 2011). There was no consensus in the literature on the best way to measure medication decision-making or to measure if a decision was a good one.

### **Interventions to Improve Decision-Making about Medication Adherence**

A range of behavioral, educational, social, and practical strategies have been tested for improving medication adherence. The most common behavioral interventions seek to change patients' attitudes, motivations, or beliefs about medication-taking behaviors through counseling from a nurse, pharmacist, or physician. Education

interventions aim to increase patients' knowledge with written, verbal, or electronic information. Social interventions typically attempt to enhance medication adherence utilizing peer support, group meetings, or family involvement. Practical strategies include simplifying medication dosing schedules and utilizing an assortment of reminders, memory strategies, and technology applications. Education and behavioral interventions are the most commonly studied approaches (Russell, Ruppert, & Matteson, 2011; van Dalem et al., 2012; Wu, Moser, Lennie, & Burkhart, 2008). Although several interventions were found to be beneficial, the evidence from the literature does not clearly support one single or combination of interventions to optimize CHF medication adherence.

Meta-analyses of randomized controlled trials aimed at improving medication adherence have shown small effect sizes. One study analyzed 23 trials of interventions to improve medication adherence and found an educational intervention effect size of 0.11 (small effect), a behavioral intervention effect size of 0.07 (small effect), and a combined intervention effect size of 0.08 (small effect) (Peterson, Takiya, & Finley, 2003).

Another examined 28 medication adherence studies with older patients and found that only 12 (43%) studies showed improvement in adherence (Schlenk, Bernardo, Organist, Klem, & Engberg, 2008). A meta-analysis could not be done due to insufficient data and variations in measurement across studies. However, when adequate data were available, effect sizes using Cohen's *d* were computed. Effect sizes for the statistically significant educational interventions ranged from 0.14 (small effect) to 4.93 (very large effect). Of

the statistically significant practical interventions (memory aids, cues, and technological applications), effect sizes ranged from 0.26 to 2.72. Multiple researchers attempted a meta-analysis of studies aimed at improving medication adherence, but found it impossible due to heterogeneity of methodology and data (Garcia-Caballos, Ramos-Diaz, Jimenez-Moleon, & Bueno-Cavanillas, 2010; George, Elliott, & Stewart, 2008; Molloy et al., 2012).

Narrative review findings corroborate meta-analyses findings that medication adherence interventions have limited benefits. Statistically significant improvements were demonstrated in only half of reviewed studies (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008; Russell et al., 2011; van Dalem et al., 2012; Wu, Moser, Lennie, & Burkhart, 2008). Haynes and colleagues (2008) found that even the most effective interventions did not lead to large improvements in medication adherence or impact clinical outcomes. In addition, follow-up times were short which gives limited data on the sustainability of an intervention (Molloy et al., 2012). Many intervention studies were of poor quality in that they failed to sufficiently describe the intervention, were absent of any theoretical underpinning to support the interventions being studied, or reported incomplete data (Banning, 2009; Haynes et al., 2008; Ruppert, Conn, & Russell, 2008; Williams, Manis, & Walker, 2008).

### **Chapter Summary**

As evidenced in the literature, medication adherence to CHF medications is poor. Research suggests that medication nonadherence is primarily a consequence of

intentional decisions by patients to forgo medication recommendations (Cholowski & Cantwell, 2007; Gadkari & McHorney, 2012; Henriques et al., 2012; Jimmy & Jose, 2011; Johnson, 2002; Riegel & Carlson, 2002; Wroe, 2002). Decision-making seems to be the point at which adherence to medications desists, yet this aspect of CHF management has received very little attention from researchers or clinicians. A search of the literature revealed an overall lack of systematic research in the area of decision-making about CHF medication adherence. Consequently, understanding of how older adults with CHF make medication choices is limited.

In the absence of research specific to decision among patients taking CHF medications, published research regarding decision-making in CHF self-care and medication decision-making among those with other chronic illnesses was appraised. The existing literature, however, yields more questions than it answers. The literature supports that when presented with several medication-taking or self-care options, patients respond with a process to select a course of action. Investigations in these populations also informs us that daily, patients contemplate their medication-taking choices. Although decision-making appears to be a fundamental component of medication adherence, no clearly defined process for making CHF medication decisions was evident in the literature. How older adults go about making CHF medication decisions is unknown, suggesting that more research is needed.

Medication decision-making is consistently shown to be a complex, dynamic, and iterative process that is highly intuitive and individualistic (Riegel & Carlson, 2002;

Riegel et al., 2013). Published research acknowledges that both internal and external factors influence patients' medication adherence decisions. To date, however, evidence regarding factors that may influence decisions specific to CHF medications is largely unknown. To more fully capture the medication-taking experience among older adults with CHF, further investigation from the patients' perspective is needed.

In summary, of the numerous interventions and intervention combinations, education and counseling were the commonly studied interventions for improving medication adherence. Although some interventions enhanced medication-taking, no single intervention or pattern of interventions emerged from the literature as sufficient in improving medication adherence and/or clinical outcomes. Absent from the literature is research regarding ways to improve medication adherence decision-making. This review suggests that more research is needed regarding strategies to improve medication adherence and new research about medication decision-making could be used to inform the development or improvement of medication adherence interventions.

## CHAPTER III

### METHODOLOGY

#### **Statement of the Problem**

Despite efforts to increase medication adherence among patients with CHF, nonadherence remains a problem. To date, there are no interventions proven to be effective in increasing adherence to medications prescribed to treat CHF. Patient education, although recommended, has not been shown to be sufficient at increasing adherence rates, even when combined with other behavioral and practical interventions. More research is needed to inform the development of effective interventions to increase medication adherence among those with CHF.

The literature reports that the majority of medication nonadherence is intentional, involving deliberate decisions to forego medication recommendations. All research regarding decision-making and medication adherence among those with CHF, however is in the generalized area of CHF self-care. Although taking medications is considered a self-care activity, absent in the literature is research looking specifically at medication decision-making in those with CHF. This study proposed that medication decision-making should be investigated as a separate component of self-care for the following three reasons: (1) the relationship between clinical CHF outcomes and medication adherence is more clearly defined in the existing research, (2) adherence to medications is a different behavioral phenomenon than other aspects of self-care (e.g. daily weight, diet

changes, smoking cessation), and (3) future intervention strategies for medication adherence are likely to be different from other self-care adherence interventions.

The methodology chosen for this study was narrative inquiry, using Riessman's framework of narrative analysis (1993, 2008). Narrative researchers believe that embedded within personal accounts and narratives, are explanations to understand why people behave the way they do (Polkinghorne, 1988; Riessman, 1993, 2008). A narrative approach was used to capture the rich data within patients' discourses, revealing the full scope of the medication-taking experience in ways observation alone could not. Since narrative inquiry elicits a multi-sensory, contextualized, and unique perspective of individual experiences, this methodology allowed for the greatest opportunity to render refined and rich descriptions of medication decision-making among older adults with CHF.

## **Narrative Inquiry**

### **Historical Overview**

“Narrative inquiry is based firmly in the premise that, as human beings, we come to understand and give meaning to our lives through story” (Trahar, 2009, p.1). It is a form of qualitative research that understands narrative (written, oral, or visual) to be a powerful tool for gaining insight into the complexity of human lives. Positioned in a world of experience, narrative is a mode of inquiry that gives attention to not only *what* was told but *how* and *why* a story was told (Riessman, 2008).

The study of narrative works in literature, history, anthropology, sociology, and education has a long history. Narrative inquiry, in the human sciences however, is regarded as a 20<sup>th</sup> century development (Creswell, 2013; Munhall, 2012; Riessman, 2008). Gradual shifts in thinking from positivism to postpositivism occurred across the human sciences in the 20<sup>th</sup> century, feeding the development of methods “designed to preserve agency and subjectivity” (Riessman, 2008, p. 16). Changes in philosophical thought gave way to a reshaping in how knowledge was produced. Scholars disagreed on the exact origin of narrative inquiry and described the field as not fitting in the boundary of a single philosophical pattern, having realist, postmodernist, and constructionist strands (Riessman, 2008).

The beginnings of the field are referred to as “the narrative turn” (Riessman, 2008, p. 14). Some say early beginnings of the narrative turn can be seen in the sociological fieldwork of the Chicago School. In the realist tradition, the narrative accounts of Polish peasants, urban boys and men, and tenant farm workers represented a source of data for the investigator’s analytic descriptions of cultures and lives (Riessman, 2008). Other researchers, however, locate a narrative turn in the 1960s. Critiques of positivist methods of inquiry and larger social movements such as those that advocated for the emancipation of women, gays, lesbians, and minorities, fostered a shift away from realism and fed an interest in gaining insight into human experiences from the stories people tell about themselves (Riessman, 2008). Furthermore, developments in

audiovisual technology made verbatim transcripts possible, opening up new forms of gathering and analyzing narrative data.

Classic work by Labov and Waletzky (1967) was one of the first to suggest that stories and conversation could be subject to formal analysis. Based on Labov and Waletzky's work, the research interview was re-visioned as a narrative event (As cited in Mishler, 1986) and spoken language became research data. Their analytic approach had a significant impact on how narrative was gathered, analyzed, and interpreted. Narrative researchers became concerned with analyzing people's stories, rather than merely presenting them (Riessman, 2008).

In the 1980s, classic works by Jerome Bruner (1987) and Donald Polkinghorne (1988) proposed discourse and narrative accounts as a way of knowing and constructing reality (Riessman, 2008). Taking a constructivist approach to narrative inquiry, Bruner asserts that stories people tell about themselves are purposely constructed to convey or possibly hide thoughts, feelings, and intentions (Bruner, 2004). Polkinghorne (1988) claims that narrative is well suited for research in the human sciences, noting that narrative is essential to the work of health practitioners. He describes practitioners as concerned with patient's stories, using case histories and patient narratives to understand why patients behave the way they do (Polkinghorne, 1988).

In recent decades, narrative as a research method has surged in popularity with scholars such as D. Jean Clandinin, F. Michael Connelly, and Catherine K. Riessman. Riessman (2008), mixing both postmodern and constructionist thought, believes the

stories people construct of past experiences reflect who they are and how they want to be known by the listener. Examining issues in depth through exploratory, open-ended conversations, the narrative inquiry approach is for those that want to reveal truths about everyday experiences “...through an ordinary communicative act- storytelling” (Riessman, 2008, p.13-14).

### **Central Concepts of Narrative Inquiry**

In recent years, a growing number of qualitative researchers have made contributions to understandings of narrative analysis. As a result, there are a multitude of definitions and assumptions underlying the field of narrative research. For this reason, this investigation drew upon the narrative inquiry perspectives and strategies developed and applied by Catherine Kohler Riessman. Central to Riessman’s (1993, 2008) representation of narrative inquiry are four key concepts: (a) narrative is a window into the individual, (b) meaning is constructed from narrative, (c) narrative is both an approach and an object, and (d) truths from narrative are fluid. This section will present and discuss the four key concepts central to Riessman’s narrative inquiry.

Since narrative is an important tool humans use to communicate information, identity, and ideas, Riessman (1993, 2008) asserts that personal accounts are a window into the individual. Positioned in a world of experience and subjectivity, narrative inquiry is a deeply humanized research design. According to Riessman, “Nature and the world do not tell stories, individuals do” (Riessman, 1993, p. 2). Locating narratives of personal experience is not difficult since language is universal to human existence. “A

primary way individuals make sense of experience is by casting it in narrative form” (Riessman, 1993, p. 4). Riessman (1993) assumes all personal narratives are stories about past experiences, purposely and rhetorically constructed to make a point. How individuals recount their histories, such as what they emphasize and omit, the choice of words, the sequence of events, and the characters, all reflect how individuals make sense of an experience. Rooted in time, place, and personal perspective, the context of an experience cannot be independent of the story. Central to narrative inquiry is the idea that the teller projects through the story who they are and how they want to be perceived by the listener, offering a window into understanding individuals’ thoughts and actions.

Important to narrative inquiry is the assumption that meaning is constructed from personal narratives. Through storytelling, individuals recapitulate and reinterpret their lives for an audience. There is choice and individuality in how experiences are perceived and storied. By thinking about events, individuals actively organize a story to tell about past action and how they understand those actions (Riessman, 1993). Furthermore, “narrators indicate the terms on which they request to be interpreted by the styles of telling they choose” (Riessman, 1993, p. 19). How the teller acts out the narration, such as pauses, facial expressions, pitch, and repetition is meaningful to the interpretation of the story. According to Riessman (1993, 2008), events become meaningful because of their placement in a story. The story itself, however, goes beyond a retelling of events. It opens up a way for the audience to view the experience from the teller’s point of view, revealing intentions, motivations, decisions, thoughts, emotions, actions, and

consequences. Like Polkinghorne (1988), Riessman (1993, 2008) understands that these stories provide models of how actions, thoughts, feelings, and consequences are interrelated.

Attention to narrative as both an approach and an object is a defining characteristic of Riessman's narrative inquiry. Building on and extending multiple narrative traditions, Riessman (1993) views the story as a method for conducting inquiry and as an object for study. Narrative is not only a stage for the research participants to be heard and tell their stories, but is also is a source of powerful research data. According to Riessman (1993, 2008), the story should not be fragmented or reduced to mere themes, but rather held as a discrete unit that can be systematically evaluated. Riessman (1993, 2008) acknowledges three modes of analysis, that is, structural, meaning, and performance. Riessman's narrative analytical strategies interrogate the textual features as well the content of stories, asking *how* and *why* incidents are storied. Stressing the idea of sequence or succession of events, Riessman asks, what is the chronology of events and why are the events configured in that way? Are there gaps and inconsistencies? What is the message of the story? Because stories are received and told in context, for whom was *this* story constructed, and for what purpose? What sociocultural influences does the story refer to? How does the audience affect what is told? In Riessman's (1993, 2008) narrative analysis, particularities of the story and the narrator can be evaluated, allowing for many voices and subjectivities to emerge in the research.

Working within a postmodern paradigm, Riessman (1993) asserts that meaning constructed from narrative is subjective, fluid and contextual, not fixed and universal. The narrative "...represents reality partially, selectively, and imperfectly" (Riessman, 1993, p. 15). Although subjectivity has a history of being mistrusted in the human sciences, Riessman (1993) believes that it is because of the subjectivity that narratives have value. Riessman (1993) describes her position on narrative truths with a quote from The Personal Narratives group (1989):

When talking about their lives, people lie sometimes, forget a lot, exaggerate, become confused, and get things wrong. Yet they *are* revealing truths. These truths don't reveal the past "as it actually was," aspiring to a standard of objectivity. They give us instead the truths of our experiences...Unlike the Truth of the scientific ideal, the truths of personal narratives are neither open to proof nor self-evident. We come to understand them only through interpretation, paying careful attention to the context that shape their creation and to the world views that inform them. Sometimes the truths we see in personal narrative jar us from our complacent security as interpreters "outside" the story and make us aware that our own place in the world plays a part in our interpretation and shapes the meanings we derive from them (as cited in Riessman, 1993, p. 22).

In summary, stories that are lived and told have the capacity to render life experiences in relevant and meaningful ways, offering insight into the reality of the individual (Riessman, 1993, 2008). It is hoped that the stories that participants tell will

shed light on how they experience the medication-taking process in terms of medication adherence or nonadherence. Important to an in-depth understanding of decision-making about medications, are questions about how past, present, and future experiences influence medication decisions. Such questions point firmly in the direction of the defining feature of narrative inquiry to convey chronology (Creswell, 2013). Since participants may fear being judged negatively for choosing to disregard medication recommendations, it was hoped that through storytelling, decisions regarding medication nonadherence could be examined in a less threatening way. It was anticipated that the lived stories as heard and shaped by the researcher, would reveal significant information about the way in which older adults manage their medications and offer insight into the choices older adults make about taking or not taking their CHF medications.

## **Methodology**

### **Site and Setting**

The site for this research was a large metropolitan area in the southwestern United States. The recruitment sites for this research were locations within the community that were frequented by older adults, specifically churches, senior community centers, senior living communities, medical clinics, and physician offices. The research interview setting was a mutually agreed upon site that was convenient and protected the privacy, anonymity, and confidentiality for the study participant. The majority of interviews were conducted in a private meeting room within a senior living community or church. Four interviews were conducted in the participant's private living space and one participant

chose the back room of a community establishment. Each interview location had adequate lighting, comfortable seating, and was conducive to confidential conversation.

### **Participants**

Given that CHF medication-taking decisions are primarily made by patients in their homes, community-dwelling older adults were the focus of this study. According to Polkinghorne (2005), participants and documents for a qualitative study are selected based on the substantial contribution they can provide in exploring the structure and character of the experience under investigation. To obtain narratives of lived experiences, I purposively selected individuals that were a good source of data for the study (Patton, 2015; Polit & Beck, 2012). Purposive and snowball sampling were utilized to recruit older community-dwelling adults with personal knowledge of taking daily medications for CHF and the decisions that accompany this medication-taking.

To ensure the selection of information-rich cases that would most benefit the study, potential study participants were screened using the following inclusion criteria: (1) individuals age 65 and older, (2) take at least two daily medications for CHF, (3) self-administer daily medications, (4) have experience making a decision not to take a CHF medication or to take a CHF medication differently than prescribed, (5) live independently in the community setting, (6) be able to speak and read English, and (7) no history of a prior neurological event or other factor that could cause an inability to effectively answer interview questions.

Study recruitment began in February 2016 and concluded in September 2016. Potential study participants were identified through advertising to the general public via flyers. The recruitment process began with distributing study flyers to three IRB approved recruitment sites. Recruitment was slow and six more recruitment sites were added over the course of the study. It is possible that the recruitment rate was slower than expected due to the reluctance of individuals to contact a stranger and the fact that many older adults do not recognize that their prescribed medications are to treat CHF. Thus, they did not view themselves as potential study subjects.

The recruitment sites included three senior adult independent living communities, two churches, two community centers for seniors, an indigent care clinic, and a physician office. I regularly visited the sites to monitor the status of the flyers and maintain a relationship with the agency. To avoid any ethical issues such as participant confidentiality, I was not a member or affiliated with any of the agencies chosen for participant sampling. Riessman (2008) suggests selecting a small number of individuals with significant lived experiences. Since it was anticipated that a large amount of in-depth data would be collected from each study participant and that data redundancy would be reached, the planned sample size of this study was 10 to 15 participants (Patton, 2015).

Each site varied in how they made the flyers available to individuals. One senior living community placed study flyers in the mailboxes of over 200 residents on two occasions. Three individuals interested in participating in the study called or emailed me

and a fourth study participant was referred by another study participant. One senior living community placed flyers at dining tables during a meal. The activity director from this location stated that residents expressed an interest in meeting me versus emailing or calling me. An announcement was made to residents that I was available in one of the private meeting rooms off the lobby of the main building and those interested in participating in the study could voluntarily meet me. Six individuals were screened and four met study eligibility criteria. The third senior living community placed study flyers on a table with other brochures and local advertisements. There were no study participants from this location.

The two churches placed study flyers throughout the building. One study participant was identified from a church who then recruited another study participant. Flyers with tear-offs with the researcher's contact information were placed on bulletin boards at the community centers for seniors. Although tear-off tabs on the flyers were missing, no one from these sites contacted me. No study participants were identified at the indigent care clinic, but two were located through the practice of a medical doctor. The physician, during an office visit, gave study flyers to potential study participants. Those interested in participating in the study could contact me by phone, email me, or voluntarily meet with me in an empty examination room. Two individuals chose to speak with me in person and one qualified for the study.

A total of 19 individuals made contact with me, expressing interest in being a study participant. In this initial conversation, I introduced myself as a doctoral student in

the nursing program at Texas Woman's University and acknowledged that I had previous experience caring for patients with CHF. I explained the purpose of the study and gained permission from each individual to ask eligibility questions. Each potential study participant was screened for study eligibility, using the Participant Eligibility Screening Tool (Appendix D). Eleven older adults met study inclusion criteria and agreed to participate in the study. Next, an interview was scheduled for a time and location that was convenient for the study participant.

Participant consent (Appendix E) was obtained on the day of the interview. Prior to conducting the interview, the consent form was reviewed with each study participant and the study explained in detail. Study participants were given time to read the consent form and ask any questions. The consent form was read to two study participants by their request. All 11 of those eligible to participate in the study gave consent to be interviewed. The selection process remained open throughout the research process until new sources repeated what had been previously learned (Patton, 2015; Polkinghorne, 2005). Preliminary analysis showed that I had achieved data redundancy after the 11<sup>th</sup> interview.

### **Researcher as Instrument**

Keeping with narrative inquiry methodology the researcher was the primary instrument used to gather study data. The goal of the narrative researcher was to be a "facilitating" interviewer who actively participated with respondents in jointly constructing narrative and meaning. The quality of the information obtained during an

interview was largely dependent on the quality of the interviewer-interviewee interaction and relationship (Patton, 2015). Thus, establishing rapport mattered (Patton, 2015). Creating a climate that was nonjudgmental, authentic, and trustworthy was key to encouraging storytelling (Patton, 2015; Riessman, 2008). Generating narrative required asking clear, open-ended questions, follow-up questions, and when appropriate, probing questions to provide insight and details. Interviewing also involved the art of listening (Patton, 2015).

Since the goal in narrative interviewing was to generate detailed personal accounts rather than short answers or general statements, I asked questions that opened up topics and encouraged participants to speak in their own ways (Riessman, 2008). Although certain kinds of open-ended questions were more likely than others to provide narrative opportunities, “the specific wording of a question was less important than the interviewer’s emotional attentiveness and engagement and the degree of reciprocity in the conversation” (Riessman, 2008, p. 24). A structured interview format could have inhibited respondents from including events and details that were significant to the full-scope of their experience (Riessman, 2008). Therefore, questions that stimulated stories were asked, and participants were allowed to construct answers in ways they found meaningful (Riessman, 2008).

This study used in-depth, semi-structured interviewing that was conversational in nature. The following strategies were used when conducting interviews: (a) establishing rapport, (b) encouragement, (c) probing and prompting, (d) listening, and (e)

summarizing. According to Hollway and Jefferson (2008), the narrative interview should begin with pleasantries and an introduction to the topic. The researcher should aim to build rapport and trust with the respondent. Interview questions should be broad, open-ended, and framed in everyday language to turn topics into storytelling invitations (Hollway & Jefferson, 2008; Mishler, 1986; Patton, 2015; Riessman, 1993). Each interview started with a straight forward and simple statement that focused the interview to the participant's life experiences such as, "tell me about how you began taking medications for your heart." Since asking questions about a specific time frame or situation elicits a better response than asking about the participant's life over a long time span (Hollway & Jefferson, 2008), requests such as "tell me about a time when you made a decision not to take one of your CHF medications" were also used. Due to the conversational nature of the interview, I adjusted the flow of the conversation with questioning, probing, and prompting. Follow-up questions using the respondents ordering of events and phrasing was used to summarize responses and elicit further narratives (Hollway & Jefferson, 2008). Nonverbal and verbal prompts, such as leaning forward, making eye contact, and stating phrases such as "yes" or "go on," were also used to encourage the respondent to talk further (Mishler, 1986). For each interview, I listened carefully, attentively, and analytically (Patton, 2015) and with minimal interruptions (Riessman, 1993).

The exact direction in which a story can go hinges on factors that pertain to both the teller's perception of the listener and the listener's perception of the teller (Mishler,

1986). Narrative inquiry assumes that the interview process "...is an unfolding dialogue that includes the voice of the investigator who speculates openly about the meaning of a participant's utterance" (Riessman, 2008, p. 137). This active engagement in co-constructing meaning, however demands that the researcher explicitly locate themselves (Polit & Beck, 2012; Riessman, 2008). I engaged in ongoing reflexivity in this study, reflecting critically on personal values, presuppositions, and opinions that could affect data collection and interpretation (Polit & Beck, 2012; Riessman, 2008). The process of self-reflection was used to make transparent the values and beliefs that lay behind the researchers questions and interpretations.

### **Strategies for Interviewing Older Adults**

Interviewing older adults presented some specific challenges, requiring adaptation of interviewing skills. According to Patton (2015), older adults may take more time to establish a trusting relationship and may tell lengthy stories. The first part of each interview session was a time of getting to know each other and developing rapport. Longing to have company and talk, interviews with older adults may go longer than planned. To keep the interview focused and moving along, an interview guide was used to adjust the flow of the conversation as needed. The majority of interviews lasted no more an hour and none lasted more than an hour and one-half. When the older adult had trouble remembering accurately or struggled to focus, I waited quietly for them to gather his/her thoughts then gave a gentle reminder of the topic at hand.

