

EMOTION REGULATION AND ILLNESS PERCEPTIONS IN AFRICAN
AMERICAN WOMEN WITH HEART FAILURE

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ABSTRACT

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African American women with heart failure (HF) are recognized to have compounded stressors that augment the strain of disease self-management and heighten the occurrence of negative health events. Emotion regulation, the experiencing, processing, and modulating of emotional responses, is required to facilitate adherence to HF self-management in the face of stressors. Research has identified relationships between emotional and physical health in African American women, but less is known about how illness perceptions and emotion regulatory capacity affect adherence and unanticipated negative health events. Thus, this prospective observational study examined emotion regulation, illness perceptions, and adherence to medications, exercise, and diet in African American women with HF.

An integration of the common sense model of illness and process model of emotion regulation guided the project. **Aims:** The study examined the: 1) associations between psychological factors and emotion regulation, 2) relationships of contributing factors and illness perceptions with emotion regulation, and 3) effects of illness perceptions and emotion regulation on adherence and negative health events.

Instruments: Socio-demographic, health, and medical record data, Perceived Stress, Hospital Anxiety and Depression, Attention Function Index, Illness Perception Questionnaire–Revised, Difficulties in Emotion Regulation (DERS), and Medical Outcomes Adherence Scales were included. **Methods:** A descriptive correlational

design was used. Data analysis involved descriptives, regression, and path models.

Procedure: Patients completed intake and follow-up interviews 30 days later. Medical records were reviewed 90 days post-recruitment. **Results:** 54 African American women with HF ages 49 to 84 years participated. Aim 1 findings demonstrated significant relationships among age, education, income, clinical severity, and stress. Age ($\beta = -.03$) and stress ($\beta = .06$) predicted increased difficulties with emotion regulation. Aim 2 findings showed relationships between younger age and increased DERS scores ($\beta = -.02$). In Aim 3, the only significant relationship discovered was between New York Heart Association functional classification and negative health events. No associations were revealed between predictors and adherence behaviors. **Limitations:** Limited follow-up time, small sample size, and measurement issues impacted generalizability of the study's findings. **Implications:** It is essential that care providers consider individualized illness perceptions and emotion regulatory processes when determining how to best support patients' self-management. Current information for practitioners to support African American women with HF is limited. Findings demonstrated that African American women in this sample experienced high numbers of negative health events. It is necessary to understand how cognitive and emotional perceptions impact health outcomes in vulnerable populations such as African American women with HF. Further, research examining larger samples is warranted to better understand interactions between illness perceptions and emotion regulation in the presence of chronic illness in this population.

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Chapter 1: Introduction

To manage their disease, heart failure (HF) patients must conscientiously adhere to a complex medical regimen that includes multiple medications, dietary restrictions, and prescribed exercise. Improving adherence is critical among patients in the United States with HF, a vulnerable population of 5 million people (Go et al., 2013). Improving adherence has the potential to reduce the costly 24 billion dollars spent annually on direct healthcare expenses (Heidenreich et al., 2011), which are expected to triple over the next 20 years (Heidenreich et al., 2011). Notably, poorer outcomes are highest in minority populations, particularly in African American patients with HF (Adams et al., 2013; Wu et al., 2010).

African American patients with HF experience a greater risk of negative health events than Caucasian patients with HF (Adams et al., 2014; Rathore et al., 2003). In addition, African Americans are highly vulnerable to social stressors, such as lower socioeconomic status, which negatively impact health (Schulz et al., 2000). The combination of increased vulnerability to social stressors, poorer health outcomes, and the relative lack of empirical research conducted with African American patients to date (George, Duran, & Norris, 2014), makes research in this population critical.

African Americans with HF are a particularly vulnerable population (Wu et al., 2010). Aversive stressors such as limited income, compounded with complex disease management create strain beyond the scope of the disease, which may alter illness management prioritization (Gebreab et al., 2012). Compounding problems with adherence are depression (Luyster, Hughes, & Gunstad, 2009; Song, 2009) and anxiety (Luyster et al., 2009; Olafiranye, Jean-Louis, Zizi, Nunes, & Vincent, 2011), which are

1.3 times more prevalent in African American women than in white women (Bromberger, Harlow, Avis, Kravitz, & Cordal, 2004; Moe & Tu, 2010). The recognition of factors leading to HF re-hospitalizations and non-adherence for African American women needs to expand beyond clinical factors to include sociopsychological factors such as emotion regulation and illness perceptions.

Emotion regulation, the experiencing, processing, and modulating of emotional responses (de Ridder, Geenen, Kuijer, & van Middendorp, 2008), is necessary to manage the emotional stressors common to patients with HF. A better understanding of the role of emotion regulation in adherence and the use of healthcare services is essential to making gains in improving HF self-management. This chapter provides an overview of how HF outcomes may be impacted by how patients process cognitive and emotional stimuli and by the concurrent illness environment. In particular, this introduction focuses on African American women with HF in regards to the outcomes of adherence and negative health events.

Outcomes of HF: Adherence and Negative Health Events

Adherence is the persistent maintenance of a prescribed behavior (Cohen, 2009; DiMatteo, Haskard, & Williams, 2007), and it is a key predictor of negative health events in HF patients (American Heart Association, 2010; Esposito, Bagchi, Verdier, Bencio, & Kim, 2009; Vasan & Wilson, 2012; Wu et al., 2009). Adherence for HF patients means persistently following disease management guidelines to mitigate exacerbations of HF. These guidelines include eating a physician-directed diet, exercising, and taking prescribed medication (American Heart Association, 2010).

Medication adherence is a significant predictor of time to negative health events in the HF patient population (Wu et al., 2010; Wu, Moser, Chung, & Lennie, 2008). With a HF diagnosis, negative health events are typically measured in terms of the amount of time until a first healthcare utilization event such as a visit to the emergency department or hospitalization, or until death occurs.

Many factors influence the level of adherence and healthcare utilization for patients with HF. Adherence is lower and healthcare utilization is higher for patients who are African American (Wu et al., 2010), female (Williams, 2009), older (Karasek et al., 2012), lower income (Roe-Prior, 2007), and less formally educated (Hawkins, Jhund, McMurray, & Capewell, 2012). Adherence is also lower for patients with higher disease severity (Karasek et al., 2012), and who experience depression and anxiety (Luyster et al., 2009), carry more life stressors (Gebreab et al., 2012), have negative perceptions about their illness and its control (Chen, Tsai, & Chou, 2011), and utilize maladaptive emotion regulation strategies (Karademas, Tsalikou, & Tallarou, 2011). Healthcare utilization and poorer adherence are greater among African American patients than among Caucasian patients even after controlling for age, gender, education, and disease severity (Adams et al., 2013; Wu et al., 2010). Both patients' illness perceptions and the illness environment contribute to issues with severity, adherence, and healthcare utilization. Further, there may be distinct differences in the illness environment and how it is perceived by vulnerable populations such as African American women with HF.

Primary Psychological Factors Contribution to Poor Outcomes in HF

Illness perception. The role of illness perceptions in self-regulation and adaptive behavioral outcomes is well documented (Chen et al., 2011). From the ‘common sense’ theoretical perspective, illness perceptions reflect underlying cognitive representation components that include identity, cause, timeline, consequences, control, illness coherence, and emotional representations (Leventhal, Diefenbach, & Leventhal, 1992). This project focuses on the illness coherence and control components of the cognitive representations of illness.

Illness perception control is an indication of the potential for the illness to be managed through personal or treatment methods. Illness control is likely also impacted by other factors such as anxiety (Luyster et al., 2009; Olafiranye et al., 2011), depression (Luyster et al., 2009; Song, 2009), and stress (Olafiranye et al., 2011). Illness coherence refers to the patient’s understanding of their illness and whether or not it makes sense to them (Abubakari et al., 2012). Associations between illness perceptions and adherence behaviors in patients with chronic illness are evident, but the relationships between adherence and components of illness perceptions vary greatly between illness populations (Kucukarslan, 2012). Specifically, relationships between illness coherence and control are not well documented in an HF-specific population in regards to adherence or negative health events.

Patients experiencing negative perceptions of their illness also tend to experience higher psychological burdens (Luyster et al., 2009). Moreover, they are less likely to adhere to treatments (Kucukarslan, 2012). As African American women may be exceptionally vulnerable to psychological factors, it is important to consider how

these may relate to perceptions of illness coherence and controllability as well as how they may relate to emotion regulation.

Emotion regulation. Emotion regulation is the experiencing, processing, and modulating of emotional responses (de Ridder et al., 2008), and it is related to the capacity to inhibit impulses—a characteristic that is essential for adherence to HF regimens. Empirical literature regarding emotion regulation and health outcomes is limited in patients with HF. It is recognized that emotion regulation is associated with heightened aversive affect and illness perceptions that negatively impact adherence to disease management regimens (Gross & Thompson, 2006; Leventhal et al., 1992). The role of emotion regulation, although recognized as essential for modifying adherence behaviors (Karademas et al., 2011), has not been identified as a contributing factor of poor adherence in HF patients. Understanding the impact of emotion regulation and illness perception on negative health events and adherence has the potential to broaden understanding of factors that may contribute to less positive clinical outcomes. Such knowledge is essential to making gains in improving HF self-management and is consistent with the common sense model of illness (Leventhal et al., 1992).

Demographic Contributors to Poor Outcomes in HF

Demographic, clinical, and psychological factors are also known contributors to poor outcomes in patients with HF.

Race. African American patients use greater urgent care resources with rates of HF readmissions far exceeding those of Caucasians (Menash, Mokdad, Ford, Greenlund, & Croft, 2005; Philbin & DiSalvo, 1998; Roe-Prior, 2007; Wu et al., 2010). There is less information about this vulnerable population, but available evidence

reveals 32% lower rates of medication adherence and earlier negative health events as compared to Caucasian patients (Wu et al., 2010). Gaps remain in the literature on HF outcomes and emotion regulation in African Americans. More information is needed to understand the factors that influence adherence in African American patients with HF, including broadening knowledge about illness perceptions and emotion regulation.

Sex. Women with HF incur greater expenses related to hospitalizations (Philbin & DiSalvo, 1998) and have longer hospital stays (Fonarow et al., 2009), despite having similar mortality up to 90 days post-hospitalization and similar quality of in-hospital care as compared to men (Fonarow et al., 2009). They also have comparatively higher rates of psychological distress than men (McGrady, McGinnis, Badenhop, Bentle, & Rajput, 2009). Notably, women are underrepresented in studies of HF (Fonarow et al., 2009), yet have unique problems with adherence to treatment regimens and negative health events, which are not clearly understood.

African American women with HF are more susceptible to unanticipated exacerbations (Hussey & Hardin, 2005; Wu et al., 2010), and experience greater use of episodic care such as emergency department use and hospital admissions, compared to Caucasian patients with HF (Karasek et al., 2012; Roe-Prior, 2007; Wu et al., 2010). Additionally, there are indications that African American women experience greater rates of depression (Bromberger et al., 2004; Evangelista, Ter-Galstanyan, Moughrabi, & Moser, 2009) and anxiety (Evangelista et al., 2009) than Caucasian women, both when healthy and with HF (Bromberger et al., 2004; Evangelista et al., 2009). It is unknown how these higher rates of psychological distress impact adherence and negative health events in African American woman. Understanding the link between

negative health events and heightened non-adherence for African American women must expand beyond known clinical factors to include sociopsychological factors.

Age. Advancing age is predictive of both hospitalizations and mortality, with the risk of hospitalizations and mortality increasing with each subsequent year of age (Karasek et al., 2012). Age is the strongest predictor of avoidable hospitalizations in patients with HF (Bagchi, Stewart, McLaughlin, Higgins, & Croghan, 2011). Despite the clear link between age and outcomes in patients with HF, there is little information on the combined effects of age, race, and gender.

Income and education. The high cost of HF care challenges patients with low incomes and is shown to lead to increased urgent care use (Roe-Prior, 2007). Income is the amount of financial means that an individual has access to regularly (Hawkins et al., 2012), both independently and through familial relations (e.g., household income). Low income also predicts the prevalence of HF (Menash et al., 2005) and the number of hospitalizations those patients experience (Roe-Prior, 2007).

Education refers to the structured life experiences targeted at increasing knowledge or influencing attitudes (World Health Organization, 2014). Individuals with less than a high school education typically have more risk factors for heart disease, regardless of race or ethnicity (Menash et al., 2005). Patients with less education also experience more severe disease burden (Menash et al., 2005), visits to the emergency department (Roe-Prior, 2007), and readmissions and hospitalizations, as compared to patients with higher levels of education (Hawkins et al., 2012). Socioeconomic factors such as income and education may play a role in contributing to stressors that African American women experience (Schulz et al., 2006). It is therefore essential to consider

income and education when examining the impact that resources have on vulnerable populations (Hawkins et al., 2012; Menash et al., 2005).

Disease severity. Disease severity is the intensity of disease as measured by patient perception and/or the objective measurement of bio-physiological indications of HF disease status (DiMatteo et al., 2007). Elevated severity is associated with both mortality (Karasek, Widimsky, Ostadal, Hrabakova, & Penicka, 2012) and the use of healthcare services (Karasek et al., 2012). Although increased severity is associated with poor outcomes, less is known about whether these relationships are impacted by psychological factors such as emotion regulation.

Secondary Psychological Factors Contributing to Poor Outcomes in HF

Effective psychological function is necessary to manage the myriad of demands associated with chronic illness (de Ridder et al., 2008; Kubzansky et al., 2011).

Cognitive function. Directed attentional capacity, a component of cognitive function, is required for focus and concentration and becomes fatigued with sustained effortful activity (Cimprich, 1992; Moser, Most, & Simons, 2010), such as inhibiting reactivity to emotional distress (Pessoa, Padmala, Kenzer, & Bauer, 2012). Likewise, emotion regulation is also needed to maintain the cognitive effectiveness necessary for adherence, such as inhibiting behavioral impulses and making good decisions like seeking medical support when needed (Gross, 2001; Karademas et al., 2011). This relationship between emotion regulation and cognitive function is pivotal to understanding adherence to HF regimens.

Depression and anxiety. Important to patients with HF, depression can be predictive of both non-adherence and negative health events (Adams et al., 2013; De

Jong et al., 2011; Luyster et al., 2009; Olafiranye et al., 2011; Song, 2009). Depression refers to the sustained feelings of discouragement, sadness, hopelessness, or disinterest in general life (Anxiety and Depression Association of America, 2014). Anxiety is defined as an unpleasant emotional reaction to stress (Anxiety and Depression Association of America, 2014).

Difficulties with emotion regulation may lead to heightened negative affect that also contributes to less effective illness management behaviors (Agency for Healthcare Research and Quality, 2010). Minimal empirical research exists to explain the relationships between emotion regulation and psychological distress, however patients with psychological distress are less likely to use adaptive emotion regulation skills (Ehring, Tuschen-Caffier, Schnülle, Fischer, & Gross, 2010) and have associated difficulties with emotion regulation (Kemeny et al., 2012; Kubzansky et al., 2011). Individuals instructed to use less adaptive emotion regulation (suppression) experienced greater anxiety than those instructed to use reappraisal techniques (Hofmann, Heering, Sawyer, & Asnaani, 2009).

Stress. Stress, an individual's perception of the degree to which situations cause tangible and intangible harm, can have negative physiological and emotional consequences (Cohen, Kamarck, & Mermelstein, 1983; Ebrecht et al., 2004; Schulz et al., 2006). Thus, stress can also contribute to the development of depression and anxiety (Gross, 2001; Saxena, Dubey, & Pandey, 2011) and increase the demand on an individual's capacity to regulate emotions (Gross, 2001). Furthermore, perceived stress may exhibit a carryover effect that impacts illness perceptions and outcomes in patients with HF. African American patients report that aversive stressors make prioritization of

managing complex disease increasingly difficult (Gebreab et al., 2012), which is one example of how perceived stress may impact adherence. No identified empirical literature has established a link between perceived stress in HF patients and negative outcomes.

Summary of the Problem

There is limited research targeting issues of adherence and use of healthcare services in African American women with HF. Clinical factors, such as disease severity and demographics including gender, age, income, education, and race, may contribute to how illnesses are perceived and how emotions are regulated (Bagchi et al., 2011; Daniels et al., 2006; Hawkins et al., 2012; Karasek et al., 2012; Roe-Prior, 2007; Wu et al., 2010). Additionally, psychological factors such as depression, anxiety, and stress are known predictors of poor adherence. It is recognized that African Americans exhibit higher prevalence rates of psychological distress. A better understanding of the relationships among these aforementioned outcomes and the sociopsychological factors of depression, anxiety, stress, illness perceptions, and emotion regulation in African American women with HF is therefore needed.

Purposes of the Study

This study represents an important step in advancing the science toward better understanding clinical outcomes for African American women with HF by identifying factors associated with emotion regulation that contribute to negative health events and adherence. A prospective observational study was used to examine relationships between emotion regulation and health outcomes of adherence and negative health events. The specific aims included:

- 1. Aim 1. Determine the associations between psychological factors (anxiety, stress, and depression) and emotion regulation in African American women with HF (time 1).**
 - a. Hypothesis 1: Higher levels of anxiety, stress, and depression will be associated with less effective emotion regulation.
- 2. Aim 2. Determine the associations of the contributing factors (clinical, demographic, and psychological) and illness perceptions with emotion regulation at intake (time 1) for African American women with HF.**
 - a. Hypothesis 2: Illness perceptions and emotion regulation are associated with the clinical, demographic, and psychological factors.
- 3. Aim 3. Determine the effects of illness perceptions and emotion regulation on the outcomes of adherence and negative health events (death, hospitalization, emergency department, urgent care, and unanticipated primary care visits) in African American women with HF at 30 days (time 2).**
 - a. Hypothesis 3: Less effective emotion regulation and worse illness perceptions will be associated with lower adherence and greater negative health events.

The subsequent chapters of this dissertation address these aims. In Chapter 2, a conceptual framework is discussed to aid understanding of emotion regulation and health outcomes. This framework is supported by health literature and was developed by integrating components of two theoretical frameworks. In Chapter 3, a review of the literature provides background information on emotion regulation in health research. Chapter 4 describes the methods selected to address the aims, whereas Chapter 5

reports on the study results. Finally, Chapter 6 discusses how the study findings impact what is known about emotion regulation and health outcomes. Further, discussion is included relative to practice implications, needs for further research, and study limitations.

Chapter 2: Conceptual Framework for the Study

It is recognized that managing the multiple demands of heart failure (HF) challenges the emotional balance that is essential for the maintenance of health promoting behaviors (Büssing & Koenig, 2010). Emotion regulation, the experiencing, processing, and modulating of emotional responses, is necessary but often undermined by chronic life-threatening health problems (de Ridder et al., 2008). Despite growing cross-disciplinary research that has increased our understanding of emotion regulation and its critical importance to quality of life, nursing has been slow to adopt a framework that includes this important concept for self-management of chronic illness. Using theory derivation methodology, this critical gap is addressed through the development of a conceptual framework of emotion regulation for application to HF adaptation (Walker & Avant, 2011). The adapted framework (see Figure 1), utilizing relevant health and psychology theories as a foundation, is fundamental to advancing nursing science relative to the study of emotion regulation and health outcomes.

Theoretical Background for the Study

Common sense model of chronic illness. The common sense model (CSM) of illness has been applied to chronic illness populations and accounts for an understanding of how patient's unique backgrounds contribute to individualized adaptation and variations in behavioral outcomes (Chen et al., 2011; Heydari, Ahrari, & Vaghee, 2011). The CSM recognizes that individuals create mental models or representations of their illnesses and that these representations guide health behaviors. These models encompass cognitive and emotional representations that shape illness

perceptions, including what the illness is and what it means to the person (Diefenbach & Leventhal, 1996).

Illness perceptions reflect content from underlying cognitive representations of illness that impact (and are impacted by) how emotions are regulated (Leventhal et al., 1992) and influence behavioral outcomes (Chen et al., 2011; Kucukarslan, 2012; Moss-Morris et al., 2002). Important dimensions of the cognitive representations of illness include patient perceptions about the identity of the illness and symptoms, what caused the illness, consequences of the illness to well-being, illness coherence, duration, course, and controllability (Kucukarslan, 2012; Leventhal et al., 1992). Patients differ in cognitive representations of illness, such as their perceptions of illness controllability, the belief that they can personally modify the illness course, or whether the treatments are even effective (Chen et al., 2011; Leventhal et al., 1992). When patients do not view medical treatments as effective or perceive that they personally have the ability to control the illness, they may be less likely to adhere to their medical regimens (Chen et al., 2011).

The CSM emphasizes that emotional and cognitive processing occurs interactively to impact coping behaviors (Kucukarslan, 2012). Coping, as defined in the CSM, are the actions taken to manage health threats (Leventhal et al., 1992). Emotional representations refer to the emotional responses elicited by a health threat and impact coping actions (Diefenbach & Leventhal, 1996) that can be either more or less adaptive (Fowler & Baas, 2006). For example, negative emotions can lead to adaptive learning and behaviors such as when mild anxiety provokes action, but can also be detrimental to constructive action when they are overwhelming (Diefenbach &

Leventhal, 1996). The emotional responses impact illness perceptions and may influence the developing cognitive representations of the illness (Fowler & Baas, 2006).

A limitation to the CSM framework is that emotional representations are less frequently emphasized as compared to the cognitive representations (Kucukarslan, 2012). In a systematic review, construct validity ($n = 45$ studies) of the dimensions of the cognitive representation were established with the exception of emotional representations (Hagger & Orbell, 2003). Patients who view their illness as curable or controllable may view other components (i.e., identity of the illness and symptoms, what caused the illness, consequences to well-being, illness duration and its course) as less pressing (Hagger & Orbell, 2003). Emotional representations were not included in the analysis by Hagger and Orbell (2003) because of the inconsistent inclusion of emotional representations in empirical literature. The lack of inclusion of emotional representations is unsurprising, as original versions of measurement tools did not include this component (Moss-Morris et al., 2002).

In a review of the literature, conflicting evidence was reported in more recent studies of correlations between emotional representations and adherence in cardiovascular disease ($n = 11$ studies) (Kucukarslan, 2012). Contributing to the conflicting evidence is a lack of clarity regarding the impact of emotional representations across studies. Greater attention and explication of emotional representations are needed, particularly in identifying how the process of emotion regulation impacts illness perceptions and emotional responses.

A limitation of the CSM is that the contributions of emotional responses to illness adaptation have not been fully developed. Primarily, emotional representations are not

fully integrated in empirical literature examining representations of illness (Hagger & Orbell, 2003; Kucukarslan, 2012; Moss-Morris et al., 2002). Emotional representations of illness may thus be simplified in this critically influential process (Vilchinsky, Dekel, Asher, Leibowitz, & Mosseri, 2013), which consequently reduces understanding about the contributions of emotional processing of health behaviors. Thus, the process model of emotion regulation is integrated into the framework used in this study.

Process model of emotion regulation. Emotions are complex psychological states that include “a subjective experience, a physiological response, and a behavioral or expressive response” (Hockenbury & Hockenbury, 2010, p. 353). Aversive emotions can negatively impact health outcomes, social outcomes, and are related to psychopathology when they occur at an incompatible time or intensity level (Gross & Thompson, 2006). Overwhelming emotional responses can lead to impaired mental health (Gross & Thompson, 2006; Saxena et al., 2011). The process model articulates how emotion regulation occurs to change coping outcomes during a situational stressor (Gross, 2001). Emotion regulation can be, but is not necessarily, coping or a conscious effort to solve problems (Leventhal et al., 1992).

Emotion regulatory responses are implicitly (unconsciously) and/or explicitly (consciously) experienced (Gross, 2001; Gross & Munoz, 1995). Illness perceptions, automatically activated in the illness context, impact the personal meanings that are associated with a health stressor, and set emotion regulation via response modulation to alter behavioral outcomes (Gross, 2001; Gross & Munoz, 1995; Karademas et al., 2011). Importantly, the ability to modulate emotional responses is associated with how the illness is perceived (de Ridder et al., 2008; Ehrling et al., 2010; Gratz & Roemer,

2004; Gross, 2001). Thus, illness perceptions and emotion regulation jointly influence adherence to health behaviors and negative health events (see Figure 1).

The strength of the process model of emotion regulation stems from its explanatory nature in detailing sequential processes of developing and responding to the emotional experience. The process model of emotion regulation reflects the complex processes in which emotion regulation impacts behavioral responses to stressors (de Ridder et al., 2008; Gross, 2001; Kemeny et al., 2012). The process includes situation selection, situation modification, attentional deployment, cognitive change, and response modulation (Gross, 2001). The process model of emotion regulation recognizes that there are multiple divergent emotional tendencies, which are process points where the development of emotion can take different paths representative of the individual's inclinations (Gross, 2001). These divergent tendencies impact the responding behavior or coping response (Gross, 2001). A limitation of the process model of emotion regulation is that much of the model testing has been conducted with healthy university students under experimental paradigms (Kemeny et al., 2012; Saxena et al., 2011). As such, the process model has undergone limited predictive testing relative to how it impacts health outcomes.

In summary, by combining aspects of both the process model of emotion regulation and the CSM, a more comprehensive explanatory model is possible.

Integrated framework. The integrated framework depicted in Figure 1 delineates relationships among key concepts integral to the process of adaptation to chronic illness. Demographics such as race (Karasek et al., 2012; Roe-Prior, 2007; Wu et al., 2010), and income level (Hawkins et al., 2012; Roe-Prior, 2007), in addition to

clinical and psychological factors such as stress, mental illness (Luyster et al., 2009; Song, 2009), or physical illness (Daniels et al., 2006; Hicken, Gragg, & Hu, 2011; Karasek et al., 2012), can influence the perceptions of illness, which in turn are shown to impact patient's health outcomes. These concepts and their relationships are described in the following sections.

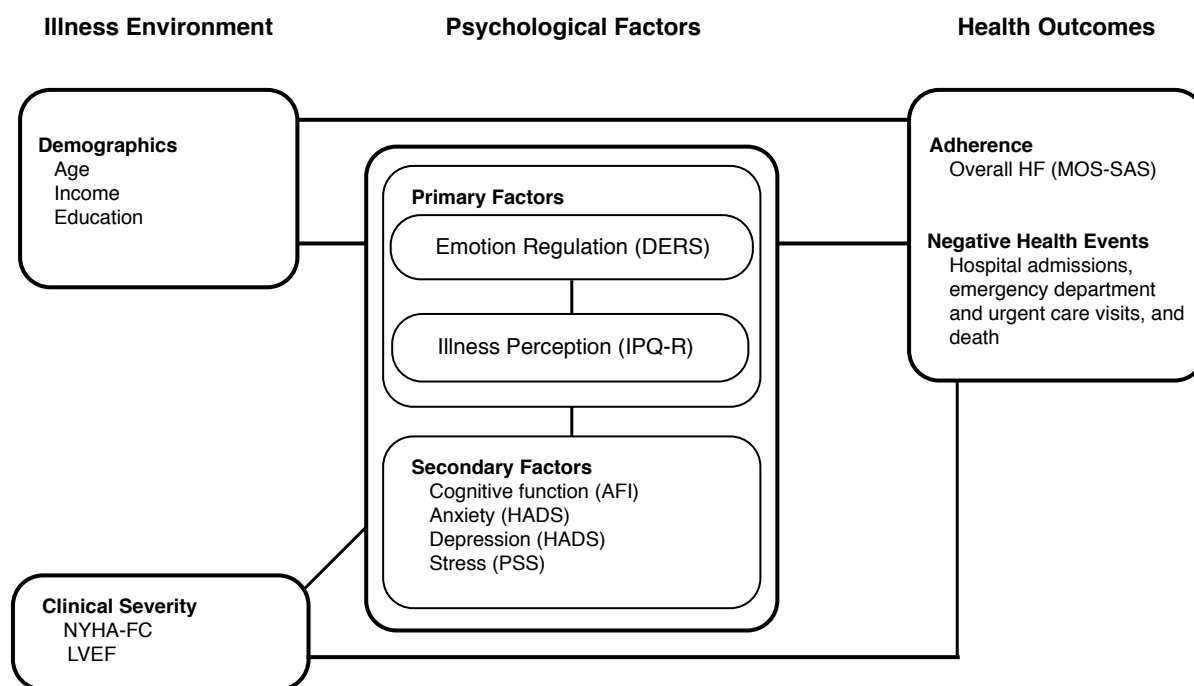


Figure 1. A model of emotion regulation, adherence, and negative health events. Adapted from "Emotion Regulation in Adulthood: Timing is Everything," by J. J. Gross, 2001, *Current Directions in Psychological Science*, 10(6), p. 214-219 and "Illness Cognition: Using Common Sense to Understand Treatment Adherence and Affect Cognition Interactions," by H. Leventhal, et al., 1992, *Cognitive Therapy and Research*, 16(2), p.143-163.

Model Concepts and Relationships

Illness environment. The illness environment comprises the situational elements that contribute to challenging and threatening circumstances (Leventhal et al., 1992). Illness environment factors, such as advancing age, adverse socioeconomic

circumstances, lower education, and increased disease severity influence illness perceptions and impact illness adaptation (de Ridder et al., 2008; Ehring et al., 2010; Shiota & Levenson, 2009). As such, these factors contribute to the clinical situation and how the illness is perceived (de Ridder et al., 2008; Leventhal et al., 1992).

Demographics. Demographics include age, sex, years of education, and income. For HF patients, age is the best predictor of avoidable hospitalizations (Bagchi et al., 2011). Sex is another important factor to consider with racial-ethnic groups who have HF. For example, African American women experience greater morbidity and poorer outcomes than African American men or Caucasian men or women (Karasek et al., 2012; Roe-Prior, 2007; Williams, 2009; Wu et al., 2010).

Components of socioeconomic status (SES) such as income, are known contributors to the use of healthcare services in HF patients (Hawkins et al., 2012; Roe-Prior, 2007). SES can encompass a wide variety of resources available to an individual (Braveman, 2010). Individuals with lower SES are at a 30–50% increased risk of developing HF and are at a higher risk of negative health events (Hawkins et al., 2012).

Significant aspects of SES in the HF population are income and education. Patients with lower education experience a higher disease burden (Menash et al., 2005), more visits to the emergency department (Roe-Prior, 2007), and readmissions and hospitalizations at a greater rate than those with higher levels of education (Hawkins et al., 2012). Income can be a proxy for access to care. Lower income, particularly in African American women, increases their perceived stress related to their illness (Schulz et al., 2006).

Clinical factors. Clinical factors, including disease severity, impact the patient's well-being. Disease severity refers to the health status of an individual relative to the specific disease (HF) (DiMatteo et al., 2007). Increased severity of HF is associated with higher mortality (Karasek et al., 2012) and increased use of healthcare services (Karasek et al., 2012). Disease severity in this population can be measured in many different ways, however the New York Heart Association (NYHA) functional classification system is widely understood and used by both researchers and clinicians (Luyster et al., 2009; Song, 2009). The NYHA functional classification value is a range from I to IV with higher scores indicating greater HF severity. Greater clinician and patient-reported NYHA functional status are predictive of poorer patient outcomes (Holland, Rechel, Stepien, Harvey, & Brooksby, 2010).

Primary Psychological Factors. Psychological factors are mental processes, including cognitive and emotional function, that are necessary to manage the myriad demands associated with chronic illness.

Illness perceptions. As a method of organizing cognitive information related to health, individuals create mental schemas to represent their illness (Hagger & Orbell, 2003). These representations are based on life experiences and patient beliefs about their illness in the context of their environment (Leventhal et al., 1992). Illness perceptions are proxies for the patient's underlying cognitive representations of the illness (Chen et al., 2011; Leventhal et al., 1992; Moss-Morris et al., 2002). These perceptions contribute to how emotions are regulated and to illness adaptation (de Ridder et al., 2008; Leventhal et al., 1992). Perceptions are influenced by both the illness environment and existing memory structure (Leventhal et al., 1992) and they can

change over time in patients with chronic illnesses (Bonsaksen, Lerdal, & Fagermoen, 2015).

Individuals may not consciously recognize their own emotional reactions and are often not aware that their emotional state is influencing their behaviors and perceptions (de Ridder et al., 2008; Gross & Munoz, 1995; Leventhal et al., 1992). Often, patients with chronic illness need to make decisions for which there are competing priorities. Cognitive representations of illnesses are key in the selection of coping responses and in the prioritization of the health threats (Chen et al., 2011; Leventhal et al., 1992). Competing priorities can create situations where choices detrimental to health are made (Yiend, 2010). Competing priorities may include decisions that carry immediate satisfaction versus decisions that would maintain treatment parameters, such as the decision to omit a medication in favor of reducing side effects.

Emotion regulation. Many chronically ill individuals, such as those with HF, must make daily lifestyle modifications that reduce quality of life and challenge their ability to cope. Such lifestyle modifications require emotional balance to maintain an optimistic outlook and to cultivate an attitude of acceptance that promotes healthy behaviors (Yiend, 2010). It is recognized that less adaptive emotion regulation is directly associated with lowered emotional well-being, less adaptive coping, and poorer physical function (Karademas et al., 2011).

Emotion regulation is required to promote situational acceptance, which is necessary for adaptation to aversive stressors—a frequent occurrence in the life experiences of patients with chronic illness (Gratz & Roemer, 2004). Emotion regulation allows patients to refocus and to make reality-based appraisals of threat-

provoking circumstances. Further, emotion regulation reduces the occurrence of distress that patients feel when there is incompatibility between expectations of how things should be versus how they actually are. Emotion regulation can also help patients to better tolerate the uncertainty of the unknown future (Hofmann et al., 2009; Moser et al., 2010).

Relationship between illness perceptions and emotion regulation. The concepts of illness perceptions and emotion regulation are represented by a reciprocal relationship. Some imprudent health behavior decisions are made based on reactions to how the individual feels; their emotional state. Thus, the ability to modulate emotional responses contributes to how the illness is perceived (de Ridder et al., 2008; Ehrling et al., 2010; Gross, 2001). Illness perceptions are impacted by, and impact, emotional regulation. Moreover, how these two major constructs jointly relate will influence behavioral adherence (Chen et al., 2011; Karademas et al., 2011).

Secondary Psychological Factors. Cognition, the mental processes associated with judgment and decision making, have been shown to be diminished in patients with HF (Almeida et al., 2012). Diminished cognitive function can make following detailed care plans difficult, and predicts poorer self-management (Dickson, Lee, & Riegel, 2011) and poorer adherence to medical regimens (Alosco et al., 2012) in patients with HF. Further, negative psychological factors such as depression, anxiety, and perceived stress, increase demands on cognitive functioning (de Ridder et al., 2008). Thus, cognitive function impacts illness perceptions and the capacity to regulate emotions, although research examining this relationship is minimal in patients with HF.

Depression, sustained feelings of discouragement, sadness, hopelessness, or disinterest in general life (Anxiety and Depression Association of America, 2014), are independently associated with negative health events in patients with HF (Song, 2009). Depressed HF patients are less adherent to medical regimens (Luyster et al., 2009; Song, 2009). Poor adherence has been attributed to depressed patients exhibiting lowered medication renewal rates for both anti-depressant and HF medications (Priest, Cantrell, Fincham, Cook, & Burch, 2011).

Anxiety, an unpleasant emotional reaction to stress, is associated with worry and may reflect responses to concerns (Anxiety and Depression Association of America, 2014; Olafiranye et al., 2011). Patients with increased anxiety and HF are less adherent to medical regimens than those without anxiety (De Jong et al., 2011; Luyster et al., 2009). Highly anxious HF patients have been reported to have a 2.2 hazard ratio of increased risk for negative health events (De Jong et al., 2011). Patients who experience depressive affect and are anxiety-prone may have heightened vulnerability to difficulties with emotion regulation.

Stress, an individual's perception of the degree to which situations cause tangible and intangible harm, can have negative emotional consequences (Cohen et al., 1983). Stress responses can provoke changes in physiological and psychological systems, placing an individual at risk for illness (King & Hegadoren, 2002; Koolhaas et al., 2011). The tangible harm of stress for HF patients is poorer health outcomes, with those individuals perceiving high levels of stress at a 1.51 higher chance of experiencing a negative health event (Chung, Lennie, Dekker, Wu, & Moser, 2011).

Health Outcomes. Associations among emotion regulation, illness perceptions, and health outcomes are not well-established in studies of African American women with HF (de Ridder et al., 2008; Ehrling et al., 2010; Evangelista et al., 2009; Kravvariti, Maridaki-Kassotaki, & Kravvaritis, 2010). Important outcomes to the HF population that were examined in this project included adherence and negative health events.

Adherence. Minimizing HF exacerbations is achieved by the patient's ability to engage in adherence behaviors (Samar, 2001). Adherence specific to HF is defined as the persistent behavioral maintenance of traditional treatments including prescribed exercise, diet, and medications (Cohen, 2009; DiMatteo et al., 2007; Heydari et al., 2011). Each of these behaviors is critical for the HF patient to minimize exacerbations and hospital readmissions (Luyster et al., 2009; Shahian et al., 2011).

In order for the patient to adhere, they need to perceive their condition as a manageable threat, understand the disease and expected behaviors, and engage in measurable behaviors prescribed by a healthcare provider (Cohen, 2009; Dickson et al., 2011). Patients with HF report general non-adherence at 16% (Alosco et al., 2012). Examining each behavior separately, medication adherence is particularly problematic in HF, with less than half of prescribed medications taken (Haynes, Ackloo, Sahota, McDonald Heather, & Yao, 2008; Wu et al., 2010; Wu et al., 2008). Adherence to diet and exercise are also uniquely challenging for patients with HF with non-adherence reported by patients at 17% and 61% respectively (van der Wal, 2006). Reasons patients report for not adhering to diet and exercise includes a lack of motivation, forgetting, changes in symptoms, and practical problems associated with the prescribed behaviors (van der Wal, 2006). Processing and managing emotions and perceptions

about the illness may impact some of these rationales. As such, it is critically important to address adherence as an outcome and to examine how difficulties with emotion regulation and illness perceptions impact this outcome.

Negative health events. Important to the successful treatment of HF patients is maximizing the amount of time before a negative health event occurs such as seeking emergent medical treatment or death (Song, Moser, Rayens, & Lennie, 2010; Wu et al., 2010). Because comorbid conditions interact with, and are extremely prevalent in the HF population, it is difficult to isolate how any specific condition contributes to negative health events. For this reason, capturing all cardiovascular causes is indicated over isolating HF-specific negative health events.

It is recognized that both adherence and negative health events are impacted by the illness environment and psychological factors. In addition to what is known in relation to these factors, the model (see Figure 1) provides a mechanism for better understanding how illness perceptions and emotion regulation are associated with these relationships. It is important to determine how emotion regulation impacts the health events that are detrimental to both the individual, and to the public impact relative to the increased use of unanticipated health services.

Conclusion

By integrating the CSM and the process model of emotion regulation, the resulting framework incorporates illness perceptions, emotion regulation, adherence, and negative health events, to enhance our understanding of behavioral outcomes in patients with chronic disease. In nursing, linking emotion regulation to adherence and negative health events may further our understanding of the cognitive and emotional

interface between chronic illness and behavioral adaptation. This framework provides an early foundation for building empirical knowledge for nursing practice, theory, and research with the potential to improve health-related quality of life outcomes for patients facing chronic illness.

Chapter 3: Review of the Literature

A literature review was conducted to examine the state of science relative to the impact of emotion regulation in chronic illness populations. In particular, this review focused on heart failure (HF) populations. Databases including PsychINFO and CINAHL were used to locate studies conducted within the last 15 years (1999–2014). Keywords included emotion regulation, patient, cardiovascular, physical health, and chronic illness. Additional articles relevant to the research questions were added through a manual search of references cited in journals. Articles were included if they focused on adults with chronic illness, were written in English, and targeted emotion regulation outcomes. Articles were excluded if the research population did not include patients with chronic physical illnesses and/or if the articles focused on the emotion regulation of the care provider or the family.

The literature review reported in this chapter was limited in focus. Although the full dissertation includes many concepts that impact negative health events and adherence, this chapter focuses on emotion regulation and health outcomes. Rationale for this limited focus include that emotion regulation has been shown to impact behaviors in healthy individuals and that empirical literature regarding emotion regulation and health outcomes has not been previously reviewed. For these reasons, a critical evaluation of literature related to emotion regulation and health outcomes in patients with chronic illness was fundamental to understanding potential relationships within the model presented in Chapter 2 (see Figure 1). Following this discussion, the review is then applied to the model of emotion regulation, adherence, and negative

health events (Gross, 2001; Leventhal et al., 1992). Also included in this chapter is a report of findings on patients with HF with an emphasis on African American women.

Results

The literature search yielded 263 articles. The abstracts of these articles were reviewed, and after excluding duplicates and those not meeting the inclusion and exclusion criteria, 11 articles remained. Most articles not meeting inclusion criteria addressed the emotion regulation of healthy populations or clinical populations with mental illness. An additional three articles were obtained from the manual search. Presentation of the results is organized into findings regarding the framework, design, methods, sample, setting, quality, and overall value of the work to this project. This is followed by a report of findings relevant to each of the variables from the model of emotion regulation, adherence, and negative health events (i.e., illness environment, psychological factors, and health outcomes).

Individual Studies: Purpose and Findings

Overall themes of the articles obtained for this integrative literature review included chronic conditions such as rheumatoid arthritis, pain, eating disorders, morbid obesity, cardiovascular diseases, Addison's disease, diabetes, and HIV. These studies are outlined in Table 1. Notably, each of these studies examined the important role of emotion in the health of individuals. Within each of the articles there were some differences in the terminology used such as emotion regulation, emotional awareness, emotional intelligence, and others. These terms all have common themes and as such, the term emotion regulation is used throughout the current study. A brief review of each article's content is initially presented. Beyond this description of the individual studies,

the subsequent sections review the findings related to the theoretical frameworks of the studies, the designs and methods, and the samples and settings. Quality of the research and value of the work to this dissertation are also highlighted.

Quality of the health outcomes research was assessed based on the pyramid of evidence, with randomized control trials rated the highest, followed by case-control, panel, and finally, cross-sectional studies (Ho, Peterson, & Masoudi, 2008). Additionally, sample size and sampling technique were used to determine generalizability. In addition, each article was also assessed for value (see Table 1) in terms of information regarding emotion regulation and representativeness to chronically ill populations (Whittemore & Knafl, 2005).

In the article by Baeza-Velasco et al. (2012), 39 women with a rheumatologic condition and 22 controls were studied in a cross-sectional design to determine differences in emotion regulation (see Table 1). In this study, the authors reported increased difficulty with emotion regulation and higher levels of depressive symptoms and trait anxiety in the rheumatologic group as compared to the control group. Comparison of control and chronic illness populations provides evidence of increased difficulties with emotion regulation and additional evidence of increased symptoms of depression and anxiety in the case group.

In another article, 58 patients with low back pain were examined in a randomized control design for mismatch in emotion regulation strategies with and without anger inducing pain impulses (Burns et al., 2011) (see Table 1). Patients were assigned to groups that were instructed to regulate emotions in two different ways while participating in an anger-inducing task. The patients showed more pain behaviors such as grimacing

when they were asked to suppress emotions as compared to when they were not told to suppress. Additionally, the patients who preferred expression exhibited more sighing when requested to suppress emotion as opposed to those who were not instructed to suppress. The patients who preferred suppression exhibited more guarding and bracing when asked to suppress as opposed to those who were not instructed to suppress. Controlling for preferred emotion regulation strategies (expression versus suppression), this study provided useful information regarding emotion regulation and anger. This evidence is strengthened by the type of design, but has limited generalizability because of the sampling technique.

The purpose of the article by Gerolimatos and Edelstein (2012) was to compare the differences in health anxiety in 86 older adults versus 119 younger adults with general health problems using a cross-sectional design (see Table 1). The younger adults as compared to older adults had higher levels of health anxiety, perceptions of illness likelihood, perceptions of negative illness consequence, anxiety sensitivity, and intolerance of uncertainty. Older adults reported higher perceived anxiety control and a greater use of the emotion regulation strategy of reappraisal, than the younger adults. Anxiety sensitivity significantly contributed to the perception of negative consequences for older adults, but not for younger adults. Anxiety sensitivity and the use of the emotion regulation strategy of reappraisal significantly contributed to perceived illness likelihood for both groups and was predicted by the number of health problems. The study reported that those with higher illness likelihood use reappraisal to manage emotions associated with the heightened levels of concern about their illnesses (Gerolimatos & Edelstein, 2012). Information regarding the differences in age group is

important in understanding illness perceptions and emotion regulation. The sampling technique minimizes generalizability of this work.

In a cross-sectional study that investigated the connection between emotion regulation and emotional overeating, Gianini et al. (2013) examined differences in 326 obese patients with binge eating disorders (see Table 1). They found that emotion regulation explained 21% of the variance in emotional overeating, and that the combination of negative affect, sex, and emotion regulation accounted for 25% of the variance in emotional overeating. Further, the remaining 75% of the variance was unaccounted for, suggesting that there are undetermined factors contributing to emotional overeating. The limited use of adaptive emotion regulation strategies and a lack of emotional clarity were the best predictors of emotional overeating. This work may be meaningful for understanding emotion regulation in the presence of a condition requiring inhibition control, such as adherence to diet in patients with HF. The larger number of participants and broader inclusion of varied racial groups strengthens this study, however the cross-sectional design and sampling technique decreases the overall generalizability of this work.

To examine if emotion regulation and coping strategies impact perceived health, 135 cardiac outpatients participated in a cross-sectional study by Karademas et al. (2011) (see Table 1). Suppression and wishful thinking diminished emotional well-being. Higher levels of suppression were related to decreased physical function and more negative emotions. Of the emotion regulation strategies of reappraisal and suppression, reappraisal was found to be the more adaptive strategy leading to enhanced emotional well-being, but did not impact general adherence. This research

provides value in understanding strategies of emotion regulation and how those strategies relate to physical function and general adherence specifically in a cardiovascular patient population. The cross-sectional design, moderate sample size, and convenience sampling make this work difficult to generalize to other populations.

Kravvariti et al. (2010) examined the association between emotional intelligence and the incidence of coronary heart disease (CHD) in 56 CHD and 56 control patients using a cross-sectional design (see Table 1). Patients with CHD expressed more negative emotions and perceived a decreased ability to regulate their emotions than patients in the control group. The sampling of participants and the lack of prospective design are limitations that impact generalizability.

In a longitudinal panel design study that spanned 17 years, Kubzansky and Thurston (2007) examined emotion regulation and the development of CHD in 6,265 individuals without CHD at baseline (see Table 1). Individuals with lowered perceived difficulty regulating their emotions had decreased odds of developing CHD over time. The large sample size, sampling techniques, and stronger study design provide for greater generalizability potential.

In a literature synthesis paper, 11 studies were included for the purpose of reviewing empirical literature that examined the connection between medication adherence and illness perceptions (Kucukarslan, 2012). Fewer studies in this article included the illness perception component of emotional representations, which captures the perceived emotional impact of illnesses. Studies reported in this article with younger patient populations reported more significant positive relationships between emotional representations and adherence than those with older populations. Overall,

there was inconsistency in reported results of emotional representations and adherence. Although not the focus of this review, this synthesis provided excellent insight into illness perceptions. It is however, rather limited in aiding in the understanding of emotion regulation. This article provides general information, but lacks additional analyses to provide synthesis of data from included studies.

To evaluate the relationship between emotion regulation and type D (distressed) personality, Messerli-Bürgy et al. (2012) reported results of a cross-sectional study of 163 cardiac outpatients (see Table 1). Maladaptive emotion regulation strategies (avoidance and distortion) were related to type D personality. Additionally, adaptive emotion regulation strategies (controlling and expression) were inversely related to social inhibition, negative affectivity, depressed mood, and partner-related stress. Adaptive and maladaptive emotion regulation knowledge is broadened in this study by demonstrating associations of the included strategies with other psychosocial concepts. Particularly relevant to this dissertation is the demonstrated connections with affect, depression, and stress.

Samar (2001) examined the relationship between emotion regulation and self-management of 90 type I diabetic patients using a cross-sectional design (see Table 1). Assimilation of emotions in thoughts, regulation of emotions, and understanding emotions were each found to contribute to self-management. This study demonstrated that regulation of emotions impacts self-management and outcomes. Valuable additions to knowledge from this study include the connection of emotion regulation with self-management and health outcomes in patients with chronic illness.

To determine how illness perceptions account for the association between attachment orientation and psychological distress, Vilchinsky et al. (2013) studied 111 acute coronary syndrome patients using a panel design (see Table 1). The study reported that general negative perceptions of illness are associated with attachment-related anxiety and depression. Associations were also discovered regarding general illness perceptions and more general symptoms of depression and anxiety. The short follow-up time and the lack of distinction between aspects of illness perceptions limit the value of this study. Narrow sample characteristics, sampling technique, and size diminish generalizability.

Warmuz-Stangierska et al. (2010) evaluated the psychological indices in 15 patients with Addison's disease, and found the patients to have moderate to severe depressive symptoms (see Table 1). They also noted that the ability to regulate emotions was low in six participants, average in eight participants, and high in just one participant. The small sample size and cross-sectional nature significantly limit the generalizability.

Willard (2006) examined the relationship of emotion regulation to medication adherence in 52 patients with HIV using a cross-sectional design (see Table 1). There was no difference found in emotion regulation in relation to gender and no association between emotion regulation and adherence in these patients. Lack of significant findings may indicate that there is no association between emotion regulation and adherence. The small sample size, sampling technique, and design may have impacted the ability to detect findings and impacts generalizability.

Comparing women with morbid obesity to those in the general population in a case-control design, Zijlstra et al. (2012) examined how emotion regulation differed between these groups and if emotion regulation was associated with emotional eating (see Table 1). Strategies of emotion regulation were not associated with any of the eating behaviors studied (i.e., emotional eating, external eating [allowing external cues to impact eating behaviors], or restrained eating). Emotional eating and external eating were associated with more negative affect and difficulty with identifying feelings. The comparison revealed less positive and more negative affect, more difficulty identifying feelings, and greater suppression of emotions in patients with morbid obesity as compared to those in the general population. Associations between eating behaviors and emotion regulation may provide direction in terms of the effect of emotion regulation on dietary adherence. A moderate sample size and the design strengthen the value of the study, however convenience sampling impacts generalizability of the results.

Overall, these articles share commonalities in the discussion of emotion and emotion regulation in the presence of chronic illness. There are many differences and similarities discussed thematically in the following section, including framework, design, methods, sample, setting, and variables of interest to this dissertation.

Table 1.