Older adults can also be particularly vulnerable in that increasing age often corresponds with cognitive changes, physical impairments, hearing and vision changes, and waning independence (Dillon, Gu, Hoffman, & Ko, 2010). Before the interview began, I briefly assessed if the participant's current state of health would negatively affect the quality of the interview. The interview location was quiet and well lit. Because many of the participants were hard of hearing, I positioned myself close to the participant during the interview. I asked questions slowly, made eye contact when speaking, and clearly enunciated each word. To account for diminished vision, the font size of the consent form and demographic data form was 14 point. I made every effort to make sure the participant was physically comfortable and relaxed during the interview. Of particular concern for older adults with CHF is easy fatigability and shortness of breath. Throughout each interview I was cognizant of signs that the participant needed a break, such as frequent repositioning, looking at the time, or beginning to lose focus. Before each interview, participants were informed that they could take a break at any time. All participants tolerated the interview session without complaint.

### **Data Generation Strategies**

Data were gathered from face-to-face, in depth, semi-structured interviews with older adults. In the time leading up to the interview, I initiated casual conversation to develop a comfortable relationship with the individual. Participants were asked to complete the Demographic Data Collection Form (See Appendix B). Data were collected from each participant to include: current age, gender, race, level of education, marital

status, living arrangements, job status, annual income, source of income, source of healthcare payments, use of online patient portals, other diagnoses, CHF symptom inventory, number of medications taken daily, dosing schedule, and names of current medications.

Interviews began with an open-ended question similar to “Tell me the story of how you got started taking medications for your heart.” After the fifth interview, I sensed that study participants were hesitant to discuss issues of medication nonadherence. To encourage the participant to share his or her story without the fear of judgment, I began reading a statement at the beginning of the interview. Starting with the sixth interview, the following preamble was read:

Every patient, at some time in their life, has adjusted the way they take medications to suit their needs. It is a known fact that people want to feel good and will customize their medications to feel the best that they can. I want you to know that anything you tell me today about your medication choices will be used to help nurses understand their patients better and provide the best possible care.

To further alleviate any potential sources of intimidation or anxiety, I also began asking if the participant had a preference for how the interview was audio recorded, either a small recording device (the size of my hand) or a mini laptop computer (the size of a piece of paper). Participants 6 to 11 expressed no preference in audio recording device. All interviews were recorded using a small password protected computer. An unwillingness to discuss nonadherence to medications was not as apparent in subsequent interviews.

Although narrative researchers recommend preparing an interview guide, it is the researcher's judgment that determines how closely to adhere to the guide (Brinkman & Kvale, 2015; Mishler, 1986; Riessman, 2008). Since interviews that are spontaneous and unstructured are more likely to obtain unprompted and richer narratives than the more structured interviews, an interview guide was available during each interview, but was not strictly adhered to. The interview guide contained thematic questions that aimed to produce knowledge specific to the purpose of the study and dynamic questions that promoted quality interaction between myself and interviewee (Brinkman & Kvale, 2015; Mishler, 1986). The methods of data analysis were taken into account when preparing the interview guide. Interview questions were brief and easy to understand.

I attempted to give the study participants as much freedom as possible to tell their stories in their own words. Other varying types of questions were crafted during the interview as the need arose. These question types included: (a) introductory, (b) follow-up, (c) probing, (d) specifying, (e) direct, (f) indirect, (g) structuring, (h) silence, and (i) interpreting (Brinkman & Kvale, 2015; Hollway & Jefferson, 2008; Mishler, 1986; Patton, 2015). The interview also explored new directions as new topics came into the dialogue. For example, when discussing decisions of medication nonadherence, one participant directed the conversation to his battle with depression.

True to narrative inquiry, the interviews were centered on stories that arose during dialogue between myself and the respondent. The interview was conversational in nature and participants were given the freedom to direct the flow of the dialogue (Riessman,

2008). If it appeared that the discourse was losing focus, I used questioning and probing to adjust the flow of the conversation. During lulls in the conversation and at the end of the interview, I would refer to the interview guide to make sure all topics had been addressed. Probes were used to encourage each older adult to tell his or her story and to explore deeper into a topic. At times in the first several interviews, I found myself slipping into the nurse educator role and wanting to provide patient education. Once aware of this tendency, I concentrated more on listening carefully, attentively, and analytically during the interview with minimal interruptions (Patton, 2015; Riessman, 1993).

After the completion of the interview, the audio recording was saved with the participant's assigned research number. The screening form, the demographic data document, and the consent form were also labeled with the assigned research number that corresponded to the participant's initials. A reflexive journal was maintained with field notes, insights, and decisions made during the study. Field notes included details about the environment and observations regarding the interview. Two study binders were kept in a locked file cabinet in the researcher's office. One binder for all participant consent forms and another for all other study documents, including the enrollment log, the screening log, completed screening forms, and demographic data documents. All digital recordings were stored on a password protected computer. As part of the informed consent process, all study participants were made aware of the procedures planned to maintain their confidentiality and anonymity.

## **Data Analysis**

The data in this study were organized and analyzed using Riessman's framework for narrative analysis (1993, 2008). Riessman presents three levels of narrative analysis: (1) narrative telling, (2) transcribing, and (3) analyzing. Riessman believes that data analysis begins with the telling of the story. During the interview, I was continuously processing and interpreting what was being said and what I observed. Being careful to let the study participant talk as freely as possible, listening and questioning was used to shape and clarify meanings. Questioning, in the natural flow of conversation, aimed to generate spontaneous and rich descriptions (Brinkman & Kvale, 2015, Riessman, 1993, 2008). After each interview, field notes were used to capture detailed observations, thoughts, reflections, and ideas.

The next level of narrative analysis was transcription of the data. According to Riessman, the interpretation of the narrative may change based on the type of transcription used and who is transcribing. Given that separate individuals can transcribe the same "stretch of talk" (Riessman, 2008, p. 29) very differently, translating spoken conversation into written text is highly interpretive. In accordance with Riessman's recommendation, data transcription was performed by the researcher and not delegated.

Each interview was transcribed verbatim to include pauses, false starts, and nonlexicals such as "um" or "ah" (Mishler, 1986). Identifying information such as names and places were deleted during transcription. Other features of how the text was delivered such as laughing, crying, or tone of voice was also captured in transcribing the

interviews. Transcripts were reviewed for accuracy and necessary revisions were made. After multiple readings, idle discourse was removed and transcripts were pared down to the essential components of told stories. Segments of the story that were considered significant were re-transcribed for detailed analysis. Other interpretative decisions regarding how the data were transcribed was made based on the NDM theoretical framework, the precepts of narrative inquiry, and the study questions.

The third level of narrative analysis was the systematic evaluation of the narrative. According to Riessman (2008), data analysis is not a set of rules but rather a methodical approach to working with narrative data. Attention was given to details and particulars in the recounted story. Within the third level of narrative analysis, three modes of systematic evaluation were utilized in this investigation: thematic, structural, and performance.

In thematic analysis, "...content is the exclusive focus" (Riessman, 2008, p. 53). Focusing on *what* was said, the analysis sought to uncover themes in the participant's experience. Different from other qualitative forms of inquiry, the unit for analysis was the complete story of each case rather than selected component themes across cases (Riessman, 2008). Working with a single interview at a time, I summarized the main point to each story then "zoomed in" (Riessman, 2008, p. 57) on the particulars and meanings of what was said. I read each interview once for an overview. Each interview was read again to pull out major themes, thoughts, and ideas that emerged from the participant's story. The NDM was used as the starting point in making decisions about

emerging themes and interpreting their meanings. The computer software NVivo was used to organize transcribed narrative data and assist with data analysis.

Structural analysis gave attention to *how* the story was told, organized, and put together to depict the intended message. This was a shift from looking at “what happened” to how the participant attempts to persuade the listener to his or her point of view (Riessman, 2008). According to Riessman (1993, 2008), a fully formed story has six structures: (1) a summary or point of the story, (2) an orientation to time, place, characters, and situation, (3) a turning point or culminating action, (4) an evaluation, (5) a resolution, and (6) a coda that ends the story and brings action back to the present. The above structural parts of each narrative was organized into a table and the chronology of each story reconstructed to look for patterns (Riessman, 2008). Not every story had all six elements and they often occurred in a different order. Also of particular importance were phrases that reoccurred often in the story and gaps in the sequence of events. Reinforcing thematic analysis with structural analysis was applied to help clarify ambiguities, illuminate insights that could be missed, and aid in determining the relationship between meaning and action. Structural and thematic analysis of the study data was positioned within the naturalistic decision-making (NDM) theoretical framework.

The last form of narrative analysis was performance analysis. This form of analysis asked *to whom* was the story directed and for what purpose. Riessman (2008) believes that participants project who they are and how they want to be perceived in the

telling of the story. Aware of a listener, the teller constructs the story with language and gestures that convey their identity. To “save face” (Riessman, 2008, p. 107), some participants make a concerted effort to act out what they think is a more desirable self. Performance analysis added another dimension to the other two in that the contexts of the narrative was interrogated (Riessman, 1993, 2008). Since stories are formed and told in context, the influence of the investigator, the setting, and social circumstances were considered during performance analysis.

The results of the narrative analysis were reported by cases and by themes. A summary of the narrative account of each participant and the main plot of their story was presented. Context and particulars about the participant were also illuminated. Thematic findings were presented by recurrent themes. Structural and production analytic findings were described as they interpreted or clarified identified themes.

The narrative gathered in this investigation was examined by three forms of data analysis, but for different purposes. Thematic analysis was used to convey plots and themes that the stories had in common to point toward medication-taking decisions that lead to courses of action. Structural analysis of the spoken narrative, to give important clues about how the parts of the story fit into the overall meaning of the experience (Riessman, 2008). Performance analysis was used to identify any influences the setting, circumstances, or myself may have had on the told stories.

The demographic data collected in this study was analyzed to describe the characteristics of the study sample (Polit & Beck, 2012). The Statistical Package for the

Social Sciences (SPSS) software was used for statistical analysis of collected demographic data. Before entering the data into SPSS, questionnaire response options were coded. For example, the variable “Male” was coded as “1” and “Female” was coded as “2.” All of the study variables were given a code except for age which was entered as a continuous numerical value. Descriptive statistics, including frequencies, means, and percentages, were used to analyze and portray the sample characteristics.

### **Methodological Rigor Assessment**

Unlike quantitative research, qualitative research is naturalistic and results in socially constructed realities that cannot always be experimentally tested. Thus, plausibility and trustworthiness of the qualitative research process is demonstrated through rigor (Holloway & Wheeler, 2002; Patton, 2015). Lincoln and Guba (1985) posit that trustworthiness involves establishing the credibility, transferability, dependability and confirmability of study findings. To assure rigor in the study findings, this research study employed specific validation strategies recommended by Lincoln and Guba (1985) as well as Riessman (1993, 2008).

One of the ways a researcher can establish credibility is to spend an extended amount of time with the study informants which Lincoln and Guba (1985) termed *prolonged engagement*. Sufficient time was spent with each informant to enable an understanding of the informants’ environment and culture (Krefting, 1990). This also allowed time to develop a rapport with the study participant. I believe that familiarity between the informant and myself encouraged the informant to be more open about their

thoughts, motivations, and decisions. Prolonged engagement was also an important strategy for strengthening my ability to verify identified connections between narrative and larger social structures, such as social norms and stigmas.

A hazard of prolonged engagement was becoming enmeshed with the informants causing the researcher difficulty in separating her own ideas from that of the informants (Krefting, 1990). To counteract this threat and establish confirmability, Lincoln and Guba (1985) recommend the strategies of an *audit trail* and *reflexivity*. From the beginning, I used a field journal to record and describe personal perceptions, thoughts, experiences, and reflections. Journaling assisted in identifying influences, potential biases, and threats to objectivity. The field journal also recorded problems, frustrations, and questions about the research process. For example, once aware that participants were hesitant to discuss issues of nonadherence, approaches to data collection were altered to get more information about the phenomenon.

Lincoln and Guba (1985) assert that rich, thick description allows readers to make decisions regarding the transferability of study findings to other settings. In presenting the data, Thick description was used to thoroughly portray participants' experiences in making decisions about taking medications for CHF and to establish transferability. thick descriptions included contextual information such as past experiences, relevant events, and verbatim narratives of individuals' accounts of perceptions, ideas, and experiences (Polit & Beck, 2012).

Riessman (1993) states that narrative accounts should be as “thick” as possible to show *coherence* between the participants’ stories and analytic interpretations. According to Riessman (2008), validity is strengthened if “the analytic story the investigator constructs links pieces of data and renders them meaningful and coherent theoretically” (Riessman, 2008, p. 191). Riessman claims that good narrative analysis persuades the reader that findings and interpretations are valid. *Persuasiveness* was strengthened with presenting evidence from informants’ accounts, using verbatim quotes to present data in the informant’s own voice.

Within the process of using thick description to describe participant experiences, there are possibilities for the researcher to provide descriptions that are contaminated by the researcher’s bias. A researcher committed to reflexivity, however, will be self-critical of her preconceptions and stance throughout the inquiry process and make that transparent in her research report (Creswell, 2013). The finished report was faithful to participant perspectives in context and enabled readers to see the story as it unfolded (Munhall, 2012; Riessman, 1993, 2008). Because there is a risk of contaminating participant’s words in qualitative research, I habitually kept a field journal and was keenly aware of the contextual factors that readers need to know to understand the study findings (Erlandson, Harris, Skipper, & Allen, 1993).

To ensure the consistency of findings and dependability, Lincoln and Guba (1985) suggest having a researcher not involved in the research examine the research process and findings (as cited in Robert Wood Johnson Foundation, 2008). Creswell (2013)

describes it as a peer review process where an individual serves as a “devil’s advocate” and asks hard questions about methods, meanings, and interpretations. The peer reviewers for this study were individuals with expertise in caring for CHF patients and in qualitative methodology. Both peer reviewers and the principal investigator kept written accounts of peer debriefing sessions (Creswell, 2013).

### **Human Subjects Protection**

Prior to the recruitment of study participants, approval of the Texas Woman’s University (TWU) Institutional Review Board (IRB) was attained. Informed consent was obtained from each prospective study participant prior to participating in any study related activities. With the age of the study participants in mind, the consent process took place in a quiet, well-lit area that was private. The consent form font was 14 point and was read to participants who had visual difficulties. The purpose of the study and a description of the study procedures was provided to potential study participants. All individuals were given sufficient time to read the consent form and ask questions prior to signing.

The following steps were taken to protect the confidentiality and anonymity of study participants: (1) the use of study codes on data collection and study related documents in place of identifying information, (2) the maintenance of a separate document of identifying information and assigned study codes that were stored in a locked and secure file cabinet, (3) the storage of all digital documents on a password

protected device, and (4) not including identifying information in any study papers or publications.

Some older adults may feel coerced into becoming participants, with a fear of losing health services if they do not participate. Some may agree to participate with the expectation of assistance or an intervention. It was made clear to the participants at the time of consent that participation was voluntary and there would be no negative repercussions for not participating. Each participant had the right to withdraw from the study at any time. It was also made clear that there may not be any benefit to the participant for taking part in the study.

### **Pilot Study**

A pilot study was conducted after IRB approval from the Texas Woman's University (TWU) Institutional Review Board (IRB). The purpose of the pilot study was to evaluate the feasibility of recruiting study participants that would be appropriate for future research regarding medication-taking decisions among community-dwelling adults with CHF from local churches. Churches are community-based institutions that may serve as potential recruitment sites for community-dwelling adults who take medications for CHF. CHF is most common among older adults, thus church activities aimed at older adults may be a point of contact for potential study participants. In addition, the ease and speed of recruitment procedures may be facilitated by regular church meetings. Since Internet and email could be effective communication tools for study recruitment, this study explored the level of Internet use among the study sample. Participants were asked

if they felt comfortable using the Internet to check or send an email, complete a survey, search for information, read or post to a blog, or look up a website. This study sought to answer the following questions: (a) what are the characteristics of the sample population?, (b) what is the number of potentially eligible study participants?, and (c) what is the level of Internet use among this population?

### **Data Collection**

Purposive sampling was used to recruit study participants from a regular monthly meeting of senior adults that were gathered at a local church for a community fellowship. Data were collected using self-administered, standardized questionnaires developed by the researcher (See Appendix C). Respondents were asked to read the questionnaires and give their answers in writing. With the exception of age, all questions were closed with pre-coded response options. The estimated time for completing the questionnaire was 30 minutes or less. The content of the nine question survey was limited to respondent characteristics (age, gender, race, primary language, highest level of education, marital status, and employment status), level of Internet use, and medication use for CHF. Out of the 14 distributed questionnaires, 10 were returned completed (71%) and one was returned blank.

### **Data Analysis**

The Statistical Package for the Social Sciences (SPSS) software was used for statistical analysis of study variables. Before entering the data into SPSS, questionnaire response options (variables) were coded. For example, the variable “Male” was coded as

“1” and “Female” was coded as “2.” All of the study variables were given a code except for age which was entered as a continuous numerical value. For each of the variables analyzed, univariate descriptive statistics examined the overall distribution of the data. For continuous variables and sample size percentages are presented to summarize the mean. For categorical variables, frequency counts and percentages are presented as summary statistics for the variables of interest. The denominator for calculating percentages is relevant to the number of completed questionnaires. A careful examination revealed no missing or invalid questionnaire data.

### **Findings**

Of the 10 participants who completed the study questionnaire, one reported taking medications for heart failure. The study sample consisted of five males and five females, giving a total of 10 respondents. The respondents ranged in age from 70 to 88 years, with a mean of 76.5. English was the primary language for all the respondents, with nine reporting their race as White and one African American. The respondents were well educated, with the majority (80%) attending college. While two female respondents were widowed and 1 male was single, seven of the 10 respondents were married. When asked about employment status, 50% reported being retired and 50% reported being employed. Given the age of the participants, reported Internet use was surprisingly high with the majority (80%) of the participants reporting using the Internet.

## **Implications for Further Research**

The pilot study indicates that although it is possible to recruit study participants from local churches for future research regarding CHF medication-taking decisions among community-dwelling adults, the potential number may be low. The single participant that responded affirmatively for taking CHF medications was also willing to participate in a future research study about how people make decisions about their CHF medications.

One insight gained from this pilot study is the possibility that participants may not be aware that they have CHF or understand that the medications they are taking are typically prescribed to treat CHF symptoms. In future recruitment efforts, asking individuals if they take specific medications, such as those common to treat heart failure, may be more effective at identifying potential participants than simply asking if they have CHF or take CHF medications. Also learned was that study participants were willing to complete the study questionnaire, but they preferred completing it at home. Any future research involving study questionnaires will take into account the potential desire to complete the questionnaire at an alternative location other than the recruitment site.

Another insight gained through this pilot study was the high level of Internet use among study participants in their 70<sup>th</sup> and 80<sup>th</sup> decade. The two who did not report Internet use were aged 73 and 82. There was no evident cutoff age for using the Internet, thus the Internet may be an effective communication tool during future recruitment or

study communication efforts. Seeing that older adults frequently use the Internet, study advertisement flyers might include email and web addresses.

Although this study demonstrated that local churches are feasible sites for recruiting study participants who take medications for CHF, potential difficulties in identifying these individuals was illuminated. Information learned about participant characteristics would be considered in the development of future recruitment efforts. Given the need to recruit study participants that would make good informants for future research regarding medication-taking decisions among community-dwelling adults with CHF, local churches can be a possible location for effective recruitment efforts.

### **Chapter Summary**

This chapter presented the methodological procedures that were be used to study the narratives of medication decision-making among those with CHF. An overview of narrative inquiry and the central constructs of the NDM theoretical framework were also presented. The following components of the methodology implementation plan were outlined: (a) site and setting, (b) participants, (c) researcher as instrument, (d) strategies for interviewing older adults, (e) data generation strategies, (f) data analysis, (g) methodological rigor assessment, and (h) human subjects protection. Results from a pilot study were reported.

## CHAPTER IV

### RESULTS

#### **Overview**

The purpose of this narrative inquiry study was to gain understanding and insight into older adults' decision-making experiences and perceptions in choosing to take or not to take medications for CHF in the community setting. The central question of this study was: What are patients' storied decisions about choosing to take medications for CHF? The specific aims of the study were: (a) to identify the role of decision-making in medication adherence, (b) to elicit descriptions regarding how individuals make decisions regarding medication adherence, and (c) to describe how individuals comprehend medication adherence and nonadherence.

Data were gathered through audio-taped, semi-structured, face-to-face interviews that were subsequently transcribed verbatim. The data in this study were organized and analyzed using Riessman's (1993; 2008) three levels for narrative analysis previously described in chapter III. The following chapter will present the findings of the study, including an overall description of the participants, a brief introduction to each participant and the story they told (individual names were changed to protect anonymity and confidentiality), and themes that emerged from the stories of community-dwelling, older adults that take medications for CHF.

## **Participant Demographics**

Eleven older adults that take at least two medications for CHF participated in the study. There were six males and five females who were between the ages of 69 and 92 years ( $M= 80.7$  years) at the time of the initial interview. All participants described themselves as White and English speaking ( $N=11$ ). The majority of the study participants were married and lived with a spouse ( $n=6$ ). The other five participants lived alone, among whom two were divorced, two were widowed, and one had a spouse that resided in a memory care facility. The majority of the participants were college graduates. Six of the participants had a bachelor's degree and two had a graduate degree. Two participants reported attending some college (two years or less) and one participant's highest level of education was high school.

All study participants were retired and received their annual income from Social Security, retirement savings/stocks, and/or pensions. In addition, one participant reported income from current employment and one reported income from rental properties. In the demographic data form, 36.4% ( $n=4$ ) of participants reported their annual income as greater than \$100,000, whereas two participants reported an annual income between \$31,000 and \$90,000 and two had an annual incomes less than \$30,000. One participant did not want to answer. All study participants paid for healthcare costs with Medicare benefits and the majority (81.8%) with supplemental private insurance ( $n=7$ ), a drug prescription plan ( $n=7$ ), and/or out-of-pocket money ( $n=6$ ).

While 10 of the 11 participants described their CHF as well controlled, the majority reported experiencing one or more symptoms of CHF. The most common CHF symptom was shortness of breath with exercise (81.8%) followed by an irregular heartbeat, swelling, and fatigue (45.5%). Approximately one-third (36.4%) of participants reported experiencing a cough and drowsiness. Approximately 27% reported sleeping with the head of the bed raised and 18.2% having shortness of breath with rest. The least common symptoms at 9.1% were lung congestion, chest pain with exercise, and chest pain with rest. No one reported weight gain as a symptom. The number of daily medications each participant was prescribed ranged from six to seventeen with an average of 11.45 pills per day. All participants took medication doses at least two times per day and four of those reported taking medications three or more times each day. See Table 1 for a description of daily medications prescribed to study participants.

Table 1

*Frequency of Prescription Medication Use among Study Participants*

	Reported Taking	
	<i>N</i>	Percent of Cases
Beta Blocker*	7	63.6
Calcium Channel Blocker*	6	54.5
Digoxin*	1	9.1
ACE inhibitor*	5	45.5
ARB*	4	36.4
Diuretic*	9	81.8
Antihyperglycemic	3	27.3
Anticoagulant*	11	100.0
Thyroid Replacement	3	27.3
Antidysrhythmic	3	27.3
COPD medication	3	27.3
Nitrates*	1	9.1
Antidepressant or Antianxiety	3	27.3
Statin	7	63.6
Sleeping medication	4	36.4

*Note.* \*= medications used to treat or decrease symptoms of CHF, ACE = angiotensin-converting-enzyme; ARB= angiotensin receptor blocker; COPD= chronic obstructive pulmonary disease

**Introduction to the Participants**

This section presents a summary of the participant's narrative, a brief biographical profile for each participant, and describes my interaction with them. The names of participants were changed and randomly assigned using alphabetical order. The dynamics of the rapport that shaped the narrative that the participant and I created are illuminated. In addition, contextual information, the presence of comorbidities, and the

main plot of each participant's story is brought forth. I consider how participants continually contributed to study decisions and interpretations of the data.

**Adam.** Adam was the first participant interviewed. After meeting me in person at his retirement facility, Adam agreed to participate in the study. He was interviewed that same day in a meeting room within the retirement community. At 72 years old, he lived alone while his wife resided in a separate facility for the memory impaired. His medical history included a heart attack, diabetes, hypertension, a stroke, poor vision, difficulty hearing, reduced mobility, depression, chronic obstructive pulmonary disease (COPD), and trouble sleeping. His symptoms included shortness of breath with exercise, cough, difficulty sleeping without adding more pillows under the head, fluid buildup or swelling, fatigue, an irregular heartbeat, and chest pain. Adam ambulated with a walker, which he described as a way to "carry all his stuff." A portable oxygen tank was attached to his walker in case he needed it.

Throughout the interview, he nervously referred to a worn list of medications that had numerous handwritten edits. His daughter, a Registered Nurse, had helped him create the detailed computer printout of his medications. He knew he ought to take his medications, but the daily routine of taking the pills was "boring." He admitted to skipping some of his medications the day of the interview. Sharing his experience, he was sometimes emotional and spoke about his inability to care for his wife like a husband is supposed to. Adam spoke openly about feeling depressed and thought this was related to his medication-taking decisions:

There's times that I get depressed, but it is very easy to get depression taking so many medications. You think what the heck. My daughter is very good at, my sister used to do it, now it's my daughter, checking in, making sure that I'm not getting depressed. That's when I worried about not doing this (pointing to list of medications) correctly. And she knows my spirit and the way I think. She knows that I need to check my sugar.

**Ann.** Ann was 79 years old and lived independently in a retirement community. Ann came by to meet with me at her retirement facility and an interview was scheduled for that same day. The interview took place in a private meeting room. She was divorced and had recently moved from the northeast to be close to her daughter. Her medical history included a heart attack, hypertension, poor vision, reduced mobility, and trouble sleeping. She reported the symptoms shortness of breath with exercise, difficulty sleeping without adding more pillows under the head, and fluid buildup or swelling. Ann's speech pattern was quick and matter-of-fact as she told the story of adjusting the dose of her diuretic. After her doctor suggested that her diuretic could be contributing to her low blood pressure, she experimented with the dosing regimen. Once she found a dosing schedule that gave her an acceptable blood pressure, she made the decision to deviate from how the medication was recommended:

I take about half a dozen medications and I take them as prescribed, except for the furosemide, which I've cut down to one every day rather than two every other day

and one opposite days. And I did that because my blood pressure went very low.

So, I stopped taking it that way.

**Beth.** Beth was 81 years old, widowed, and lived alone in a retirement community. She was the third participant interviewed at the same retirement community. After meeting with me in person, her interview was scheduled for the same day. Her medical history included poor vision, reduced mobility, trouble sleeping, and atrial fibrillation. Beth reported the symptoms shortness of breath with exercise, difficulty sleeping without adding more pillows under the head, fatigue, drowsiness during daytime hours, and an irregular heartbeat. Other health challenges included having arthritis that was managed with multiple medications. Beth sat straight up in her chair, hugging her purse in her lap. She pulled out a folded, handwritten list of medications from her wallet and began talking immediately. Beth spent the majority of the interview sharing her feelings about how her medications were inconvenient. She described taking too many pills and going to the pharmacy almost every week to pick up a prescription. Conversation frequently revolved around her experiences with frequent urination and a dry mouth. "...I will urinate at least three times in the morning, and I must. So if I have somewhere to go at 9 o'clock, then it is a problem." During study screening, Beth spoke about her excessive diuresis and how she chose to skip her furosemide when she had plans for the day. Yet, during the interview, Beth excluded those experiences and said that she was a teacher and teachers "follow the directions."

**Bob.** Bob was 83 years old, was divorced, and lived alone in a retirement community. His interview took place in a meeting room within his retirement community. Bob's medical history included a heart attack, hypertension, depression, poor vision, and difficulty hearing. He was without any major symptoms. During screening, Bob spoke openly about taking his medications differently than prescribed and agreed to be interviewed. Throughout the interview, however, he repeated the exact same phrase: "I do what the doctor tells me." He was eager to communicate that he takes his medications as prescribed. After the interview was complete, he came back and said that he worked for a large insurance company and probably "knew too much to be helpful." It was at this point that I began to contemplate the effect of the interview on the researcher on how the participant constructed their stories. I considered that recording the interview with a computer may have been intimidating or caused reservations in communicating experiences of not taking a medication. I also considered that participants did not want their medication-taking decisions to be perceived negatively by the listener. Since the first four study participants were all from the same retirement facility, it was also possible that conversations with earlier interviewees could have influenced the narratives of the latter two participants. No other study subjects were recruited from this study site.

**Carl.** Carl contacted me after receiving a flyer from a church. He was 69 years old and lived with his wife. His medical history included coronary artery bypass surgery, diabetes, and difficulty hearing. He reported the symptoms of shortness of breath with

exercise, a cough, fluid buildup or swelling, and fatigue. The interview took place in one of the church offices. Carl spoke freely about experiences where he made decisions to adjust the dosage of his diuretic and blood pressure pills based on symptoms.

I doubled my Lasix about a month ago. I was having some swelling in my feet and ankles. He had already written down to take one to two pills but he had not given me a prescription for that yet. And so ...but that is taking care of that and I don't have the swelling anymore.

In his narrative he also told the story of increasing the dosage of his beta blocker prior to an eye surgery.

I guess a little beta blocker that I take a half of pill of. Because I went to have a cataract surgery sometime right after my [bypass] surgery, and uh... he wouldn't –the anesthesiologist- wouldn't put me to sleep to do that because my heart rate went up. I went straight to the cardiologist from there, which we were in [town] and we had to go to [town], and it was fine whenever I got there. So basically, from what I understand, that's what kinda helps your heart rate to not fluctuate. And uh---so he said I think you need to wait a certain length of time. AND I SAID what if I took a whole one the morning I did the cataract surgery? That's what happened. I had cataract surgery on my right eye.

Although Carl adjusted his medication dosages, he felt that those that did not take their medications on purpose did not trust their doctor.

**Chris.** Chris was the 6<sup>th</sup> study participant. From this point on I asked each study participant if they had a preference for recording device and read a preamble. He was 79 years old and lived with his wife in a retirement community. After receiving a study flyer in his mailbox, Chris contacted me by email. He was screened by telephone and an interview was scheduled. The interview took place in a meeting room within the retirement community. His medical history included atrial fibrillation, hypertension, poor vision, and difficulty hearing. He reported the symptoms of shortness of breath with exercise and fast or irregular heartbeat. Chris was professional in demeanor, arriving well-dressed and carrying an iPad. He spoke often of Medicare as a “complicated system.” “You are at the mercy of whatever insurance company you happen to pick and the formulary and everything else.”

He told the story of walking on the treadmill and experiencing new onset shortness of breath and fatigue. Since metoprolol was a new medication, he attributed his symptoms to the medication. He believed that he tried stopping the medication on his own to see if the symptoms improved and he ultimately stopped taking it. Chris’s perception was that his medications do not make him feel better:

Yeah, I have never taken any medications that I felt better from- that I can remember...The shortness of breath, exercising, I still have the sensation. You start off to exercise and within two minutes you feel like you have been climbing a mountain for two hours. You are panting (demonstrates panting), and struggling to breath and it’s not normal- not a normal reaction. The shortness of breath

persists even with my medicines today so I've just had to gradually back off. Stop doing jogging and running to walking. And then if I'm climbing real mountains, then you just have to go slow.

**Darla.** Darla was 87 years old and lived with her husband in a retirement community. Darla initially contacted me by email. She was screened by phone and an interview was scheduled at her apartment. Her medical history included hypertension, a stroke, poor vision, difficulty hearing, reduced mobility, depression, COPD, fatigue/trouble sleeping, and atrial fibrillation. Her symptoms included shortness of breath with exercise, shortness of breath at rest, cough, fluid buildup or swelling, tiredness or fatigue, drowsiness during daytime hours, and fast or irregular heartbeat. Darla's husband and four children were heavily involved in making sure she took her medications. Her husband and her son were physicians. Darla described experiencing excessive daytime sleepiness. With the help of her husband and son, she investigated which of her medications were causing her symptoms. She moved her depression medications to bedtime, but she stated that she still felt tired and sleepy. She asked her doctor to change her medications to make her feel better but no changes were made. Even though she did not feel good and was not sure how she would feel if she stopped taking her medications, she took them because she trusted her doctor. Without the help of her family she would still want to take her medications, but needed others to understand what she was experiencing:

... I am tired and people can't expect too much of me. [Husband] likes to go concerts and is pretty active. And sometimes I just don't feel like going. I need him and other people to understand that I just don't feel like doing it. I often say to myself, is it worth it? I often see something across the room, like a glass of water, and I say is it worth walking over there for it? If not, then I'm just gonna sit here. I'll go later and take care of it.

**Dean.** Dean was referred to the study by the previous study participant. After the interview with Darla, I spoke with Dean in the apartment building lobby. He expressed interest in participating in the study and an interview was scheduled for the next week at his apartment. Dean was 87 years old and lived with his wife in a retirement community. His medical history included hypertension and he was without major symptoms. Dean talked extensively about the cost of medications. For just one medication, he paid \$1500 for a 90-day supply. He spoke of weighing his options to determine if the cost was worth it. He could not tell that his medications made him feel better and spoke about what influenced his medication-taking decisions:

If I'm going to go to the doctor and he is going to give me a pill, then I am going to take it. If not, then I am going to change doctors. That's just the way it is.

Otherwise, I should just change doctors. If I don't take the medication then I don't have any trust in him.

**Earl.** Earl was 92 years old and lived with his wife in a retirement community. He initially contacted me by email. He was screened by phone and an interview was

scheduled at his apartment. His medical history included diabetes, poor vision, difficulty hearing, reduced mobility, and atrial fibrillation. He reported shortness of breath with exercise, drowsiness during daytime hours, and fast or irregular heartbeat. Earl told the story of stopping a medication based on symptoms.

Well one morning I realized that something is wrong. I wet myself. I woke up every morning and discovered that my pajamas were wet. Ok why? I'm an engineer. One of the first things you learn as an engineer is go find out what the hell is wrong. So I looked up every one of these and finally I came down to Vesicare. And oh boy. That's a belladonna. And I know what a belladonna does. So that's when I said uh oh. Let's cut this one out. I waited two to three days to see to see if that worked and it does. That is a problem. I don't know exactly why that was prescribed to begin with.

He felt there was no need to tell his doctor because he had no plans to start taking it again. Earl stated that he took without question the medicines that "check out on the Internet."

The first thing I do is head for the Internet to find out what they are and what do they do. I know what the doctor told me but I still want to know. I want to see it. I don't trust anything I can't read.

Earl not only had a computer printout detailing each medication, what it was for, and when to take it, he also made his own labels for each pill bottle and used a weekly pill organizer.

**Edith.** Edith received a study flyer during her cardiology office visit. Her study screening took place in an empty examination room and an interview was scheduled for the next week. Her medical history included heart attack, hypertension, kidney disease, poor vision, reduced mobility, COPD, and fatigue/trouble sleeping. She reported the symptoms of shortness of breath with exercise, shortness of breath at rest, cough, fluid buildup or swelling, congested lungs, tiredness or fatigue, drowsiness during daytime hours, and chest pain with exercise and at rest. The interview took place at Edith's home, where she lived alone with her small dog. When I arrived, Edith was seated at a large round table in the main room of the home. Although organized, the table and the surrounding area was crowded with pill bottles, plastic file boxes filled with medication information, stacks of spiral bound notebooks, and piles of medication information flyers from the pharmacy. Her long oxygen tubing stretched the span of the room. The entryway area had been converted to a make-shift bathroom, complete with a bedside commode, toilet paper, and hand sanitizer. Edith began the interview talking about the effects of her diuretics. Each day, depending upon how she felt, she made a decision either to take or not to take her blood pressure medication and her "water pill." She kept a detailed journal to help her make medication-taking decisions. Each day, she recorded her blood pressure, how many times she went to the bathroom, the color and quantity of her urine, her blood sugar (even though she was not a diabetic), how many times she got up at night, the time that she took each medication, the medication(s) that she did not

take, and other information such as the weather and daily activities. In her narrative, she told the story of stopping one of her angina medications.

Well... so anyway he had me taking this other medicine morning and night. Ok. I still hurt. You know that dull aching hurt. He called that angina. Well it kept hurting and I came home. And it just kept hurting so finally I called up there and I said you've got to tell him I'm still hurting. Well, he told one of the girls call me back and said [doctor] said for you to take it double. Take two every time. Well it liked to blew my head off. I couldn't function. Like if I was going to go to bed and stay there....I could not function so I could not do it.

So I just ignored it. But I did try it enough that it went into my system and made me like that. But that's about as long as I stayed on both of them like that. So, I cut it back to one in the morning and one at night. I didn't feel too good but I went along with that for a while. Then I got to thinking. Well, I wasn't hurting. I never really felt like I had had a heart attack. But uh I didn't know. A lot of time women don't. So I thought well I'm just gonna quit taking that stuff.

When I first stopped it there was a time or two where I felt like the hurt was coming back. I got up in the middle of the night and grabbed me a Renexa and took it...It never did do that anymore. So I stayed off it.

Edith also stated that she would often "stay off" her furosemide when she had somewhere to go:

I'm very careful about where I go to the bathroom when I go out because you don't know if you are going to be able to open the door or you got a place to get up off the pot.

She made the decision not to take her furosemide the day of the interview.

**Frances.** Frances was referred to the study by a church member. She contacted me by phone and she chose the back room of a small café for the interview location. Frances was concerned about the visible bruising from her anticoagulant. Although the weather was hot, she wore long sleeves and long pants. She pulled back her clothing to reveal large, dark bruises in different stages of healing. She discussed the bruising with her doctor and he did not agree that she should stop the medication. She responded with "I basically told him- I am." She admitted to regularly stopping and starting her anticoagulant based on her symptoms. She also told the story of stopping and starting her diuretic.

...it was almost like I had IBS. It tends to dehydrate you. What I have done is stop that for like three days. I don't need more loss of water in my system. So that one I stop myself....When I had these occurrences with IBS I think that I feel dehydrated. I figured this is what that pill is for and therefore if I don't take it then I should recover faster.

Frances described herself as "type A" and felt like it was important to ask questions.

## Thematic Findings

Through narrative analysis of participants' rich narratives, six shared themes emerged. The application of structural and production analysis was used to identify deeper meanings and clarify identified themes. These themes illuminated a deeper understanding of the role of decision-making in participants' medication-taking behaviors, the sequence of events in making a medication-taking decision, and participant's perceptions of medication adherence and nonadherence. An overview of these themes are presented in Table 2. Themes are discussed in depth and presented by study aim.

Table 2

### *Study Aims and Themes of Medication-Taking Experiences*

Study Aims	Themes
Identify the role of decision-making for medication adherence	<ul style="list-style-type: none"><li>• I Don't Do It Just 'Cause They Said To Do It</li><li>• That Worried Me</li><li>• How I Feel</li></ul>
Describe how decisions are made for medication adherence	<ul style="list-style-type: none"><li>• I Connect the Dots</li><li>• It Is Complicated</li></ul>
Describe how individuals comprehend medication adherence and nonadherence	<ul style="list-style-type: none"><li>• I Am Not Nonadherent</li></ul>

## **Aim 1: The Role of Decision-Making for Medication Adherence**

**Theme 1: I don't do it just 'cause they said to do it.** The theme, *I don't do it just 'cause they said to do it*, is related to participants' intentional decisions to forego medication recommendations. Edith captured the theme with her statement:

Well I listen to them-what they've got to say to start with. How it affects me is the thing. If what they tell me proves to be true then I'll go along with it, but I don't do it just 'cause they said do it.

Shared in the narratives recounting medication-taking experiences were stories of making a decision to adjust medication doses, skip doses, or stop a medication altogether. Four individuals spoke of past experiences of adjusting or stopping a medication, while others described an ongoing lifestyle of making routine decisions to modify their prescribed medication regimen. None of the participants reported making adjustments to all their prescribed medications. Instead, they told stories of making deliberate and intentional decisions to disregard medication recommendations of selected medications. After describing decisions to skip doses of her anticoagulant and diuretic, Frances stated, "...those are the only two that I mess with because they affect me the most." Carl shared, "the only thing that has happened is I doubled my Lasix about a month ago." Ann said, I take about half a dozen medications and I take them as prescribed, except for the furosemide, which I've cut down to one every day rather than two every other day and one opposite days.

Edith stated,

I took it today [Lisinopril-hydrochlorothiazide]. That's the reason why I wrote down that I took it and I wrote out here that 12.5. So anytime I don't take something, I put a mark out here, a minus sign. If I don't take this [a blood pressure medication], I put a line through that too. And the water pill up here, I did not take a water pill today so out here beside it you see where I put my little minus sign. I put "see blood pressure" and that way I underline my blood pressure, 140.

Despite purposeful nonadherence to selected medications, the study participants were not anti-medication. On the contrary, each study participant in this study insisted that "you ought to take your medications" and "you should take your medication." Adam shared,

Well this morning I did not take it. I was up real early and I...I took my medications down here (pointing to list) with my breakfast, but I did not take my [diabetes medication] yet and I should have already taken it before I came down and checked my blood. But, I didn't (shrug shoulders).

Furthermore, participants in this study did not describe failing to remember their medications. Some participants reported that they rarely forgot to take a medication and others reported that they never forget. Earl shared that he had "forgotten maybe once or twice" and described his weekly pill organizer as working for him. Frances stated, "I have never forgotten. I feel like they are too important to me. Even those I mess around

with, those two.” When asked if she believed her decisions to stop her medications were based on logic she replied, “Yes! It’s not that I’ve forgotten.”

All participants in the study described having elaborate daily medication-taking practices aimed at remembering to take their medications. Participants also employed multiple memory strategies, such as using plastic weekly pill organizers, calendars, and journals. At the time of the interview, each study participant also presented a list of medications, which they referred to often. When asked about accidentally missing a medication participants frequently responded by describing their daily medication-taking routine. Chris said,

...I go through a routine so it works out good. I’ll have breakfast. At that time I take my morning medicine, which is about half of the medicine. The other half I take before dinner and the late afternoon and that seems to be something that I can remember and be a routine.

He went on to say that he forgets a medication dose, “Probably once every six months maybe. I’ve got a good routine (smiling). I very seldom miss it.” Dean shared,

I’m just one of those people that does everything by routine. I get up in the morning and I take my medication. Then, I brush my teeth and shave.

And when I get ready to go to bed, I take my medications before I go to bed. I brush my teeth then I go on to bed. It’s just a routine.

Carl described his routine as well.

The morning medicine I just about always take it because I fix my own breakfast. So when I go to the refrigerator to make my coffee for the morning, my insulin comes out and my pill rack comes out. ...I doubt if it is one time in six months... I mean that is just a regimen. You learn to do that.

Earl stated,

Well I might would forget if it weren't for this (pointing to pill organizer). Now I don't forget. I have forgotten maybe once or twice. But, I rely on that and it works.

Edith shared that she would not “attempt” to “do all this without writing it down.”

Pointing to her journal she said, “What I’ve got in here and I can remember.”

**Theme 2: That worried me.** The theme, *that worried me*, is related to participants’ uncertainty about a medication. Common across the narratives was uncertainty about the safety of a medication, the need for a medication, and the reason for a medication. Participants in this study expressed the most concern about the medications they had chosen to adjust or stop taking.

Several participants expressed uncertainty about the safety of a medication. Beth spoke of a conversation with her doctor, “[he] said just get used to it because you are going to be on that aspirin for the rest of your life. That worried me because I was already on Coumadin.” Edith spoke about how increasing the antianginal medication

scared her to death and Carl told how one of his pills changed shape to a round pill and he worried about that.

Participants expressed worry about the need for a medication. This was most prominent in stories about the excessive therapeutic effect of a medication such as a diuretic or anticoagulant. More than one participant expressed that the cycle of thirst and “expelling” more urine “did not make sense.” Edith expressed her concern and discontent with going to the bathroom 6-10 times per night. “I take the water pill, but even that has fouled me up, so I break it in two.” She added, “...I stand up and just wet my pants. It’s just awful. You have to go in there, bathe, then dress.” Frances was worried about the bruising and bleeding from her anticoagulant when she stated, “I am wondering, is there a benefit for me to still be on it?”

Several participants shared that they were uncertain about the reason for most of their medications. Beth shared that she only knew some of her medications. She pointed to the list of medications and said, “and this is as far down as I can get.” She did not understand all of her heart medications. Adam started the interview with questions about a new medication. He was bothered that it was a new prescription and he was unsure of what it was for. He expanded later in the interview, “there have been times when the doctor has told me not to take a high blood pressure medication, but I have a problem with which one of these is for high blood pressure.” Carl expressed that he did not know enough about his medications. Earl pointed to his blood pressure medication and stated, “This one, I’m not really sure what it does.”

Several participants presented their worry about a medication as a justification for adjusting it. Earl's narrative about stopping his bladder medication began with concern about which medication could be causing him to wet himself at night. After researching his medications on the Internet, Earl felt that he had identified the culprit but concluded his story with, "I don't know why that was prescribed to begin with." In her story, Edith expressed uncertainty about the need to take her angina medication:

I didn't feel too good but I went along with that for a while. Then I got to thinking, well I wasn't hurting. I never really felt like I had had a heart attack. But uh I didn't know. A lot of time women don't. So I thought, well I'm just gonna quit taking that stuff.

Of note, Earl and Edith describe adding over-the-counter supplements to their medication regimen to self-treat their symptoms.

Several participants discussed encountering conflicts of information from different sources. Edith identified a conflict between her doctor's recommendation for the angina medication and the pharmacy medication flyers.

There are several things that I have to take and it said if you take any of that stuff, don't take this medicine- conflicting information...It said on some of these papers I got (holds up pharmacy information flyers), if you take this, this, and this, don't take this medication. Well I read that line and I thought, oh! And so I quit taking it.

Carl also expressed confusion about information he heard from the television.

But like right now, I'm so dry in my mouth and I heard on TV what causes that-my medications. Why? Which medication or is it all of them?...And that bothers me to. Is my kidneys getting bad? This is a change to my routine. And I just had surgery on my leg and I wonder if the change in that is causing a change.

Several participants also shared that an understanding of the medication helped them make medication-taking decisions. Carl shared how an understanding of his beta blocker helped him made the decision to increase his dosage just before his cataract surgery. Adam stated that understanding his medications influenced his thoughts about his medications: "I am a person who wants to know what causes things. Maybe a lot of people wouldn't, but I want to know." Edith spoke about using the notes in her journal to help her make medication-taking decisions, "I can go back if I get worried about something and see how I was feeling." It was common for participants to speak about reading the medication flyers from the pharmacy or researching the medication on the Internet. "You get the starter information from the doctors and then you can do some research. You get the pharmacist information which is helpful. The Internet is helpful if you really got more questions."

Participants frequently ended a story with expressing a desire for more information. Ann stated, "I would say that doctors don't have time to go into long detailed explanation about medications. But, someone should give me more instructions on medications when they are prescribed." Edith believed that she received too little

information at a doctor visit and stated, “The doctor didn’t tell you anything. They just prescribe it. You go get it and unless you make them tell you what they’re writing on there, you don’t even know how to take it.” Adam stated, “When teaching new nurses, make sure to talk to them and tell them to say why. Why they are taking that particular medication because I don’t know. I don’t know.” Structural analysis of participant narratives revealed that for most of the participants, issues of uncertainty were largely unresolved. Even those that made a decision to stop or adjust a particular medication, still experienced worry and concern about their medications and their health.

**Theme 3: How I feel.** The theme, *how I feel*, is related to the personal values that participants used to guide their medication decisions. Participants in this study spoke often of their feelings when recounting their medication-taking experiences. Influenced by what was perceived as important to them at the time, participants established personal priorities and values in life. A query of the most commonly spoken words, revealed that the word “feel” was the 9th most often spoken word within the narratives. Evident in the narratives were two types of personal values, physical and emotional.

Physical values were expressed in the narratives in terms of *how a medication made the participant feel*. Very often a concern over a negative symptom, such as activity intolerance, bleeding, or low blood pressure caused the participant to investigate their medications. The majority of participants shared frustration with the side-effects or the excessive therapeutic effect of particular medications. Many participants were distressed by the inconvenience of the diuretics. Several of the participants talked about

“hurrying” to the bathroom and the “embarrassment” of wetting themselves. Adam said, “And it’s so uncomfortable that you know I am unsure of just wearing underwear- whether I’ll be able to make it to the bathroom. I don’t have much time.” Participants also shared that the diuretic prevented them from going places. Edith commented, “I’ve been wanting to get back in church. Well there’s no way you can go to church and have to get up every 15 minutes and go pee.” She went on to say, “I’m very careful about where I go to the bathroom when I go out because you don’t know if you are going to be able to open the door or you got a place to get up off the pot.” More than one participant shared that side effects of a medication negatively impacted their quality of life.