Review of Emotion Regulation Literature

Author, Year	Framework	Design	Age range (mean $\pm$ SD)	Race/ Ethnicity	Patient Population, Sampling Technique, n = (% female)	Emotion and Emotion Regulation Measures	Major Findings	Overall Value Statement
Baeza-Velasco et al. 2012	Theory of cognitive–emotional development	Cross-sectional	Case NR (52 $\pm$ 9) Control NR (54 $\pm$ 8)	NR	Rheumatologic diagnosis NR 61 (100)	Levels of Emotional Awareness Scale (LEAS) The Toronto Alexithymia Scale (TAS-20) State-Trait Anxiety Inventory (STAI) The Beck Depression Inventory, Second Edition (BDI-II)	Patients had a decreased emotional awareness and had higher depression and trait anxiety scores than controls.	Valuable information regarding emotion regulation, depression, and anxiety between case and control. Low generalizability.
Burns et al. 2011	NR	Randomized Control Trial	NR (39 $\pm$ 10)	67.2% Caucasian 15.5% African American 10.3% Hispanic 1.7% Asian 5.2% Native American	Chronic low back pain patients Convenience Sampling 58 (52)	Spielberger Anger Expression Inventory	Overall, patients attempting to suppress anger showed more pain behaviors (grimacing) during pain induction than those not told to suppress. Patients who preferred to express anger and who attempted to suppress during provocation exhibited more sighing than similar patients not told to suppress. Patients who preferred anger suppression and who attempted to suppress during provocation exhibited more guarding and bracing than similar patients not told to suppress.	Valuable information regarding emotion regulation and objective responses to induction of anger. Low generalizability.

Table 1 (cont'd)

Author, Year	Framework	Design	Age range (mean ± SD)	Race/ Ethnicity	Patient Population, Sampling Technique, n = (% female)	Emotion and Emotion Regulation Measures	Major Findings	Overall Value Statement
Gerolimos et al., 2012	Cognitive-behavioral model for understanding the development and maintenance of health anxiety	Cross-sectional	86 older adults 60–90 (NR) 119 young adults 18–30 (NR)	94% Caucasian	Non-differentiated health problems NR Sampling 205 (52)	The Short Health Anxiety Inventory The Anxiety Sensitivity Index The Intolerance of Uncertainty Scale The Emotion Regulation Questionnaire The Anxiety Control Questionnaire	Younger adults had higher levels of health anxiety, anxiety sensitivity, and intolerance of uncertainty than older adults. Older adults reported higher perceived anxiety control and use of reappraisal than younger adults. Anxiety sensitivity significantly contributed to perceived negative illness consequences for older adults, but not young adults. Anxiety sensitivity and reappraisal significantly contributed to perceived illness likelihood.	Valuable information regarding the associations between some illness perception components (illness likelihood and consequences) and emotion regulation. Low generalizability.
Gianini et al. 2013	NR	Cross-sectional	19-65 (45 ± 11)	67.2% White 21.2% Black 6.7% Hispanic 0.9% Asian 4.0% Other	Treatment-seeking obese adults with binge eating disorder Convenience Sampling 326 (76)	Difficulties in Emotion Regulation Scale (DERS) Beck Depression Inventory (BDI)	Difficulties in emotion regulation and negative affect significantly predicted emotional overeating. DERS sub-scales of emotion regulation strategies and lack of emotional clarity were the best predictors of emotional overeating.	Valuable information regarding dietary behaviors and emotion regulation, particularly emotion regulation strategies and clarity. Low generalizability.

Table 1 (cont'd)

Author, Year	Framework	Design	Age range (mean $\pm$ SD)	Race/ Ethnicity	Patient Population, Sampling Technique, n = (% female)	Emotion and Emotion Regulation Measures	Major Findings	Overall Value Statement
Karademas et al. 2011	CSM Process model of ER	Cross-sectional	NR (62 $\pm$ 11)	Greek participants	Cardiac outpatients Convenience Sampling 135 (32)	IPQR – emotions subscale RAND 36 – physical functioning and emotional well-being subscales Emotion regulation questionnaire (ERQ)	Suppression and wishful thinking diminished emotional well-being. Reappraisal of emotions enhanced well-being. Higher intensity of perceived negative emotions related to their illness (from the IPQR) were associated to the worst physical functioning. Emotion suppression mediated the relationship between illness-related negative emotions and physical functioning.	Associations regarding emotion regulation, emotion related illness perceptions, and physical function provide good value. Low generalizability.
Kravvariti et al. 2010	NR	Cross-sectional	21-87 (NR)	Greek participants	56 Coronary Heart Disease patients 56 control patients Convenience Sampling 112 (30)	Wong-Law Emotional Intelligence Scale	Self-emotion appraisal, use of emotions, regulation of emotions as well as frequency of negative expressiveness were all significantly associated with greater odds of having CHD. Individuals with CHD reported less ability to regulate emotions and express negative emotions more frequently than those without CHD.	This article is valuable in providing information regarding emotion regulation in those with and without CHD. Low generalizability.

Table 1 (cont'd)

Author, Year	Framework	Design	Age range (mean $\pm$ SD)	Race/ Ethnicity	Patient Population, Sampling Technique, n = (% female)	Emotion and Emotion Regulation Measures	Major Findings	Overall Value Statement
Kubzansky et al. 2007	NR	Panel (17 year follow-up time period)	25-74 (48 $\pm$ 14)	86.6% White 13.4% non-white	Individuals without heart disease at baseline Probability Sampling 6,265 (55)	General Well-being Schedule combining items from the subscales of vitality, positive well-being, and emotional self-control to measure emotional vitality.	Low emotional vitality was more prevalent in individuals who were female, widowed, divorced or separated, non-white, or with lower reported levels of education. Those with higher levels of emotional vitality had a decreased odds of developing CHD. History of undifferentiated psychological problems is associated with an increased risk of developing CHD. Emotional vitality was associated with development of CHD even after controlling for health behaviors, metabolic factors, and blood pressure.	Value in the information presented that ties emotion regulation, psychological problems, and risk of developing CHD. Good generalizability.
Kucukarslan 2012	CSM	Literature review	NR (NR)	NR	asthma (3) hypertension (3) diabetes (1) heart failure (1) glaucoma (1) chronic pain (1) tuberculosis (1) Varied 11 (NR)	Revised Illness Perception Questionnaire (IPQ-R)	Inconsistent results comparing emotional representation and medication adherence. Studies with younger patient populations reported more significant positive relationships between emotional representations and medication adherence.	Value regarding general information about perceived emotional implications related to illness and medication adherence. Low generalizability.

Table 1 (cont'd)

Author, Year	Framework	Design	Age range (mean $\pm$ SD)	Race/ Ethnicity	Patient Population, Sampling Technique, n = (% female)	Emotion and Emotion Regulation Measures	Major Findings	Overall Value Statement
Messerli-Bürky et al. 2012	NR	Cross-sectional	NR (60 $\pm$ 11)	Swiss participants	Cardiac outpatients Convenience Sampling 163 (17)	Emotional Regulation Scale (EMOREG-24) Hospital Anxiety and Depression Scale Participant-rated perceived stress level	Maladaptive (avoidance and distortion) emotion regulation, perceived partner-related stress and depressed mood are related to type D (distressed) personality. Adaptive (controlling and expression) emotion regulation is associated negatively with social inhibition, negative affectivity, depressed mood, and partner related stress.	Valuable information present regarding emotion regulation, depression, and stress. Low generalizability.
Samar 2001	Mental Ability Theory of Emotional Intelligence	Cross-sectional	18-70 (38 $\pm$ 40)	96.7% Caucasian 2.2% Spanish 1.1% Asian	Patients with type I diabetes Convenience Sampling 90 (77)	Multifactor emotional intelligence scale (MEIS)	Assimilation of emotions is positively associated with reported self-management, this association is strongest with self-management of exercise and with blood glucose testing. Management of emotions is positively associated with general diet self-management. Understanding emotions is negatively associated with foot care self-management. In males, emotional intelligence was negatively associated with glycemic control.	Value in the connections between emotion regulation indices, self-management, and adherence. Low generalizability.

Table 1 (cont'd)

Author, Year	Framework	Design	Age range (mean $\pm$ SD)	Race/ Ethnicity	Patient Population, Sampling Technique, n = (% female)	Emotion and Emotion Regulation Measures	Major Findings	Overall Value Statement
Vilchinsky et al. 2013	CSM and attachment theory	Panel (6 month follow-up time period)	39-74 (57 $\pm$ 7)	Jewish Israelite participants	Acute coronary syndrome patients Convenience Sampling 111 (0)	Brief Symptom Inventory (depression and anxiety) Brief Illness Perception Questionnaire (Brief IPQ) Experiences in Close Relationships Scale (ECR)	Generalized poor illness perceptions are associated with greater attachment related anxiety, depression, and anxiety.	Valuable information regarding general illness perceptions, attachment related anxiety, depression, and general anxiety. Low generalizability.
Warmuz-Stangierska et al. 2010	NR	Cross-sectional	20-49 (34 $\pm$ NR)	NR	Patients with Addison's disease NR 15 (87)	Temper questionnaires Emotionality, Activity, Sociability for Adult (EASA) State-Trait Anxiety Inventory for Adults (STAI) Beck Depression Inventory (BDI)	Perceived ability to use emotions to solve problems was reported as low in 6 participants, average in 8 participants, and high in 1 participant.	Limited value indicates these Addison's disease patients may have elevated difficulty with emotion regulation. Low generalizability.
Willard 2006	NR	Cross-sectional	NR (NR)	15% White 81% Black 3% other	Patients with HIV NR 52 (40)	Mayer-Salovey-Caruso Emotional Intelligence Test (MSCEIT)	No differences in emotional intelligence between genders and no associations between emotional intelligence and medication adherence were found. Participants had significantly lower emotional intelligence scores than those seen in general populations.	Value of information provided regarding a lack of associations between emotion regulation and medication adherence. Low generalizability.

Table 1 (cont'd)

Author, Year	Framework	Design	Age range (mean $\pm$ SD)	Race/ Ethnicity	Patient Population, Sampling Technique, n = (% female)	Emotion and Emotion Regulation Measures	Major Findings	Overall Value Statement
Zijlstra et al. 2012	NR	Case- control	21-68 (46 $\pm$ 10)	Dutch participants	(102) Women with morbid obesity applying for bariatric surgery (102) Matched controls from the general population Convenience Sampling 204 (100)	Positive and negative affect schedule (PANAS) Berkeley Expressivity Questionnaire (BEQ) Toronto Alexithymia Scale 20 (TAS-20) Emotion Regulation Questionnaire (ERQ)	Patients with morbid obesity reported significantly less positive affect, more negative affect, more difficulty identifying feelings, and greater suppression of emotions than controls. No differences were reported in describing feelings, affect intensity, or expression of negative or positive emotions. More negative affect and difficulty identifying feelings are associated with more emotional eating and more external eating behavior. Emotion regulation strategies were not significantly associated with emotional eating, external eating, or restrained eating.	Valuable inferences regarding self-management and distinct components of emotion regulation (identifying feelings, describing feelings, and emotion regulation strategies). Low generalizability.

Note. NR = Not Reported

Summarized Findings

Theoretical frameworks. Three studies were guided by the common sense model of illness (Karademas et al., 2011; Kucukarslan, 2012; Vilchinsky et al., 2013). One study used the process model of emotion regulation (Karademas et al., 2011), two used a cognitive behavioral framework (Baeza-Velasco et al., 2012; Gerolimatos & Edelstein, 2012), one used the mental ability model of emotional intelligence (Samar, 2001), and eight papers did not clearly identify a theoretical framework. In summary, there was a diversity in theoretical groundings across studies with most lacking explicit theoretical premises.

The absence of studies that measured emotion regulation in chronic illness limits understanding of behavioral responses to health stressors. For studies including emotion regulation, some importance of this construct was evident. For example, in one article emotion regulation accounted for up to 21% of the variance in a specific dietary adherence measure (Gianini et al., 2013). However, only one study examined both emotion regulation and illness perceptions with the process model of emotion regulation as the supporting framework (Karademas et al., 2011). The review of these studies suggests a need for a framework that unifies illness perceptions and emotion regulation for individuals with chronic conditions.

Design and methods. The articles examined for this review used primarily quantitative analysis except for one narrative literature review (Kucukarslan, 2012). Ten articles were cross-sectional and included survey designs (Baeza-Velasco et al., 2012; Gerolimatos & Edelstein, 2012; Gianini et al., 2013; Karademas et al., 2011; Kravvariti et al., 2010; Messerli-Bürgy et al., 2012; Samar, 2001; Warmuz-Stangierska et al.,

2010; Willard, 2006; Zijlstra et al., 2012). Three of these cross-sectional studies used healthy controls to compare with the illness population (Baeza-Velasco et al., 2012; Gerolimatos & Edelstein, 2012; Kravvariti et al., 2010), and one used matched controls (Zijlstra et al., 2012). Two studies used longitudinal surveys in a panel design (Kubzansky & Thurston, 2007; Vilchinsky et al., 2013). Research using an emotion regulation strategy intervention was completed in one of the studies using a mixed between-within subjects design (Burns et al., 2011). Although some variety in study designs were noted in this review, there were no qualitative studies, and limited intervention and longitudinal studies. The use of predominantly cross-sectional study designs prohibited conclusions of causation. As such, the information presented in the included articles provided largely information on associations between emotion regulation and other psychological variables, disease status, or behaviors.

The included research methods included three types of data collection. Survey measurement alone was the most commonly used method of data collection (Baeza-Velasco et al., 2012; Gerolimatos & Edelstein, 2012; Gianini et al., 2013; Karademas et al., 2011; Kravvariti et al., 2010; Messerli-Bürgy et al., 2012; Samar, 2001; Vilchinsky et al., 2013; Warmuz-Stangierska et al., 2010; Willard, 2006). A mix of biophysiologic and survey measurement was used in two studies by adding medical exam data (Kubzansky & Thurston, 2007; Zijlstra et al., 2012). An experimental behavior task was only used in one of the included studies (Burns et al., 2011). With the majority of studies collecting survey data, it is unclear if these results would be replicated if more objective measurement methods were used.

Sample and setting. Chronically ill study participants are generally from localized geographical settings and are not a true representation of chronically ill individuals. The only exception to recruitment of non-representative participants was one study that used a national database (Kubzansky & Thurston, 2007). Sample sizes ranged from 15 to 6,265 participants (Kubzansky & Thurston, 2007; Warmuz-Stangierska et al., 2010).

African American participants. Five of the included studies that originated in Europe did not discuss race (Karademas et al., 2011; Kravvariti et al., 2010; Messerli-Bürgy et al., 2012; Vilchinsky et al., 2013; Zijlstra et al., 2012). Even within the U.S. studies, three of the eight articles did not disclose information regarding the inclusion of African American participants (Baeza-Velasco et al., 2012; Kucukarslan, 2012; Warmuz-Stangierska et al., 2010). Of those that did discuss race, Caucasians represented 67–97% of the samples (Gianini et al., 2013; Samar, 2001). In general, the studies were limited by a lack of diversity. It is unclear if the relationships demonstrated in this review are relevant to African American women with HF.

Illnesses. In this review, a wide range of illnesses were represented. Some of the studies examined multiple non-disclosed conditions (Gerolimatos & Edelstein, 2012; Kucukarslan, 2012), whereas others isolated a single condition such as type 1 diabetes (Samar, 2001).

Discussion of Study Variables: Primary Psychological Variables

Illness perceptions. In this review, negative illness perceptions were associated with increased depression and anxiety (Vilchinsky et al., 2013). Minimal delineation of how emotion regulation impacts cognitive representations of illness was

apparent. A single study in this review was able to determine that the adaptive emotion regulation technique of reappraisal was significantly associated with perceived likelihood of illness using a cross-sectional design (see Table 1) (Gerolimatos & Edelstein, 2012). It is likely that other components of illness perceptions are also associated with emotion regulation; however, in this review of literature, support of other illness perception components with emotion regulation were not identifiable. Illness perceptions are affected by emotion regulation, and jointly, illness perceptions and emotion regulation influence behavioral adherence (Chen et al., 2011; Karademas et al., 2011).

Emotion regulation. There are important relationships between emotion regulation and the variables previously discussed in this review. In particular, older adults were found to use more adaptive emotion regulation than younger adults (Gerolimatos & Edelstein, 2012), women's emotion regulation capacities were found to be lower than men's (Kubzansky & Thurston, 2007; Samar, 2001), and comparatively lower capacity to regulate emotions was observed in individuals with less education (Kubzansky & Thurston, 2007). Research that examines emotion regulation in relation to chronic disease is limited. Broadening the information available regarding relationships of emotion regulation to illness perceptions, psychological factors, and health outcomes is needed.

Measurement of emotion regulation. The measurement of emotion regulation across studies varied. Although three studies used the 6-item emotional representation subscale of the Illness Perception Questionnaire (IPQ) (Karademas et al., 2011; Kucukarslan, 2012; Vilchinsky et al., 2013), this scale alone does not actually measure

emotion regulation, but rather emotional responses such as depression and anxiety. Karademas et al. (2011) used the 10-item Emotion Regulation Questionnaire (ERQ) and the 5-item RAND 36 emotional well-being subscale. The General Well-Being Schedule (Kubzansky & Thurston, 2007), and the Emotionality, Activity, Sociability for Adults (Warmuz-Stangierska et al., 2010) were used to measure emotion regulation in two other studies.

Scales specifically designed to measure emotion regulation that were used most frequently included the ERQ (Gerolimos & Edelstein, 2012; Zijlstra et al., 2012), the Difficulties in Emotion Regulation Scale (DERS) (Gianini et al., 2013), Levels of Emotional Awareness Scale (LEAS) (Baeza-Velasco et al., 2012), and the Emotional Regulation Scale (EMOREG-24) (Messerli-Bürgy et al., 2012). The ERQ measures emotion regulation strategies of suppression and reappraisal in 10 items (Gerolimos & Edelstein, 2012). The DERS has 36 items that measure dimensions of emotion regulation yielding a total score and six subscale scores (Gianini et al., 2013). The DERS subscales include non-acceptance of emotional responses, difficulties engaging in goal-directed behavior, difficulties with impulse control, lack of emotional awareness, limitations in accessing emotion regulation strategies, and lack of emotional clarity (Gratz & Roemer, 2004). Internal consistency for the DERS total score is good, with Cronbach's alpha reported as 0.87, and 0.74–0.89 for the subscales (Gianini et al., 2013). However, the large number of items is likely responsible for some of the elevation in alpha scores. The LEAS is a performance measure wherein participants respond to emotion inducing vignettes (Baeza-Velasco et al., 2012). The responses to the LEAS are scored using structured criteria on a scale from 0 to 4, with a total scale

and two subscales of self and other (Baeza-Velasco et al., 2012). The EMOREG-24 measures how participants cope with stress and emotions (Messerli-Bürgy et al., 2012). This measure contains subscales of control, expression, avoidance, and distortion, and summed scales of adaptive (controlling and expression) and maladaptive (avoidance and distortion) emotion regulation (Messerli-Bürgy et al., 2012). All 24 items of this scale are participant-rated on a 6-point scale (Messerli-Bürgy et al., 2012).

Three authors used measures of emotional intelligence, defined as monitoring, discriminating, and altering actions and thoughts regarding personal and others' feelings and emotions (Kravvariti et al., 2010; Samar, 2001; Willard, 2006). The Wong-Law Emotional Intelligence Scale (WLEIS) contains 16 items and four subscales—self emotion appraisal, other's emotion appraisal, use of emotion, and regulation of emotion (Kravvariti et al., 2010). The Multifactor Emotional Intelligence Scale (MEIS) is based on measuring abilities related to perceiving, assimilating, understanding, and managing emotions. The MEIS contains 12 subscales that are combined into four larger branches including perceiving emotions (faces, music, designs, and stories), assimilating emotions (judgments and feeling bias), understanding emotions (blends, progressions, transitions, and relativity), and managing emotions (managing others and managing self) (Samar, 2001). This four-branch design is theoretically based, but has issues with intercorrelation between the assimilation and understanding branches ($r = 0.87$; Samar, 2001). The Mayer, Salovey, Caruso Emotional Intelligence Test (MSCEIT) was developed from the MEIS with the same theoretical framework. The MSCEIT uses scale items from 1 (none of the time) to 10 (all of the time), and yields a total emotional

intelligence score and four subscales (perceiving emotions, facilitating thought, understanding emotion, and managing emotion) (Willard, 2006).

Burns et al. (2011) used a measurement specific to regulation of anger, the Anger Expression Inventory. This instrument measures two subscales—anger expressive style and anger inhibition style.

Psychometrics. Internal consistency of emotion regulation scales was varied, and in some cases, not reported. For those that were reported, the psychometric properties of the scales were moderate to good. The ERQ reported Cronbach's alphas between 0.74 and 0.89 (Gerolimos & Edelstein, 2012; Karademas et al., 2011; Zijlstra et al., 2012). The DERS had an overall reported α of 0.79, with subscale scores ranging from 0.78 to 0.87 (Gianini et al., 2013). Subscales within larger inventories capturing emotion regulation (such as the general well-being schedule and IPQ-R) were reported with Cronbach α ranging from 0.55 to 0.89 (Karademas et al., 2011; Kubzansky & Thurston, 2007; Vilchinsky et al., 2013). However, these numbers inconsistently represented both full scales and the emotional subscales (Karademas et al., 2011; Kubzansky & Thurston, 2007; Vilchinsky et al., 2013). Scales of emotional intelligence reported internal consistency at 0.90 for the Wong-Law Emotional Intelligence Scale (Karademas et al., 2011) and 0.96 for the multifactor emotional intelligence scale (Samar, 2001). Other scales (i.e., Levels of Emotional Awareness Scale, Emotional Regulation Scale, Mayer-Salovey-Caruso Emotional Intelligence Scale, Spielberger Anger Expression Inventory) did not have reported internal consistencies (Baeza-Velasco et al., 2012; Burns et al., 2011; Messerli-Bürgy et al., 2012; Willard, 2006). Overall, the analyses with Cronbach's alphas point to moderate to

good internal consistency of the included scales. Sole use of Cronbach's alpha scores to determine quality of the instruments is insufficient. Unfortunately, deeper analysis of measures such as factor analysis were not present in the studies under review.

Discussion of Study Variables: Secondary Psychological Factors

With emotion regulation being strongly associated with the psychological distress indices of depression, anxiety, stress, and anger, all were prevalent in this review. Depression was addressed in six articles (Baeza-Velasco et al., 2012; Gianini et al., 2013; Messerli-Bürgy et al., 2012; Vilchinsky et al., 2013; Warmuz-Stangierska et al., 2010; Zijlstra et al., 2012), anxiety in five articles (Baeza-Velasco et al., 2012; Gerolimatos & Edelstein, 2012; Messerli-Bürgy et al., 2012; Vilchinsky et al., 2013; Warmuz-Stangierska et al., 2010), stress in two articles (Gerolimatos & Edelstein, 2012; Messerli-Bürgy et al., 2012), and anger in one article (Burns et al., 2011).

Many of the articles addressing psychological constructs did not discuss their connections with emotion regulation. Of those reporting associations, patients with chronic illness and with lowered capacity to regulate emotion exhibited more depressive symptoms and negative emotions than patients with higher capacity to regulate emotions (Kravvariti et al., 2010; Messerli-Bürgy et al., 2012). Generally, depressive symptoms and anxiety were found to be highly prevalent in illness populations such as patients with cardiovascular disease (Baeza-Velasco et al., 2012; Evangelista et al., 2009; Kravvariti et al., 2010), and were more common in younger patients (Kucukarslan, 2012). Perceived stress levels specific to partner-related stress were associated with maladaptive emotion regulation (Messerli-Bürgy et al., 2012). Negative emotional consequences from stress contributed to the development of depression and anxiety,

and increased demands on the individual's capacity to regulate emotions (Gross, 2001; Saxena et al., 2011). Furthermore, a history of psychological illness was predictive of developing a chronic physical illness (Kubzansky & Thurston, 2007).

This review indicated an association between psychological factors and emotion regulation for individuals with physical illnesses. Studies also demonstrated that factors such as female gender, lower levels of education, non-white race (Kubzansky & Thurston, 2007), and greater negative affect (Kravvariti et al., 2010) were associated with greater difficulty in regulating emotions. Although these associations were identified, additional research is needed. It is particularly necessary to examine how psychological factors such as depression, anxiety, and stress are associated with emotion regulation in the presence of chronic illness.

Health Outcomes

Adherence. As an important predictor of outcomes, adherence to medications, diet, and exercise regimens should be a prominent theme in the study of patients with chronic illness. Adherence was mentioned in the systematic review by Kucukarslan (2012), in which negative emotional reactions to health stressors were found to decrease medication adherence. Another study examining patients with HIV did not find any associations between emotion regulation and adherence (Willard, 2006). Of the studies under review that included adherence, the level of evidence was quite low (see Table 1). Unfortunately, there has been limited research examining this important construct in relation to emotion regulation. In studies that evaluated self-regulation, patients who reported less difficulty with emotion regulation were better at managing

their diets (Gianini et al., 2013; Samar, 2001). Further research on adherence and emotion regulation is clearly needed.

Negative health events. Negative health events are unanticipated and include death or visits for healthcare. The amount of time to a first negative health event is of critical importance in measuring patient outcomes. The majority of articles in this integrative review were cross-sectional in nature, and therefore did not address long-term patient outcomes such as negative health events.

In this review of literature, there was a general dearth of information regarding the impact of emotion regulation on health outcomes. The strength of the evidence evaluating associations between health outcomes and emotion regulation was generally weak. Although suggested associations between adherence and emotion regulation were present, more research is needed.