Many participants shared that the adverse effects from medications were just part of living. Chris complained that even after stopping his blood pressure medication, he still experienced medication side-effects. He stated, “Sometimes you have to live with the side-effects.” Chris explained that he was able to “adjust his lifestyle” and kept “functioning within those guidelines.” Some participants had resolved themselves to “this is the best I can do,” this is “the way it is,” and “this is life.” One participant said they just take it “one day at a time.”

Emotional values were expressed in terms of *how they felt about a medication*. Emotional values emerged from the narratives as beliefs or thoughts about a medication or the prescribing physician. The majority of participants in the study expressed that a belief in the medication to prolong good health influenced their decision to take the

medication. Dean stated, “I think everybody wants to live in good health and that’s the reason I take them.” Others expanded:

Frances: Well, in order to feel better this is what the doctor said, and I wanted to get back to my life, and this was the way it was going to go. So, I took them with no hesitation.

Chris: Well, it’s increasing my odds of keeping my lifestyle on an even keel. ‘Cause if you have a stroke or you have an event or with the thyroid, you know your life or your quality of life can go south on you. You don’t want to end up suffering day to day from symptoms of disease you got. So, it’s more of an odds are better with it than without it.

Earl stated, “Well, I can see the light at the end of the tunnel, but I’m not ready to get there (laughing).” When asked to elaborate on that statement, Earl described his medications as providing “comfort.” Carl shared that his heart surgery scared him and motivated him to take his medications. He and other participants spoke about wanting to be around to enjoy “the kids” and enjoy “doing things.” Participants only spoke about the health benefits in regards to the medications they were still taking. No participant stated that they felt one of the medications they had stopped had long-term benefits.

Participants in this study also frequently expressed feelings of trust toward a medication or doctor. They spoke of whether or not they had trust in a medication or in a physician. Conversations about trust in a medication frequently led to talking about trust in the doctor. Participants made the following statements: “He is someone I trust very

well,” “When someone saves your life you trust them,” and “I could trust him.” Beth said, “And the heart people, I had to trust them because six months (left to live) wasn’t enough. And I do feel good.” Later in the conversation she added, “Just got to trust your doctor I really think because you can’t just find medication like you can for your stomach. Heart medication is all prescription.” Earl shared that his relationship with his doctor influenced how he felt about his medications. He compared his former doctor to his current doctor.

If Dr. [name] in [town] prescribed anything or told me anything I listened very carefully because I knew he knew what was best for me. He took an interest in [name of wife] and I. I mean a real interest. He wanted to know how we were doing. He wanted to know how every medication was working out... Now Dr. [name], I don’t know yet.

While each participant, at some point in their narrative, shared that they trusted their doctor, many also told of negative experiences with physicians. Carl and Earl spoke of experiences with a doctor who made a mistake in diagnosing. Carl shared that if that doctor prescribed any medications he would not take them. Earl explained that “you should have a method of checking up on the doctor.” He said, “I will quiz the doctor when he recommends something. I want to know why, what he knows. But then I still go look it up.” Edith shared more than one experience where she felt she needed to protect herself from unnecessary or dangerous procedures. Adam lamented that he had not found a good doctor to replace his former one. Darla wondered if her doctor could do

more for her to make her feel better and Frances wished her doctor would listen to her more.

Interestingly, those that expressed an unwavering trust in their doctor and the medication also reported that the medications did not make them feel any different. Two participants, Bob and Dean, stated they could not tell they were taking their medication. Dean added that he did not read the side-effects and said, “Now if you read the side-effects you probably won’t take any of it.” Chris stated, “I don’t get any positive feedback from my meds. They are there, but I’m not getting any warm fuzzies from them.” When discussing getting a reaction from a medication, Darla stated,

I don’t feel any different whether I take it or not. Now occasionally I go for a blood pressure check or we take it here and the question comes up, ‘Did you take your blood pressure meds this morning?’ And that might have an effect on it.

But as far as how I feel, I don’t notice any difference.

Although she did not feel a difference, Darla explained that she was motivated to take her medications, “Because the doctor says to. I don’t know how’d I feel if I didn’t take them. So, I think it’s best to do what they say and take my medications.” Darla shared that she would be motivated to stop a medication if it made her “feel bad or worse.”

Evident in the participants’ narratives was an intertwining of both physical and emotional values. Each story went back-and-forth between expressions of physical and emotional factors that were important to the study participants and their medication-taking decisions. It was also common for participants to contradict themselves as they

talked about their physical symptoms and their beliefs about the medication or doctor. For example, many participants stated that they trusted their doctor but made a decision to go against their doctor's orders. The flow of the narrative followed the participants' thought processes as they determined what they valued the most. Frances' narrative exemplified this well. The following narrative represents a physical value.

Frances began her story by acting out the physical effects of her anticoagulant. She pulled up her sleeves to show off large, dark bruises. She ran her hands up down her arms and pointed out spots of blood on her shirt sleeve. She then pulled up her pants to reveal similar bruising. With her face and body language, she acted out the emotion of shock and exclaimed "Look!" After the researcher acknowledged the bruising, she responded.

Yes! Extreme and it is Plavix...I look like I have been in a fight. My legs, especially the lower part, the hands, these are stained, these are new. Something fell on my hand. These will last for two weeks...I call him, the doctor, and I said, 'Let's try every other day' and he said, 'Only for a week and then you have to go back on it.' He said, 'Everything you're taking is working.' I want to wear short sleeves. I can't wear shorts. That's embarrassing...I was the one who suggested it [stopping the anticoagulant] and I basically told him, 'I am', because this is ridiculous.

Next, Frances talked about a recent eye surgery where she again asked to stop the Plavix. She described the emotional value of trust in her physician. "And the

ophthalmologist wanted me to go off the Plavix for two weeks, but he wasn't going to hear about it. He said five days and that's it." She stated that she obeyed his recommendation of five days, "Because I do trust his judgment and I'm here still."

Immediately after sharing that she trusted the judgment of her doctor, Frances told another story about her anticoagulant. The following narrative describes her physical values.

We have a rental. We had to redo the house because it was such a mess...Up there nobody could help us and lots of bumps and bruises...The slightest bump that causes this (pointing to bruise)...A small cut, when I come off of it, it will stop bleeding almost immediately. With pressure it does.

In continuing the story, Frances' stated that she would not "wholly" go against her doctor but instead would make minor adjustments to her medication regimen. "Every other day would please me 'cause I think I might heal. Maybe not get so bruised." Next, Frances announced, "Now there is another medication, HCTZ."

I have a polyp that needed to be tested...I went to have that taken care of. Maybe it was after that, it was almost like I had IBS. It tends to dehydrate you. What I have done is stop that for like three days. I don't need more loss of water in my system, so that one I stop myself.

Later in the narrative Frances expressed her belief about her medications. The following describes an emotional value. "I have never forgotten. I feel like they are too important to me. Even those I mess around with, those two." Frances went on to say that

she trusted her doctor and believed he was a “good” doctor. Not long after, Frances returned to talking about her physical symptoms and values.

I wish they could read my mind and help me, especially with this Plavix. I left this on (long sleeve shirt) because it is starting to bleed. This is part of it. I have stains all over my clothes. This happened this morning (pointing to blood stain on sleeve).

Her next comment displayed a questioning of her belief in the medication and an emotional value. “I am wondering, is there a benefit for me to still be on it?” Frances concluded her narrative by sharing her fear about losing her quality of life and her desire to stay as active as long as possible. In choosing between her physical and emotional values, how she felt came first.

## **Aim 2: Describe How Decisions are made for Medication Adherence**

**Theme 1: I connect the dots.** The theme, *I connect the dots*, is related to how participants’ made decisions about taking their medications. A progression of events in participants’ medication decision-making emerged from the narratives. Some participants described their medication decision-making experience as a past, one-time event. They stopped the bothersome medication and things returned to normal. Others described their medications decision-making experience as cyclical or a daily sequence of events.

The need to make a medication-taking decision was usually initiated by recognizing that something was “unusual.” Dean shared, “I developed a cough.” “I

never smoked...I have excellent lungs. I rarely have any trouble with my breathing.”

Ann described how her blood pressure went very low and Carl started having swelling in his feet and ankles. Edith told how it scared her when her antianginal medication “blew her head off.” Mary participants described wetting themselves, excessive nocturia, mysterious bruises, or prolonged bleeding from minor cuts.

Concern regarding the unfamiliar symptoms prompted participants to look for a cause. The first place many participants looked was to their medications. Earl discussed that once he “realized that something was wrong” the first thing he did was look up each medication. Darla described discussing her daytime drowsiness with her family to determine which medication was the cause. Several participants were able to connect the medication to the symptom associating the timing of the taking the medication with the timing of the symptom. Chris said, “Once I start a medicine and I start having problems then I start asking questions about the side effects.” Edith described how her doctor increased the dose of a medication and right away “she could not function.”

Participants in this study reported that they relied on information that was available to them at the moment to inform their medication-taking decision. Across the narratives participants reported consulting the Internet, medication information flyers from the pharmacy, the pharmacist, friends, and family members to learn more about a medication. Edith stated, “...I need to know why I’m doing something. If I know why I’m doing something then I’m ok.” Several participants shared that their doctor was difficult to access and was not their primary source of information. Chris explained,

“...to get access. It’s not easy. Like... I’d like to be able to email with them and things like that. But, they are not friendly or easy to contact. Their phone contacts are difficult.” Ann noted that “Doctors don’t have the time to go into long detail explanation about medications.” Similarly, Edith said, “I think they are pushed for time. I think on people like me 15 minutes or less is probably what’s on their orders. Because, that’s all the time I ever get.” Beth stated that she consults her pharmacist: “’Cause I just think they know more about medicine than doctors do.”

Once participants in this study began to associate a medication with the concerning symptom, they thought about all the possible options and the outcomes of each option. Carl talked about thinking, “What if I took a whole one on the morning I did the cataract surgery.” Ann spoke about adjusting her diuretic dose “for a week or two” to see what happened. When her blood pressure improved, she said, “I’m just going to keep doing this. But, he never changed the prescription.” Frances described how she came to the decision to stop and start her diuretic by saying, “I connect the dots.”

When I had these occurrences with IBS I think that I feel dehydrated. I figured this is what that pill is for and therefore if I don’t take it then I should recover faster. And, I’ll go back on it because I have recovered and it makes sense... You connect the dots. This happens, then this (demonstrating ‘connecting the dots’ with hand gestures)...And then I will be ok. And then I get back on it and here we go again. It is a cycle.

Each participant described a period of trial-and-error while making a medication-taking decision. Participants described a trial run of adjusting or stopping a medication to see if there was any change. After identifying his bladder medication as the “problem,” Earl made the decision to “cut” it out and wait “two to three days to see if that worked.” Edith’s narrative described experimenting with her antianginal medication before stopping it completely.

Well it liked to blew my head off. I couldn’t function. Like, if I was going to go to bed and stay there....I could not function so I could not do it. So I just ignored it. But I did try it enough that it went into my system and made me like that. But, that’s about as long as I stayed on both of them like that. So, I cut it back to one in the morning and one at night. I didn’t feel too good but I went along with that for a while. Then I got to thinking, Well I wasn’t hurting. I never really felt like I had had a heart attack. But uh I didn’t know. A lot of time women don’t. So I thought well I’m just gonna quit taking that stuff. So I thought well...I’ll tell you why. Because it said on some of these papers I got, if you take this, this, and this, don’t take this medicine. Well I read that line (pointing to pharmacy medication flyer). And I thought oh!...And so I quit taking it.

She added,

When I first stopped it there was a time or two where I felt like the hurt was coming back. I got up in the middle of the night and grabbed me a Renexa and took it. And uh... So I thought well I know what else but it never did do that

anymore. So I stayed off it. Because I took ...it was like ....well you know I take that Plavix and stuff. There are several things that I have to take and it said if you take any of that stuff, don't take this medicine. That's what got me off of it.

There was about five things that if I'm taking it then I'm not supposed to take this with it. So I quit it...

Then I got to thinking, he said it worked together and if I didn't feel too good that day I might take one. So, I'm going to try it and see what happens and I did. I did that two or three times. But uh I just finally weaned myself off that.

Weighing the pros and cons was evident in the participants' narratives.

Participants considered each of their medication-taking options and evaluated the advantages and the disadvantages of each option against what was important to them at that time. Participants appraised each medication individually, in that one medication was deemed worth taking as prescribed while another was not. Although Carl made the decision to adjust the dose of his beta blocker to have cataract surgery, he chose to take another medication despite the side-effects.

I feel that there is something I take that makes you not care about sex and stuff like that. I don't know what it is. I can't remember. The Dr. did tell me. And you know I kinda in a way miss that. But again, we have a loving life and we love each other and those things are not important after you've been married 50 years and you're 69 years old. You know it's time to...yeah (he dropped his head and rubbed his forehead with his hand).

Chris also chose to take his other medications despite side-effects.

Sometimes you have to live with the side effects. I never got rid of the side effects completely. The shortness of breath....exercising, I still have the sensation. ...it's not normal- not a normal reaction. The shortness of breath persists even with my medicines today so I've just had to gradually back off.

He added,

Well, it's increasing my odds of keeping my lifestyle on an even keel. Cause if you have a stroke or you have an event or with the thyroid you know your life...or your quality of life can go south on you. You don't want to get into suffering day to day from symptoms of disease you got. So, it's more of an odds are better with it than without it.

Some participants continually weighed the pros and cons of a medication and made a different decision each day based on the current circumstances. Adam shared that some days he didn't see the point to taking his medications. Edith reported that each day she examined her symptoms and considered whether or not she should take her diuretic or blood pressure medication. Frances reported a cycle of evaluating if it was beneficial to take her diuretic or anticoagulant or if she should skip a dose. Both Edith and Beth described making a determination if it was feasible to take the diuretic when they had somewhere to go.

Participants reported using their own health data to help them understand the consequences of their decisions. Carl concluded that increasing his diuretic was a good

decision when the swelling in his feet and ankles subsided. Adam and Ann talked about recording their blood pressure to inform their thoughts about their blood pressure medicine. Bob and Dean reasoned that since they did not feel worse, the pills must be working. Edith kept a daily journal of her symptoms and studied her past entries when she “got worried about something” and wanted to see how she was feeling. Of interest were the verb tenses in Earl’s statement. Earl said, “I waited two to three days to see if that worked and it does.” He began the expression in the past tense but ended with the word *does*, which is in the present tense. His choice of verbs gave the impression that his choice to stop the medication was presently still stopping the “problem” of “wetting himself.” Each participant reported that they were satisfied with the outcome of their medication-taking decisions.

**Theme 2: It is complicated.** The theme, *it is complicated*, is related to the various factors that accompanied participants’ medication-taking decisions. Participants in this study shared that there was more to taking their medications than just getting the prescription filled and swallowing the pill. The participants’ narratives revealed a myriad of factors that impacted the medication-taking experience. These factors fell into two main categories, external and internal. External factors were anything in the situation or background that impacted participants’ medication-taking experience. Internal factors were anything that had to do with the participants’ health or inner self.

One of the first external factors participants spoke about in their narratives, was the number of prescribed medications. Several participants in this study felt they were

taking “too many” medications. More than one participant stated that when they looked at their list of medications they thought “It was too much.” Participants shared that they wished they did not have to take them and worked to “keep them to a minimum.” Due to the number of prescribed medications, participants developed elaborate and strict routines to help them remember. When discussing the management of their multiple medications, more than one participant commented about having to “work at it” and “figure it out.”

Another external factor was the involvement of family and friends in participants’ medication-taking experiences. Many participants included the role that friends and family played when recounting their medication-taking experiences. Adam reported that his daughter, a nurse, helped him make a list of his medications and checked to make sure he was taking them.

My daughter is very good at, my sister used to do it, now it’s my daughter, checking in, making sure that I’m not getting depressed. That’s when I worried about not doing this (pointing to list of meds) correctly. And she knows my spirit and the way I think.

He added,

I discuss things with my family and my daughter. We have so many things going on with my wife being in a memory care unit. We are talking all the time about what we need to do. I’ve got a list like this. She helps me keep up with it. And her husband comes and jumps me too if my blood pressure gets too high.

Edith described how her niece and her niece's husband bought her pill organizers and drove her to appointments and to get medications. Beth described how her daughter "fusses" at her about her health. Earl stated that he sought the advice of a neighbor who was a nurse. "I had her check everything that I didn't think was quite right." Darla, Dean, and Earl all shared that their spouses help them remember their medications, look up side-effects, and make medication-taking decisions. Darla also described how her daughter helped her fill her weekly pill organizer and her son gave her medication advice.

Another external factor that emerged from the narratives was cost. Although no participant reported that costs prevented them from taking a medication, they stated that it was something they thought about. Darla explained, "Some of them are very expensive; some of them are not. But, they average out, even with our supplemental and our Medicare, they average out to be expensive." Cost was frequently discussed in regards to struggles with Medicare. Carl explained,

There are some things that have happened with that over the years. They put me on a (insulin) pen many years ago which is so costly. You know it was going to cost me over a \$1000 for 90 day supply of the pens. That's after my insurance. And that's because I had gone over the donut hole. So that's...come to find out we can do the 70/30 in a vial and we don't know how long we are going to be able to do that without going over the donut hole. But, that affects all my medicine once I go over the donut hole. But no doctor told me that ...he is no longer my doctor either... but no doctor telled me that 'Hey, this is going to cost

you this much. This is \$3000 against your donut hole'. You know. But uh...that's the biggest problem we have is getting the medication that we need through Medicare...

Chris also spoke of the "donut hole" as being expensive.

Once you get into the donut hole I say that is the beginning of it getting expensive...Medicare ...Medicare D. It's a real complicated system, insurance companies that do Medicare D. You've got deductibles on the front end that you pay. Then, you go through phase one. The insurance company will pay for most of the medicine but then when you hit a certain threshold, a total cost, then you go into the donut hole.

Dean shared that he had to consider the cost of his new anticoagulant. The copay for a three month supply was \$1500. He did not want to take warfarin because "one of those things is really rat poison." Dean made the decision that, "\$6,000 per year is not gonna kill" him. He understood how someone else might not be able to afford the medication, but he had trust in the doctor and the medication.

Chris discussed his choices when managing the cost of his medications. He summed it up for many participants with his comments.

You just have to research to see. You might ask the doctor what the alternatives are. Then you have to figure out if the insurance company is going to help you. At first, you don't know how much they cost. Then you have to look on the formulary. Are they on there? What are the alternatives if they are not? You

may get into negotiation between the doctor and insurance company. And ah... depending on the cost of the medicines, you may spend more time on it. If it's not a big deal, it's already generic and low cost then it's not a big deal. Then you try it out and see what side-effects come into play. And then that can have another dialogue-negotiation. See if there is a better alternative. But you gotta be willing to go to the doctors and negotiate with them.

Internal factors that emerged from participants' narratives were poor physical health and depression. Many participants shared that they were bothered by issues of poor health. Participants complained of poor vision, diminished hearing, impaired mobility, fatigue, activity intolerance, trouble breathing, swelling, high blood sugar, an irregular heartbeat, high blood pressure, constipation, and other assorted symptoms. Many participants discussed difficulty distinguishing the source of the symptom, which also led to confusion about which medication to adjust. Adam began his narrative with questions about the purpose of his medications. He was distressed that he took so many pills and still experienced shortness of breath. He asked, "Is that maybe why I'm having oxygen problems getting (acts out trouble breathing)... feel like I can't hardly breathe sometimes?" Chris discussed that despite stopping the beta blocker he still had "breathing problems" that forced him to adjust his activity level and lifestyle. He was not sure if his lingering shortness of breath was from his heart or his blood pressure medicines. Since he was unclear of the source of his symptoms, he made the decision to "just keep functioning within those guidelines." Darla reported that she felt "wiped out

all the time” despite adjusting the timing of her depression medications. Darla went on to say that without the help of her physician husband she would not have been able to “connect the two.”

I knew I was sleepy. I knew I was taking that medication but I was also taking a bunch of other medications too. Plus the a-fib business. I had not connected those at all.

Edith discussed checking her blood sugar and leaving the “sugar alone” when her ankles swelled. Although she described daily examining her symptoms to inform her medication-taking decisions, her narrative did not demonstrate an understanding of the relationship between the swelling and her CHF or her nonadherence to her prescribed diuretic regimen.

A few participants discussed their struggles with other health conditions unrelated to their heart. All but two participants reported difficulty with hearing, vision, or both. Also common were problems with mobility. Beth spoke of suffering from “extreme” arthritis and a muscle condition that was left her tired and in constant pain. Dean described how his knees started giving him problems. Edith described dealing with glaucoma, muscle weakness, and a problem with a cyst on her leg. Darla stated that it was “difficult for her to do a lot of things.” After a small stroke affected her vision and she hurt her shoulder, she began using a walker for balance. She went on to explain that she didn’t feel like doing things. “I often say to myself, is it worth it? I often see

something across the room, like a glass of water, and I say is it worth walking other there for it?”

Another internal factor that impacted the medication-taking experience was depression. A number of participants reported that they suffered from issues of depression. Two participants specifically described the impact of depression on their daily life. Adam described depression as influencing his medication-taking decisions. He stated that sometimes when he thought about how many medications he was taking he would say, “What the heck” and not take the pills. He reported that living separately from his wife also contributed to him getting depressed. Adam described the daily routine of managing his medication regimen as “boring” and “tiring.” Darla also described that depression caused her to feel bad. She stated, “If I didn’t have anything scheduled for today, I could lay here or go in there and get in bed and go to sleep...And that’s not much fun.” Darla reported currently taking her medications as prescribed, but admitted that without the help of her family things could be different.

### **Aim 3: Describe How Individuals Comprehend Medication Adherence and Nonadherence**

**Theme 1: I am not nonadherent.** The theme, *I am not nonadherent*, is in regards to what participants thought about medication adherence and nonadherence. Thematic analysis supported by structural and performance analysis, revealed that participants in this study recounted their story to avoid being perceived as someone who was nonadherent. Participants’ narratives portrayed those that are nonadherent to their

medications in a negative light. Frances commented that those that makes choices not to take a medication “are not very smart.” Dean described medication nonadherence as “stupid.” Dean added, “If you are going to go to the doctor, and he is going to give you a medication, and you hear what he thinks, it would be stupid to go to him if you are not going to take the pills.” Carl stated that making a decision to not take a medication was “not trusting your doctor’s ideas that are to keep you healthy....you should take your medication.” Of note, some of the same participants that reported an experience of not taking a medication as prescribed, also described medication nonadherence as foolish.

Participants indicated in their narratives that they did not view their decisions to adjust a medication dose, adjust their medication regimen, or quit taking a single medication as being nonadherent. It was evident in the narratives that participants in this study wanted to be perceived as discerning and making warranted medication-taking decisions. Frances’ narrative demonstrated that she saw her medication-taking decisions as logical. She stated that she had a reason for choosing to take her anticoagulant and diuretic differently than it was prescribed. Edith also expressed that she was making medication decisions that were based on reason. In discussing the idea that not taking medications as prescribed means you are a bad person, Edith said,

A bad person to who? If you don’t take your medicine then you don’t believe in them or something? I tell you I don’t care what they think. I’m looking out for me. I don’t care. My health comes first to me. You know they may seem to be... they care and all that but I’m the proof in the pudding. But, you know I just

can't...I need to know why I'm doing something. If I know why I'm doing something then I'm ok. But you know you gotta be there and work at it.

Many participants talked about a past profession or personality characteristic to illustrate their ability to make sound decisions. Adam stated,

I am a person who wants to know what causes things. Maybe a lot of people wouldn't but I want to know. I was an accountant, an administrator and that's the way I did things. Why I did that and what caused it. You know... people would come look at me..."

Beth told,

With the medicines- I read those sheets even though they are fine print. I don't read them every time because that is almost every week. But, I do read them because it says something. And see I have been a teacher and you follow the directions.

Edith told that she worked for a corporation for over 30 years and worked her way up to a high-level manager. She described teaching herself how to read medical documents and helping her brother make important health decisions. Dean talked about decisions he made as the owner of a construction business and frequently described himself as a customer of the doctor. Earl stated, "I'm an engineer. One of the first things you learn as an engineer is go find out what the hell is wrong." Earl also told that he was at one time a "medical photographer" and had a "small amount of education in the medical field."

Frances described herself as “type A” and stated she had no problems talking with the doctor and asking questions.

During screening, both Beth and Bob discussed choosing to take one or more of their medications differently than prescribed. Dean also stated that he had taken a CHF medication differently than prescribed. Their narrative, however, excluded these experiences. During the interview, Bob acted out his resistance to being perceived as someone who was nonadherent. His body language was closed and his answers to the interview questions were abrupt. He repeatedly said, “...I am not a doctor. I do what the doctor tells me.” After the interview, Bob returned and apologetically stated that he used to work for a large insurance company and probably knew too much to be helpful. He patted me on the shoulder before leaving the room. Dean was adamant that nonadherence was “stupid” and he did not stray from the doctor’s recommendations.

### **Chapter Summary**

This chapter presented the findings of the study that examined the medication-taking decisions of older adults with CHF. Participant aggregate demographic data was described as well as an introduction to each participant, which included contextual information, the dynamics of the rapport, participants’ comorbidities, and the main plot of their story. This was followed by an in-depth description of the themes that represented the decision-making experience of those in this study.

## CHAPTER V

### CONCLUSIONS AND RECOMMENDATIONS

#### **Overview**

Despite efforts to increase medication adherence among older adults with CHF, nonadherence remains a problem. Since no interventions have proven to be effective in increasing adherence to CHF medications, including patient education, more research was needed to inform the development of effective strategies to increase medication adherence among older adults with CHF. Furthermore, the literature reported that the majority of medication nonadherence was the result of deliberate decisions to forego medication recommendations. All research regarding decision-making and medication adherence among older adults with CHF, however, was in the generalized area of CHF self-care (Allen et al., 2012; Dickson et al., 2013; Dickson et al., 2007; Hicks & Holm, 2003; Horowitz et al., 2004; Jaarsma et al., 2000; Jeon et al., 2010; Riegel & Carlson, 2002; Riegel et al., 2013; Scotto, 2005; Siabani et al., 2013). Absent in the literature was research looking specifically at decision-making for medication adherence in those with CHF.

The purpose of this qualitative study was to gain understanding and insight into older adults' decision-making experiences, practices, and perceptions in choosing to take or not to take medications for CHF in the community setting. Using a narrative approach, 11 older adults were asked to recount their medication-taking experiences to

reveal the full scope of the medication-taking experience. The 11 study participants were purposively selected based on the following inclusion criteria: (1) age 65 or older, (2) took at least two daily medications for CHF, (3) self-administered daily medications, (4) had experience making a decision not to take a CHF medication or to take a CHF medication differently than prescribed, (5) lived independently in the community setting, (6) spoke English, and (7) had no history of a prior neurological event or other factor that could inhibit the inability to effectively answer interview questions. The audio-recorded narratives of these older adults collected during face-to-face, semi-structured interviews generated the data for this study. Data analysis was conducted using Riessman's (1993, 2008) framework of narrative analysis. Data analysis revealed six themes (see Table 2), describing the experience and meaning of decision-making for medication adherence or nonadherence. Methodological rigor was demonstrated using specific validation strategies recommended by Lincoln and Guba (1985) and Riessman (1993, 2008).

The purpose of this chapter is to provide a discussion of the findings identified in Chapter IV. In this chapter, conclusions are presented that include a discussion of the overall themes that emerged from the personal narratives. Findings will be related to current and relevant literature. The effectiveness of narrative inquiry as a method for decision-making research in older adults is discussed. The potential utility and implications of these findings for nursing research and science, nursing practice, and nursing education is discussed. Recommendations for future research is addressed.

## **Discussion of Themes**

The following discussion presents the themes and overall meanings that emerged from the study data. Themes included: (a) *I Don't Do It Just 'Cause They Said to Do It*, (b) *That Worried Me*, (c) *How I Feel*, (d) *Connect the Dots*, (e) *It Is Complicated*, and (d) *I Am Not Nonadherent*. I was able to identify broad patterns and thematic similarities across the sample but also variation in meanings for individuals. Medication adherence was not an objective event, but an individually formed experience.

### **I Don't do it Just 'Cause They Said Do It**

Participants in this study described making intentional and purposeful decisions to take medications differently than prescribed. Participants shared stories of making purposeful decisions to adjust medication doses, skip doses, or stop a medication altogether. The degree of nonadherence among the study participants varied. Some told of past experiences of choosing to stop or adjust a single medication, while others described routinely modifying their prescribed medication regimen based on how they felt at the moment.

Although research looking directly at decision-making for adherence to medications for CHF is absent in the literature, the intentional and purposeful medication nonadherence that the study participants described is consistent with the literature regarding intentional nonadherence in other populations. Several investigations demonstrated that in older adults, much of medication nonadherence is intentional (Gadkari & McHorney, 2012; Henriques et al., 2012; Jaarsma et al., 2000; Johnson,

2002; Lindquist et al., 2012; Unni & Farris, 2011; Wroe, 2002). Researchers also reported that among patients with chronic conditions, medication nonadherence is primarily intentional (Cholowski & Cantwell, 2007; Gadkari & McHorney, 2012; Henriques et al., 2012; Jimmy & Jose, 2011; Johnson, 2002; Riegel & Carlson, 2002; Wroe, 2002). Given that the study sample was aged 65 or older and CHF is a chronic condition, it can be asserted that the findings that medication nonadherence was primarily intentional is supported in the literature.

Although this study did not seek to exclude individuals that were nonadherent to all their medications, none of the study participants described making decisions to adjust all of their medications. Instead, participants told of deliberate decisions to disregard medication recommendations of selected medications. Throughout the narratives, participants told stories of choosing a particular medication to “mess with” or stop taking. Participants reported taking the majority of their prescribed medications exactly as recommended. Similarly, the literature reports that patients may be adherent to one medication while being nonadherent to another (Gadkari & McHorney, 2012; Henriques et al., 2012; Jimmy & Jose, 2011; Johnson, 2002; Riegel & Carlson, 2002; Wroe, 2002). One study by Marti et al. (2013) found that the majority of CHF patients demonstrated selective adherence to self-care behaviors, one of which was medication-taking.

Participants in this study were not anti-medication. On the contrary, all study participants insisted that patients ought to take prescribed medications. Participants felt that their medications were important to their health and worked hard to incorporate them

into their lifestyle. Each participant described an elaborate daily routine designed to avoid forgetting a medication. Participants utilized medication reminders, such as pill organizers, calendars, and homemade pill bottle labels. In addition, each participant had a list of medications, many of which detailed how and when to take a pill.

Investigations regarding CHF medication adherence acknowledge that forgetting to take a medication is common (Cholowskik & Cantwell, 2007; Doggrell, 2010; Wu, Moser, Lennie, & Burkhart, 2008). For example, Ekman et al. (2006) reported that 24% of patients described forgetting to take regular heart medication from one to five times per week. Although unintentional nonadherence (forgetfulness and carelessness in taking medications) was evident in the literature (Gadkari & McHorney, 2012; Henriques et al., 2012; Jaarsma et al., 2000; Johnson, 2002; Lindquist et al., 2012; Unni & Farris, 2011; Wroe, 2002), participants in this study reported that they rarely forgot their medications. Predominant in the narratives were participants stating that they “do not forget” or rarely forget a dose. One participant shared that he probably forgot to take a medication once every six months. No participant reported that they chronically forgot to take any of their medications.

The literature suggested an association between unintentional nonadherence and demographics, unplanned changes in routine, cognitive changes, or unavailable resources (Jimmy & Jose, 2011; Johnson, 2002; Wroe, 2002). While participants in this study did not recount forgetting or being careless with a medication due to unavailable resources, a few participants shared that a change in routine might cause them to forget a medication.

One participant shared that he forgot to take one of his medications on a trip. Another stated that she might forget to take a pill if she was involved in an evening activity. An association between demographics or cognitive changes and unintentional nonadherence was not evident in the narratives.

Medication nonadherence in the study sample was primarily the result of intentional decisions. They did not forget or misunderstand medication instructions. Each participant knew how to take their medications and they knew they should, but they chose to act differently. There is limited research that describes decision-making for medication adherence among older adults with CHF. Research in other conditions supports the study findings that older adults' nonadherence to medications for CHF was the result of individual choice. In a multivariate analysis study among those with a chronic respiratory condition, Wroe (2002) found that intentional nonadherence was more associated with decisional balance while unintentional adherence was more associated with demographics. Of the few published studies where medication adherence decision-making is presented as an aspect of CHF self-care, adherence to CHF self-care is presented as the result of decision-making (Allen et al., 2012; Dickson et al., 2013; Dickson et al., 2007; Hicks & Holm, 2003; Horowitz et al., 2004; Jaarsma et al., 2000; Jeon et al., 2010; Riegel & Carlson, 2002; Scotto, 2005; Siabani et al., 2013).

### **That Worried Me**

The theme, *that worried me*, is related to participants' concern and uncertainty about a medication. Participants in this study were often plagued with uncertainty.

Participants often worried about the safety or need for a medication. More than one participant described concern about whether their medications were compatible.

Participants in this study expressed alarm at how medications made them feel. For example, one participant expressed fear in regards to how her antianginal medication “blew” her head off. Many times the development of unusual symptoms, such as urinary incontinence, shortness of breath, or daytime sleepiness was the trigger to concerns about a medication. Excessive therapeutic effects of medications were also worrisome to participants. Participants were most commonly concerned that they were taking too much of their diuretic or anticoagulant. Conflicting medication information between sources also spurred uncertainty about the safety or necessity of a medication.

Participants reported making decisions to stop or adjust medications they were uncertain about.

These findings are consistent with the literature, which reported an association between uncertainty and medication nonadherence. In a survey of over 700 older adults enrolled in Medicare, Unni and Farris (2011) found that concerns and uncertainties in a medication were significant for intentional nonadherence. Similar to the findings of this study, the literature demonstrated that patients are less motivated to take medications for CHF when they are uncertain about the necessity or risks of the medication (Allen et al., 2012; Bissonnette, 2008; Elstad et al., 2012; Fenwick et al., 2012; Riegel & Carlson, 2002; Riegel et al., 2013; Sale et al., 2011; Schüz, Marx et al., 2011; Thorne et al., 2003; Wu et al., 2008b). When uncertainty about a medication was high, participants in this

study tended to negatively evaluate the perceived need for a medication, resulting in decisions of nonadherence (McHorney et al., 2012).

Participants in this study, and those described from other research literature often experienced conflicting or incompatible advice (Auduly et al., 2009; Donovan & Blake, 1992; Elstad et al., 2012). For example, participants described being confused when their doctor prescribed a combination of medications that pharmacy medication flyers or TV commercials advised against. Participants also described receiving conflicting advice between health providers. Concern and uncertainty from a conflict in advice caused many study participants to seek comparative information. Some participants described researching their medications on the Internet, while others consulted friends and family. Supported by the literature, if participants received similar information from multiple sources their beliefs in the accuracy of the information was reinforced (Elstad et al., 2012; Goff et al., 2008; Haverhals et al., 2011; Hicks & Holm, 2003; Pierce & Hicks, 2001; Salt & Peden, 2011).

The majority of participants were unsure about the purpose for each of their medications. Participants typically reported that they knew why they were taking some of their medications, but not all of them. Participants found this unsettling. In fact, the majority of study participants ended their narrative by expressing a desire for more medication education. Each participant had a homemade medication list that they referred to throughout the interview. During the interview, participants would often point to the list of medications and anxiously ask the researcher about the purpose of a

medication or ask for advice. One participant reported his doctor told him he was taking some medications at the wrong time and another participant shared that she was not sure if a medication had been discontinued or not. Participants also reported that they struggled to follow their doctor's orders when they did not know the purpose of each medication. For example, one participant told that his doctor advised that he stop his blood pressure medication, but he had a problem knowing which one was for blood pressure. Interestingly, all participants were able to name their diuretic and anticoagulant. As one participant put it, "they affect me the most." Poor recall of prescribed medications among those with CHF is echoed in the literature. Multiple investigations found that at least half of study participants could not name their CHF medications or why they were taking them (Ekman et al., 2006; Jaarsma et al., 2000; West et al., 2010).

Some participants expressed that an understanding of their medication influenced their medication-taking decisions. Knowing medication side-effects helped participants determine if a symptom was from a medication or a health condition. Understanding the purpose of a medication or how it worked, helped participants gauge its importance or think about the consequences of adjusting the dosing. Medication knowledge, however, did not always lead to decisions for medication adherence. While some stated that they took a pill because they understood the importance of the medication to their health, others presented what they knew about a medication as justification for adjusting or stopping it. Different from an investigation by Riegel and Dickson (2008) that found

self-care was better in those with more knowledge, this finding may suggest that medication education may not treat or prevent decisions for medication nonadherence.

These findings reflect the literature in areas of low health literacy. Published research data regarding the influence of health literacy on medication nonadherence is inconsistent. Much of the literature attributed poor medication adherence to low health literacy (Allen et al., 2012; Falk et al., 2013; Hope et al., 2004; Horowitz et al., 2004; Morrow et al., 2006; Morrow et al., 2007; Moser et al., 2005; Murray et al., 2009; Noureldin et al., 2012; Riegel & Carlson, 2002; Siabani et al., 2013). A recent integrative review of 14 qualitative studies found the themes *insufficient knowledge* and *lack of knowledge* to be associated with reports of nonadherence to prescribed therapies (Jeon et al., 2010). In contrast, Gallagher, Warwick, Chenoweth, Stein-Parbury, and Milton-Willey (2011) found that those with low medication knowledge had the highest adherence rates. This was seen in study participants who stated that they took some pills “automatically” or without question, even though they were not sure what they were for. A literature review by Wu and colleagues (2008) also found no clear association between health literacy and medication nonadherence. Particular to self-care in those with CHF, Riegel and Dickson (2008) found that patient level of knowledge had no significant effect on adherence to self-care behaviors.

In conclusion, participants in this study frequently expressed uncertainty and worry about the safety and necessity for certain medications. Perceived conflicts in medication advice compounded their worry. When uncertainty about the risks or the

need for a medication was high, participants tended to report decisions of nonadherence. Study participants also reported uncertainty about the purpose for many of their medications. Although participants in this study expressed a strong desire for more medication education, more knowledge about a medication did not necessarily result in decisions for medication adherence.

### **How I Feel**

The theme, *how I feel*, is related to the personal values that participants used to guide their medication-taking decisions. In an attempt to gain control over their illness and achieve balance in life, participants established personal values or goals in their medication-taking decisions (Hicks & Holm, 2003; Riegel et al., 2013). Two types of personal values emerged from the narratives, physical and emotional. Physical values were expressed in the narratives in terms of *how a medication made them feel* while, emotional values were expressed as *how they felt about a medication*.

**Physical values.** In this study, participants frequently shared making medication-taking decisions based on how the medication made them feel. In making these decisions, they were specifically motivated by desires to feel good, look good, and live as normally as possible. Participants vigilantly monitored their body for what they perceived as an untoward response to their medication therapy. All described developing an awareness of their own unique responses to their prescribed medication regimen. When faced with what they perceived as a negative response, participants increased their efforts to learn about their medications. They reflected upon their bodily cues and the

information that was available to them at the moment to establish personal values about physical comfort.

Participants in this study frequently began a medication-taking story with a description of how the medication made them feel. Although many of the study participants were taking similar medications, the negative health events varied. Some of the untoward responses participants described include: hypotension, dry mouth, fatigue, activity intolerance, excessive diuresis, bruising, and urinary incontinence. Common to participants across the narratives was the influence of medication side-effects on decisions to adjust or stop taking a medication. Medication side-effects are frequently referred to in the literature as barriers to medication adherence (Laba et al., 2012; Leventhal et al., 2005; McHorney & Gadkari, 2010; Mishra et al. , 2011; Oosterom-Calo et al., 2013; Schüz, Marx et al., 2011; Wu, Moser, Lennie, Peden et al., 2008). A study by Wu, Moser, Lennie, Peden et al. (2008) found that when patients connected an adverse event to a CHF medication, they were less likely to persist in taking the medication. Similar to the findings of an investigation by West, Lefler, and Franks (2010), participants that described a side-effect as problematic to a physical value also spoke of making a decision to stop or adjust a medication.

In this research and that of Granger et al. (2005), medication-taking decisions were based on individual perception of a symptom. For instance, all participants were taking anticoagulants and many displayed bruising, but only one person perceived the prolonged bleeding time and the bruising as a negative outcome. Nine study participants

reported shortness of breath with exercise as a symptom, but only one participant made a medication-taking decision based on this symptom. In the case of diuretics, what one participant viewed as a therapeutic effect, another perceived as an adverse effect. Furthermore, it was difficult for some participants to distinguish between a medication side-effect and a disease symptom. For example, some spoke of fatigue as part of their illness or aging, while others described it as a consequence of their medications. Whereas there are known side effects to CHF medications, it is possible that participants in this study made medication adherence decisions based on perceived side-effects rather than actual side-effects.

Many study participants described their medications as inconvenient. Participants described the effects of certain medications as interfering with their lifestyle. In particular, participants complained about their diuretics and the perpetual need to go to the bathroom. More than one participant described the embarrassment of not making it to the bathroom and wetting themselves. Participants also complained that nocturia was interfering with their sleep. One participant described getting up six to eight times per night, which was almost hourly. Participants in this study shared how the effects of the medications interfered with their standard of health, their social life, and their happiness. Based on participants' narratives, it appears as if motivation to have good quality of life was important to participants' decisions for medication adherence. This study found that when participants felt that a medication interfered with their quality of life, they coped by adjusting their prescribed medication regimen to try and live as normally as possible.

Participants in this study also described the prescribed medication regimen as inconvenient. Participants described the daily medication-taking routine, the frequent trips to the pharmacy, and the memory strategies (i.e. pill organizers) as troublesome. More than participant shared that they had to “work” at it. Consistent with the literature, participants not only individualized how the medications were taken to feel well, they also individualized the medication-taking tasks (Allen et al., 2012; Granger, Sandelowski et al., 2009; Leventhal et al., 2005; Riegel et al., 2009; Thorne et al., 2003). In an effort to “make it convenient” participants made decisions to tailor the prescribed regimen to their personal preferences and values.

Very little research exists regarding quality of life and medication adherence decision-making in those with CHF. One study was identified that examined health-related quality of life and adherence rates to antihypertensives (Holt, Munter, Joyce, Webber, & Krousel-Wood, 2010). These researchers concluded that low health-related quality of life was associated with higher rates of nonadherence to antihypertensives. Marti et al. (2013) found that quality of life, physical limitations, symptom frequency, and symptom burden were all better in patients with good adherence to self-care behaviors. In these studies, however, it is difficult to know if the quality of life was better because of good medication adherence or if the adherence was influenced by perceived quality of life. In another study aimed at CHF self-management decisions, investigators utilized an investigator-developed instrument to assess the degrees of influence various sources had on individuals’ self-management decision-making (Hicks

& Holm, 2003). The researchers found that personal values regarding quality of life are likely to influence self-management decisions in CHF. The influence of quality of life on decisions for CHF medication adherence warrants further investigation.

The current study found that study participants had a keen sense of what mattered in life and developed or changed physical values based on a new set of circumstances. For example, one participant shared that a medication decreased his libido and voiced, “And you know I kind of in a way miss that, but again we have a loving life and we love each other and those things are not important after you’ve been married 50 years and you are 69 years old.” One participant ended her story describing how an upcoming trip to the beach might influence her decision to take her anticoagulant. Moreover, many participants described making a determination about what was important to them on any given day. Participants in this study did not describe physical values as static. Due to changes in real-world living, they continually established new goals and priorities for how they felt.

**Emotional values.** In this study, participants frequently shared making medication-taking decisions based on how they felt about a medication. In making these decisions, they were specifically motivated by beliefs that their medications for CHF provided necessary health benefits. The majority of participants in the study acknowledged that they had conditions that needed treatment and expressed a belief in certain medications to increase their odds of prolonging good health. One participant, who shared a story of stopping one of his medications without consulting his physician,

stated that he took his other medications because they gave him “comfort.” Consistent with the literature, this study found that participants’ belief in the efficacy of the medication influenced decisions for CHF medication adherence (Cholowski & Cantwell, 2007; DiMatteo et al., 2000; Ekman et al., 2006; Gadkari & McHorney, 2012; Henriques et al., 2012; Hicks & Holm, 2003; Horne & Weinman, 1999; Riegel et al., 2007; Schüz, Marx et al., 2011; Scotto, 2005; Unni & Farris, 2006).

Participants in this study spoke often about trust in the medication or the prescribing physician. Conversations about trust in a medication frequently led to the participants talking about trust in the doctor. The majority of participants included expressions of trust toward a health provider when recounting a decision to adhere to their prescribed medication regimen. Participants’ confidence in a physician was supported with a positive past experience where they felt the physician saved their life or successfully treated a serious illness. Having confidence in the prescribing health provider influenced participants’ medication-taking decisions. Consistent with the literature, despite the risks, participants made deliberate decisions to take medications based on positive thoughts toward the medication or the prescribing physician. The findings of this study supported past research that found that a trusting relationship with care providers was a motivator to taking the medication (Allen et al., 2012; Jeon et al., 2010; Riles et al., 2014; Salt & Peden, 2011; Wu, Moser, Lennie, Peden et al., 2008).

The participants’ narratives displayed varying levels of trust in health providers. Participants also spoke of making decisions not to take a medication prescribed by health

providers they did not trust. For example, one participant told of a misdiagnosis by a health provider and shared that he did not take the pill prescribed by that doctor. Another participant shared that she refused to take certain medications because she knew her body better than the health provider. Another participant spoke extensively about what he believed were the different levels of quality in health providers. He judged each health provider against a personal ranking system. Other participants shared that past bad experiences caused them to be skeptical of medications prescribed by a health provider that they did not already have a trusting relationship with. As reported in the literature, this study found that wavering trust in a healthcare provider negatively influenced decisions about whether or not to take a medication (Elstad et al., 2012; Goff et al., 2008; Sale et al., 2011). The level of willingness to accept a prescribed medication regimen typically corresponded with participants' perceptions about the health provider.

In reaching a decision for medication adherence, many participants described grappling with strife between physical and emotional values. The intrapersonal conflict experienced by the participants in this study was the result of tension between how a medication made them feel and how they felt about a medication. The literature regarding decision-making for medication adherence in other populations or decision-making for adherence to CHF self-care activities has identified that individuals frequently experience conflict in personal goals and values (Allen et al., 2012; Donovan & Blake, 1992; Elstad et al., 2012; Fenwick et al., 2012; Goff et al., 2008; Henriques et al., 2012; Ivers et al., 2000; Johnson, 2002; Noone, 2002; Paterson et al., 2001; Pierce & Hicks,

2001; Riegel & Carlson, 2002; Riegel et al., 2013; Riegel et al., 2009; Sale et al., 2011; Schüz, Marx et al., 2011; Thorne et al., 2003; Wu, Moser, Lennie, Peden et al., 2008).

Participants' narratives gave voice to the inner conflict between the need to feel good and beliefs about a medication or the prescribing health provider. Participants deliberated the best course of action through a process of inner debate. These findings are similar to an investigation by Auduly, Norgergh, Asplund, and Hornsten (2009) who conducted a Grounded Theory study among 26 adults with various chronic illnesses, including heart disease. The researchers found that the decision-making process for self-management was an ongoing inner negotiation between different incompatible perspectives. One participant, for instance, negotiated between her visible bruising and her trust in the medication and the doctor. More than one participant negotiated between the inconveniences of the diuretic and their beliefs about the necessity of the medication. Still others internally debated between medication side-effects and beliefs about long-term benefits. The narratives illustrated the rationalization that occurs while coping with significant internal conflict. In the end, each participant believed they had made the decision that was best for them at the moment. Participants forged medication-taking decisions based on a creative combination of personal theories and standardized criteria.

This study found that participants who perceived a lower level of threat to their physical values often experienced less inner conflict. For instance, the participants that reported little to no symptoms from their medications also reported more experiences of trusting their doctor and taking their medications as prescribed. The narratives of these

participants demonstrated less wavering between emotional and physical values. Of the few participants that shared that they could not tell they were taking their medications and received little to no physical feedback from them, all reported they were motivated to take their medications simply because their doctor said to. Although the majority of these participants stated they would make a decision to go against their doctor's orders if a medication made them "feel bad or worse", the participants that reported that they currently felt good also reported taking some of their medications "automatically" and without much thought.