Illness Environment

Demographics. The studies presented in this review reflect a narrow population profile, particularly in terms of income level, education, sex, and race.

Age. Of the studies reporting age ranges, the individuals represented were between the ages of 18 and 87 years (Gerolimos & Edelstein, 2012; Kravvariti et al., 2010). In the individual studies, a narrower scope of ages were included, largely because some illnesses that were represented are more prevalent in younger populations (Warmuz-Stangierska et al., 2010), whereas others occur more frequently in older populations (Karademas et al., 2011). Of those studies that analyzed the connection between age and emotion regulation, results suggested that older adults utilize more adaptive emotion regulation strategies than younger adults (Gerolimos &

Edelstein, 2012). The age correlation is congruent with other literature on emotion regulation that indicates that the ability to regulate emotion is maintained and enhanced as individuals age (Shiota & Levenson, 2009).

Sex. Both men and women were included in the studies reviewed. Those reporting gender differences noted that women have lower emotion regulation abilities (Kubzansky & Thurston, 2007; Samar, 2001). The study by Kubzansky and Thurston (2007) included a large sample and seemed to be generalizable to other patients with chronic illness in the United States (see Table 1). It is unclear why this link between poorer emotion regulation and gender exists, and thus a greater understanding of the vulnerability of poor emotion regulation in women is necessary.

Income and education. Income level and education were poorly represented in this review. For patients with chronic illness, lower levels of income and education can make adherence challenging. It is recognized that some patients who know that they are experiencing an exacerbation in HF symptoms delay seeking treatment because the financial burden is too great (Horowitz, Rein, & Leventhal, 2004). Not only is poverty a predictor of the prevalence of HF (Menash et al., 2005), it is also a predictor of hospitalizations (Roe-Prior, 2007). One of the stronger studies with a large sample size found that participants with lower education exhibited lower emotion regulation ability (Kubzansky & Thurston, 2007). While the study examined relationships between lower emotion regulation ability and education in a cardiovascular population, it did not include sufficient numbers of African American participants (Kubzansky & Thurston, 2007).

African American participants. The majority of participants in this review were either Caucasian or drew participants from European groups and did not disclose the

racial make-up of the sample. The only study to examine the impact of race noted that non-white individuals had greater difficulties with emotion regulation (Kubzansky & Thurston, 2007). This study grouped non-white individuals together and provided little information relative to which population had increased vulnerability relative to emotion regulation.

Clinical factors. In general, the articles included in this review did not examine clinical factors in-depth. The presence of chronic physical illness, for example rheumatic disease or CVD, was related to a decreased ability to regulate emotions (Baeza-Velasco et al., 2012; Kravvariti et al., 2010; Kubzansky & Thurston, 2007). A decreased ability to regulate emotions was also associated with cardiovascular disease development even after controlling for demographic factors (Kubzansky & Thurston, 2007). Poorer physical function was also prevalent in those with low emotion regulation ability in one study (Karademas et al., 2011). As none of the articles were specific to HF, none used the NYHA functional classification to examine severity.

Interpretations

Articles in this review offered key information for developing knowledge of emotion regulation in illness populations. In particular, it was apparent that there may be varying predictors of increased difficulties with emotion regulation (Baeza-Velasco et al., 2012; Gerolimatos & Edelstein, 2012; Kubzansky & Thurston, 2007; Messerli-Bürgy et al., 2012) and there was support for difficulties with emotion regulation impacting health (Gianini et al., 2013; Kravvariti et al., 2010; Kubzansky & Thurston, 2007; Kucukarslan, 2012; Samar, 2001). With the limited number of articles and the wide range of illness populations included, only general themes can be discussed.

Conceptual Framework

Many key concepts from the framework discussed in Chapter 2 (see Figure 1) were present in this review of literature, including demographic variables, psychological variables, emotion regulation, illness perceptions, adherence, and negative health events. As identified in Figure 2, many of the relationships from this review of literature were present. Because emotion regulation was the key concept in the review, some of the other central concepts to the framework were absent or not well represented in this literature. Information presented in Chapters 1 and 2 can aid in further explaining these associations. By adding relationships identified in the earlier chapters with those presented in this chapter, a fuller representation of the conceptual model is apparent.

Many of the relationships represented consistently identified directionality in effects. The positive and negative determinations of the paths presented in Figure 2 are described in Table 2. One path had an unclear or mixed association—the association between emotion regulation and adherence. Each of the articles pertaining to emotion regulation and adherence presented fairly low levels of evidence (Kucukarslan, 2012; Samar, 2001; Willard, 2006). Another article showed a connection between emotion regulation and self-management (Zijlstra et al., 2012), which has similarities to behavioral adherence. Additionally, the relationship between emotion regulation and illness perceptions may be bidirectional. It is possible that components of emotion regulation and illness perceptions may have clear directional relationships. The literature in this review did not provide insight into the associations between emotion regulation and illness perceptions. Finally, other relationships hypothesized in the conceptual framework were absent in this review of literature. The absent relationships

included the impact of clinical factors on adherence and the effect of illness perceptions on negative health events.

Most of the relationships presented in this review of literature had limited empirical evidence to support the findings, and many of the studies had weak designs and small sample sizes. Stronger associations supported by multiple sources were: 1) the positive relationship between increased depressive symptoms and increased difficulties with emotion regulation (Kravvariti et al., 2010; Messerli-Bürgy et al., 2012), 2) detrimental impact on health of negative psychological symptoms (Karademas et al., 2011; Kubzansky & Thurston, 2007), and 3) the negative impact of difficulties with emotion regulation on health events (Gianini et al., 2013; Kravvariti et al., 2010; Kubzansky & Thurston, 2007).

There are many ways that the current study adds to the literature presented in this chapter. Of primary importance, Aim 1 expanded information on the impact of the psychological factors on emotion regulation. Aim 2 examined the limited understanding of the association between contributing factors, emotion regulation, and illness perceptions. Additionally, linking illness perceptions and emotion regulation to negative health events and adherence was examined in Aim 3. Testing these relationships strengthened the overall evidence regarding these constructs, and also provided evidence regarding the experiences of African American women with HF in particular.

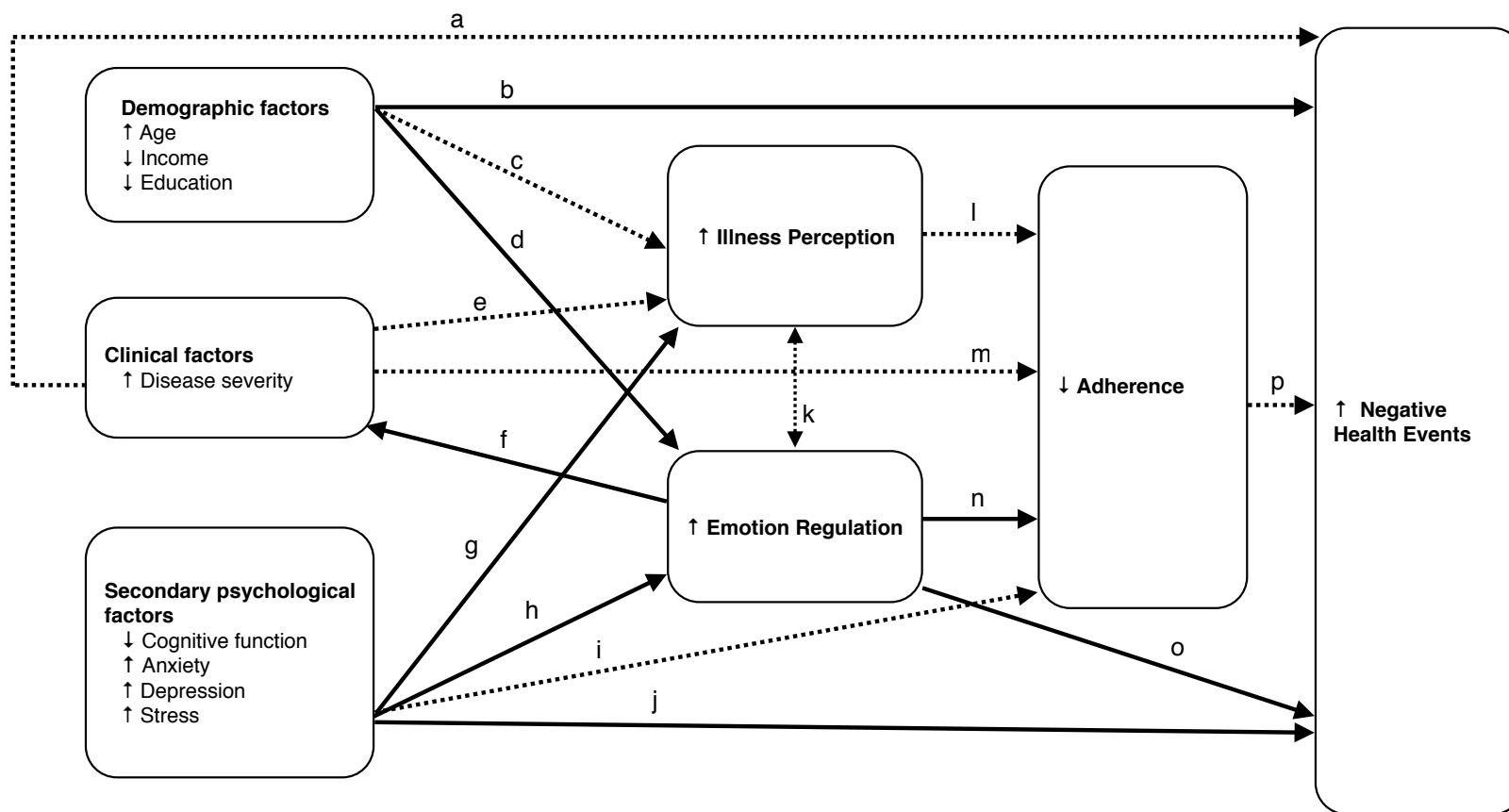


Figure 2. Relationships of Study Variables from the Literature. This figure is a graphic representation of the relationships between study variables as presented in the literature. Solid lines represent relationships documented within the literature review on emotion regulation. Dashed lines represent relationships determined in the literature discussed in Chapter 1. See Table 2 for information regarding relationship paths.

Table 2.

Associations Between Study Variables in the Literature

Path	Variables	Direction	Citations
a	Clinical Factors Negative Health Events	positive	(Karasek et al., 2012)
b	Demographic Factors Negative Health Events	positive	(Hawkins et al., 2012; Roe-Prior, 2007; Wu et al., 2010)
c	Demographic Factors Illness Perceptions	negative	(Hawkins et al., 2012; Roe-Prior, 2007)
d	Demographic Factors Emotion Regulation	negative	(Gerolimos & Edelstein, 2012; Kubzansky & Thurston, 2007)
e	Clinical Factors Illness Perceptions	negative	(Daniels et al., 2006)
f	Clinical Factors Emotion Regulation	negative	(Kravvariti et al., 2010; Kubzansky & Thurston, 2007)
g	Psychological Factors Illness Perceptions	negative	(Olafranye et al., 2011; Vilchinsky et al., 2013)
h	Psychological Factors Emotion Regulation	negative	(Baeza-Velasco et al., 2012; Messerli-Bürgy et al., 2012)
i	Psychological Factors Adherence	positive	(De Jong et al., 2011; Luyster et al., 2009; Song, 2009)
j	Psychological Factors Negative Health Events	positive	(De Jong et al., 2011; Karademas et al., 2011; Kubzansky & Thurston, 2007; Song, 2009; Zijlstra et al., 2012)
k	Illness Perceptions Emotion Regulation	bi-directional	(Chen et al., 2011; de Ridder et al., 2008; Ehrling et al., 2010; Moss-Morris et al., 2002)
l	Illness Perceptions Adherence	positive	(Chen et al., 2011)
m	Clinical Factors Adherence	negative	(Karasek et al., 2012)
n	Emotion Regulation Adherence	mixed/ unclear	(Karademas et al., 2011; Kucukarslan, 2012; A. Samar, 2001; Willard, 2006)
o	Emotion Regulation Negative Health Events	negative	(Gianini et al., 2013; Kravvariti et al., 2010; Kubzansky & Thurston, 2007)
p	Adherence Negative Health Events	positive	(Luyster et al., 2009)

Note. Direction is in reference to the relationships seen in Figure 2.

Limitations

In addition to unclear delineation of relationships among the major study constructs, other limitations existed in reference to the sample populations and outcomes. There was minimal information available regarding African American women with chronic illness (see Table 1). With such limited empirical evidence, including diverse samples, it was unclear if the identified relationships were present in the current study. There was also a lack of consistency between studies in the types of health outcomes measured. There may have been other outcomes that were more or less sensitive to difficulties with emotion regulation. There were differences in the operationalization of adherence as well. Without consistency in measurement, results from literature reviews with limited numbers of empirical studies must be evaluated with caution.

Conclusions

In conclusion, although there were limitations to this review of literature, emotion regulation appears to have an impact on patient outcomes and is impacted by the illness environment. Patients with chronic illness are burdened by physiological and psychological challenges (Baeza-Velasco et al., 2012; de Ridder et al., 2008). Adaptive psychological function is necessary to manage the myriad demands associated with chronic illness. The recognition and understanding of the role of emotion regulation in illness management is essential to making gains in improving behavioral outcomes for patients with chronic illness (de Ridder et al., 2008; Folkman & Moskowitz, 2004; Gross & Munoz, 1995).

Chapter 4: Methods

The purpose of this study was to examine relationships among emotion regulation, illness perceptions, and health outcomes of adherence and the use of healthcare services in African American women with HF. This chapter provides descriptions of the study design, setting, sample selection, instrumentation, procedures, human subject protection, and the data analysis plan used to explore the aims of this study. The aims were as follows:

- 1. Aim 1. Determine the associations between psychological factors (anxiety, stress, and depression) and emotion regulation in African American women with HF at intake (time 1).**
 - a. Hypothesis 1: Higher levels of anxiety, stress, and depression will be associated with less effective emotion regulation.
- 2. Aim 2. Determine the associations of the contributing factors (clinical, demographic, and psychological) and illness perceptions with emotion regulation at intake (time 1) for African American women with HF.**
 - a. Hypothesis 2: Illness perceptions and emotion regulation are associated with the clinical, demographic, and psychological factors.
- 3. Aim 3. Determine the effects of illness perceptions and emotion regulation on the outcomes of adherence and negative health events (death, hospitalization, emergency department, urgent care, and unanticipated primary care visits) in African American women with HF at 30-days (time 2).**

- a. Hypothesis 3: Less effective emotion regulation and more negative illness perceptions will be associated with lower adherence and greater negative health events.

Design

This observational study examined the relationships among emotion regulation, illness perceptions, and health outcomes of adherence and negative health events in female African American patients with HF. Psychological factors (including illness perception and emotion regulation), clinical factors, and demographic data were collected as covariates using surveys and medical record review. Illness perceptions and emotion regulation were documented using telephone surveys at intake. General adherence and negative health events were the primary outcome measures assessed. Outcome data were collected through participant telephone surveys at 30 days following the intake interview, and verification of negative health events was documented via medical record review at 90 days post-consent (see Figure 3).

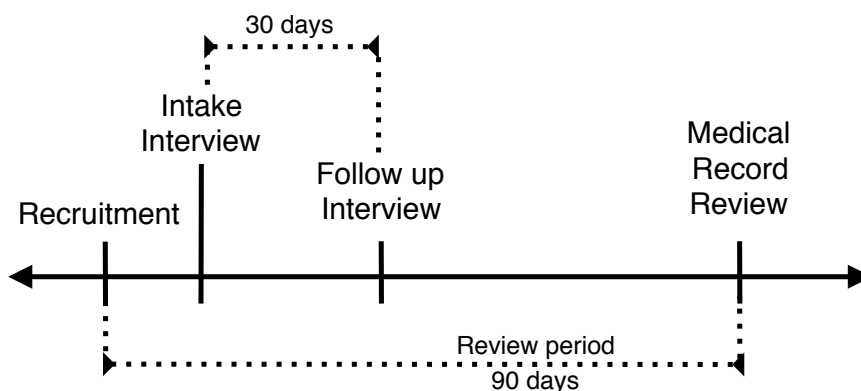


Figure 3. Study Timeline. This figure shows the study timeline. Patients were recruited and then contacted for intake interview. Follow-up interviews were scheduled for 30 days following completion of intake interview. Medical record review was scheduled 90 days following recruitment.

Setting. Multiple community sites were used to aid in recruitment efforts. Two mid-Michigan hospitals are the primary sources for HF care for African American residents (making up 12.2% of the residents) in Ingham County (U.S. Census Bureau, 2010). These sites, in addition to the largest HF clinic in Ingham County, were used for recruitment. The two inpatient sites included a 676-bed community hospital, and a 389-bed community hospital. The HF clinic used for recruitment sees approximately 350 patients daily at eight distinct locations.

Methodology

A prospective observational design was used to complete this study.

Sample selection. The target sample size was developed based on project duration and available resources; the appropriate size was determined to be 60 participants. Power and effect size were calculated to provide information on the marginal contributions of predictor variables consistent with pilot study research. The projected sample size of this pilot study provided data on participants regarding psychological, clinical, and outcome variables. These data were used to inform the planning of a larger study of African American women with regard to the impact of emotion regulation and illness perceptions on health behaviors and outcomes.

Criteria. Eligibility for the study was determined based on the following criteria:
Inclusion criteria: 1) African American female patients who were 45 years of age and older; 2) diagnosis of HF; 3) physician prescribed dietary, exercise, and medication regimens; 4) able to understand both written and spoken English.

Exclusion criteria: 1) documented major psychiatric (patients with bipolar disorder, schizophrenia, or severe drug abuse), or cognitive disabilities that would limit their

ability to answer survey questions within the medical record or as determined by recruiters; 2) discharge to a long-term care facility or palliative care where independent decisions to adhere would be muted or the focus of care would vary from the proposed aims.

Instrumentation

The instruments are listed in Table 3, along with psychometric properties and timing of measurement. Full instrument information is listed in the appendices. Instruments included those that examined demographics (age, income, and education), disease severity, primary psychological factors (illness perceptions and emotion regulation), secondary psychological factors (stress, anxiety, depression, and cognitive function), and health outcomes (adherence, and negative health events).

Demographics. Demographic data included age, reported household income level, and highest level of education (see Appendix A).

Age. Age was measured in years. The incidence of HF in African Americans occurs at a younger age as compared to Caucasians (Bondmass, 2007). Because patients with HF experience significant health changes, even within a single decade (Saczynski et al., 2009), years of age was used as a continuous variable.

Income level. As defined for this study, income level was the amount of financial means that an individual had access to, and was operationalized as annual household income. Income was grouped in \$15,000 dollar increments from \$0–\$14,999 to greater than \$150,000 dollars per year. Examining income incrementally allowed for the examination of variation in income, particularly in the lower and middle classes where income may prevent the use of healthcare services.

Table 3.

Summary of Study Instruments

Variables	Instrument Used	Intake	Interview Time	
			Follow-up	Medical record review
Demographics and Clinical Indicators				
Age, Income, Education	Demographic questionnaire	X		
Disease Severity				
• NYHA	• Medical record review of NYHA			X
• LVEF	• Medical record review of most recent LVEF			X
Primary Psychological Factors				
Illness perception	IPQ-R 70 items	X		
	Identity scale (14 items)			
	Structure scale (38 items)			
	Causal scale (18 items)			
Emotion regulation perception	DERS 36 items	X		
Secondary Psychological Factors				
• Stress	PSS 10 items	X		
• Anxiety & Depression	HADS 14 items	X		
	○ Depression HADS-D (7 items)			
• Cognitive function	○ Anxiety HADS-A (7 items)			
	AFI 13 items	X		
Outcome Instruments				
Adherence	MOS-SAS for Heart Disease 8 items		X	
Negative Health Events	Electronic medical record review of emergency department visits, hospital admissions, and death for time to first event and type of event		X	X
Key: NYHA - New York Heart Association Functional Classification; LVEF - left ventricular ejection fraction; PSS - Perceived Stress Scale; HADS – Hospital Anxiety and Depression Scale; AFI – Attentional Function Index; IPQ-R - The Illness Perception Questionnaire-Revised; DERS - Difficulties in Emotion Regulation Scale; ERQ - Emotion Regulation Questionnaire; MOS-SAS - The Medical Outcomes Study Specific Adherence Scale				

Disease severity. Disease severity specific to HF was obtained both from medical record review of a bio-physiological marker (left ventricular ejection fraction [LVEF]) and patient reported severity (New York Heart Association [NYHA] functional classification). LVEF measures how much blood is being pumped from the left ventricle of the heart, while NYHA measures HF symptom severity. Each of these clinical values was collected from the patient medical record at 90 days following consent, with the values closest to intake being utilized (see Table 3). These clinical values may have been from a recent hospital admission or visit to the emergency department. In terms of describing the sample, LVEF was examined both as a range as well as by dichotomizing those with LVEF < 40 (non-preserved ejection fraction) and those > 40 (preserved ejection fraction) (Fonarow et al., 2009). An ejection fraction between 55%–70% is considered normal, while below 40% is typically indicative of HF with systolic dysfunction. NYHA functional classification values were used to draw inferences on severity during data analysis.

The NYHA functional classification is used regularly and successfully in measuring HF patient severity for both clinical and research purposes (Luyster et al., 2009; Song, 2009). The NYHA functional classification value is a range from I to IV with higher scores indicating decreased physical function specific to HF. Weaknesses of this instrument are largely in the narrow diversification (only four options) of patients with HF. NYHA was the primary instrument used for measuring disease severity for data analysis. Both clinician and patient-reported NYHA functional statuses are predictive of patient outcomes, with higher NYHA predicting increased readmissions, mortality, and decreased quality of life (Holland et al., 2010). The intake NYHA functional

classification value obtained from the medical record review was used as a covariate for analyzing the data for the study aims.

Primary Psychological Factors.

Illness perceptions. The revised Illness Perception Questionnaire (IPQ-R) was used to measure illness perceptions (Cronbach's alpha subscales all > 0.70). It has been tested in ethnically diverse, chronic disease populations (see Appendix A; Kim, Evangelista, Phillips, Pavlish, & Kopple, 2012; Moss-Morris et al., 2002). The original operationalization of the cognitive representation of illness included the five subscales of identity, cause, consequences, timeline, and control/cure (Diefenbach & Leventhal, 1996). Revisions to this scale prompted the addition of subscales on perceived coherence and emotional representations while the subscales of timeline and control were divided into two subscales each (Moss-Morris et al., 2002). Scales include illness identity, which measures symptoms and if the patient identifies them as being a part of their illness, and a causal scale that measured what the patient perceives as the causes of their illness (Moss-Morris et al., 2002). In addition, there are seven other subscales (timeline acute/chronic, timeline cyclical, consequences, personal control, treatment control, illness coherence, and emotional representations). The IPQ-R has been validated in African American populations (Kim et al., 2012).

Timeline acute/chronic contains six items with a possible score range of 6 to 30; timeline cyclical contains four items with a range of 4 to 20; consequences contains six items with a range of 6 to 30; personal control contains six items with a range of 6 to 30; treatment control contains five items with a range of 5 to 25; illness coherence contains five items with a range of 5 to 25; and emotional representations contains six items with

a range of 6 to 30 (Kim et al., 2012). Lower scores on the personal and treatment control subscale indicate a lack of perceived illness controllability, and lower scores on the illness coherence subscale suggest lowered usefulness of the illness representation or that the illness does not make sense. Higher scores on the timeline acute/chronic, timeline cyclical, and consequences subscales indicate a perception of the illness as chronic, changing, and with greater negative consequences. Higher scores on the emotional representation dimension indicate heightened aversive emotional responses in reference to the illness (Moss-Morris et al., 2002).

Emotion regulation. The Difficulties in Emotion Regulation Scale (DERS) was used to measure emotion regulation at intake (Cronbach's alpha = 0.93), and is a survey that provides subjective feedback about perceived emotion regulation (see Appendix A; Gratz & Roemer, 2004). DERS subscales include non-acceptance of emotional responses (6 items), difficulties engaging in goal-directed behavior (5 items), difficulties with impulse control (6 items), lack of emotional awareness (6 items), limited access to emotion regulation strategies (8 items), and lack of emotional clarity (5 items) (Gratz & Roemer, 2004), with all subscales maintaining Cronbach's alphas > 0.76 (Cohn, Jakupcak, Seibert, Hildebrandt, & Zeichner, 2010; Gratz & Roemer, 2004; Salters-Pedneault, Roemer, Tull, Rucker, & Mennin, 2006). Construct validity confirmed the legitimacy of this instrument in reference to measures of emotional expressivity, negative mood regulation, and avoidance (Gratz & Roemer, 2004). Factor analysis that confirmed the subscales, test-retest reliability ($\rho = .88$), and predictive validity further validate the usefulness of this scale in general populations (Gratz & Roemer, 2004).

Weakness in the use of this instrument is the sparse use of the DERS in African American and cardiovascular populations thus far.

All DERS items are measured on a Likert scale with a range of 1 to 5, where 1 is almost never (0–10%), 2 is sometimes (11–35%), 3 is about half the time (36–65%), 4 is most of the time (66–90%), and 5 is almost always (91–100%). Summed subscale scores are combined to create an overall global score (Gratz & Roemer, 2004). Total and individual subscale scores are each examined as continuous variables.

Secondary Psychological Factors.