In contrast, participants who perceived a higher level of threat to their physical values often experienced more inner conflict. When voicing this inner conflict, some participants described perceptions that were incompatible. For instance, they stated that they trusted their doctor, but reported going against their doctor's orders. Participants oscillated between thoughts about how the medication made them feel and reasons why they probably should take the medication. Ultimately, many valued how they felt the most when making decisions to not take a medication. One participant stated, "I trust the medication, but how I feel is going to come first." Those that continually adjusted their medications described a daily negotiation between threats to quality of life or physical well-being vs. trust in the medication or the doctor. Although each participant shared that they had trust in their doctor and the medication, the higher the symptom burden the more they reported experiences of nonadherence. Since medications are modifiable, many participants made decisions for nonadherence in an effort to feel better. Adjustments to

the medication regimen were customized to the situation. Some increased the dosage, some decreased the dosage, some skipped a dose, and others stopped a medication altogether. Participants knew they ought to take their medications and generally had trust in the doctor and the medication, but if they experienced a conflict in values, participants in this study preferred to feel good.

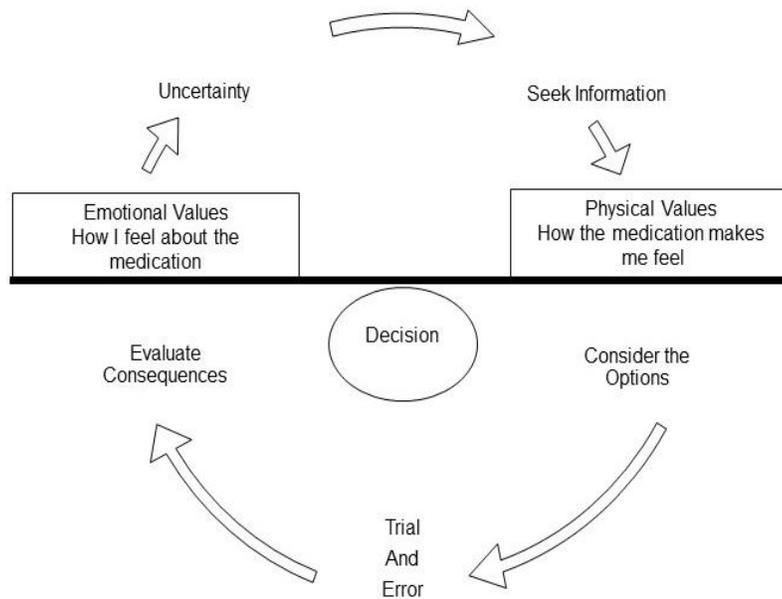
The literature consistently reported that patients make decisions for medication adherence based on a desire to feel well (Benson & Britten, 2002; Cholowski & Cantwell, 2007; Donovan & Blake, 1992; Laba et al., 2012; Hicks & Holm, 2003; Salt & Peden, 2011). Only one study regarding decision-making for self-management in those with a chronic illness, suggests physical values have a significant influence on decisions for nonadherence. Auduly and colleagues (2009) found that when participants experienced worsening symptoms or undesired side effects, the motivation to adhere to the self-management behavior decreased. An investigation by Salt and Peden (2011) found that in women with rheumatoid arthritis, a trusting relationship with the physician played an important role in decision-making and potential and perceived side-effects affected participants' decisions to stop a medication. Yet, the study did not provide any data about what patients valued most in decisions for medication nonadherence. Paterson, Russell, and Thorne (2003) found that patients with chronic illness make self-care decisions based on what matters most to them. Their study, however, did not describe what those preferences were.

A number of investigations have suggested medication adherence decisions are primarily based on beliefs about a medication or physician (Allen et al., 2012; Benson & Britten, 2002; Elstad et al., 2012; Hicks & Holm, 2003; Jaarsma et al., 2000; Percival et al., 2012; Salt, & Peden, 2011; Unni & Farris, 2011). Although reservations about medications are noted, these studies fail to explain patients' preferences for one set of values over another. In this study, when faced with a high level of inner conflict, participants placed a greater emphasis on physical values and the lifestyle consequences of a medication. There is limited research that describes how patients make decisions for nonadherence to medications for CHF, specifically the decisional balance between patients' emotional and physical values. More research is needed in this area.

### **I Connect the Dots**

The theme, *I connect the dots*, is related to how participants made medication-taking decisions. The data from this study revealed a pattern in decision-making behaviors. Across the narratives, participants voiced a progression of events that framed the full decision-making experience. Participants described an unusual or bothersome symptom as the trigger to their medication decision-making. Uncertainty about a medication stimulated them to seek more information. Next, participants weighed the pros and cons of each medication-taking option against their personal emotional and physical values. Participants tested their theory that a medication adjustment was needed with a period of trial and error. They looked to their bodily responses to evaluate the consequences of their medication-taking decisions. Some participants described their

medication decision-making experience as a past, one-time event, while others described the medication decision-making process as a cyclical, daily sequence of events. See Figure 1 for a description of the decision-making pattern.



*Figure 1.* I Connect the Dots. This figure illustrates participants’ decision-making pattern.

**Uncertainty.** In this study, the need to make a medication-taking decision was usually triggered by uncertainty or concern about a symptom. Study participants described recognizing a particular symptom, such as a new cough or urinary incontinence, as “unusual.” Concern regarding unfamiliar symptoms prompted participants to look for a cause. The first place many participants looked was to their medications. Consistent with the literature, perception of a change in usual health

prompted the medication-taking process (Fenwick et al., 2012; Hicks & Holm, 2003; Johnson, 2002; Pierce & Hicks, 2001; Riegel et al., 2013; Siabani, Leeder, & Davidson, 2013; Sale et al., 2011; Salt & Peden, 2011). In one investigation exploring the process used by CHF patients to make self-care decisions, *situation awareness*, the recognition and interpretation of a symptom, was found to initiate the decision-making process (Riegel et al., 2013). This study supports past research that suggests symptom recognition and situation awareness are important to stimulating the medication decision-making process in the CHF patient (Allen et al., 2012; Dickson et al., 2007; Lipshitz et al., 2001; Lipshitz & Strauss, 1997; Moser & Watkins, 2008; Pierce & Hicks, 2001; Riegel et al., 2013; Riegel et al., 2009).

Participants in this study, and those described from other research literature (Allen et al., 2012; Benson & Britten, 2002; Cohen, 2009; Gadkari & McHorney, 2012; Haverhals et al., 2011; Johnson, 2002; Wroe, 2002), experienced uncertainty about their prescribed medications. Once a participant began to suspect a particular medication as the source of an undesired symptom, participants reported uncertainty of the necessity for a medication, the benefits or effectiveness of a medication, or the safety of a medication. Participants also described being unsure of whether a particular symptom was a consequence of an illness or a medication (Riegel et al., 2013; Riegel et al., 2009). Mirrored in the literature (Fenwick et al., 2012; Lipshitz et al., 2001; Lipshitz & Strauss, 1997; Pierce & Hicks, 2001; Riegel et al., 2013), uncertainty was subjective in that even though the participants were taking similar or identical medications, different individuals

experienced different doubts and made different decisions to suit the situation. The study narratives revealed that issues of uncertainty were largely unresolved. Even those that made a decision to stop or adjust a particular medication, still experienced worry and concern about their medications and their health. For many participants, unresolved uncertainty stimulated an ongoing cycle of inner negotiation and medication decision-making.

**Seek information.** Participants in this study reported reacting to uncertainty about a perceived negative response with increasing efforts to learn more about their medications. Across the narratives participants reported consulting the Internet, medication information flyers from the pharmacy, the pharmacist, friends, and family members to learn more about a medication. One participant, for instance, reported that after the wetting the bed the first thing he did was “head for the Internet” to find out about his medications. The literature consistently described information seeking as part of patients’ decision-making processes (Enriquez et al., 2004; Johnson, 2002; Riegel & Carlson, 2002; Siabani et al., 2013; Stravropoulou, 2011; Thorne et al., 2003). Similar to the findings of other researchers (Donovan & Blake, 1992; Salt & Peden, 2011; Wroe, 2002), this study found that participants desired more information before making a medication-taking decision.

An investigation by Hicks and Holm (2003) found that patients rely on interpersonal interactions with healthcare professionals to determine the CHF self-management strategies best suited to them and their life goals. This was not true in all

cases for this study. The majority of study participants reported that they did not feel that their healthcare providers were easily accessible and were too busy to discuss medications. Participants relied, instead, on information that was available to them at the moment to inform medication-taking decisions and personal values.

**Consider the options.** Participants described associating a medication with a concerning symptom then pondering all the possible options and outcomes of each option. Participants gave voice to their inner thoughts about adjusting their medications with statements like, “what if I took a whole one,” or “therefore if I don’t take it then I should recover faster.” It was at this point that participants reflected upon their own bodily cues, learned knowledge, and past experiences to “connect the dots.” This process of considering all the options and mentally simulating the outcome of each option is well documented in the literature (Allen et al., 2012; Cohen, 2009; Elstad et al., 2012; Ivers et al., 2000; MacNeal, 1997; Pierce & Hicks, 2001; Reach et al., 2011; Riegel et al., 2013; Salt & Peden, 2011; Thorne et al., 2003; Wroe, 2002).

**Weigh options.** Integral to the appraisal of each medication-taking option was weighing the pros and cons. Data revealed that participants in this study held a set of personal emotional (how I feel about the medication) and physical values (how the medication makes me feel). Through a process of inner debate, participants weighed the advantages and disadvantages of each option against their personal values, goals, beliefs, and learned lessons. This study found that participants attempted to find a satisfactory compromise between following the prescribed standard and living life as normally as

possible. Participants in this study chose the option that aligned with what was most important to them at that time. Each medication was appraised individually, in that one medication was deemed worth taking as prescribed while another was not. One participant, for example, chose to stop a medication after having a negative response, but chose to take his other medications despite experiencing similar side-effects. Participants also modified and adapted decisions to the situation. If a participant had somewhere to go for the day, then they would make the decision to skip a diuretic dose.

Several investigators suggest that patients taking chronic medications perform a risk-benefit analysis when making a medication-taking decision (Auduly et al., 2009; Benson & Britten, 2002; Donovan & Blake, 1992; Elstad et al., 2012; Enriquez et al., 2004; Henriques et al., 2012; Laba et al., 2012; Sale et al., 2011). These investigations describe patients weighing the medication benefits against the risks or perceived adverse effects when making a medication choice. While participants in this study acknowledged that there were benefits and risks associated with their medications, their appraisal process more closely resembled that of other literature which supports that individuals select a course of action based on desired personal goals and lifestyle values (Donovan & Blake, 1992; Enriquez et al., 2004; Hicks & Holm, 2003; Jaarsma et al., 2000; MacNeal, 1997; Riegel et al., 2013; Salt & Peden, 2011; Thorne et al., 2003). Prior to making a decision, potential courses of actions were balanced against personal values such as convenience, pleasure, comfort, freedom, outward appearance, and physical well-being. Consistent with past research, participants intentionally ignored or violated medication

rules to make room for physical and emotional values (Donovan & Blake, 1992; Goff et al., 2008; Henriques et al., 2012; Ivers et al., 2000; Johnson, 2002; Paterson et al., 2001; Pierce & Hicks, 2001; Riegel & Carlson, 2002; Riegel et al., 2013; Thorne et al., 2003).

**Trial and error.** Each participant tested their medication-taking predictions with a period of trial and error. Some participants described experimenting with the dosage or timing of selected medications, while others described a period of stopping a medication. In this experimentation phase, participants monitored their physical response and symptoms to determine if they were on the right track. Some participants shared that “messing with” their medications helped them define therapeutic boundaries in order to develop decision templates for future situations. One participant, for instance, described how her body reacted to different adjustments to her anticoagulant. Testing options before making a final decision is evident in a few decision-making reports (Donovan & Blake, 1992; Elstad et al., 2012; Ivers et al., 2000; Thorne et al., 2003). Thorne, Patterson, and Russell (2003) found that trial and error was an important aspect of making self-care decisions among those with a chronic illness. In a qualitative study, Elstad and colleagues (2012) found that when faced with conflicting medication information, patients with a chronic illness come to a medication-taking decision by trial and error.

**Evaluate consequences.** Participants described evaluating their own health data and bodily responses to help them understand the consequences of their decisions. For example, one participant described measuring her blood pressure and another noted trips

to the bathroom to know if diuresis had diminished. Many participants reported writing down or journaling their health data for later review. One participant, who made daily decisions to adjust their medication regimen, described looking back over past journal entries to remember and make sense of past medication-taking decisions. The literature supported that individuals frequently look to health responses for feedback regarding a selected course of action (Johnson, 2002; Noone, 2002; Thorne et al., 2003). For many participants, effectiveness of a decision was also measured against individualized standards of personal values, philosophies, and lifestyle expectations. Other researchers have identified that often times, evaluation of a choice is based on a creative combination of personal theories and habitual criteria (Henriques et al., 2012; Thorne et al., 2003).

Each study participant reported that they were satisfied with their medication-taking decisions. Those that made a one-time decision to stop or adjust a medication stated they would make the same decision again under similar circumstances. Those that continually adjusted their medication regimen, voiced satisfaction with their choices and did not describe any of their decisions as a mistake. In a qualitative study by Riegel, Dickson, and Topaz (2013), patients with CHF responded that they knew a self-care decision had been correct when symptoms were alleviated or prevented. The current study found that a decision was perceived as a good decision when the participants' goals were met. For some it was relief from a side-effect, while for others it was prolonging good health.

Some participants in this study, and those described in other research literature (Elstad et al., 2012; Enriquez et al., 2004; Johnson, 2002; Pierce & Hicks, 2001; Scotto, 2005; Thorne et al., 2003), made routine decisions to adjust their medication regimen. Participants described established patterns and routines for medication-taking decisions based on consequences of past decisions. For example, one participant shared that she routinely skipped diuretic doses based on morning blood pressure readings. Another described stopping and starting her diuretic each time a gastrointestinal condition flared. Participants constantly monitored their body for cues to implement their unique medication-taking routine. In their narratives, participants indicated that they knew their body better than anyone and what worked for another person might not work for them.

### **It is Complicated**

The theme, *it is complicated*, is related to the various factors that accompanied participants' medication-taking decisions. Participants' narratives brought to light a number of factors surrounding the medication-taking experience. For participants in this study, decisions for medication adherence were complicated by factors that were external and internal to the participant. External factors were anything in the context of the situation or background that impacted the medication-taking experience. Internal factors were anything associated with participants' health or inner self.

**External factors: polypharmacy.** One of the first external factors participants spoke of in their narratives, was the number of medications they took each day. Participants frequently started their narrative by pointing out the long list of daily

medications. Many participants complained that they were taking “too many” medications and expressed a desire to “keep them to a minimum.” Several participants shared that they were happy when a medication was discontinued or decreased. The number of daily medications participants took ranged from six to seventeen, with an average of 11.45 drugs per day. All participants took medication doses at least two times per day and four participants reported taking medications three or more times per day.

A number of investigations have demonstrated that polypharmacy contributes to medication nonadherence (Chapman, Petrilla, Benner, Schwartz, & Tang, 2008; Knafl & Riegel, 2014; Pasina et al., 2014; Sengstock, Vaitkevicius, Salama, & Mentzer, 2012; Tsai et al., 2012). In an investigation involving 202 participants with CHF, Riegel et al. (2012) found that those with two or more medication doses per day were more likely to have a steep decline in adherence over time. A qualitative study among 16 adults with CHF, reported the number of pills ( $M = 11$ ) taken and the medication dosing schedule as barriers to medication adherence (Wu, Moser, Lennie, Peden et al., 2008). The researchers suggest that issues of polypharmacy contributes to patients forgetting to take their medications. Although the sample in this study were similar in dosing schedule and number of daily medications as these two studies, participants in this study reported that they didn't forget medications; they worked at it and figured it out. When discussing the management of their multiple medications, participants described elaborate daily routines designed to help them remember the large number of medications they were required to take each day. Although the majority of participants felt they were taking too many

medications, participants in this study did not describe polypharmacy as influencing decisions to intentionally disregard medication recommendations.

**Involvement of family and friends.** Participants, when recounting their medication-taking experience, included the role that friends and family played. Participants reported that family members provided practical assistance by helping them make a list of their medications, arrange their pills in plastic weekly organizers, and drive them to the pharmacy. Friends and family were also consulted for medication advice, especially if they had medical experience. For instance, one participant asked his neighbor, who was a nurse, about his medications. One participant relied on his daughter, a Registered Nurse, to give him medication advice. Another participant, who had a husband and a son who were physicians, reported that her family helped her connect her symptoms to medication side-effects. Spouses were influential in helping participants to remember their medications, look up side-effects, and make medication-taking decisions. Multiple participants shared that their family members “fuss” over them and make sure they are taking care of themselves.

The current study found that the support of friends and family was a factor in decisions regarding adherence and nonadherence to medications for CHF. Much of the literature reports that high levels of social support are associated with higher medication adherence (Moser et al., 2012; Moser & Watkins, 2008; Riegel et al., 2009; Sayers et al., 2008; Scotto, 2005; Simpson et al., 2000; Wu, Moser, Lennie, Peden et al., 2008). More than one investigation concluded that living with a spouse or significant other had

beneficial effects on CHF medication adherence and self-care (Granger et al., 2005; Rich et al., 1996; Riegel et al., 2009; Scheurer et al., 2012; Sebern & Riegel, 2009; Wu, Moser, Lennie, & Burkhart, 2008; Wu et al., 2012). A study by Marti et al. (2013) in 308 CHF patients, however, failed to associate marital status with medication adherence rates. Although it may be true that social support makes medication adherence easier, this study found that advice from friends and family also inform decisions for nonadherence.

**Cost.** The cost of medications frequently appeared in participants' narratives. No participant reported that costs prevented them from taking a medication, but they did state that it was something they thought about. One participant, for example, shared that he had to consider the high cost of his new anticoagulant. The out-of-pocket expense for a 3-month supply was \$1500. Similar to other narratives, he made the decision to continue the medication because he believed it was the best decision for his health. Despite having supplemental health insurance and/or a prescription drug benefit plan, participants reported they perceived their medications to be expensive.

The literature regarding medication adherence and cost is inconsistent. In a study examining medication adherence in older women with heart disease, West, Lefler, and Franks (2010) found that the majority of the participants (71.9%) reported they had difficulty affording their medications and had to give something up to buy their medications. Additionally, approximately one in five participants indicated that they had not filled needed medications because of costs. In contrast, a large investigation regarding cost-related nonadherence in 3,071 older adults found that only 20% reported

some form of cost-related nonadherence (Zivin et al., 2010). Consistent with the literature, the current study found that factors other than medication costs were more influential on medication-taking decisions.

**Internal factors: poor health.** Issues of poor health and aging were evident in the participants' narratives. Poor vision, diminished hearing, impaired mobility, arthritis, fatigue, trouble sleeping, activity intolerance, trouble breathing, edema, hyperglycemia, abnormal blood pressure, an irregular heartbeat, and constipation were just some of the problems participants reported. Additionally, participants reported the effects of aging and worsening illness had negatively impacted their functional status. Many participants expressed difficulty distinguishing the source of a symptom, which led to confusion about whether a medication should be adjusted and if so, which one. For example, one participant explained that when her ankles swelled she cut back on her sugar intake. She did not associate her fluid overload with her heart condition or her decisions to skip doses of her diuretics. Another participant explained that her fatigue made it difficult for her to do a lot of things. She was unsure if her fatigue was related to her medication or her atrial fibrillation. The presence of poor health was found to complicate medication adherence decisions.

Compared to the literature, the number of comorbidities per study participant was typical (Abete et al., 2013). The number of other illnesses ranged from two to twelve with an average of almost six comorbidities per participant. Findings of this study are supported by the literature, which reported that patients with CHF have difficulty

interpreting and distinguishing the symptoms of each condition, interfering with adherence to self-care and medications for CHF (Jeon et al., 2010; Knafl & Riegel, 2014; Moser et al., 2012; Riegel et al., 2009; Siabani et al., 2013). Studies that investigated whether the number of comorbidities in patients with CHF is related to the degree of medication adherence, however, have generated conflicting results (Dickson et al., 2013; Granger et al., 2005; Moser et al., 2012; Moser et al., 2005; Oosterom-Calo et al., 2013; Riles et al., 2014; Siabani et al., 2013; Wu et al, 2008b). Although the presence of poor health was found to complicate medication-taking decisions, more research is needed to fully understand the level of influence aging and comorbidities have on decisions for medication nonadherence.

**Depression.** Three participants reported that they suffered from issues of depression and two participants specifically described the impact of depression on their daily life. One participant described depression as directly influencing his medication-taking decisions. He expressed feelings of despair over his current life circumstances. He stated that sometimes when he thought about his medications he would say, “What the heck” and not take the pills. He became emotional during the interview, expressing feelings of grief and worthlessness over not being able to care for his aging wife. He described the daily routine of managing his multiple medications and illnesses as “boring” and “tiring.” Another participant with depression complained of chronic fatigue and feelings of apathy. She commented, “I often say to myself, is it worth it? I often see something across the room, like a glass of water, and I say is it worth walking other there

for it? If not, then I'm just gonna sit here." She lamented her condition and shared that without the help of her attentive family her medication-taking habits could be different. She stated she had no interest in activities and would choose to sleep all day if she could.

This study found that depression and issues of emotional health were factors in decisions for medication-taking. Numerous publications present depression as a barrier to medication adherence in cardiac patients (Allen et al., 2012; DiMatteo et al., 2000; Falk et al., 2013; Marti et al., 2013; Moser et al., 2012; Riegel et al., 2009; Riegel & Carlson, 2002; van der Wal et al., 2005). Research reports suggest that depression affects decisions for medication adherence due to slowed information processing and deficits in cognition (Allen et al., 2012; Riegel et al., 2009). This study, however, also suggests that the emotions and feelings associated with depression influences how patients weigh their medication options. As the worth of a medication-taking action was being weighed, participants in this study factored in the negative emotions associated with depression. There is limited research that describes from the patient perspective how depressive emotions affect decisions for adherence to medications for CHF. More research is needed in this area.

The literature suggests that medication decision-making is influenced by more factors than what was found in this study. These factors are: gender, education level, impaired cognition, sleep disturbance, and self-efficacy. There was no clear evidence in the literature regarding the influence of gender and education level on medication adherence decisions. The sample size in this study was small, but consistent with the

literature, this study did not demonstrate that differences in gender or education level was a factor in medication decision-making.

The literature shown impaired cognition (Moser et al., 2012; Riegel et al., 2009; Schwarz & Elman, 2003; Siabani et al., 2013) and problems with sleep (Knafl & Riegel, 2014; Moser et al., 2012; Riegel et al., 2009; Riegel et al., 2011; Riegel et al., 2012) to be associated with poor treatment adherence and ineffective decision-making. The recruitment criteria of this study excluded those with overt cognitive dysfunction, but almost half of the participants in this study reported problems with sleep and/or taking a medication to sleep. Although problems with sleep can accentuate and contribute to poor cognition, which limits decision-making abilities (Knafl & Riegel, 2014; Moser et al., 2012; Riegel et al., 2009; Riegel et al., 2011; Riegel et al., 2012), the participants' narratives did not demonstrate that poor sleep was a factor in medication decision - making.

Lastly, much of the literature suggests that self-efficacy is an important predictor of adherence to medications and CHF self-care (Audulyv et al, 2009; Cholowski & Cantwell, 2007; Dickson et al., 2013; Jaarsma et al., 2000; Maeda et al., 2013; Riegel & Dickson, 2008). Past investigations report that patients' lack of confidence to manage their CHF medications or self-care activities led to decisions for nonadherence (Dickson et al., 2013; Granger, Sandelowski et al., 2009; Riegel & Carson, 2002; Riegel et al., 2012). Participants in this study reported that they were nonadherent to their medications, yet they did not describe uncertainty or apprehension about managing their

medications. On the contrary, all study participants described comprehensive medication management routines that they believed were effectual.

### **I Am Not Nonadherent**

The theme, *I am not nonadherent*, is in regards to how participants perceived medication adherence and nonadherence. The data in this study revealed that participants constructed their story to avoid being perceived as someone who was nonadherent. Participants described those that are nonadherent to their medications in a negative light. When discussing thoughts about intentionally making a decision to forgo medication recommendations, several participants described it as “not very smart” and “stupid.” Participants also believed that medication nonadherence was a lack of trust in the health provider and patients should take their medications. Sentiment toward medication nonadherence, however, was contradictory and did not always match actions. Some of the same participants who described medication nonadherence as foolish also reported experiences of making intentional decisions for medication nonadherence.