Perceived stress. The 10-item Perceived Stress Scale (PSS) was used to assess stress (Cronbach's $\alpha > 0.84$ Cohen et al., 1983), which demonstrates strong validity and reliability (see Appendix A; Lopez, Antoni, Fekete, & Penedo, 2012; Mwendwa et al., 2011). The PSS has shown good internal consistency when used with African American women who have a chronic illness ($\alpha = 0.82$; Lopez et al., 2012). The PSS examines the degree to which events are perceived as stressful (Hewitt, Flett, & Mosher, 1992). Items are on a 5-point Likert-type scale and include subjective statements related to stress experienced in the last 30 days (Lopez et al., 2012). Four items are reverse scored and all items are summed to gain a composite score. Higher scores indicate higher perceived stress (Cohen et al., 1983). Psychometric evaluation of this instrument includes testing in both clinical and health populations with findings demonstrating higher perceived stress in clinical populations (Hewitt et al., 1992).

Anxiety and depression. The Hospital Anxiety and Depression Scale (HADS) was used to measure anxiety and depression (see Appendix A; Zigmond & Snaith, 1983). This instrument is highly validated and standardized with good internal

consistency (Cronbach's alpha > 0.83 for anxiety [HADS-A] and Cronbach's alpha > 0.82 for depression [HADS-D]; Haworth, Moniz-Cook, Clark, Wang, & Cleland, 2007). The scale was designed for use in chronically ill populations and shows good specificity and sensitivity in patients with HF for both the HADS-A (specificity = 0.85 and sensitivity = 0.94) with a cut-point of 7, and the HADS-D (specificity = 0.79 and sensitivity = 0.86) with a cut-point of 4 (Haworth et al., 2007). The 14 items of the HADS are each rated on a 4-point scale with scores of 0–21 on each of the 7-item anxiety and 7-item depression subscales. Higher scores indicate more symptoms of anxiety and depression.

Perceived cognitive function. The 13-item Attentional Function Index (AFI) was used to assess perceived cognitive function in this study (see Appendix A; Cimprich, Visovatti, & Ronis, 2011). This instrument was developed for use in healthy and chronic illness populations with good internal consistency for the entire instrument (Cronbach's alpha > 0.92), as well as for the subscales (Cronbach's alpha = 0.80–0.92; Cimprich et al., 2011). Subscales of the instrument include effective action (7 items), attentional lapses (3 items), and interpersonal effectiveness (3 items). The instrument was originally designed as a visual analogue scale (Cimprich et al., 2011). As the scale was delivered via telephone interview, participants were asked to score their function on a 0–10 scale. Internal consistency remained high (Cronbach's alpha = 0.95) in another study using the numeric scale (Miaskowski et al., 2012), but thus far has not been tested in cardiovascular populations. Four of the items are reverse scored. Higher scores indicate more effective subjective perceptions of attentional function.

Health Outcomes: Adherence and Negative Health Events. The following sections review the measurement of the health outcomes in this study. Adherence was measured by telephone surveys completed 30 days following the intake surveys. Negative health events were measured by medical record review spanning from the date of consent to 90 days after (see Figure 3).

Adherence. Self-reported adherence was measured using the Medical Outcomes Study Specific Adherence Scale (MOS-SAS) at follow-up (Cronbach's alpha = 0.81; Hays, 2012) for Heart Disease (see Appendix B). The MOS-SAS test measures both general adherence and cardiac disease specific adherence (Chung et al., 2008; Hays, 2012; Ziegelstein, 2000). The MOS-SAS has been utilized with HF patients focusing on questions specific to the aims of the proposed study such adherence to a low sodium diet and medications (Chung et al., 2008). One adherence question related to each particular behavior was selected from the specific adherence MOS-SAS questions (exercise, medication, and diet) and these were analyzed on a 6-point Likert scale to determine adherence since hospitalization. These additional items were designed for selective use in various illness populations, with specific items relevant to HF treatments selected (Hays, 2012). Responses ranged from "none of the time" to "all of the time." "All of the time" is the suggested cut-point for adherence in heart failure patients (Chung et al., 2008); however, cut-points were not used in this study for analysis. The summed items from the scale were used in analysis as a general measure of adherence.

Negative health events. Use of healthcare resources, type of healthcare resources used, and time to first unscheduled care event or death were examined.

Negative health events for patients with HF were defined as death, hospitalizations or emergency department (attached to hospitals), or urgent care visits (non-emergent walk-in care facilities). Since the disease process of HF impacts multiple body systems and functional capacity, other conditions may lead to a negative health event, but may be intensified by the presence of HF. Comorbid conditions for patients with HF frequently include diabetes, respiratory disorders, cardiovascular disorders, renal failure, and cognitive dysfunction (Krum & Gilbert, 2003). Patients admitted to the hospital with HF have been shown to have a mean of 3.3 comorbid conditions (Wu et al., 2010). Since comorbid conditions may potentially impact each other and are extremely prevalent in the HF population, it is difficult to isolate cardiovascular events from HF events. For this reason, all cardiac negative health events were included as opposed to isolating HF-specific events only. Studies with smaller numbers of participants have discovered significant predictors of negative health events, but typically use a longer follow-up time (Moser et al., 2011). For the purposes of this pilot study, negative health events within 90 days were examined.

In this study, medical record reviews were completed at the conclusion of data collection to determine event dates, times, and reasons for hospitalizations and emergency department visits. Patient records were reviewed from consent through the subsequent 90 days. The time to first event, types of events, and length of stay information were collected. Occurrence of an event within 90 days was used in the analysis as the outcome measure.

Procedures

Training procedures. All members of the research team participated in HIPPA and IRB training. Recruiters received dedicated training that included: 1) manuals describing the study and their roles, 2) one-to-one training from the primary investigator (PI) on all research procedures, and 3) observed patient recruitment of the first study patient by the PI.

Recruitment procedures. Participants were recruited during hospitalizations, from associated HF clinics, and at HF community classes. Charge nurses, care managers, and HF nurses within these hospitals and clinics aided in identifying patients for recruitment. The PI reviewed potential participant medical records to ascertain if the patient met study inclusion criteria based on a screening checklist (see Appendix D). The PI then approached eligible patients to ask if they would be interested in hearing about this study. If interested, the PI explained the study to the potential participant and reviewed the consent form with the patient prior to obtaining documented consent. A copy of the consent form was provided to the patient.

Data collection procedures. Contact information for the patient and a close friend or family member was obtained. If still hospitalized, patients in private hospital rooms were asked if they would like to complete the initial data collection at the bedside. For those in shared rooms, those not interested in completing the survey immediately, or those recruited outside of the hospital, the PI arranged to call the patient at home.

The PI provided participants with instructions that explained the surveys and proceeded to collect demographic information. Survey testing instruments were then explained and data were collected in a standardized order. The PI read the items to the

patient whether in person or by telephone survey, and patient responses were recorded electronically at the time of interview. Patients were provided with a response guide so that they could visualize the responses and refer to the guide during data collection. These processes were maintained regardless of in-person versus telephone survey so as to minimize any measurement differences.

Patients contacted at home were called approximately two days after discharge from the hospital or the day following their clinic appointment to set up a time to complete the interview. Attempts to set up an interview time with patients occurred twice daily for three weeks unless otherwise indicated. Patients were contacted with preference to their stated best time of day for calls. If a patient was not expected to be home (still hospitalized) or had provided a future day and time for preferred survey completion, calls were postponed. Once initiated, intake surveys took approximately 40 minutes to complete. Participants were free to refuse any questions and, if they became fatigued, breaks were offered.

Participants were also contacted by the PI via telephone 30 days following intake survey completion for the follow-up data collection of outcome measures (see Figure 3). Call frequency and attempts were the same as the methods for contacting patients for the initial interview. Follow-up calls took approximately five minutes to complete. Participant records from the health systems were reviewed 90 days following consent (see Figure 3) to assess hospitalizations and emergency department usage. Additionally, NYHA functional classification and LVEF testing results were ascertained during the medical record review.

Participation was voluntary, and as such, patients were free to withdraw from the study at any time. Participation was defined as completion of the intake survey. Patients withdrew from the study by either directly requesting no further contact or by not responding to contact attempts for greater than three weeks.

Human subject protection. All research was conducted under the supervision of the Michigan State University (MSU) IRB and the respective IRBs of the recruitment sites (see Appendix E). All members of the research team complied with IRB guidelines and required training. Patient confidentiality was maintained with special attention to data collection and management. Patients were offered information regarding risks of the research and were notified that they could withdraw from the study at any time.

Data management. Hard copies of enrollment and consent forms were maintained in a designated, locked file room at MSU. Survey data were collected on password protected laptop computers. When computer access was unavailable, paper versions of the surveys were used and the data manually entered. All data were stored on a HIPAA compliant Survey Monkey research management system (Survey Monkey). The de-identified data files were exported from Survey Monkey to the MSU-secured file servers for analysis and storage.

Data Analysis Plan for Specific Aims

All data analysis were performed using SPSS 23 and STATA 14 (IBM, 2015; StataCorp LP, 2014). The scales were first examined for fit within the sample. Full discussion of factor analyses conducted are presented in the results section. All scales were examined for reliability using Cronbach's alpha; scales with scores greater than 0.7 were included in the analysis.

Education years and income were evaluated as single numerical values. Education in years was estimated based on the amount of education reported. The categories of income were converted by using the mean of each category. The categorical variable of NYHA was simplified to be either class I/II or class III/IV.

Aim 1. Determine the associations between psychological factors (anxiety, stress, and depression) and emotion regulation in African American women with HF at intake (time 1). Relationships between emotion regulation and psychological factors (anxiety, stress, depression) were evaluated with correlation analysis. Potential collinearity was examined. Limitations in sample size prohibited extensive testing with regression models, however a single regression model with a limited number of variables was used. A regression model was tested to further evaluate the association between emotion regulation and a single psychological factor. In the final regression model, age, education, income, and NYHA disease severity were included as controlling variables. Relationships found to have p values less than .05 were considered significant.

Aim 2. Determine the associations of the contributing factors (clinical, demographic, and psychological) and illness perceptions with emotion regulation at intake (time 1) for African American women with HF. Relationships were examined using correlation analysis and regression models. Variables included were those used for Aim 1 in addition to specified IPQ-R subscales. The selected subscales were those that were conceptually distinct and that demonstrated appropriate item-rest correlations during the exploratory factor analysis. Because of the small sample size, only a limited

number of variables were included. These variables were selected to represent major constructs (clinical, demographic, and psychological) from the conceptual model.

Aim 3. Determine the effects of illness perceptions and emotion regulation on the outcomes of adherence and negative health events (death, hospitalization, emergency department, urgent care, and unanticipated primary care visits) in African American women with HF at 30-days (time 2). For this aim, multivariate linear and logistic regression models were used to examine the relationships of illness perceptions and emotion regulation on adherence and negative health events. In the first model, multivariate regression tested predictors of adherence. Negative health events were dichotomized into those individuals who did, versus those who did not, experience an event between consent and the 90-day follow-up period. In the second model, logistic regression was used to predict negative health events.

These analyses provided foundational information to determine the direction of future research.

Chapter 5: Results

This study examined the relationships of emotion regulation and illness perception on adherence behaviors and negative health events of African American women with HF. Demographic and health characteristics are described as well as the core instruments used for the analysis. Information pertaining to internal validity and psychometrics are addressed for each of the instruments. A description of the study results is presented in relation to each of the study aims.

Demographic and Health Characteristics

A total of 58 African American women with a diagnosis of HF were recruited from inpatient (n = 38, 65%) and heart failure clinic sites (n = 20, 35%). Of the 58 patients who completed the intake interview, 54 completed the intake surveys fully and 51 completed both the intake survey and follow-up interview. Table 4 presents the demographic and health characteristics of the study sample.

Study participants varied in age from 49 to 84 years. No differences were noted in the demographics of the study participants between those who were recruited in the hospital and those who were recruited in clinics, except for disease severity (see Table 4). Clinically, the patients in this study varied in symptom severity, with 32 (55%) in NYHA functional classification I/II and 26 (45%) in III/IV. Patients recruited in the hospital had greater NYHA functional classifications (2.7 ± 0.8) than those recruited in clinics (1.9 ± 0.6 ; see Table 4). Documented ejection fractions indicated that 21 (39%) had a LVEF > 40% or physician-indicated preserved systolic function, whereas 33 (57%) had non-preserved systolic function. Half of the patients completed some college (n = 29) and most were of lower socioeconomic status, with 82% (n = 42) reporting

household incomes of less than \$30,000. Overall, multiple comorbid conditions were common, with the patients in this study reporting a range of 4 to 12 illnesses with an average of 4.8 ± 2.0 comorbid conditions. The most frequently self-reported comorbid illnesses were hypertension ($n = 49$, 91%), arthritis ($n = 41$, 76%), arrhythmias ($n = 36$, 67%), diabetes ($n = 29$, 54%), and respiratory disease ($n = 25$, 46%). A full list of items in the Index of Co-Existent Disease (ICED) can be found in Appendix A (Miskulin et al., 2001).

Table 4.

Demographic and Health Characteristics by Recruitment Type

Characteristic	Overall ($n=58$)		Hospital ($n=38$)		Clinic ($n=20$)		<i>p</i>
	Mean	SD	Mean	SD	Mean	SD	
Age	64.5	9.5	66.1	10.3	61.5	6.9	.077
Income (in thousands)	23.2	26.7	20.6	28.3	23.2	26.7	.296
Education in years	13.1	2.0	13.1	2.0	13.2	2.3	.797
NYHA-FC	2.4	.9	2.7	.8	1.9	.6	.000
Ejection fraction (LVEF)	38.2	16.2	36.9	16.6	41.2	15.4	.372
Comorbidities (number reported)	4.8	2.0	4.9	2.0	4.6	1.9	.521
Adherence (MOS-SAS)	3.8	1.0	3.6	1.0	4.2	1.0	.091
	Percentage		Percentage		Percentage		
Negative Health Event experienced	48		58		30		.050

Note. NYHA-FC = New York Heart Association Functional Classification; LVEF = Left Ventricular Ejection Fraction; MOS-SAS = Medical Outcomes Study – Specific Adherence Scale. Of the negative health events, 5 deaths were recorded and all from patients recruited in the hospital.

Comparison of significance evaluated between hospital and clinic patients.

Primary Psychological Variables

Emotion regulation. Emotion regulation was measured with the Difficulties with Emotion Regulation Scale (DERS) (Gratz & Roemer, 2004). The DERS scale contains 36 items with responses ranging from 1 to 5, with higher numbers indicating more

difficulty (see Appendix A for a full list of DERS items). The sum of the items can be calculated into a total scale score. Previous studies suggest a six subscale structure (Gratz & Roemer, 2004). These subscales consist of non-acceptance of emotional responses (6 items), difficulties engaging in goal-directed behavior (5 items), difficulties with impulse control (6 items), lack of emotional awareness (6 items), limited access to emotion regulation strategies (8 items), and lack of emotional clarity (5 items). Mean responses to scale and subscales from the original 36 items in this sample can be seen in Table 5 (for total scale information see Appendix F).

The 36-item DERS subscales had numerous interscale correlations between subscales and with the total scale in this study sample. Subscales had between scale correlations as high as .79. While some correlation is expected between subscales as components of emotion regulation, of concern was how many high correlations existed. Thus, it seemed unclear if the subscales were measuring distinct constructs. An exception among the high interscale correlations was the awareness subscale, which did not correlate with the other subscales. Even if a particular subscale does not correlate with the others, the reliability coefficient for the total scale may not substantially change (Streiner, 2003). As such, awareness, although distinct (as shown in the correlations), does not influence the overall reliability coefficient of the DERS due to the large number of items. With concern for both high and low correlations between subscales, further exploration into the structure of the scale was completed.

Table 5.

Descriptive Statistics of Variables in this Study

Characteristic (Total scale range of scores)	Overall sample N = 54 mean $\pm$ SD or %	Results Range	Cronbach's alpha
Perceived Stress (0-40)	21.2 $\pm$ 5.0	9-32	.84
HADS State Anxiety (0-21)	6.2 $\pm$ 4.3	0-16	.80
HADS Depression (0-21)	6.7 $\pm$ 4.4	0-18	.77
Global Distress (HADS Depression and Anxiety 0-42)	12.8 $\pm$ 8.0	0-34	.87
Cognitive Function (1-100)	69 $\pm$ 19	29-99	.88
Illness Perception structure			
<i>Timeline acute/chronic (1-5)</i>	3.5 $\pm$ 0.8	1.7-5.0	.81
<i>Timeline cyclical (1-5)</i>	3.1 $\pm$ 0.8	1.0-4.8	.74
<i>Consequences (1-5)</i>	3.7 $\pm$ 0.7	2.3-5.0	.74
<i>Personal control (1-5)</i>	3.9 $\pm$ 0.5	2.2-5.0	.69
<i>Treatment control (1-5)</i>	3.7 $\pm$ 0.6	2.0-5.0	.61
<i>Illness coherence (1-5)</i>	3.2 $\pm$ 0.8	1.6-5.0	.80
<i>Emotional representations (1-5)</i>	3.0 $\pm$ 0.8	1.0-4.8	.86
Emotion Regulation (1-5)	1.8 $\pm$ 0.6	1.0-3.5	.91
<i>Non-acceptance of emotional responses (1-5)</i>	1.7 $\pm$ 0.8	1.0-4.0	.80
<i>Difficulties engaging in goal-directed behavior (1-5)</i>	2.1 $\pm$ 1.0	1.0-5.0	.85
<i>Difficulties with impulse control (1-5)</i>	1.7 $\pm$ 0.7	1.0-3.2	.79
<i>Lack of emotional awareness (1-5)</i>	2.2 $\pm$ 0.9	1.0-4.3	.74
<i>Limited access to emotion regulation strategies (1-5)</i>	1.7 $\pm$ 0.6	1.0-3.6	.74
<i>Lack of emotional clarity (1-5)</i>	1.8 $\pm$ 0.7	1.0-3.4	.67
Adherence MOS-SAS (0-40)	30.2 $\pm$ 5.8	1-5	.65
<i>Medications (0-5)</i>	4.9 $\pm$ 0.7	1-5	
<i>Diet (0-5)</i>	4.1 $\pm$ 1.4	1-5	
<i>Exercise (0-5)</i>	1.9 $\pm$ 1.6	1-5	

Note. All scales reported here are the original scales with all items included; HADS = Hospitalized Anxiety and Depression Scale; MOS-SAS = Medical Outcomes Study Specific Adherence Scale. Psychometric discussions can be found in chapters 5 with the respective scales and in chapter 6 limitations.

Factor analysis. To determine if the factor structure of the DERS was reproducible in this sample, an exploratory principal component factor analysis of the DERS scale was conducted with principal axis factoring. A six-factor structure,

representing the six subscales was reported in other research (Gratz & Roemer, 2004). This structure was not supported in this sample. Exploratory factor analysis initially revealed nine factors with eigenvalues > 1.0 (see Table 6). An examination of individual items was conducted to determine items that may be problematic to isolating a unidimensional scale in this sample. Items were removed based on lack of commonalities as well as their factor loadings on the extracted factors, leaving 18 items.

Table 6.

Initial Exploratory Factor Analysis of DERS

Component	Total	Initial Eigenvalues	
		% of Variance	Cumulative %
1	12.06	33.50	33.50
2	4.64	12.90	46.40
3	4.24	11.78	58.18
4	2.76	7.65	65.83
5	2.27	6.31	72.14
6	1.81	5.04	77.18
7	1.63	4.51	81.70
8	1.59	4.41	86.11
9	1.32	3.67	89.78

Note. DERS = Difficulties in Emotion Regulation

Exploratory factor analysis of the remaining 18 items was completed with eigenvalues > 1.0 and a direct oblimin rotation (see Tables 7 and 8). Items converged on four factors with all items loading > .50 relative to the primary factor. This analysis supported a unidimensional scale with a single factor accounting for 51% of the variance. Reliability analysis revealed that no remaining items demonstrated low item-rest correlations (< .35; see Table 9). This item-rest value represents how each item correlates with the other items in the scale (Acock, 2008). Further elimination of items (i.e., item 28) may further strengthen the scale in this sample due to items converging on multiple components (see Table 8).

Table 7.

Exploratory Factor Analysis Eigenvalues of Abbreviated DERS

Component	Total	Initial Eigenvalues	
		% of Variance	Cumulative %
1	9.24	51.31	51.31
2	1.79	9.96	61.27
3	1.17	6.51	67.78
4	1.04	5.79	73.57

Note. DERS = Difficulties in Emotion Regulation

Table 8.

Final Exploratory Factor Analysis Components of Abbreviated DERS

Item	Component			
	1	2	3	4
3 I experience my emotions as overwhelming and out of control	.66	.06	.50	-.12
5 I have difficulty making sense out of my feelings	.59	-.20	.60	.01
11 When I'm upset, I become angry with myself for feeling that way	.65	.10	.08	.48
12 When I'm upset, I become embarrassed for feeling that way	.70	.16	.05	.49
13 When I'm upset, I have difficulty getting work done	.72	.39	-.05	-.02
18 When I'm upset, I have difficulty focusing on other things	.71	.37	.16	-.30
19 When I'm upset, I feel out of control	.64	.28	.01	-.58
21 When I'm upset, I feel ashamed with myself for feeling that way	.59	.48	-.18	.26
23 When I'm upset, I feel like I am weak	.72	-.01	.34	.11
26 When I'm upset, I have difficulty concentrating	.77	.44	-.04	.00
28 When I'm upset, I believe that there is nothing I can do to make myself feel better	.57	-.56	.21	-.08
29 When I'm upset, I become irritated with myself for feeling that way	.69	-.40	-.08	-.02
30 When I'm upset, I start to feel very bad about myself	.83	-.32	-.06	.08
31 When I'm upset, I believe that wallowing in it is all I can do	.69	.33	-.18	-.10
32 When I'm upset, I lose control over my behaviors	.79	-.30	-.34	-.05
33 When I'm upset, I have difficulty thinking about anything else	.87	-.20	-.16	-.13
35 When I'm upset, it takes me a long time to feel better	.80	-.24	-.35	-.08
36 When I'm upset, my emotions feel overwhelming	.81	-.25	-.20	.08

Note. DERS = Difficulties in Emotion Regulation. All items from "Multidimensional Assessment of Emotion Regulation and Dysregulation: Development, Factor Structure, and Initial Validation of the Difficulties in Emotion Regulation Scale," by K.L. Gratz and L. Roemer, 2004, *Journal of Psychopathology and Behavioral Assessment*, 26(1), p. 41-54.

Table 9.

Abbreviated DERS Reliability Item Analysis

	Item	Item-rest Correlations	Alpha if Item Deleted
3	I experience my emotions as overwhelming and out of control	.62	.94
5	I have difficulty making sense out of my feelings	.55	.94
11	When I'm upset, I become angry with myself for feeling that way	.61	.94
12	When I'm upset, I become embarrassed for feeling that way	.66	.94
13	When I'm upset, I have difficulty getting work done	.68	.94
18	When I'm upset, I have difficulty focusing on other things	.67	.94
19	When I'm upset, I feel out of control	.59	.94
21	When I'm upset, I feel ashamed with myself for feeling that way	.54	.94
23	When I'm upset, I feel like I am weak	.68	.94
26	When I'm upset, I have difficulty concentrating	.74	.94
28	When I'm upset, I believe that there is nothing I can do to make myself feel better	.52	.94
29	When I'm upset, I become irritated with myself for feeling that way	.64	.94
30	When I'm upset, I start to feel very bad about myself	.80	.94
31	When I'm upset, I believe that wallowing in it is all I can do	.65	.94
32	When I'm upset, I lose control over my behaviors	.75	.94
33	When I'm upset, I have difficulty thinking about anything else	.83	.94
35	When I'm upset, it takes me a long time to feel better	.70	.94
36	When I'm upset, my emotions feel overwhelming	.77	.94

Note. DERS = Difficulties in Emotion Regulation. All items from "Multidimensional Assessment of Emotion Regulation and Dysregulation: Development, Factor Structure, and Initial Validation of the Difficulties in Emotion Regulation Scale," by K.L. Gratz and L. Roemer, 2004, *Journal of Psychopathology and Behavioral Assessment*, 26(1), p. 41-54.

Face validity indicates that the 18 DERS items captures the conceptualization of difficulties with emotion regulation. The abbreviated scale had an average inter-item correlation of 0.42 and good reliability with Cronbach's alpha of 0.94. Analysis of the study aims was conducted using this abbreviated DERS instrument (see Table 9). Although the factor analysis provided information regarding items in this sample, with such a small sample size, this information will likely not be reproducible in other samples. The use of mean scores has no effect on correlations and the significance of

regression coefficients for the analysis of study aims, however with elimination of items, no clear comparison to the original scores from the literature can be conducted.

Abbreviated DERS descriptives. To allow for comparison with other studies, mean scores were calculated rather than total scores. Mean item responses from the abbreviated DERS items were calculated to create a 1–5 scale. On the 18-item abbreviated DERS scale, patients reported mean difficulty with emotion regulation as a 1.8 ± 0.8 (see Table 10). The range of these mean scores (1 to 4.8) indicated that patients responding to this scale varied from having low to high difficulties with emotion regulation (see Figure 4). The pattern of responses was not distributed normally with responses skewed toward fewer difficulties with emotion regulation. This abbreviated scale was used for analysis of study aims.

Table 10.

Descriptive Statistics of Final Difficulties with Emotion Regulation Scale

Characteristic (Total scale range of scores)	Overall sample N = 54 mean $\pm$ SD or %	Results Range	Cronbach's alpha
Emotion Regulation abbreviated version (1-5)	1.8 ± 0.8	1.0- 4.8	.94

Note. Emotion regulation abbreviated version contains the items used for data analysis.