Participants indicated in their narratives that they did not view their own decisions to adjust or stop selected medications as nonadherent. Rather, they perceived that they were making logical and warranted medication-taking decisions. As if making a case for decisions for nonadherence, participants recounted experiences of medication nonadherence like a person on trial for an offense. In addition to presenting each motivation for stopping or adjusting a particular medication, participants’ tone of voice and body language reinforced the seriousness of their decision. Participants tended to

raise their voice, sit up straighter, lean closer to the researcher, or use gestures to strengthen their point. One participant even purposely wore clothing stained with blood to demonstrate the negative effects of the anticoagulant. It was evident that participants in this study wanted to be perceived as discerning and justified in their actions.

Unsolicited, many participants spoke of a past profession or personality characteristic to illustrate their ability to make sound decisions. One participant, who openly talked about not taking his medications on the day of the interview, stated that he was an accountant and administrator. He stated, people would look to him as someone who knew things. Another participant, who routinely adjusted medications to suit her needs, included that she worked for a corporation for over 30 years and worked her way up to a high-level manager. Other participants spoke about being a teacher, company owner, an engineer, and a type-A personality that was not afraid to ask questions.

Three participants, during eligibility screening, stated they had taken a medication for CHF differently than prescribed. One participant even went into detail about skipping her diuretic when she had somewhere to go. Their narratives, however, excluded these experiences. After the interview, one of the participants returned and apologetically stated that he used to work for a large insurance company and probably knew too much to be helpful. He patted me on the shoulder before leaving the room. These participants were eager to convince the listener that they followed their doctor's directions.

On the other end of the spectrum, the majority of participants spoke openly about decisions to intentionally adjust or stop a medication. These participants did not perceive

that they were doing anything wrong. On the contrary, they believed they were being proactive in taking control of their own health. After weighing all the options, many perceived their medication alterations to be the best decision for them and their health. In discussing the idea that not taking a medication as prescribed means you are a bad person, one participant summed it up for most everyone. “A bad person to who? If you don’t take your medicine then you don’t believe in them or something? I tell you I don’t care what they think. I’m looking out for me...My health comes first to me...I’m the proof in the pudding.” It was difficult for participants to view their nonadherence, which was purposeful and reasoned, as deviant behavior. Many times the healthcare provider was not made aware of medication adjustments, because participants did not plan to change, regardless of provider recommendations. This study found that despite making intentional decisions to violate medication recommendations, participants did not want to be perceived as nonadherent.

In this research and other medication adherence literature (Ho et al., 2009; National Community Pharmacist Association [NCPA], 2013; Wroe, 2002), patients may be reluctant to admit to what is perceived as an undesirable behavior. Given that participants in this study and that of Wroe (2002) based medication-taking decisions on personal beliefs and values, it is possible that individuals fear that their nonadherence decisions may be perceived as irrational. According to this study, nonadherence to medications for CHF may remain hidden in visits with healthcare providers for multiple reasons: (1) patients fear being negatively judged, (2) patients do not view their

medication adjustments as nonadherence, and (3) patients do not plan to change. Accordingly, estimations of adherence to medications for CHF may be largely overestimated.

Only one study was identified that suggested patients do not perceive medication non-compliance as a deviant or abnormal behavior (Donovan & Blake, 1992). The purpose of this particular study was to examine patients' reactions to advice and medications prescribed by doctors in a rheumatology clinic in the United Kingdom. In this research and that of Donovan and Blake (1992), participants did not view decisions to ignore or alter medication recommendations as an issue that needed to be addressed. Since patient perceptions of medication adherence and nonadherence could not be identified in any recent literature regarding medication decision-making in the patient with CHF, more research is needed to explore this concept.

### **Recommendations**

This section will discuss the effectiveness of narrative inquiry as the research methodology for this study. The discussion includes specific research strategies that were utilized, including those that worked and those that did not. A review of the Naturalistic Decision-Making Model as the framework of this study will also be presented. Based on what was learned in this study, I will present recommendations for nursing research, practice, and education.

## **Narrative Inquiry**

The qualitative methodology of narrative inquiry was effective in eliciting the patient perspective regarding decisions for medication adherence and nonadherence in older adults. The narrative data provided a rich description of the full experience of taking medications for CHF. Storytelling opened up the opportunity for participants to speak in their own ways and include information that was important to their experiences. The spontaneous and unstructured nature of storytelling was a strength, in that participants were free to talk about anything that they felt the listener should know. I believe that a more structured research methodology would have constrained the voice of study participants. The stories told not only described the chronology of participants' medication-taking decisions, but also gave insight into the relationships between medication-taking decisions and thoughts, intentions, motivations, feelings, and personal values. Riessman's (1993, 2008) framework for narrative analysis was effectual in uncovering meaning from the narrative data. The three levels of narrative analysis employed in this study were (1) narrative telling, (2) transcribing, and (3) analysis.

**Interviews.** Narrative telling, processing and interpreting what is being said and observed during an interview, was foundational to gathering rich and in-depth narrative. According to the literature (Hollway & Jefferson, 2008; Mishler, 1986; Patton, 2015; Riessman, 2008), in-depth, semi-structured interviewing that is conversational in nature should use the following strategies: (a) establishing rapport, (b) encouragement, (c) probing and prompting, (d) listening, and (e) summarizing. Because older adults may tell

lengthy stories, the literature recommends using questioning and probing to adjust the flow of the conversation (Patton, 2015). An interview guide can help to keep the interview focused. It is also recommended that interview questions be broad, open-ended, and framed in everyday language to turn the topic into storytelling invitations. Each of these strategies was used in the current study (Riessman, 2008).

According to Patton (2015), the research interview may be intrusive and evoke thoughts and feelings. Since older adults may take more time to establish a trusting relationship, it may be more pronounced in this population. Early in the study, I experienced problems with the third and fourth participants neglecting to share experiences of medication nonadherence. I sensed that these participants were hesitant to discuss issues of medication nonadherence. To encourage participants to share their stories without fear of judgement, I began reading the preamble described in chapter III to participants before the start of the interview. To further alleviate any potential sources of intimidation or anxiety, I also began asking participants if they had a preference for how the interview was audio recorded, either a small recording device (the size of my hand) or a mini laptop computer (the size of a piece of paper). All interviewees stated they did not have a preference for recording device. Additionally, before the start of the interview I made a concerted effort to make the participant feel comfortable through casual conversation. An unwillingness to discuss nonadherence to medications was not as apparent in subsequent interviews.

The literature warns that persons being interviewed often ask for advice, but the researcher is not there to give advice (Patton, 2015). The interview questions sometimes led the participants to express uncertainty about their medications. As a novice interviewer, I found myself slipping into the educator role early in the study. Once I recognized this tendency, I concentrated more on listening, carefully, attentively, and analytically during the interview with minimal interruptions (Patton, 2015; Riessman, 1993). This adjustment removed me from the equation and encouraged the participants to outwardly think through their conflict, opening a window into their inner thoughts.

Interviewing older adults regarding a sensitive topic was challenging. According to Patton (2015), demonstrating care and empathy during the interview is essential to eliciting information for participants. There was a risk, however, that participants would interpret my compassion as supporting their medication-taking decisions. Whereas, being too aloof might have seemed judgmental. In an effort to communicate neutrality, nonverbal prompts, such as leaning forward, eye contact, and nodding were used to convey my personal interest. After introspect and practice it was a skill that got better over the course of the study.

Supplemental strategies that were useful in interviewing older adults in this study included making sure the interview location was well lit, easily accessible, and quiet. At the beginning of the interview time, performing a brief assessment of hearing and vision needs, physical impairments, and overall state of health gave me an idea of how loudly I needed to speak and the best seating arrangement for the interview. Another strategy that

worked well in this study, included reviewing the interview guide at the end of the interview to ensure that all topics had been addressed.

Strategies that could have been improved in this study included when the interviews were scheduled. The first four participants were all from the same retirement center. Thus, all their interviews were scheduled on the same day. Spacing out the interview times or doing them on different days might have minimized interactions between the study participants, giving the best opportunity for an unprejudiced interview.

**Data transcription.** The second level of Riessman's narrative analysis was transcription of the data. According to Riessman (2008), the interpretation of the narrative may change based on the type of transcription and who is performing the transcribing. The literature recommends that transcription be performed by the researcher. This strategy was useful in the initial interpretation of the data and making decisions about future interviews. During the transcription process I re-lived the interview experience, so that notes about body language, tone of voice, emotions, and implied ideas could be included in the transcribed narrative. Based on the findings in this study, data transcription by the researcher is highly recommended.

**Data analysis.** The third level of Riessman's data analysis was the systematic evaluation of the narratives. According to the literature, there is not standard or set of prescriptions for narrative analysis. Multiple approaches to examining and analyzing narrative data are evident in the literature (Hollway & Jefferson, 2008; Mishler, 1986; Patton, 2015; Riessman, 2008). The three modes of data analysis chosen for this study

were thematic analysis, structural analysis, and performance analysis. The analysis of each narrative as a whole, intact story, gave the best opportunity to capture the meanings of the recounted experiences. How a story was constructed and retold by the participant clarified and expanded the themes that emerged from the data. By working through these very different interpretative approaches, the analysis generated a more three-dimensional representation of the medication decision-making experience. Employing more than one mode of data analysis is highly recommended.

### **Theoretical Framework**

The Naturalistic Decision-making Model (NDM) provided an excellent foundation for this study. Since medication-taking decisions are based on individual choice and made in real-world contexts, the NDM theoretical framework was a perfect match for explaining the full-scope of the medication-taking experience. Based on the NDM assumptions presented in chapter I, adherence and nonadherence to medications for CHF is a naturalistic decision-making process. The following discussion will illustrate how the results of this study support that older adults with CHF use the NDM to make medication-taking decisions.

According to Lipshitz and colleagues (2001), the NDM is a blend of intuition and rational decision-making theory. The NDM asserts that while a task may be understood to have benefits and be easily performed, people may deviate from the rational choice based upon emotions, intuition, and personal values. The study findings of this study aligned with each of the assumptions of the NDM:

1. Decisions are complex and dynamic. Evident in the narratives were both external and internal factors that complicated the medication decision-making experience. For example, one participant described the effect of depression on his medication-taking decisions. Others complained about the number of medications they take and the complexity of the Medicare system. Participants described basing their medication-taking decisions on feelings, goals, values, emotions, and beliefs.

2. Decisions are intentional and people do not always adhere to algorithms, policies, rules, or prescriptions. These two assumptions were reflected in participants' intentional decisions to take medications for CHF differently than prescribed. They knew what they ought to do and they knew how to do it, but made purposeful decisions to deviate from prescribed medication recommendations.

3. Decisions lead to actions that have consequences. Evident in the narratives, participants made decisions that resulted in a medication-taking action. The consequence of the action was judged against personal goals and values.

4. Decisions are preceded by uncertainty. Uncertainty about the safety and need of a medication was evident in participants' narratives. Consistent with the assumption, evident in the narratives was worry and concern about unusual symptoms. Participants frequently described not knowing enough about their medications and sought information from healthcare providers, the Internet, pharmacists, friends, family, and pharmacy information flyers. Participants reported conflicts in medication information.

5. Decisions are influenced by past, present, and future experiences and to make a decisions, an option must be feasible, and decisions develop in situational contexts. These last three assumptions were seen in participants' awareness of the situation and mental simulation of medication-taking options. Both *situation awareness* and *mental simulation* (Riegel et al., 2013) was evident in the participants' narratives. Situation awareness encompassed recognition and interpretation of a symptom with an appraisal of its significance. Mental simulation was predictive contemplation about plausible courses of action and potential outcomes. For example, participants who experienced concern about an unusual symptom and assessed a particular medication as the source described mentally thinking through possible options and the consequences of each action. Participants described recalling a past experience to categorize the situation, imagine the outcome of each option, and weigh the pros and cons of each option. One participant described wondering if he could have his cataract surgery if he increased his beta blocker dose. Another participant recalled past experiences with her anticoagulant and contemplated what would happen if she stopped taking her anticoagulant or just skipped doses. More than participant recognized the severity of their diuretic treatment and made a determination if it was feasible to take a dose when they were going to be away from home.

### **Assumptions**

In this section, I will re-examine the assumptions I had at the beginning of the study. This set of beliefs about what is true regarding decisions for medication adherence

and nonadherence in older adults with CHF were all supported by this study. The assumptions include:

1. Older adults with CHF have a story to tell about how they make medication-taking decisions and are willing to share this story with the researcher. This assumption was supported in this study by the stories that the study participants told regarding their medication-taking experiences.

2. Although unintentional nonadherence exists, patients make intentional decisions to deviate from their prescribed CHF medication regimen. This study found that decisions to deviate from prescribed CHF medication regimens are primarily intentional. Participants in this study reported they never or rarely forgot to take a medication.

3. Daily, patients follow a decision-making process about whether to take or not to take a CHF medication. This assumption was supported by the data in the participants' descriptions of how they came to a decision for medication adherence or nonadherence. Each day, participants in this study were faced with the choice to either take or not take a prescribed medication.

4. To make medication-taking decisions, patients rely heavily on personal experiences and preferences rather than standardized teaching and knowledge. This was illustrated in many ways. Participants described seeking medication information, yet through a process of weighing the pros and cons, participants based their medication-

taking decisions on their personal beliefs about the medication, their level of trust of the provider, and their physical well-being.

### **Implications for Nursing**

Affecting over 5 million older Americans, CHF is the most common chronic disease and reason for hospitalization among older adults (Hall, Levant, & DeFrances, 2012; Lloyd-Jones et al., 2010; Rattiner et al., 2012). The primary treatment for CHF is pharmacological. Yet, recent estimates suggest that 40% to 60% of all adults with CHF are nonadherent to their medications, indicating little progress has been made in improving medication adherence (Molloy et al., 2012; Riegel et al., 2012; Wu, Moser, Lennie, & Burkhart, 2008). Nurses' continuous and visible presence with patients places them in the unique position to assist patients with issues of medication adherence. Findings from the analysis of the data gathered in this study have implications for nursing practice, nursing education, and nursing research.

### **Nursing Practice**

The National Council on Patient Information and Education (NCPIE) issued a nationwide call to action for an increased focus on poor medication adherence in patients with chronic conditions (NCPIE, 2013). According to NCPIE (2013), everyone in the healthcare environment, from the patient to the nurse, has a significant role to play in improving patient medication adherence. Nurses have the responsibility to help patients manage their medication regimen. The following discussion includes recommendation for nursing practice based on the findings of this study.

The findings of this study brought to the forefront that decisions for medication adherence or nonadherence are intentional and based on personal goals and values. This means first and foremost, nurses should provide patient-centered care that is meaningful and valuable to the individual patient. The IOM (2001) defines patient-centered care as, “Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” (pg. 40). Respecting the autonomy of the individual, nurses should be concerned with what patients *do* want as opposed to what they *should* want. This can be accomplished by asking questions to uncover patients’ unique needs and preferences and work to devise common medication-taking goals that are harmonious with patient’s values.

Medication nonadherence poses a serious risk to the health of the patient and should be discussed in nurse-patient interactions. Issues of nonadherence may bring to the surface emotions within the nurse and the patient, thus nurses should self-reflect for an awareness of uncomfortable feelings or thoughts. The literature is clear that the majority of CHF patients do not take all their medications as prescribed. Therefore, the nurse should not assume patients are taking medications as prescribed. On the contrary, the nurse has a responsibility to ask each patient about medication adherence in a nonjudgmental manner, allowing participants the freedom to openly discuss taking medications differently than prescribed. Based on the findings in this study that patients may not perceive that they are nonadherent to the prescribed medication regimen, the nurse should ask pointed questions about medication-taking habits and routines. The

need exists for nurses to devote more time to relationship-building and to pay attention to person-specific qualities.

The nurse-patient relationship facilitates exchange of necessary health information. Additionally, nurses are qualified and educated for the role of educator. In interviews, participants worried that they were not being completely informed about their medications. To counter this fear, nurses should become involved in a process of assessing what the patient needs to know and how the information should be delivered. The nurse should seek to develop effective, efficient ways of providing teaching to inform medication-taking decisions. The teaching process should involve listening to understand the unique learning needs of the patient before performing generic teaching. Teaching could be more effective if the nurse develops a consultation style that provides pros and cons of the medication and participates with the patient in weighing medication-taking options. I recommend that nurses contemplate medication-taking decisions together with patients to help them make the best medication-taking decisions possible.

If the patient's goals, preferences, and values compete with the health provider's goals, nurses are in the unique position to coordinate care and foster a relationship between patients and healthcare providers. Patient-centered care coordination is a core professional standard and competency for nursing practice. Based on a working relationship between the patient, nurse, and other health professionals, the nurse can support the patient in making medication-taking decisions that are both therapeutic and satisfactory to personal needs. Since this study found that social support is a factor in

medication adherence decisions, the nurse should include caregivers and family members in patient education regarding the patient's medical condition and treatment options. Since decisions for medication adherence are more difficult for patients with depression or poor emotional health, resources and referrals to support effective medication decision-making may also be necessary.

### **Nursing Education**

Despite efforts to ensure that patients take medications as prescribed, medication nonadherence among older adults with CHF remains a significant problem. Medication nonadherence is a problem that has profound social, economic, and individual implications. Since the prevalence of CHF is projected to increase with the aging of the population (AHRQ, 2011), future nurses should be educationally prepared for the growing problem of medication nonadherence in the chronically ill.

Given that issues of medication nonadherence in those with CHF is prevalent and often times goes undetected, I recommend that future and practicing nurses receive education regarding the findings this study generated. In presenting concepts of pharmacological treatments, I recommend that nurse educators assist nurse learners in achieving a clearer understanding of medication nonadherence. In addition to teaching about the negative social, economic, and individual consequences of not taking medications as prescribed, nurse learners should be educated regarding the differences between intentional and unintentional nonadherence. I recommend that nurse educators prepare nurse learners in how to recognize even the most subtle signs of medication

nonadherence. What was learned in this study regarding medication decision-making motivations, influences, and patterns in those with CHF should be incorporated into nursing school curricula and shared with nurses in the clinical setting. Significant for the future is to proactively address patients' medication decision-making before they choose to discontinue medication therapy all together.

The older adults in this study made intentional decisions to forego medication recommendations based on what was important to them at the time. Patient decision-making, a critical aspect of self-management, should be emphasized in the classroom and in the clinical setting. Nurse learners should be made aware of the processes patient use to make a medication adherence decision. I recommend that nursing faculty promote and support a patient-centered approach to caring for the older patient taking chronic medications. Instruction should reinforce the significance of acknowledging patients' values, goals, and preferences, providing individualized patient teaching, and partnering with the patient to make medication-taking decisions.

Since medication nonadherence may be perceived in a negative light, it is important for nurse educators to coach potential nurses to have a nonjudgmental attitude toward patients' medication-taking habits. Providing the evidence from this study can be used to support that those who are nonadherent are not "bad" patients or irrational. These individuals made decisions that they believed were necessary for their well-being.

## **Nursing Research**

Narratives articulated by the participants of this study expand what is currently known about the experience of older adults making decisions for adherence or nonadherence to medications for CHF. Since very little is known about how patients with CHF go about making medication-taking choices, this study utilized a qualitative methodology to investigate the experience from the patient's perspective. This investigation brought to light the variables associated with participants' decisions for medication adherence and how they occur in real-world contexts. Although this study adds to nursing's body of knowledge, further investigation is needed to gain a better understanding of decisions for medication adherence and generate evidence for practice. The findings in this study can be used for the initial development of a model or framework for medication adherence decision-making in older adults with CHF, which can guide future investigations.

The literature suggests that medication adherence may be more difficult for ethnic minorities, particularly the Black and Hispanic races (Bagchi et al., 2007; Marti et al., 2013; Monane et al., 1994; Wu et al., 2008b; Wu et al., 2010). In this study, each participant reported their race as White. It is possible that the findings generated in this study may not be applicable for CHF patients of other races. To fully understand decisions for adherence in CHF patients of other races and ethnicities, I recommend repeating this study with a more diverse study sample.

The majority of the literature recognizes the influence of beliefs and emotional values on decisions for medication adherence, but very little focuses on the influence of physical values. In this study, decisions for nonadherence were primarily based on physical values. Specifically, participants had positive thoughts about their medications but still chose not to take them. More research is needed to understand the influence of physical values on decisions for medication nonadherence. I recommend an investigation that generates empirical data to learn more about the decisional balance between emotional and physical values in decisions for nonadherence to CHF medications. This information may also be used to inform the development of assessment and screening tools that are needed to determine if there is cause for concern regarding medication nonadherence.

One insight gained from this study is that the physical value, live life as normally as possible, was important to medication-taking decisions. Very little is known about perceptions of quality of life and medication adherence decisions. I recommend an exploratory study to gain a clearer understanding of the aspects of quality of life that are most influential on decisions for medication adherence or nonadherence.

This study suggests that medication nonadherence in older adults with CHF is primarily attributed to intentional decisions, based on personal values, to deviate from the prescribed regimens. Absent from the literature, however, is research regarding ways to improve medication adherence decision-making. I recommend a randomized controlled

trial to test a nursing-led decision support intervention to promote medication adherence in those taking CHF medications.

### **Chapter Summary**

This chapter presented the conclusions of this study. The themes that emerged from the study data were discussed. This study found that decision-making was a foundational and critical element of medication adherence to medications for CHF. Although unintentional nonadherence exists, older, community-dwelling adults with CHF made intentional decisions to forego medication recommendations. Experiencing physical symptoms that were perceived as negative often triggered uncertainty about the safety or need for a medication. When faced with a conflict between how they felt about a medication or provider and how a medication made them feel, participants went through a complex decision-making process. Initially, participants sought more information about how their medications worked and their possible side effects. Once they identified a suspect medication, they thought about their options and imagined the outcomes. Through a process of weighing the pros and cons and balancing the risks and benefits, participants based their medication-taking decisions on their personal beliefs about the medication, their level of trust of the provider, and their physical well-being. Participants tested their decision by a period of trial and error. For some, decisions not to adhere to a prescribed medication regimen was a one-time event, while for others it was a lifestyle. Participants in this study valued how they felt in regards to making medication adherence decisions.

The reasons narrative inquiry was an effective method for generating data for this study were presented. The appropriateness of NDM as the theoretical framework was also discussed. Based on the findings of this study, recommendations for nursing practice, nursing education, and nursing research were proposed.

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APPENDIX A

Texas Woman's University IRB Approval Letter



**Institutional Review Board**

Office of Research and Sponsored Programs  
P.O. Box 425619, Denton, TX 76204-5619  
940-898-3378  
email: IRB@twu.edu  
<http://www.twu.edu/irb.html>

DATE: February 26, 2016

TO: Ms. Rebecca Meraz  
Nursing

FROM: Institutional Review Board (IRB) - Denton

*Re: Approval for Making Medication Adherence Decisions: Stories from Older Adults Taking Medications for Congestive Heart Failure (Protocol #: 18870)*

The above referenced study has been reviewed and approved by the Denton IRB (operating under FWA00000178) on 2/25/2016 using an expedited review procedure. This approval is valid for one year and expires on 2/24/2017. The IRB will send an email notification 45 days prior to the expiration date with instructions to extend or close the study. It is your responsibility to request an extension for the study if it is not yet complete, to close the protocol file when the study is complete, and to make certain that the study is not conducted beyond the expiration date.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Anita Hufft, Nursing  
Dr. Vicki Zeigler, Nursing  
Graduate School

APPENDIX B

Baylor Scott and White Hospital IRB Approval



**IRB Approval – Expedited Review of New Study**

**To:** Rebecca Meraz, RN, MS, CCRC

**Copy to:** Rebecca Meraz, RN, MS, CCRC

**Date:** July 25, 2016

**Re:** 016-149  
 Making Medication Adherence Decisions: Stories from Older Adults  
 taking Medications for Congestive Heart Failure  
 Reference Number: 101457

Your new proposal was reviewed by a designated member of Baylor IRB Red via expedited review.