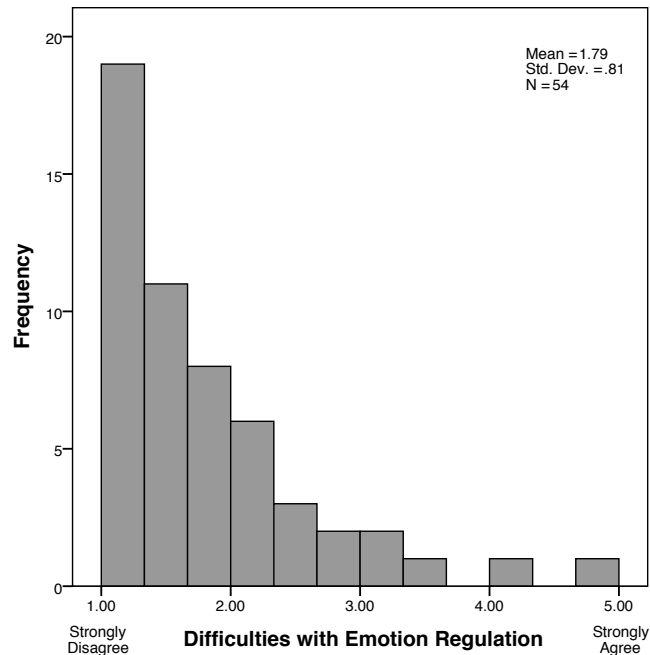


Figure 4. Frequency histogram of scores in sample participants on the Difficulties with Emotion Regulation Scale (DERS).

Illness perceptions. Illness perceptions were measured with the Illness Perceptions Questionnaire-Revised (IPQ-R) (see Appendix A for full list of IPQ-R items). According to the literature/previous findings, there are many distinct subscales of the IPQ-R. The identity subscale measures symptoms that the patient associates with their illness. The cause subscale measures perceived causal attributions. While other subscales examine perceived chronicity vs. acute timeline, cyclical timeline, illness consequences, personal and treatment control, and the emotional representations of the illness. The majority of items on the IPQ-R are on a 1 (strongly disagree) to 5 (strongly agree) scale, with the exception being the identity subscale, which has a yes/no format (see Appendix A). Cronbach's alphas for the rest of the subscales in the current data ranged between .61 and .86 (see Table 5). This internal reliability was similar to other studies with minority populations (Kim et al., 2012).

Limitations in sample size necessitated that only a subset of the subscales be used for the analysis of the aims (total score information from all subscales can be seen in Appendix F). As, identification of symptoms is difficult to discriminate with the numerous and varied comorbid conditions experienced by patients with HF and patients enrolled had a variety of causes for their HF, the cause and identity subscales were not considered for final analysis. A factor analysis was completed to examine which of the remaining subscales performed well in this sample and would be appropriate for use in the final analysis.

Factor analysis. An exploratory factor analysis of the items in the subscales of acute/chronic timeline, cyclical timeline, consequences, personal control, treatment control and emotional representations was completed with isolation of factors that had eigenvalues > 1.0 , with principal axis factoring. Findings revealed an 11-factor structure (see Table 11). Closer examination of the items revealed that only the illness coherence subscale was converging on a single factor. Reliability testing of this subscale revealed good item-rest correlations $> .30$ and a Cronbach's alpha of $.80$ (see Table 12). Additionally, the items from the two subscales of personal control and treatment control were largely converging on a single factor using the criteria of eigenvalues > 1.0 . These control subscales were merged to represent overall perceived illness controllability. Further analyses of the combined control subscales items were conducted, with two items that exhibited low item-rest correlations removed. All remaining item-rest correlations in the new illness controllability subscale were $> .30$ and had a final subscale Cronbach's alpha of $.80$ (see Table 12).

Table 11.

Initial Exploratory Factor Analysis of IPQ-R

Component	Total	Initial Eigenvalues	
		% of Variance	Cumulative %
1	7.34	19.31	19.31
2	5.04	13.26	32.57
3	4.34	11.41	43.98
4	2.46	6.48	50.46
5	1.73	4.54	55.00
6	1.67	4.39	59.39
7	1.44	3.79	63.19
8	1.36	3.57	66.76
9	1.22	3.22	69.98
10	1.11	2.92	72.90
11	1.03	2.71	75.61

Note. IPQ-R = Illness Perceptions Questionnaire Revised

Table 12.

Illness Perceptions Questionnaire Coherence and Controllability Reliability Item Analysis

Item	Item-rest Correlations	Alpha if item deleted
<u>Illness Coherence</u>		
24r The symptoms of my condition are puzzling to me	.39	.82
25r My illness is a mystery to me	.74	.70
26r I don't understand my illness	.71	.71
27r My illness doesn't make any sense to me	.55	.77
28 I have a clear picture or understanding of my condition	.53	.77
<u>Illness Controllability Subscale</u>		
12 There is a lot which I can do to control my symptoms	.54	.78
13 What I do can determines whether my illness gets better or worse	.38	.80
14 The course of my illness depends on me	.59	.78
15r Nothing I do will affect my illness	.41	.80
16 I have the power to influence my illness	.53	.78
17r My actions will have no effect on the outcome of my illness	.37	.81
19r There is very little that can be done to improve my illness	.54	.78
22 My treatment can control my illness	.66	.77
23r There is nothing which can help my condition	.59	.78

Note. r = reverse scored. All items from "The revised Illness Perception Questionnaire (IPQ-R)," by R. Moss-Morris, et al., (2002), *Psychology & Health*, 17(1), p, 1-16.

The controllability and coherence items were retained and examined again to verify the structure of these items. To confirm a two-factor structure, only these items

were entered into a factor analysis with eigenvalues > 1.0 and a direct oblimin rotation. A model emerged with 30% of the variance on the first factor and 19% on the second (see Table 13). Item analyses show the illness controllability items largely converging on the first and third factors, while illness coherence items were converging on the second factor (see Table 14). The items from the first and third factors represented a blend of items from each the personal and treatment controllability subscales. The remaining subscales from the IPQ-R did not converge on factors. Without the factor structure there was a lack of support that the subscale concepts in this sample were being reliably measured. Validity testing on all of the subscales was documented elsewhere and revealed good discriminant and predictive validity in varied illness groups (Moss-Morris et al., 2002). Due to the small sample size in this study, additional validity testing was not possible to determine if the subscales were equally valid in this group. With the combined control subscale for this study, it was unclear if, as a group, these scales would maintain discriminant and predictive validity. Because of the issues with many of the subscales, only the illness controllability and illness coherence were used in the analysis of the aims.

Table 13.

Exploratory Factor Analysis Eigenvalues of Abbreviated IPQ-R

Component	Total	Initial Eigenvalues	
		% of Variance	Cumulative %
1	4.18	29.86	29.86
2	2.67	19.05	48.90
3	1.55	11.07	59.98

Note. IPQ-R = Illness Perceptions Questionnaire Revised

Table 14.

Final Exploratory Factor Analysis Components of Abbreviated IPQ-R

	Component		
	1	2	3
The symptoms of my condition are puzzling to me	-.20	.58	-.11
My illness is a mystery to me	.05	.88	.17
I don't understand my illness	.20	.86	.28
My illness doesn't make any sense to me	.10	.69	.34
I have a clear picture or understanding of my condition	.24	.67	.15
There is a lot which I can do to control my symptoms	.74	.03	.27
What I do can determine whether my illness gets better or worse	.34	.08	.50
The course of my illness depends on me	.44	.02	.79
Nothing I do will affect my illness (r)	.16	.12	.82
I have the power to influence my illness	.75	.05	.26
My actions will have no effect on the outcome of my illness (r)	.14	.33	.79
There is very little that can be done to improve my illness (r)	.73	.29	.22
My treatment can control my illness	.85	-.00	.36
There is nothing which can help my condition (r)	.81	-.02	.20

Note. r = reverse scored. All items from "The revised Illness Perception Questionnaire (IPQ-R)," by R. Moss-Morris, et al, (2002), *Psychology & Health*, 17(1), p, 1-16.

IPQ-R subscale descriptives. The results of the original IPQ-R subscales are reported in Table 5. Mean scores between 3 and 4 suggested responses between neutral and agree for each original subscale.

Abbreviated IPQ-R illness coherence and controllability descriptives. The 6-item illness coherence scale was unchanged from the original subscale as described by Moss-Morris et al. (2002). With alterations in the number of items for the controllability subscale, mean scores and mean score ranges are described to aid in comparing those to original subscales.

The mean score of illness coherence was 3.2 ± 0.8 with a range of mean scores from 1.6 to 5 (see Table 15). The 9-item illness controllability subscale had a mean score of 3.9 ± 0.5 with a mean range of 2.1 to 5. These mean scores and ranges

indicate that patients responding to these subscales varied from very negative to highly positive perceptions of illness coherence and controllability (see Figures 5 and 6). The illness coherence scale had an almost symmetrical distribution centered on the neutral response, with similar numbers either agreeing or not agreeing on how coherently they viewed their illness. The responses on the illness controllability subscale were not quite as symmetrical, with the responses skewed toward greater perceived controllability.

Table 15.

Descriptive Statistics of Final Illness Perception Subscales

Characteristic (Total scale range of scores)	Overall sample N = 54 mean $\pm$ SD or %	Results Range	Cronbach's alpha
Illness Perception structure			
<i>Illness coherence (1-5)</i>	3.2 $\pm$ 0.8	1.6-5.0	.80
<i>Illness controllability abbreviated (1-5)</i>	3.9 $\pm$ 0.5	2.1-5.0	.80

Note. Illness controllability abbreviated version and illness coherence subscales contain the items used for data analysis.

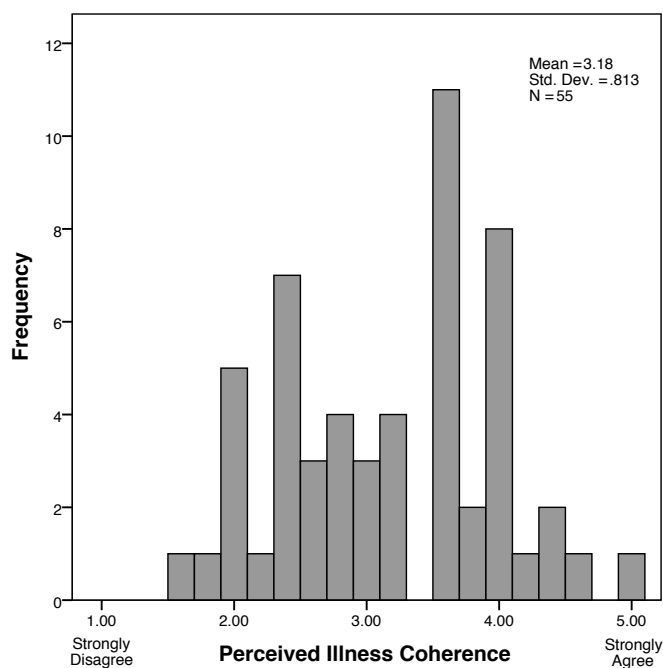


Figure 5. Frequency histogram of scores of sample participants on the IPQ-R Illness coherence subscale.

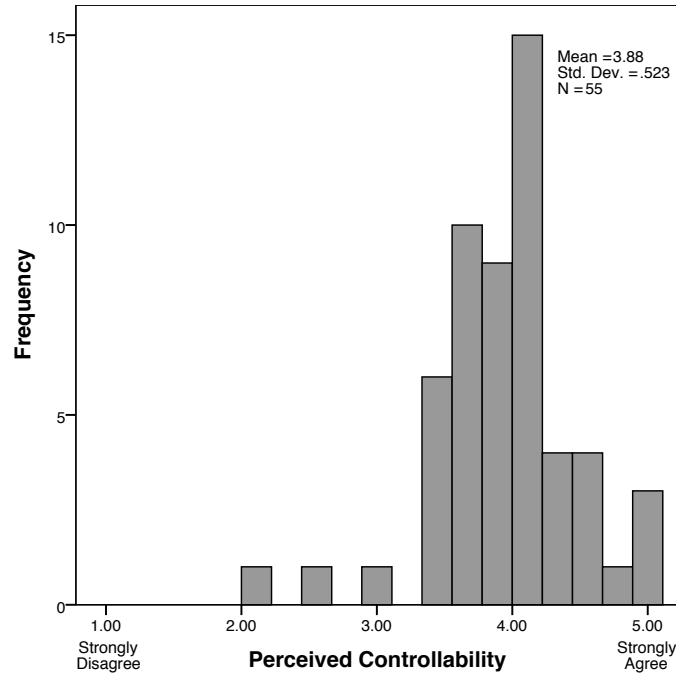


Figure 6. Frequency histogram of scores of sample participants on the adapted IPQ-R illness controllability subscale.

Secondary Psychological Variables

Anxiety and depression. The Hospital Anxiety and Depression Scale (HADS) includes 14 items with two subscales; one each for depression (HADS-D) and anxiety (HADS-A) (see Appendix A; Zigmond & Snaith, 1983). This scale has good specificity and sensitivity in patients with HF (Haworth et al., 2007). General established cut-points for possible depression or anxiety diagnoses are recommended as scores greater than 7 for each subscale with a 0–21 range of scores for each (Bjelland, Dahl, Haug, & Neckelmann, 2002; Covic et al., 2012). Cut-points were not used in this analysis, but do provide clinical relevance for the description of patients in this sample. The patients in this sample reported depressive scores just below the cut-point for

possible depression with mean scores of 6.7 ± 4.4 , and a range of 0 to 18 (see Table 5). Scores were also near the anxiety cut-point at 6.2 ± 4.3 with a range of 0 to 16.

The HADS scale demonstrated unidimensionality appropriate for use as a global scale. In terms of validity, there were strong associations between the anxiety and depression subscales with a Pearson Correlation Coefficient of 0.68. A previous study examined the HADS using a factor analysis and also determined strong overlap between items in the depression and anxiety subscales with a female cardiac patient sample (Roberts & Bonnici, 2001). Considering the high correlations between the two subscales in this study, a single global measure of distress (both anxiety and depression) was used and included all items from the original instrument (Zigmond & Snaith, 1983). These combined instruments had good face validity for global distress. Analysis supported the use of the single global instrument that measured distress with item-rest correlations all $> .30$ with the unidimensional scale. Reliability coefficients for these subscales were consistent with the literature, with Cronbach's alphas for the HADS-D, $\alpha = 0.77$ and HADS-A, $\alpha = 0.80$ (Bjelland et al., 2002). The global distress scale had high internal consistency with a Cronbach's alpha reliability of 0.87 (see Table 5).

Stress. The 10-item Perceived Stress Scale (PSS; see Appendix A) has shown good internal consistency when used with an African American female sample with chronic illnesses ($\alpha = 0.82$; Lopez et al., 2012). In this study, the scale demonstrated unidimensionality in a factor analysis, and the alpha reliability was also good at 0.84 (see Table 5). All items in the reliability testing demonstrated item-rest correlations

greater than .30 with the unidimensional scale. Mean perceived stress was 21.2 ± 5.0 (range 9 to 32) on a scale from 0 to 40, with higher numbers indicating greater stress.

Cognitive function. Perceived effectiveness in cognitive function was measured with the Attention Function Index (AFI; see Appendix A) using a 0–10 Likert scale for individual items rather than the original visual analogue scale, which was scored by marking a 0–100mm line. Exploratory factor analysis indicated that the items loaded on two factors with eigenvalues > 1.0 . The two factors with separable factor loadings represented the positively worded and negatively worded items. Previous psychometric analysis has shown this scale to be a valid instrument using both the positively and negatively worded items (Cimprich et al., 2011; Miaskowski et al., 2012). As such, reliability was examined by including all items. Internal consistency was high for this instrument with Cronbach's $\alpha = 0.87$ (see Table 5). This was similar to another study that used the numeric scale version and reported a Cronbach's α of 0.95 (Miaskowski et al., 2012). Analysis revealed that items had acceptable average item-rest correlations (all $> .30$). The complete AFI scale, combining positively and negatively worded items, was used in this study to measure cognitive function. Mean cognitive function scores were 69 ± 19 on a scale of 0 to 100 (range 29–99), with the higher numbers indicating better perceived functioning (see Table 5).

Health Outcomes

Adherence. Adherence was measured with the Medical Outcomes Study Specific Adherence Scale (MOS-SAS) for patients with cardiovascular disease (DiMatteo, Hays, & Sherbourne, 1992). This instrument measures general adherence (5 items) with an additional 3 items specific to cardiovascular expectations of diet,

medications, and exercise (see Appendix B). Adherence is measured by asking the patients how they performed in the past month. To examine the dimensionality of the items within this sample, a factor analysis was conducted.

The 8-item MOS-SAS scale had less than optimal internal reliability in this sample with a Cronbach's alpha of 0.64, which is lower than that of $\alpha = 0.81$ seen in another study of patients with cardiovascular disease (Hays, 2012). Another study using slightly different items than those used in this study also had a lower Cronbach's alpha of 0.54 (Shively et al., 2013). The five general adherence items had a Cronbach's alpha of 0.69 in this sample with the reliability coefficient decreasing with the addition of the single items of adherence to diet, medication, and exercise.

Factor analysis. Exploratory factor analysis was completed to examine the general adherence questions with principal axis factoring and a direct oblimin rotation. Initial factor analysis with eigenvalues at > 1.0 indicated that all five items loaded on a single factor, which explained 46% of the variance (see Table 16). Further reliability testing revealed that one of the five items (item 2, "I followed my doctor's suggestions exactly") had a low item-rest correlation and was removed (DiMatteo et al., 1992). After the removal of this item, exploratory factor analysis of the four remaining items indicated a single factor explaining 53% of the variance (see Table 17). This final analysis did not include any rotation as all items converged on a single factor (see Table 17). Reliability analysis found that the item-rest correlation was $> .30$ (see Table 18) with a Cronbach's alpha of .70 (see Table 19). Single responses to diet, medications, and exercise adherence were retained for descriptive purposes only. The 4-item general adherence scale was used in the analysis of the aims.

Table 16.

Adherence Initial Exploratory Factor Analysis of MOS-SAS

Component	Total	Initial Eigenvalues	
		% of Variance	Cumulative %
1	2.29	45.71	45.71
2	.98	19.59	65.30
3	.76	15.15	80.45
4	.52	10.39	90.84
5	.46	9.16	100.00

Note. MOS-SAS = Medical Outcomes Study Specific Adherence Scale using the five general items measuring adherence.

Table 17.

Exploratory Factor Analysis Eigenvalues of Abbreviated MOS-SAS General Adherence

Component	Total	Initial Eigenvalues	
		% of Variance	Cumulative %
1	2.12	53.16	53.16
2	.84	20.92	74.09
3	.53	13.17	87.26
4	.51	12.74	100.00

Note. MOS-SAS = Medical Outcomes Study Specific Adherence Scale

Table 18.

General Adherence Medical Outcomes Study Final Item Analysis

Item		Item-rest Correlations	Alpha if Item Deleted
1r	I had a hard time doing what the doctor suggested I do.	.42	.67
3r	I was unable to do what was necessary to follow my doctor's treatment plans.	.42	.67
4	I found it easy to do the things my doctor suggested I do.	.55	.59
5	Generally speaking, how often during the past 4 weeks were you able to do what the doctor told you?	.55	.59

Note. r = reverse scored. All items from "Adherence to Cancer Regimens: Implications for Treating the Older Patient," by M. R. DiMatteo, et al., 1992, *Oncology (Williston Park)*, 6(2 Suppl), p. 50-57.

Table 19.

Descriptive Statistics of Final MOS-SAS

Characteristic (Total scale range of scores)	Overall sample N = 54 mean $\pm$ SD or %	Results Range	Cronbach's alpha
Adherence MOS-SAS abbreviated version (0-5)	3.8 $\pm$ 1.0	1-5	.70

Note. MOS-SAS = Medical Outcomes Study Specific Adherence Scale. MOS-SAS abbreviated version contains the items used for data analysis.

Abbreviated MOS-SAS descriptives. Overall, the mean scores of 3.8 ± 1.0 on the 5-point scale, suggest positive adherence (see Table 19). With the diet, medications, and exercise items, patients reported the lowest adherence to exercise (1.9 ± 1.6) on a 1 to 5 scale, and the highest adherence to diet (4.1 ± 1.4) and medications (4.9 ± 0.7 ; see Table 5).

Negative health events. Medical records were reviewed for the 90-day period from consent to ascertain negative health events (i.e., death, hospitalization, emergency department, or urgent visits to a healthcare provider) related to HF, cardiac, or other reasons. In four cases, not enough information was provided in the medical record to determine the cause of the event (unable to discern). Negative health events were relatively common in this group ($n = 28$, 48%) with first events identified as 15 hospital admissions, six emergency department visits, and seven urgent visits to healthcare providers (see Table 20). Although the outcome was determined based on the first negative health event, some patients experienced multiple events. For example, after hospitalization, five patients died during the 90-day period. Cause of death was heart failure-related in four patients and for other cardiac reasons in one patient. Patient days to negative healthcare events varied over the 90-day follow-up period with a mean of 40.9 ± 25.6 days and a range of 4–92 days (see Figure 7). Although types of events varied, the small sample size prevented a more sophisticated analysis that would have accounted for event severity. As there is significant overlap between seeking care for cardiac versus heart failure reasons, all cardiac events were included to determine the outcome analyzed in the aims. To simplify the outcome, all cardiac events were

combined into a single binary outcome variable: 1 = 'negative health event' occurred, 0 = did not occur.

Table 20.

First Event Health Outcomes of Study Patients

Negative Health Events	N	mean $\pm$ SD or %
<i>Time to first event (days)</i>	28	40.9 $\pm$ 25.6
<i>Type of first event</i>		
<i>Death</i>	0	0
<i>Hospitalization</i>	15	53.6
<i>With Death as Final Outcome*</i>	5	17.9
<i>Emergency Department visit</i>	6	21.4
<i>Urgent clinic or primary care visit</i>	7	25.0
<i>Reason for first event</i>		
<i>Heart Failure</i>	12	42.8
<i>Cardiac</i>	4	14.3
<i>Other</i>	8	28.6
<i>Unable to Discern</i>	4	14.3

Note. n = 51

*All deaths were preceded by a hospitalization and occurred in patients who were originally recruited from the hospital settings.

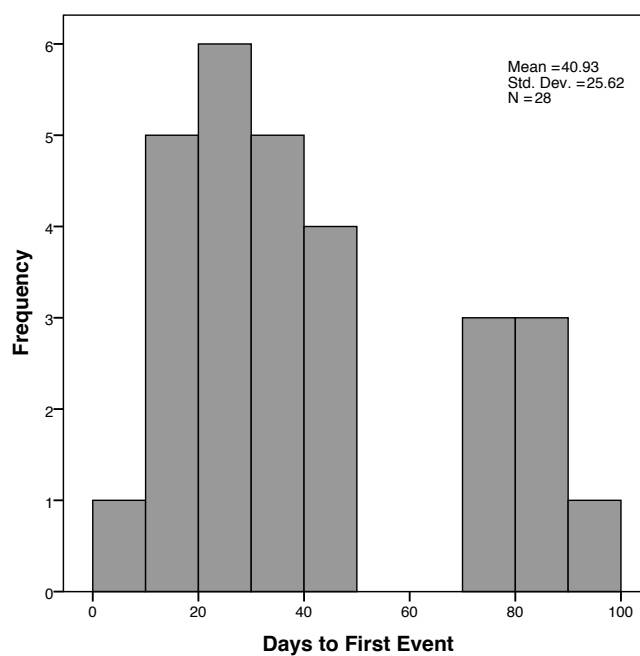


Figure 7. Frequency histogram of the number of days to the first negative health event for sample participants.

Overall, study outcomes revealed that although patients perceived themselves as generally adherent, negative health events were common. Out of the 51 patients completing the study, 28 experienced at least one negative health event within the 90-day follow-up period. These negative health events were largely attributed to cardiac-related issues.

Summary of Instruments

Following factor analysis and reliability testing, the following instruments were used in the analysis: 1) 18 items from the DERS; 2) illness coherence subscale of the IPQ-R; 3) nine items from the illness controllability subscales of the IPQ-R; 4) four items from the MOS-SAS general adherence subscale; 5) binary information on negative health events for cardiac reasons; 6) HADS; 7) PSS; and 6) AFI.

Analysis of Data by Study Aims

Aim 1. *To determine the associations between psychological factors (anxiety, stress, depression, and cognitive function) and emotion regulation in African American women with HF (time 1).* Hypothesis 1: Higher levels of anxiety, stress, depression, and poorer cognitive function will be associated with less effective emotion regulation.

Pearson correlation analyses were conducted to determine the relationships between psychological factors and emotion regulation. Higher global distress (HADS, $r = .42$, $p = .002$.) and perceived stress (PSS, $r = .29$, $p = .033$), and lower cognitive function (AFI, $r = -.33$, $p = .014$.) were significantly correlated with more difficulties in emotion regulation (DERS; see Table 21).

Table 21.

Aim 1. Pearson Correlations between Psychological Factors and DERS

Psychological Factor	M	SD	1	2	3
1. Global Distress (Depression and Anxiety)	12.7	8.0	-		
2. Stress	21.2	5.0	.49**	-	
3. Cognitive Function	83.8	25.0	-.56**	-.42**	-
4. Abbreviated DERS	1.8	0.8	.42**	.29*	-.33*

Note. Abbreviated DERS = Difficulties in Emotion Regulation 18-item abbreviated scale

* $p < .05$; ** $p < .01$

To further explore this relationship, a multiple linear regression was conducted to determine possible predictors of emotion regulation. Because of strong correlations among the psychological variables in this analysis, only one psychological variable was used. All patients in this study reported some perceived stress, whereas not all patients reported anxiety or depressive symptoms (see Table 5). The PSS was selected as the predictor variable given its relationship to other psychological constructs such as distress. Additionally, controlling variables were selected to minimize the effect of confounding factors in this non-random sample.

The final model included control variables of age, education, income, NYHA functional classification, LVEF, in addition to the psychological predictor variables of the PSS. The robust estimates of standard errors were used to adjust for non-homogeneity of variance (see Table 22). The total model was significant, with an $R^2 = .34$, $F(6, 37) = 3.72$, $p = .005$. Variables that significantly predicted association with increased difficulties with emotion regulation included age ($b = -.03$, $t(37) = -2.48$, $p = .018$), and perceived stress ($b = .06$, $t(35) = 2.95$, $p = .005$). Older patients in this sample, and those with lower perceived stress scores had significantly fewer difficulties with emotion regulation as measured by the abbreviated DERS.

Table 22.

Aim 1. Regression of Emotion Regulation on Predictors

Model	B	Robust Standard Error	t	Sig. p=	95.0% Confidence Interval for B	
Age	-.03	.01	-2.48	.018*	-.06	-.01
Education	-.11	.07	-1.53	.134	-.25	.04
Income	.01	.01	1.19	.243	-.01	.02
NYHA	-.25	.25	-1.00	.322	-.74	.25
LVEF	-.003	.01	-.37	.720	-.02	.01
PSS	.06	.02	2.95	.005*	.02	.10
(Constant)	4.34	1.53	2.83	.007*	1.23	7.44

Note. The dependent variable for all regressions was Difficulties in Emotion Regulation (DERS 18-item abbreviated scale); NYHA – New York Heart Association functional classification; LVEF – Left Ventricular Ejection Fraction; PSS – Perceived Stress Scale.

* $p < .01$

The high collinearity among the psychological variables was clearly evident in this analysis, as shown in Table 21. The abbreviated DERS and PSS included in the regression model were known to be correlated ($r = .29$, $p = .033$). Based on this analysis, even when controlling for demographic and clinical variables, the significant relationships between age $b = -.03$, $t(37) = -2.48$, $p = .018$, and stress $b = .06$, $t(35) = 2.95$, $p = .005$ on emotion regulation remained. In summary, Aim 1 revealed associations between emotion regulation and each age and perceived stress (see Figure 8). These associations remained even when controlling for education, income, NYHA functional classification, and LVEF.

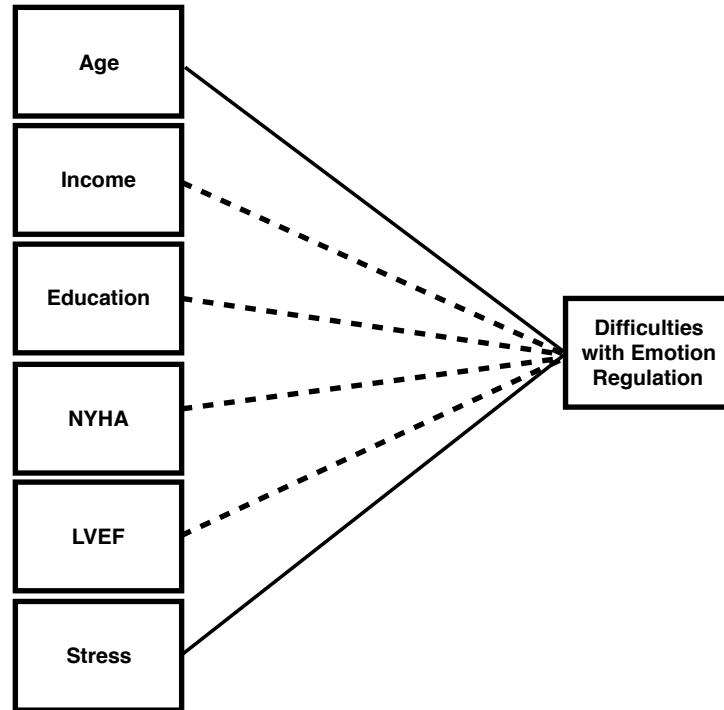


Figure 8. This figure shows the results of Aim 1. Supported relationships are indicated with solid lines; unsupported relationships are indicated by dashed lines. NYHA = New York Heart Association functional classification; LVEF = Left Ventricular Ejection Fraction.

Aim 2. *To determine the associations of the contributing factors (clinical, demographic, and psychological) and illness perceptions with emotion regulation at intake (time 1) for African American women with HF.* Hypothesis 2: Illness perceptions and emotion regulation are associated with the clinical, demographic, and psychological factors.

Pearson correlation analyses were conducted to determine the relationships between contributing factors (clinical, demographic, and psychological) and illness perceptions with emotion regulation. Age ($r = -.34$, $p = .010$), higher global distress (HADS, $r = .42$, $p = .002$) and perceived stress (PSS, $r = .29$, $p = .033$), and lower cognitive function (AFI, $r = -.33$, $p = .014$) were significantly correlated with more difficulties with emotion regulation (DERS; see Table 23). No significant correlations

were noted between emotion regulation and either illness coherence or illness controllability.

The final model for Aim 2 included the variables of age, NYHA functional classification, PSS, emotion regulation, illness coherence, and illness controllability. The Breusch-Pagan Cook Weisberg test for heteroskedasticity was significant, indicating that it was necessary to test the relationships using robust standard errors (Baum, Schaffer, & Stillman, 2003). The robust estimates of standard errors were used to adjust for non-homogeneity of variance (see Table 24). The total model was significant, with an $R^2 = .22$, $F(5, 48) = 2.76$, $p = .029$. The only variable that significantly predicted association with increased difficulties with emotion regulation was age, ($b = -.02$, $t(48) = -2.17$, $p = .035$). As was also shown in Aim 1, older patients in this sample had significantly lower difficulties with emotion regulation as measured by the abbreviated DERS.

Table 23.

Aim 2. Pearson Correlations between Demographic, Clinical, and Psychological Factors

Variables	M	SD	1	2	3	4	5	6	7	8	9	10	11
1. Age	64.5	9.5	-										
2. Income (in thousands)	23.2	26.7	-.04	-									
3. Years of Education	13.1	2.0	-.26*	.42**	-								
4. NYHA	2.4	.9	.05	-.25	-.09	-							
5. LVEF	38.2	16.2	.19	.22	.19	-.34*	-						
6. Global Distress (Depression and Anxiety)	12.7	8.0	-.34*	-.05	-.14	.05	.09	-					
7. Stress	21.2	5.0	-.07	-.17	.01	.25	-.08	.42**	-				
8. Cognitive Function	83.8	25.0	.07	-.20	.01	.17	-.15	-.57**	-.41**	-			
9. Abbreviated DERS	1.8	.81	-.33*	.16	-.02	.01	-.08	.42**	.29*	-.33*	-		
10. Illness Consequences	3.7	.67	-.06	-.25	-.01	.24	-.01	.48**	.43**	-.32*	.19	-	
11. Illness Coherence	3.9	.52	-.25	.03	.22	-.05	-.01	.22	.32*	-.11	.15	.21	-

Note. NYHA = New York Heart Association functional classification; LVEF = Left Ventricular Ejection Fraction; Abbreviated DERS = Difficulties in Emotion Regulation 18-item abbreviated scale

* $p < .05$; ** $p < .01$

Table 24.

Aim 2. Regression of Emotion Regulation on Predictors

Model	B	Robust Standard Error	t	Sig. p=	95.0% Confidence Interval for B	
Age	-.02	.01	-2.17	.035 [*]	-.05	.01
NYHA	-.24	.20	-1.21	.231	-.65	.16
PSS	.04	.02	1.98	.053	-.01	.08
Illness coherence	-.19	.13	-1.48	.146	-.45	.07
Illness controllability	.07	.21	.32	.752	-.36	.50
(Constant)	2.93	1.45	2.02	.049 [*]	.01	5.86

Note. The dependent variable for all regressions was Difficulties in Emotion Regulation (DERS 19-item abbreviated scale); NYHA – New York Heart Association functional classification; PSS – Perceived Stress Scale.

*p < .05

In summary, Aim 2 revealed associations between emotion regulation and age (see Figure 9). With the inclusion of the illness perception components of coherence and controllability, stress no longer remained a predictor of difficulties with emotion regulation. Younger age was predictive of increased difficulties with emotion regulation ($\beta = -.02$; see Table 24).

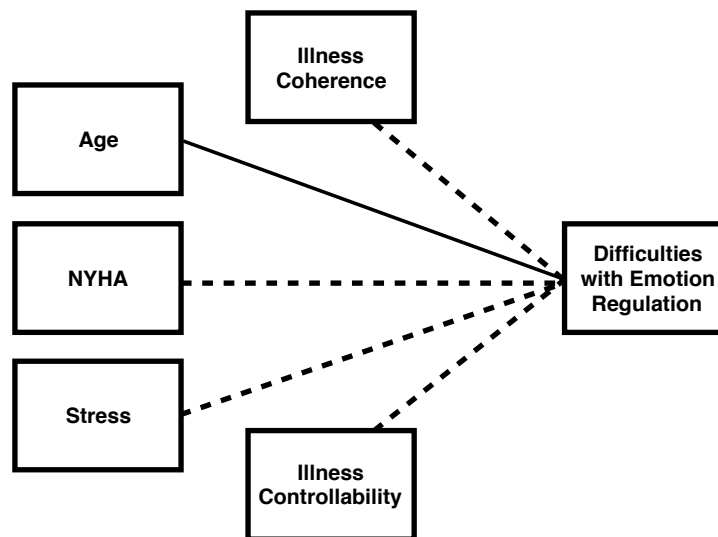


Figure 9. This figure shows the results of Aim 2. Supported relationships are indicated with solid lines; unsupported relationships are indicated by dashed lines. NYHA = New York Heart Association functional classification.

Aim 3. *To determine the effects of illness perceptions and emotion regulation on the outcomes of adherence and negative health events (death, hospitalization, emergency department, urgent care, and unanticipated primary care visits) in African American women with HF at 30-days (time 2).* Hypothesis 3: Less effective emotion regulation and worse illness perceptions will be associated with lower adherence and greater negative health events.

Two models were used to test these relationships. Both models used a subset of the predictor variables (age, education, and NYHA functional classification) as described in the results of the previous aims. To examine the outcome variable of adherence, a linear regression model was used. As the second outcome variable was dichotomous (either an event occurred or it did not), a logistic model was used.

For the linear regression model, the Breusch-Pagan Cook Weisberg test for heteroskedasticity was significant, indicating that it was necessary to test the relationships using robust standard errors (Baum et al., 2003). In the first linear regression model, age, education, IPQ-R adapted illness controllability, IPQ-R illness coherence, and the abbreviated DERS were predictor variables for the adherence outcome. This model was not statistically significant, with an $R^2 = .08$, $F(5,44) = .99$, and $p = .43$ (see Table 25).

Table 25.

Aim 3. Linear Regression of Adherence on Illness Perceptions and Emotion Regulation

Model	B	Robust Standard Error	t	Sig. p=	95.0% Confidence Interval for B	
DERS	-.10	.18	-.54	.594	-.46	.27
Illness coherence	-.32	.18	-1.79	.080	-.68	.04
Control	.14	.43	.32	.752	-.72	.99
Age	.01	.02	.51	.615	-.02	.04
Education	.12	.09	1.41	.165	-.05	.30
(Constant)	2.40	2.64	.91	.370	-2.94	7.74

Note. The dependent variable for all regressions was Adherence using the abbreviated 4 item MOS-SAS (Medical Outcomes Study-Specific Adherence Scale); DERS - Difficulties in Emotion Regulation (DERS 18-item abbreviated scale); Coherence – IPQ-R perceived illness coherence; Control – IPQ-R personal and treatment controllability; Education – years of education

In the logistic regression model predicting the odds of a first emergency use of healthcare services, the predictors were age, education, illness severity using the NYHA, IPQ-R adapted illness controllability, IPQ-R illness coherence, and the abbreviated DERS. The findings were non-significant for predicting the use of emergent healthcare services ($p = .140$). There were limited significant single relationships between the predictor variables and healthcare use (see Table 26). The Hosmer-Lemeshow test indicated that the goodness of fit was appropriate ($p = .523$), but the small sample size limited the power of the analysis both for finding significant relationships and for testing the model's goodness of fit.

A single significant relationship existed within this second model. NYHA was found to be associated with the use of emergent healthcare services for cardiac events ($\beta = 1.47$, $p = .027$). Although no clear relationships were found in regards to illness perceptions or emotion regulation and the outcomes of adherence and use of healthcare services for cardiac events, results of this study indicate that these concepts warrant further study.

Table 26.

Aim 3. Logistic Regression of Negative Health Events on Illness Perceptions and Emotion Regulation

Model	B	Standard Error	Wald	Sig. p=	95.0% Confidence Interval	
DERS	.80	.44	3.30	.069	.94	5.28
Illness coherence	-.27	.41	.44	.507	.34	1.70
Control	-.09	.70	.02	.902	.23	3.61
Age	.01	.04	.07	.799	.94	1.08
Education	-.02	.17	.01	.922	.70	1.38
NYHA	1.47	.66	4.91	.027*	1.19	15.83
(Constant)	-1.92	4.77	.16	.687		

Note. The dependent variable for all regressions was negative health events using a dichotomized yes/no within a 90-day medical record review; DERS - Difficulties in Emotion Regulation (DERS 18-item abbreviated scale); Coherence – IPQ-R perceived illness coherence; Control – IPQ-R personal and treatment controllability; Education – years of education; NYHA – New York Heart Association functional classifications I/II and III/IV.

*p < .05

Other Findings

Beyond the scope of the aims, other findings related to the study are important to note. Of importance challenges with recruitment and retention and psychometric issues are discussed below.

Recruitment. Overall recruitment challenges existed in each setting and were unique to the setting. For example, patients were more challenging to identify within the hospital setting due to miscellaneous unit conditions such as personal nurse assignments, patient–provider interaction, and off-unit procedures. The prioritization of patient care was expected, however the difficulty experienced in identifying patients was unexpected. Charge nurses were often unaware of patient census information necessary to identify potential participants. In the clinic settings, personnel were able to aid in identifying patients prior to appointment times. However, patients did not always show up for their appointments. Inquiry to clinic personnel indicated that no-show appointments were frequent. The frequency of missed appointments was also an unexpected barrier to recruitment.

Retention. Of the 71 participants consented, 58 completed portions of the intake survey. Reasons for not participating included patients not answering the phone, loss of interest, and family member decisions. Once patients completed the intake survey, most completed the follow-up survey. Attrition after intake was related to patient death ($n = 1$) or to loss of contact ($n = 2$).

Psychometric Issues. There were psychometric issues with the use of study instruments. As described earlier, main study instruments including the IPQ-R, DERS, and the MOS-SAS all had issues with unidimensionality and internal reliability. Psychometric analysis was completed and abbreviated scales were used for analysis (see previous sections). Limited research has deployed these instruments in populations of African American women with HF. It is unclear whether the issues with psychometrics are unique to this sample or a larger issue.

Summary

This chapter provided the results from the analyses of the study aims. In Aim 1, the hypothesis (i.e., higher levels of anxiety, stress, depression, and poorer cognitive function will be associated with less effective emotion regulation) was partially supported. Controlling for demographic and clinical variables, significant relationships between age ($b = -.03$, $t(37) = -2.48$, $p = .018$) and stress ($b = .06$, $t(35) = 2.95$, $p = .005$) on emotion regulation were evident. In Aim 2, the hypothesis (i.e., illness perceptions and emotion regulation are associated with the clinical, demographic, and psychological factors) was not supported. However, some of the modeled relationships demonstrated associations. In Aim 3, the hypothesis (i.e., less effective emotion regulation and worse illness perceptions will be associated with lower adherence and greater negative health

events) was also not supported. Minimal associations that may help guide future research were found in the analysis of Aim 3. A summary of all significant relationships is depicted in Figure 10.

The sample size and the cross-sectional nature of the psychological variables negated the possibility for fully testing the hypothesized relationships in Aims 1–3 in this exploratory study. The following is a list of significant associations, which may inform future research related to the theoretical framework adopted in this study. Significant findings included:

- Negative relationship between age and difficulties with emotion regulation
- Positive relationship between perceived stress and difficulties with emotion regulation
- Positive associations between NYHA and negative health events for cardiac reasons

The results provide preliminary information for discussing how emotion regulation may be associated with the illness environment and health outcomes in African American women with HF. The next chapter will provide further discussion and interpretation of these results, as well as practice and future research implications.

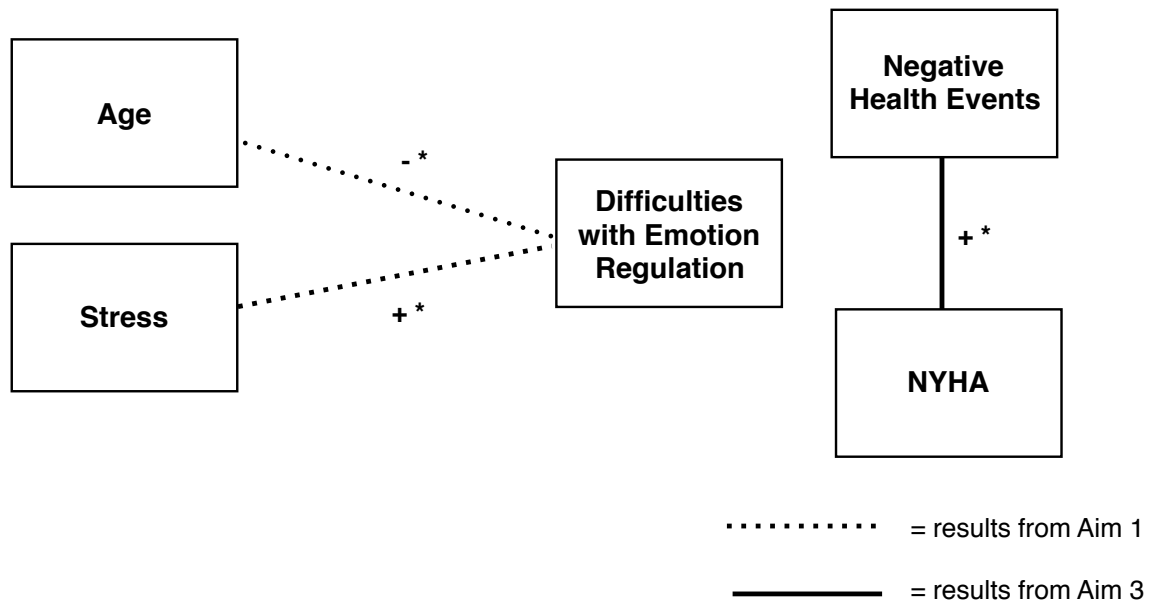


Figure 10. Summary of Relationships from Aims 1, 2, and 3.

Note. * = $p < .05$; + = positive relationship; - = negative relationship.

Chapter 6: Discussion, Interpretations, Conclusions, and Implications

The purpose of this prospective study was to examine the relationships of emotion regulation and illness perception on adherence behaviors and negative health events of African American women with HF. The study aims that were explored included: 1) associations between psychological factors and emotion regulation, 2) relationships of contributing factors and illness perceptions with emotion regulation, and 3) effects of illness perceptions and emotion regulation on adherence and negative health events. This chapter provides discussion and interpretation of findings in relation to the study aims. Further, study limitations, practice implications, directions for further research, and overall conclusions will be described.

Discussion of Sample and Scale Information

Demographics. The sample patients had low incomes and varied educational backgrounds, which was consistent with the population of African American residents in the geographical area. The average age of patients in this study was 64.5 years, which is similar to a larger study that reported on African American patients with HF (Husaini et al., 2011). By comparison, Caucasian patients with HF were reported to be in their 70s (Husaini et al., 2011). The sample population was similar to other studies of African American patients with heart failure in relation to disease severity (Bagchi et al., 2011; Wu et al., 2010).

Emotion regulation. Overall, the patients reported only minimal difficulties with emotion regulation, which could possibly be attributed to their older age, as emotion regulation abilities are developed over the lifespan. The minimal difficulties could also be attributed to social influences, gender, or other factors not addressed in this study.

No comparable study is available to determine how these study findings compare to emotion regulation in other African American patients with chronic illnesses. In other female populations, emotion regulation difficulties were slightly higher than in this study (Gratz & Roemer, 2004; Shorey, Cornelius, & Idema, 2011). Both of these aforementioned studies focused on emotion regulation in female college students. It is possible that there is less difficulty with emotion regulation in older adults than younger adults such as college students. A study by Gerolimatos and Edelstein (2012) suggested age differences in controlling and adapting to emotions, with older adults reporting greater use of more adaptive emotion regulation techniques than did younger adults. Considering the collective information, it is possible that difficulties with emotion regulation decrease with advancing age. Study findings are important to African American patients with HF, as these patients tend to be younger.

Additionally, studies have shown differences between emotion regulation in Eastern and Western cultures (Miyamoto, Ma, & Petermann, 2014). It is plausible that social contributors could explain differences in emotion regulation, as were determined between Eastern and Western cultures (Miyamoto et al., 2014)

Illness perceptions. In general, the patients in this study perceived that their illness was coherent and controllable. Such findings indicate that their illness made sense, they had personal control, and they believed that their treatments could control their HF.

Patients in the current study identified greater personal and treatment controllability than in other studies of European patients with advanced HF and African American patients in hemodialysis (Hallas, Wray, Andreou, & Banner, 2011; Kim et al.,

2012). These African American HF patients also perceived their illness as more coherent than those in the hemodialysis sample, but less so than those in the European HF patient sample.

An illness could be perceived less coherently due to illness complexity or severity, time since diagnosis, and influences of others providing meaning to the illness. Differences in illness perceptions also exist between patient populations likely due to other differing internal and external influences (Kim et al., 2012; Kucukarslan, 2012).

Perceived illness coherence evolves over time with influences from family members or care providers (Leventhal et al., 1992). Individuals who discuss their illnesses with family members demonstrate greater illness coherence than those who do not (Chittem, Norman, & Harris, 2013). For some groups differing group norms regarding illness discussions with family or care providers may impact perceived illness coherence (Chittem, Norman, & Harris, 2013). Logically, patients who have had their disease longer will have had more time to accumulate information and form illness perceptions. Time, experiences, interactions with others, and disease processes all likely contribute to illness coherence.

With perceptions of illness being highly dependent on individual and disease-related factors, studies such as that of Scisney-Matlock (1998) provide important information relative to individualized, disease-specific illness perceptions. Her work provided initial steps in developing tailored cognitive-behavioral interventions that were grounded from an understanding of the cognitive representations of African American patients with HF. More research in African American patients with HF is needed to better understand illness perceptions and how they are associated with health

behaviors, adherence and negative event outcomes, and emotion regulation. Further research is needed to fully understand how gender, age, race, time since diagnosis, and clinical environment impact illness perceptions.

Perceived adherence. The patients in the current study self-reported overall strong perceived adherence to their treatment regimen. In other studies, general non-adherence in HF patients was reported at 16% (Alosco et al., 2012), and mean adherence of 50.3 on a 0–100 scale in another (Heydari et al., 2011). In these latter two studies, general adherence and adherence to diet, medications, and exercise were measured using a short questionnaire. Although adherence was not directly measured in the current study, the MOS-SAS provided limited information regarding perceived adherence. With the MOS-SAS adherence perception instrument, differences in adherence behaviors are not well differentiated. Additionally, the MOS-SAS provided only minimal information regarding specific adherence behaviors.

Typically, adherence is studied relative to individual self-management behaviors (i.e., diet, exercise, or medications) and not general perceptions. Understanding which adherence behaviors patients find challenging is critical to targeting interventions. Further, general adherence instruments can also be useful in screening patients for perceived issues with adherence, while more specific information on adherence and outcomes requires multiple and verifiable measures. The selection and use of general measures of adherence in addition to other indices, such as biologic measures, would be beneficial to researchers and clinicians alike. For example, biologic measures provide much needed objective information such as measuring weight to assess

adherence to diet and exercise. The drawback of only using biologic measures would be the failure to account for individual perceptions of illness and adherence.

Patients reported the best adherence to medications, followed by diet, and lastly, exercises. In other studies targeting behavioral adherence in HF, non-adherence was reported at 75% in diet (Lennie et al., 2008), 61% in exercise (van der Wal et al., 2006), and 41% in medications (Wu et al., 2013). However, when examining perceived adherence of all of these behaviors, non-adherence is reported as greatest in exercise, followed by diet and medications (Heydari et al., 2011), similar to the findings in this study.

Objective measures of adherence in HF patients are numerous, particularly in relation to medication. Medication adherence measures are effective in capturing prescriptions filled, medications remaining, and medication bottle opening (Dunlay, Eveleth, Shah, McNallan, & Roger, 2011; Esposito et al., 2009). Such measures can provide greater information and better accuracy than self-report. It is also necessary to select measurements of diet and exercise that objectively evaluate adherence. Currently, little research has examined adherence behaviors in African American women with HF. Future research that incorporates both subjective and objective indices of adherence for medication, diet, and exercise is recommended.