This study was determined to be eligible for expedited review as it involves no greater than minimal risk to the subjects and fits into the following category(ies) from the 1998 approved list:

Category 5: Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis)

This review included the following components:

Study Application	
Form Name	Outcome
Administrative Review of External IRB (use only with preapproval to do so)	Approved as Presented

Study Document			
Title	Version Number	Version Date	Outcome
Form 18_making medication decisions_v1	Version 1.0	07/09/2016	Approved
Form 34_Making Medication Decisions_v1	Version 1.0	07/09/2016	Approved
Form 1_Making medication decisions_V1	Version 1.0	05/19/2016	Approved

Protocol_making medication decisions_V1	Version 1.0	05/19/2016	Approved
Participant Eligibility Screening Tool	Version 1.0	05/19/2016	Approved
Demographic Data Form_making medication decisions_V1	Version 1.0	05/19/2016	Approved
TWU IRB Approval Letter_making medication decisions	Version 1.0	05/19/2016	Approved
Flyer_making medication decisions_V1	Version 1.0	05/19/2016	Approved

Study Consent Form			
Title	Version Number	Version Date	Outcome
Making Medication Adherence Decisions: Stories from Older Adults taking Medications for Congestive Heart Failure	Version 1.0	02/25/2016	Approved

Your submission has been approved. The approval period begins on 07/25/2016 and expires on 07/24/2017. Your next continuing review is scheduled for 05/25/2017.

This study is approved to be conducted at the following locations:  
Baylor Jack and Jane Hamilton Heart Hospital

The following individuals are approved as key study personnel (research team members & administrative support):  
Laible, Emily, RN; Meraz, Rebecca, RN, MS, CCRC

Based on the information provided in your submission, the IRB has determined that this study qualifies for a waiver of informed consent in accordance with 45 CFR 46.116 (d) and a waiver of HIPAA Authorization 45 CFR 160 and 164.

All events that occur on this study including protocol deviations, serious adverse events, unanticipated problems involving risks to subjects/others, subject complaints or other similar events must be reported to the IRB in accordance with the respective policies.

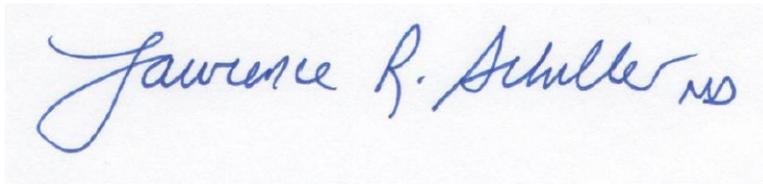
Remember that this study is approved to be conducted as presented. Any revisions to this proposal and/or any of the referenced documents must be approved by the IRB prior to being implemented. Additionally, if you wish to begin using any new documents, these must receive IRB approval prior to implementation of them in the study.

IRB approval may not be the final approval needed to begin the study. All contractual, financial or other administrative issues must be resolved through Baylor Research Institute prior to beginning your study.

For Investigator Initiated studies that meet the requirements to be posted on [www.clinicaltrials.gov](http://www.clinicaltrials.gov); as Principal Investigator, it is your responsibility to ensure that your study is listed prior to enrolling the first subject. Instructions on fulfilling this requirement can be found in iRIS under the "Help" tab.

If you need additional assistance, please contact the IRB Specialist at 214-820-9989.

Sincerely,

A handwritten signature in blue ink that reads "Lawrence R. Schiller MD". The signature is written in a cursive style with a large initial 'L' and 'S'.

Signature applied by Lawrence R. Schiller on 07/25/2016 08:42:07 PM CDT

APPENDIX C

Consent Form

TEXAS WOMAN'S UNIVERSITY  
CONSENT TO PARTICIPATE IN RESEARCH

Title: Making Medication Adherence Decisions: Stories from Older Adults taking Medications for Congestive Heart Failure

Investigator: Rebecca Meraz, M.S.N., R.N. .... RMeraz1@twu.edu

Advisor: Vicki Zeigler, Ph.D, R.N. .... VZeigler@twu.edu

Explanation and Purpose of the Research

You are being asked to participate in a research study for Ms. Meraz's dissertation at Texas Woman's University. The purpose of this research is to gain understanding and insight into decisions older adults make about taking or not taking their congestive heart failure (CHF) medications. You have been asked to participate in this study because you are an older adult and have identified yourself as taking medications for congestive heart failure.

Description of Procedures

As a participant in this study you will be asked to spend no more than two hours of your time in a face-to-face interview with the researcher. The researcher will ask you to talk about about times you made a choice to take or not take your medications for congestive heart failure. You will also be asked to complete a short questionnaire that asks questions about you and your health. This will take approximately 30 minutes of your time. You and the researcher will decide together on a private location where and when the interview will happen. The interview will be audio recorded and then written down so that the researcher can be accurate when studying what you have said. Only the researcher will have access to the audio recordings. In order to be a participant in this study, you must be at least 65 years of age or older, take at least two daily medications for congestive heart failure, have experience making a decisions to not take or take a medication differently than prescribed, live independently, take your own medications, speak and read English, and be able to answer interview questions.

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## Potential Risks

### *Risk of Loss of Time*

A possible risk in this study is a loss of your time. Your time in this study will be no more than 2 hours. During the study time, you will be asked to complete a short questionnaire and talk about your medication decisions. The researcher will take steps to keep the interview time short by preparing interview questions ahead of time. To prevent interruptions or distractions, the interview will take place in a private location.

### *Risk of Fatigue*

During the interview session, there is a risk of fatigue. If you become tired, you may take a break at any time without question or penalty. You may also stop answering questions at any time and end the interview. The researcher will do everything possible to make sure you are comfortable during the interview session.

### *Risk of Loss of Confidentiality*

Another risk in this study is loss of confidentiality. Confidentiality will be protected to the extent that is allowed by law. The interview will be held at a private location that you and the researcher have agreed upon. The audio files and the written interview will be stored in a locked cabinet and on a password protected computer in the researcher's office. Only the researcher and her advisor will hear the recorded interview or read the written interview. The audio files and the written interview will be shredded or permanently deleted within 5 years after the study is finished. There is a potential risk of loss of confidentiality in all email, downloading, and internet transactions.

### *Risk of Loss of Anonymity*

A possible risk in this study is a loss of anonymity. When the interview is written down, your name or any identifying information will not be used. The results of the study will be reported in scientific magazines or journals but your name or any other identifying information will not be included. To prevent someone from figuring out who you are from the stories you tell, names, gender, and locations will not be used or will be disguised.

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*Risk of Coercion*

Participation in this study is completely voluntary. There is no pressure to participate in this study. Deciding to participate or not to participate in this study will in no way impact your relationship with family or friends of the researcher or the agency, church, or organization allowing recruitment. There is also no penalty for withdrawing from this study. No one but the researcher will know if you decide or do not decide to participate in this study.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. There may be no benefits to you for participating in this study. If you would like to know the results of this study we will mail them to you.\*

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman’s University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at [IRB@twu.edu](mailto:IRB@twu.edu).

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Signature of Participant

---

Date

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\*If you would like to know the results of this study tell us where you want them to be sent:

Email: \_\_\_\_\_

or

Address:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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APPENDIX D

Interview Guide

## Interview Guide

<b>Research Question</b>	<b>Introductory Question</b>	<b>Potential Probing/Follow-up Questions</b>
What are patients' storied decisions about choosing to take medications for CHF?	Tell me the story of managing your heart failure with medications.	What is one thing that stands out? Tell me more about... How do you feel about... What are some of your reasons for...?
<b>Research Aims</b>	<b>Potential Interview Questions</b>	
To describe how individuals comprehend medication adherence and nonadherence.	What do you think about the most when you think of taking medications for CHF?  Do you remember a time when you experienced conflict between how the doctor says to take a medication and how you felt was best to take it?	Can you describe in as much detail as possible the experience you mentioned?
To identify the role of decision-making in medication adherence.	Tell me about a time that you chose not to take one of your CHF medications.	Do you any other examples of this?
To elicit descriptions regarding how individuals make decisions regarding medication adherence	How did you come to a decision about whether or not to take the medication?  Describe your daily medication taking routines to me.	Tell me more about what influenced your medication decision? How satisfied were you with your decision? What do you think about that?

## APPENDIX E

### A Pilot Study to Evaluate Recruitment Feasibility Questionnaire

Project Title: A Pilot Study to Evaluate Recruitment Feasibility Questionnaire

*The return of your completed questionnaire constitutes your informed consent to act as a participant in this research study.*

1. How old are you? \_\_\_\_\_
2. Male \_\_\_\_\_ Female \_\_\_\_\_
3. How would you classify yourself?  
White \_\_\_\_\_  
African American \_\_\_\_\_  
Hispanic \_\_\_\_\_  
Asian \_\_\_\_\_  
other \_\_\_\_\_
4. Is English your primary language? Yes \_\_\_\_\_ No \_\_\_\_\_
5. Highest level of education:  
High school or equivalent \_\_\_\_\_  
College- 2 years or less \_\_\_\_\_  
Bachelor's Degree \_\_\_\_\_  
Graduate degree \_\_\_\_\_
6. What is your current marital status?  
Married \_\_\_\_\_  
Single \_\_\_\_\_  
Widowed \_\_\_\_\_
7. What is your employment status?  
Employed \_\_\_\_\_  
Unemployed \_\_\_\_\_  
Retired \_\_\_\_\_  
Unable to work \_\_\_\_\_
8. Do you use the Internet? Yes \_\_\_\_\_ No \_\_\_\_\_
  - a. If yes, which of the following are you comfortable using the Internet for?
    - i. Check email \_\_\_\_\_
    - ii. Respond to email \_\_\_\_\_
    - iii. Complete a survey \_\_\_\_\_

- iv. Search for information \_\_\_\_\_
- v. Read or post to a blog \_\_\_\_\_
- vi. Look up a website \_\_\_\_\_

9. Do you take medications for heart failure also called congestive heart failure (CHF)?

Yes\_\_\_\_\_ No \_\_\_\_\_

If you answered yes, please complete the following questions.

a. Do you take these medications daily?

Yes\_\_\_\_\_ No \_\_\_\_\_

b. Are there times when you don't take your medications?

Yes \_\_\_\_\_ No \_\_\_\_\_

c. Would you be willing to participate in a research study about how people make decisions about heart failure medications?

Yes \_\_\_\_\_ No \_\_\_\_\_ Maybe \_\_\_\_\_

APPENDIX F

Participant Eligibility Screening Tool

Participant Eligibility Screening Tool  
 Project Title: Making Medication Adherence Decisions: Stories from Older Adults taking  
 Medications for Congestive Heart Failure

Date	
Research Number	

Eligible to participate in study?                      YES                      NO

	Inclusion Criteria	Yes	No
1.	Individuals age 65 and older	<input type="checkbox"/>	<input type="checkbox"/>
	AGE:		
2.	Take at least two daily medications for CHF	<input type="checkbox"/>	<input type="checkbox"/>
	2.a. What medications do you take for your heart?		
	2.b. Which medications do you take for your congestive heart failure?		
3.	Self-administer daily medications	<input type="checkbox"/>	<input type="checkbox"/>
4.	Have experience making a decision not to take a CHF medication or to take a CHF medication differently than prescribed	<input type="checkbox"/>	<input type="checkbox"/>
5.	Live independently in the community setting	<input type="checkbox"/>	<input type="checkbox"/>
6.	Able to speak and read English	<input type="checkbox"/>	<input type="checkbox"/>
7.	No history of a prior neurological event or other factor that could cause an inability to effectively answer interview questions.	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX G

Demographic Data Collection Form

Participant # \_\_\_\_\_

Date: \_\_\_\_\_

Project Title: Making Medication Adherence Decisions: Stories from Older Adults taking Medications for Congestive Heart Failure

### Demographic Data Collection Form

1. How old are you? \_\_\_\_\_

2. \_\_\_\_\_ Male          \_\_\_\_\_ Female

3. How would you classify yourself?

- \_\_\_\_\_ White
- \_\_\_\_\_ African American
- \_\_\_\_\_ Hispanic
- \_\_\_\_\_ Asian
- \_\_\_\_\_ other \_\_\_\_\_

4. Is English your primary language? Yes \_\_\_\_\_ No \_\_\_\_\_

5. Highest level of education:

- \_\_\_\_\_ High school or equivalent
- \_\_\_\_\_ College- 2 years or less
- \_\_\_\_\_ Bachelor's Degree
- \_\_\_\_\_ Graduate degree

6. What is your **current** marital status?

- |               |                 |
|---------------|-----------------|
| _____ Married | _____ Divorced  |
| _____ Single  | _____ Separated |
| _____ Widowed |                 |

7. What are your living arrangements?

- Live alone
- with significant other/friend
- with family member
- with spouse
- other \_\_\_\_\_

8. What is your **current** employment status? Check all that apply

- Employed
  - Part-time
  - Full-time
- Unemployed
- Retired
- Unable to work due to a disability
- Briefly explain \_\_\_\_\_

9. What is your annual income (or combined annual income if you have a spouse)?

- 0 to 30,000
- 31,000 to 50,000
- 51,000 to 60,000
- 60,001 to 70,000
- 70,001 to 80,000
- 80,001 to 90,000
- 90,001 to 100,000
- Greater than 100,001
- Do not want to answer

1. Where does the majority of your income come from? Check all that apply.

- Employment
- Social Security
- Pension
- Retirement/Savings/Stocks
- Other \_\_\_\_\_
- Do not want to answer

2. How do you pay for your healthcare? Check all that apply

- Private Insurance
- Medicare
- Medicaid
- Drug Prescription Plan
- Out of pocket

3. Do you communicate with your physician or healthcare provider by Internet or online patient portal?

- YES       NO

4. Please check if you have or have had any of the following:

- Heart Attack
- Diabetes
- Hypertension
- Stroke
- Kidney Disease
- Poor Vision/Contacts/Glasses
- Difficulty Hearing
- Reduced mobility
- Depression
- COPD/Emphysema/Asthma
- Fatigue/Trouble sleeping

\_\_\_\_\_ Other please describe

---

5. Do you feel like your CHF is well controlled?

\_\_\_\_\_ YES          \_\_\_\_\_ NO

6. Please check if you have or have had any of the following symptoms. Check all that apply.

\_\_\_\_\_ Shortness of breath with exercise

\_\_\_\_\_ Shortness of breath at rest

\_\_\_\_\_ Cough

\_\_\_\_\_ Difficulty sleeping without adding more pillows under the head

\_\_\_\_\_ Fluid buildup or Swelling (such as ankles, hands, belly)

\_\_\_\_\_ Sudden weight gain

\_\_\_\_\_ Congested lungs

\_\_\_\_\_ Tiredness or fatigue

\_\_\_\_\_ Drowsiness during daytime hours

\_\_\_\_\_ Fast or irregular heart beat

\_\_\_\_\_ Chest pain

\_\_\_\_\_ with exercise

\_\_\_\_\_ while resting

7. How many different medications do you take each day?

\_\_\_\_\_

8. When do you take medications? Check all that apply.

\_\_\_\_\_ morning          \_\_\_\_\_ noon

\_\_\_\_\_ afternoon/evening          \_\_\_\_\_ bedtime

10. Below, list the medications you take each day.

To verify this form was completed by the study participant, please initial here \_\_\_\_\_.

APPENDIX H  
Curriculum Vitae

## Curriculum Vita

### **Rebecca Meraz, MSN, RN, CCRC**

#### **Education**

- 2005                      Master of Science in Advanced Nursing Leadership  
Baylor University School of Nursing  
Dallas, TX
- 1994                      Bachelor of Science in Nursing  
Baylor University  
Waco, TX

#### **Professional Certifications**

- 1994- Present              Licensed Registered Nurse, Texas State Board of Examiners
- 2002- Present              Association of Clinical Research Professionals (ACRP) Clinical  
Research Coordinator Certification
- 1992- Present              Basic Life Support
- 1995- 2013                  Advanced Cardiac Life Support

#### **Professional Experience**

##### Experience in Education

- 2014-Present              Clinical Assistant Professor  
Louise Herrington School of Nursing, Baylor University  
Dallas, TX
- 2012- 2015                  Graduate Research Assistant  
Texas Woman's University, School of Nursing  
Denton, TX
- 2011- 2014                  Professor of Nursing  
El Centro College, Health and Legal Studies Department  
Dallas, TX
- 2007- 2014                  Adjunct Health Science Professor, Online instructor

	Kaplan University Fort Lauderdale, FL
2010- 2012	Adjunct Faculty, Online instructor Axia College Phoenix, AZ
2005- 2011	Professor of Nursing Collin College, Health Sciences Department McKinney, TX
2006- 2010	Part-time Nursing Clinical Examiner Excelsior College Albany, NY Administer a clinical skill examination to students seeking a degree in nursing.
2007- 2009	Adjunct Faculty Drexel University NCLEX Excel Prep Course Drexel University Philadelphia, PA Teach a 4 day NCLEX review course to graduate nursing students.
Other Professional Experience	
2005- 2011	Clinical Research Nurse Baylor Research Institute Baylor University Medical Center Dallas, TX
1999- 2005	Research Data Manager and Research Coordinator Tyler Cardiovascular Consultants Tyler, TX
2004- 2005	Graduate Research Assistant Baylor University School of Nursing Dallas, TX
2002- 2004	Research Quality Assurance and Compliance Auditor Baylor Research Institute Baylor University Medical Center Dallas, TX
1997- 1999	ICU Nurse (PRN) East Texas Medical Center Jacksonville

Jacksonville TX

1996- 1999

Clinic Nurse and CVICU Nurse  
East Texas Medical Center  
Tyler, TX

1995- 1996  
Educator

Interventional Cardiology Research Clinician and Patient  
HeartPlace Cardiology  
Dallas, TX

1994- 1995

CCU Nurse  
Baylor University Medical Center  
Dallas, TX

### **Publications, Research, and Other Scholarly Activities**

#### Publications:

Caldwell, R., **Meraz, R.**, & Sweeney, R. . Homeless no more: A Christ-centered, comprehensive homeless recovery program. *Journal of Christian Nursing*, accepted for publication

Restrepo, E, & **Meraz, R.** (2015). Development of an online data applications course using an interprofessional education model. *Nurse Educator*, 40(4):E1-4. doi: 10.1097/NNE.0000000000000130

Restrepo, E., Liu, F., & **Meraz, R.** (2013). Prevalence of Pre-Pregnancy Obesity in Urban and Rural Texas. *Communicating Nursing Research*, 46387.

#### Program Grants:

Texas Nursing Innovation Grant “Geriatric Competency Validation Toolbox for New Nurse Graduates: Utilization of DEU’s and Collaborative Clinical Partnerships for Development and Validation.” Grant team member, Louise Herrington School of Nursing, Dallas, TX. Funded fall 2014.

Department of Health and Human Services, Health Resources and Services Administration Grant (HRSA- #D09HP25021.) “Health Informatics as a Bridge to the Underserved: Primary Care Strategy.” Grant team member to develop curriculum for a post-master’s certificate program in informatics, Texas Woman’s University, PI Gail Roux. Funded spring 2012

Nursing Innovation Grant “The Texas Concept-Based Nursing Curriculum Project” for development of concept based curriculum at the ADN level. Faculty Expert in designing a concept based curriculum for Texas ADN programs, Funded 2012.

Scholarly Activities:

New course development for NURS 6903, Data Applications for Health Promotion

**Presentations**

Restrepo, E., Liu, F., **Meraz, R.** Pre-Pregnancy Weight Patterns and Pregnancy Outcomes. Presented at Southern Nursing Research Society Annual Meeting: Expanding Networks of Knowledge for Healthcare Innovations. Little Rock, AR, February, 2013 (*refereed*)

Restrepo, E., Liu, F., **Meraz, R.** Prevalence of Pre-Pregnancy Obesity in Urban and Rural Texas. Presented at Western Institute of Nursing 46th Annual Communicating Nursing Research Conference. Anaheim, CA, April, 2013 (*refereed*)

**Meraz, R.** An Interprofessional Model for Technology in Practice. Poster presentation at Sigma Theta Tau International Honor Society for Nursing 42<sup>nd</sup> Biennial Convention. Indianapolis, IN, November, 2013.

**Meraz, R.** An Interprofessional Model for Technology in Practice. Poster presentation at Texas Woman's University Student Creative Arts & Research Symposium. Denton, TX, April, 2014.

**Academic Recognitions**

2013                    Rising Star in Research by Sigma Theta Tau International Honor Society of Nursing

**Professional Memberships**

2005- Present    Sigma Theta Tau International Honor Society of Nursing, Eta Gamma chapter  
2005- Present    National League of Nursing  
2002- Present    Association of Clinical Research Professionals

**Professional Service to the Institution**

Baylor University

2016                    University Curriculum Committee- Member  
2016                    Faculty Organization- Chair Elect  
2016                    Committee on Committees- Chair  
2015                    Department Curriculum Committee- Chair Elect  
2014                    Department Curriculum Committee- Member  
2014-2016          Faculty advisor to class of December 2016  
2014-present      Special Task force: Concept Based Curriculum Development- Member

El Centro College

2011-2013          Member Research and Evaluation Committee

#### Collin College

- Member and chair of department Curriculum Committee
- Member of department Simulation Committee
- Member and chair of department Student Affairs Committee
- Member of department Testing Committee
- Member of college Emergency Communications Committee charged with developing and implementing a plan for all department classes to be taught online in case of an emergency.
- Academic advising for nursing students
- Nursing department senior level coordinator
- Member of search committee for health science prospective faculty
- Member of department Systematic Evaluation Committee charged with maintaining NLNAC accreditation standards
- Member of department Service Learning Planning Committee
- Member of Center of Excellence Advisory Committee

#### **Professional Service to the Community**

2005- Present	Volunteer church instrumentalist, First Baptist Church Prosper, Prosper TX
2012	Volunteer cabin nurse, Prosper ISD Rogers Middle School Science and Nature camp, SkyRanch, Van, TX.
2006- 2012	Volunteer Summer Camp Nurse, Student Camps, Bridgeway Baptist Church, Prosper, TX
2010-2011	Volunteer Camp Nurse, North Texas Baptist Area Children's Summer Camp, Lindale, TX.
2010	Volunteer judge, National Christian Forensics and Communications Association Speech and Debate Tournament
2009	Volunteer Collin College nursing representative to Career Day, Webb Elementary School, McKinney, TX.
2008, 2010	Volunteer Flu shot clinic nurse for City of McKinney employees sponsored by McKinney Medical Center, McKinney, TX
2007-2010	Volunteer at Collin College Community Health Fair, McKinney, TX.

## Teaching

Undergraduate courses taught at Baylor University

NUR 3225	Professional Nursing Practice: Care of Med Surg Needs (clinical)
NUR 3414	Introduction to Professional Practice (skills lab)
NUR 4338	Analysis and Synthesis of Complex Human Needs
NUR 3314	Health Assessment

Graduate courses taught at Texas Woman's University:

NURS 6903	Data Applications for Health Promotion
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Undergraduate courses taught at El Centro College:

RNSG 2460	Clinical-RN Training (3)
RNSG 2562	Clinical-RN Training (4)
RNSG 1301	Pharmacology in Nursing (online)
RNSG 1311	Pathophysiology for Nurses (online)

Undergraduate courses taught at Kaplan University:

HS111	Medical Terminology (online)
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Undergraduate courses taught at Axia College:

SCI162	Health and Wellness (online)
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Undergraduate courses taught at Collin College:

RNSG 1219	Integrated Nursing Skills I
RNSG 1360	Foundations of Nursing Practice
RNSG 1523	Introduction to Professional Nursing
RNSG 2535	Integrated Client Care Management
RNSG 2207	Transition to Nursing Practice
RNSG 1561	Clinical- Adult Health
HPRS 1271	Intro to U.S. Health Care (online)

## Mentoring

2017	Nurse Educator Preceptor for MSN student from University of Texas, Tyler Nurse Educator Preceptor for MSN student from University of Texas, Arlington
2016	Nurse Educator Preceptor for MSN student from University of Arkansas, Fayetteville Nurse Educator Preceptor for MSN student from Texas Woman's University, Denton, TX

## Professional Development

2013	Sigma Theta Tau International Honor Society for Nursing 42 <sup>nd</sup> Biennial Convention. Indianapolis, IN.
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- 2010 Southern Nursing Research Society, 24<sup>th</sup> Annual Conference, Austin, TX
- 2010 Ethical Decision Making in Research, Home study course
- 2010 Clinical Trials: Considerations for Women and Minorities, Webinar, Association for Clinical Research Professionals (ACRP)
- 2010 Conducting Culturally Sensitive Psychological Research, Webinar, ACRP
- 2009 Good Clinical Practices in Research, Baylor Research Institute, sponsored by Medtrials, Dallas, TX
- 2008 Nursing in Texas: A Regulatory Foundation for Safe Practice, Texas Board of Nurses, Austin, TX
- 2007 Effective Testing and Item Writing Workshop, sponsored by Assessment Technologies Institute (ATI) Kansas City, MO
- 2006 National League of Nursing Educators Annual Symposium, New York, NY
- 2005 Boot Camp for New Nurse Educators, sponsored by DI Associates, Albuquerque, NM