Negative health events. Compared to studies with similar samples in terms of age and disease severity, patients in this study experienced more negative health events within a shorter follow-up period (Moser et al., 2011; Song et al., 2010). These differences in frequency of negative health events could be related to differences in

socio-demographic factors (African American and poor), or other factors such as healthcare access.

More than half of the patients experiencing a negative health event in this study were hospitalized ($n = 15$, 54%), and several of these hospitalized patients died ($n = 5$, 18%). This would suggest that the negative health events were severe in nature. Use of healthcare services for cardiac reasons was found to be significantly associated with the patients' NYHA functional classifications in this study. Additionally, the causes for the majority of healthcare use and all deaths were related to cardiac reasons. It is apparent that a patient's cardiovascular health is of pivotal importance in preventing emergent negative health events. Other factors such as hospital recruitment and socio-demographic indices may also account for the severity of health events.

Participants in this study may have had lower socioeconomic statuses than those reported in other HF research (Wu et al., 2010). It is known that lowered access to financial resources is a predictor of poorer outcomes, such as increased mortality, however it is unclear why this association exists (Hawkins et al., 2012). Lower income levels of African American patients with HF may partially explain the presence of greater negative health events, however other factors are also likely contributors.

The patients in this study were younger, had lower incomes, and experienced heightened negative cardiac health events. This sample reported many perceived strengths such as less difficulty with emotion regulation, perceptions that their illness was more controllable, and overall good general adherence. There are many non-identified factors such as other social resources, physical factors, and emotional factors that could contribute to the disparity in negative health outcomes. A variety of factors

are associated with negative health events, and it is recognized that population groups, such as African Americans, are at a greater risk for poor HF outcomes (Adams et al., 2014).

Secondary psychological factors. Patients in this study reported a wide range of scores for global distress. It is unclear from the data collected what was contributing to distress. Items on the HADS are regarding general depressive and anxious symptoms. Patients could have been experiencing distress from circumstances such as exacerbations of their HF or external issues such as problems with income.

All patients in this study reported perceived stress and decreased effectiveness with cognitive function. Neuropathological changes associated with decreased cognitive function are well-documented in patients with HF (Dardiotis et al., 2012). This study was unfortunately unable to provide objective indices to match the subjective perceptions of reduced effectiveness. Perceived stress may relate to everyday issues, major events, or a change in resources available to cope with these problems (Cohen et al., 1983). Although the sample size and generalizability of the current study is limited, there are some indications that as compared to other patient populations (e.g., HF, cancer, and HIV), differences in depressive symptoms, anxiety, perceived stress, and perceived cognitive function may exist (Cimprich et al., 2011; Falk et al., 2009; Lopez et al., 2012).

This section discussed the demographics, emotion regulation, illness perceptions, adherence, and healthcare use of this group of African American women with HF. It is clear that this sample portrays unique characteristics that should be explored further. These patients had fewer difficulties with emotion regulation than

studies with younger individuals, yet the patients also experienced greater psychological distress. Aim 1 examined the important connection between emotion regulation and psychological factors.

Discussion of Aim 1

Aim 1. *To determine the associations between psychological factors (anxiety, stress, depression, and cognitive function) and emotion regulation in African American women with HF (time 1).* Hypothesis 1: Higher levels of anxiety, stress, depression, and poorer cognitive function will be associated with less effective emotion regulation. Results indicated higher levels of perceived stress are related to less effective emotion regulation. Further, increasing levels of stress and younger age were inversely related to emotion regulation.

The current study found relationships among global distress, perceived stress, and emotion regulation, similar to other studies linking psychological distress to emotion regulation in cardiac patients (Messerli-Bürgy et al., 2012). Previous findings noted relationships among global distress, perceived stress, and emotion regulation, but not within the same study and not in patients with HF (Messerli-Bürgy et al., 2012; Rusch et al., 2012).

The ability to regulate emotions is challenged by the presence of stress (Rusch, Westermann, & Lincoln, 2012). The current study adds to this evidence by determining an association between stress and emotion regulation in African American women with HF. Additional information is needed to fully explain these relationships. It is possible that patients with less emotion regulation difficulties are better able to respond to stressors (Kemeny et al., 2012). While the current study identifies relationships

between emotion regulation and stress, the nature of these relationships are unknown. Understanding how emotion regulation and perceptions of stress impact one another would be important if developing interventions to support patients with chronic illness.

It is possible that just as cognitive effectiveness is challenged by increased environmental demands (Phelps, 2006), increasing stress (a demand) may compromise emotion regulation effectiveness. It is also plausible that difficulties with emotion regulation have contributed to psychological distress in response to environmental demands.

The association between psychological distress and less adaptive emotion regulation is supported by previous research (Ehring et al., 2010). For example, patients who are depressed are less likely to use adaptive emotion regulation strategies, such as reappraisal, when faced with sadness inducing situations (Ehring et al., 2010). Further, depressed patients with heightened psychological distress exhibit greater use of less adaptive emotion regulation strategies, such as suppression (Ehring et al., 2010).

In addition to stress, younger age was also found to be associated with less effective emotion regulation (Gerolimos & Edelstein, 2012; Shiota & Levenson, 2009). It is known that difficulties with emotion regulation decrease with advanced age (Gerolimos & Edelstein, 2012; Shiota & Levenson, 2009). While individuals can learn emotion regulation strategies, they do have preferences (Ehring et al., 2010). Preferences for adaptive (reappraisal) versus maladaptive (suppression) strategies impact both how an individual adapts to stress and also the development of psychological distress (Ehring et al., 2010). Further research is needed to understand

relationships between emotion regulation and other psychological parameters such as depression, anxiety, and cognitive effectiveness.

Discussion of Aim 2

Aim 2. *Determine the associations of the contributing factors (clinical, demographic, and psychological) and illness perceptions with emotion regulation at intake (time 1) for African American women with HF.* Hypothesis 2: Illness perceptions and emotion regulation are associated with the clinical, demographic, and psychological factors. Results further verified the association between younger age and greater problems with emotion regulation. No significant effects were noted between emotion regulation and illness perceptions as measured in this study.

It is unclear if the lack of significant relationships between emotion regulation and illness perception components of controllability and coherence are due to the small sample size or to a lack of relationship. Previous research found relationships between the adaptive emotion regulation technique of reappraisal and the illness perception component of perceived illness likelihood (Gerolimatos & Edelstein, 2012). That study showed there is a relationship between illness perceptions and emotion regulation, however the number of other studies that examine these two constructs are limited (Gerolimatos & Edelstein, 2012). Further, the lack of longitudinal information is another barrier to understanding relationships between illness perceptions and emotion regulation. Given that illness perceptions impact health behaviors, additional research is needed to better understand how emotion regulation and illness perceptions might be associated.

When controlling for perceived illness coherence and controllability, the previously discussed associations between perceived stress and emotion regulation were no longer significant. The inability to understand and perceive control of an illness may be a substantial stressor. As such, the inclusion of these illness perception variables may explain more than the general perception of stress.

Patients who have higher perceived illness control also have higher stress. The phenomena of John Henryism may help explain poor outcomes of patients who perceived their illness was controllable. John Henryism is a disposition to high effort coping, particularly in marginalized groups, in the presence of external stressors (Hudson, Neighbors, Geronimus, & Jackson, 2015). Perceived controllability may only add to the perceived stress in disparate groups such as African American women and also can impact health negatively (Hudson et al., 2015; Koolhaas et al., 2011).

The lack of longitudinal information on severity prohibits the ability to test the potential impact of worsening disease on perceived illness controllability, coherence, or emotion regulation. With the heightened stress of living with HF, complex relationships among stress, emotion regulation, perceived illness control or coherence, and negative health events may be occurring that were not explained by this project. Additional research with larger sample sizes and longitudinal designs are needed to understand how varied stressors, particularly in disparate populations such as African American women, impact emotion regulation and illness perceptions.

Discussion of Aim 3

Aim 3. *To determine the effects of illness perceptions and emotion regulation on the outcomes of adherence and negative health events (death, hospitalization, emergency department, urgent care, and unanticipated primary care visits) in African American women with HF at 30-days (time 2).* Hypothesis 3: Less effective emotion regulation and worse illness perceptions will be associated with lower adherence and greater negative health events. The results of this aim were non-significant in determining relationships between emotion regulation, illness perceptions, and these health outcomes.

Data from this aim provided further information on potential relationships between illness perceptions and emotion regulation or outcomes of adherence and negative health events. Lack of significance may convey that associations are not present, a larger sample size is necessary, or that the relationships between variables are more complex than linear models can explain.

A previous systematic review also determined relationships between adherence and coherence to be non-significant (Kucukarslan, 2012). As such, perceptions of understanding one's illness may not be necessary for adherent behaviors to occur. It is plausible that a newly diagnosed patient with limited illness knowledge may be very adherent, whereas someone living with the illness for years may become more lax in adherence if the illness is stable. Further, patients may become more adherent because of changes in the acuity of the illness.

Relationships between difficulties with emotion regulation and occurrence of negative health events were not found to be significant. Unfortunately, these

relationships have not been examined in other studies to the PI's knowledge. From the common sense model perspective, relationships exist between emotional processing, coping, and outcomes such as negative health events (Moss-Morris et al., 2002). Lee et al. (2010) found that psychological distress negatively impacts health events. Emotionally distressed individuals may have difficulties regulating emotions and may increase their use of healthcare services (De Jong et al., 2011; Messerli-Bürky et al., 2012; Song, 2009; Zijlstra et al., 2012). Further, emotional processing traits have been implicated with specific disease types such as cardiac conditions (Kravvariti et al., 2010; Kubzansky & Thurston, 2007).

Just as mental distress increases the risk for negative health events like hospitalization, it is plausible that coincident emotion regulation impacts the use of healthcare services (De Jong et al., 2011; Messerli-Bürky et al., 2012; Song, 2009; Zijlstra et al., 2012). The combination of demands, whether emotional or cognitive, impact health. It is essential that cognitive resources are both conserved and restored in order to respond to illness stressors (de Ridder et al., 2008; Folkman & Moskowitz, 2004).

Other considerations in terms of interpreting study findings include patients' use of informal care and potential measurement issues associated with using a medical record to determine negative health events. Patients may have sought care in other settings such as alternate clinics, emergency departments, or hospitals, or received informal care from family members or other individuals in the community. In older African American patients, care is often provided by families rather than by formal care

providers (Stewart, 2008). Further exploration is necessary to determine if perceptions of illness coherence impact negative health events in African American women with HF.

Studies examining relationships between illness perceptions and negative health events are uncommon in African American women with HF. Subjective perceptions of health are recognized to impact perceived control more so than health (Perrig-Chiello, Perrig, & Stähelin, 1999). Further research is needed to examine relationships between illness perceptions and negative health events with larger sample sizes and with longitudinal designs.

Recognizing the potential impact of emotion regulation on healthcare use and outcomes in vulnerable groups could improve patient care. This is particularly relevant to patients who may have the most difficulty with emotion regulation, such as those who are younger and who are experiencing greater perceived stress. With heightened information relative to the impact of emotion regulation on negative health events, targeted cognitive-behavioral and/or mind-body interventions to improve adherence to medications, diet, and exercise can be developed. For example, yoga has been found to have a positive impact on emotion regulation (Daly, Haden, Hagins, Papouchis, & Ramirez, 2015) while successfully engaging patients with HF in physical activity (Kubo, Hung, & Ritterman, 2011). Hypothetically, interventions that enhance adherence to HF regimens and improve psychological well-being may also simultaneously decrease negative health events.

Study Limitations

This study was an initial exploration of emotion regulation and illness perceptions in African American women with HF. Limitations of the study include sample size,

variable disease severity and illness duration, variability in time to follow-up, recruitment site issues, and measurement problems.

Of pivotal importance, the sample size, lapse of time since diagnosis, and duration of longitudinal follow-up were restricted due to limited available resources. The small sample size impacted potential effect sizes while also potentially limiting statistical significance. The variable length of illness duration made it impossible to determine whether a patient's psychological distress was associated with a new diagnosis of HF or the impact of advancing disease. Additionally, the limited follow-up period made finding significance in relation to negative health events difficult. There was also reporting inconsistencies in the follow-up timeline. There were challenges inherent in contacting patients and their finding time to complete the interviews. Difficulties in timely completion of interviews led to extended follow-up time periods in some cases.

Additional information regarding informal care provision, worsening disease, and negative health events would have strengthened the study. With limited studies on African American women with HF, it was also difficult to identify valid tools for use in this population. It became clear after analysis that some of the instruments may not be well suited for this population. In particular, there were issues with the use of the IPQ-R, DERS, and the MOS-SAS in this study. Additionally, measurement of adherence would be strengthened by inclusion of an objective measure. Further exploration of appropriate measures is necessary to determine validated instruments for use with African American women with HF.

Additional measurement issues included demographic and medical record data limitations. Within the demographic questionnaire, household income was not tied to

household size. In the review of the medical record, disease severity values were those documented closest to the time of recruitment. As such, the values associated with LVEF and NYHA may represent the patient's condition at any time within the 90-day review. Additionally, patient condition may change over time and severity may not have been reported accurately within the medical record.

Implications for Nursing Practice

Nurse practice implications relevant to study findings are discussed in this section. Findings demonstrate that emotion regulation is impacted by age and stress. Patients with high perceived stress may have difficulty regulating their emotions. Such difficulties could be particularly relevant in younger patients, as the combination of decreased age and increased stress could heighten vulnerabilities to such problems. Difficulties in emotion regulation while under stress may lead to patients being overwhelmed by emotional issues, and thus unable to focus on health management. Nurses could potentially aid patients in finding ways to manage their daily stressors such as by discussing strategies like reappraisal that could improve their ability to regulate emotions while they are experiencing stress.

Despite a lack of significant relationships, implications regarding study findings were identified. Because chronic illness such as HF impacts both cognitive and emotional processing of health-related information, consideration of both illness perceptions and emotion regulation may help support patients.

Clinicians can be assured that patients clearly understand adjustments that are made to their treatment plans in response to changes in disease status. Further, nurses can be sensitive when patients make personal adjustments to their treatment that may

not seem rational. Patients require individualized care that is tailored to their needs, which may include adaptations based on social, cognitive, and emotional differences. Carefully constructed care plans should be collaboratively created with the patient in a way that respects their mental models.

This research examined emotion regulation and illness perceptions in African American women with HF. Final recommendations for nursing practice include the need for sensitivity to the connection between perceived stress and emotion regulation, particularly in younger African American women with HF. It is important that nurses recognize the potential impact of illness perceptions and emotion regulation on behavioral adherence and use of healthcare services. Thus, assessment of a patient's perceptions relative to coping with illness is critical.

Implications for Research

It is apparent that there is very limited information regarding the perceptions of African American women with HF and emotion regulation in patients with chronic illness. This study has identified some areas for further research.

Findings suggest that the patients in this study experienced less difficulties with emotion regulation as compared to studies involving college-age females. These differences could be related to factors such as demographics or health status, but further research is warranted to clarify these differences. In terms of illness perceptions, this study suggested that these patients with HF may have perceived greater control. Further research is needed regarding the illness perceptions of African American women with HF, as well as comparative studies with other groups such as men and patients of other diverse groups. Future research questions might include: 1)

How do difficulties in emotion regulation compare between other diverse groups or between illness populations?; 2) How do the illness perceptions of African American women with HF compare to those of patients in other diverse groups?; 3) How does health status, type of disease, or age impact emotion regulation and illness perceptions?; and 4) What are the differences in mental health, perceived stress, and cognitive function in varied chronic illness populations? Many of these questions may be best suited to a mixed-methods design that could provide more comprehensive information on emotion regulation, illness perceptions, and the differences between groups of patients.

Relationships between psychological constructs in the presence of HF, particularly in African American women, are not well understood. Further exploration of the relationship between psychological constructs and emotion regulation is needed. Limitations of this study prohibited the examination of depression, anxiety, stress, and cognitive function on emotion regulation. A relationship between emotion regulation and perceived stress was evident. Future research should examine other psychological constructs. Additionally, little information is available to understand the temporal precedence of emotion regulation and the psychological constructs. Researchers should identify whether optimal emotion regulation minimizes perceived stress, depression, and anxiety. If emotion regulation is the predicated component, further research attempts can be made to decrease difficulties with emotion regulation to address psychological distress.

The instruments used in this study require further validation in racially diverse populations. Many of the instruments did not perform as expected with African

American women with HF. Specifically, the instruments used to measure emotion regulation and illness perceptions need to be examined in varied populations. It is of paramount importance that the tools used to conduct research are valid in the specific group under study. It is also essential that dissemination of articles include information on psychometrics beyond just the reporting of internal validity. Many of the articles included in the literature review did not offer information regarding factor analysis or other validation of scales used. Lack of psychometric evaluation of instruments is a general concern in disparate populations.

Future research questions include: 1) What is the relationship between emotion regulation and depression, anxiety, and cognitive function?; 2) What are predictors of difficulties with emotion regulation in a diverse group of patients with HF?; 3) Does emotion regulation prevent psychological issues such as depression and anxiety?; 3) Is adaptive emotion regulation protective in terms of perceived stress?; and 4) How valid are the measurement tools of DERS, IPQ-R, and PSS in diverse populations with larger sample sizes?

More research is needed to examine relationships between illness perceptions and emotion regulation. Several relationships suggested in this study have limited support from previous research to aid in explaining potential relationships. Advancing the information available regarding interactions between cognitive and emotive processing will aid in a more robust understanding of the common sense framework. One way to advance the knowledge regarding emotion regulation and illness perceptions is to also include psychophysiological parameters of cognitive and emotive processing. A combined perception and biophysiologic study of emotion regulation

could enhance knowledge regarding this process in patients with chronic illnesses. A fuller understanding of emotion regulation processes and how they interact with illness perceptions and impact subsequent behaviors such as adherence and use of healthcare services is needed.

Once there is a better understanding regarding the interactions between emotion regulation, illness perceptions, and outcomes, development of targeted mind-body interventions may be useful. For example, yoga may be a good intervention strategy with HF patients and has been found to increase emotion regulation skills in adolescents (Daly et al., 2015). Mindfulness training may also be useful in diminishing less adaptive emotion regulation strategies such as avoidance and rumination, which could be detrimental to HF self-care (Kumar, Feldman, & Hayes, 2008). Interventions such as mindfulness training or yoga could help preserve the cognitive resources necessary to manage complex health maintenance.

Another concern based on the review of the literature is the limited information available to aid in determining how African American patients with HF form cognitive and emotional representations of their illness environment. If information existed that clearly indicated that certain illness perceptions or emotion regulation strategies were more adaptive for the African American HF patient population, resources could be targeted to improve outcomes. A research question from this study is: 1) How do the distinct components of emotion regulation and illness perceptions impact each other? Additionally, useful questions using mixed methodologies include: 1) What do the experiences with cognitive and emotional representations in African American patients with HF look like from their perspectives?; and 2) How do feelings, attitudes, and beliefs

regarding illness perceptions and emotion regulation impact adherence and use of healthcare services?

Further examination of the relationship of emotion regulation and illness perceptions with varying types and amount of stress, and the implications of these variables on adherence and negative health events, is needed. Types of stressors such as health, socioeconomic, and racial disparities should be discerned. By discriminating specific stressors, a better understanding of emotion regulation and illness perceptions in HF patients experiencing health-related changes could be understood. Additionally, such a study could examine how different types of stress contribute to health outcomes such as adherence and use of healthcare services.

Further exploration of psychological constructs related to emotion regulation and health outcomes in patients with chronic conditions such as HF is critical. From this study, it is clear that perceived stress is associated with emotion regulation, and that difficulties with emotion regulation may potentially increase use of healthcare services. Longitudinal and experimental studies are needed for examining the potential impact of emotion regulation on the relationship between psychological distress and adherence and use of healthcare services. Understanding these relationships would aid in determining if development of emotion regulatory abilities is helpful in improving health outcomes and lessening psychological distress.

Research on African American women with HF and other chronic conditions must continue to identify sources and solutions to the health disparities in outcomes of these patients. The difficulties noted in adherence to exercise suggest that these patients might benefit from physical activity-based interventions. Additionally, the development

of interventions that may improve emotion regulation in populations of African American women and those with chronic illnesses may be of value for decreasing negative health outcomes. Research questions might include: 1) How do emotion regulation and illness perceptions mediate the effect of different types of stressors on adherence and negative health events?; 2) Do differing emotion regulatory abilities or strategies impact psychological well-being in chronically ill patients?; and 3) Does improving emotion regulation abilities minimize the impact on negative health events?

Conclusions and Contributions to Science

There are many physiological and psychological challenges inherent in managing illnesses such as HF (Baeza-Velasco et al., 2012; de Ridder et al., 2008). This dissertation presents potential links between how individuals perceive their illness, difficulties with emotion regulation, and the impact on adherence and the use of emergent healthcare in African American women with HF. Contributions to science are evident in each aim. From Aim 1, it was noted that greater difficulties with emotion regulation are associated with greater perceived stress and younger age. This information is consistent with what has been found in other studies and shows that these relationships occur with a sample of African American women with HF. In Aim 2, no additional relationships were found to be statistically significant. Relationships between emotion regulation and illness perceptions are minimally studied. As such, lack of associations may indicate that these concepts are not associated, that the sample was too small to determine associations, or that the relationship is more complex than a linear model can explain. In Aim 3, difficulties with emotion regulation, illness coherence, and perceived control in this aim were not found to be associated

with risk of a negative health event or with adherence. As previously identified, the relationships tested may or may not exist, or the relationships may be more complicated than this study was able to determine. All relationships from this pilot study require additional testing to continue to advance nursing science related to emotion regulation and chronic illness.

It is evident that there may be complex relationships between illness perceptions, emotion regulation, and how these factors relate to adherence and negative health events. The findings from this study should lead to further exploration of the impact of cognitive and psychological contributors to health outcomes. Additionally, more research is needed to understand how emotion regulation and illness perceptions are influenced by health disparities in the population of African American women with HF.

APPENDICES

Appendix A: Complete Intake Survey

Demographics

1. Participant ID#
2. What is your full name?
3. What is your age, in years?
4. What is your household income?
5. What is your highest level of education?

Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by selecting how often you felt or thought a certain way. The choices are "Never," "Almost Never," "Sometimes," "Fairly Often" and "Very Often."

1. In the last month, how often have you been upset because of something that happened unexpectedly?
2. In the last month, how often have you felt that you were unable to control the important things in your life?
3. In the last month, how often have you felt nervous and "stressed"?
4. In the last month, how often have you felt confident about your ability to handle your personal problems?
5. In the last month, how often have you felt that things were going your way?
6. In the last month, how often have you found that you could not cope with all the things you had to do?
7. In the last month, how often have you been able to control irritations in your life?
8. In the last month, how often have you felt that you were on top of things?
9. In the last month, how often have you been angered because of things that were outside of your control?
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Hospital Anxiety and Depression Scale (HADS)

Contents of the HADS can be retrieved in the original article by Zigmond and Snaith (1983)

Attentional Function Index

*At this time, how well do you feel you are functioning in each of the areas below?
On these questions, rate yourself on a scale from 0 to 10, where 0 is "Not at all" and 10 is "Extremely well".*

1. Getting started on activities (tasks, jobs) you intend to do.
2. Following through on your plans.
3. Doing things that take time and effort.
4. Making your mind up about things.
5. Keeping your mind on what you are doing.
6. Remembering to do all the things you started out to do.
7. Keeping your mind on what others are saying.
8. Keeping yourself from saying or doing things you did not want to say or do.
9. Being patient with others.

On these questions, rate yourself on a scale from 0 to 10, where 0 is "Not at all" and 10 is "A great deal". At this time, how would you rate yourself on:

10. How hard you find it to concentrate on details.
11. How often you make mistakes on what you are doing.
12. Forgetting to do important things.
13. Getting easily annoyed or irritated.

The Illness Perception Questionnaire-Revised

Your Views About Your Illness

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by selecting "Yes" or "No," whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

1. Pain
2. Sore Throat
3. Nausea
4. Breathlessness
5. Weight Loss
6. Fatigue
7. Stiff Joints
8. Sore Eyes
9. Wheeziness
10. Headaches

- 11. Upset Stomach
- 12. Sleep Difficulties
- 13. Dizziness
- 14. Loss of Strength

We are interested in your own personal views of how you now see your current illness. Please indicate how much you agree or disagree with the following statements about your illness by selecting the appropriate options. The choices are "Strongly Disagree," "Disagree," "Neither Agree Nor Disagree," "Agree" and "Strongly Agree."

- 15. My illness will last a short time
- 16. My illness is likely to be permanent rather than temporary
- 17. My illness will last for a long time
- 18. This illness will pass quickly
- 19. I expect to have this illness for the rest of my life
- 20. My illness is a serious condition
- 21. My illness has major consequences on my life
- 22. My illness does not have much effect on my life
- 23. My illness strongly affects the way others see me
- 24. My illness has serious financial consequences
- 25. My illness causes difficulties for those who are close to me
- 26. There is a lot that I can do to control my symptoms
- 27. What I do can determine whether my illness gets better or worse
- 28. The course of my illness depends on me
- 29. Nothing I do will affect my illness
- 30. I have the power to influence my illness
- 31. My actions will have no effect on the outcome of my illness
- 32. My illness will improve in time
- 33. There is very little that can be done to improve my illness
- 34. My treatment will be effective in curing my illness
- 35. The negative effects of my illness can be prevented (avoided) by my treatment
- 36. My treatment can control my illness
- 37. There is nothing that can help my condition
- 38. The symptoms of my condition are puzzling to me
- 39. My illness is a mystery to me
- 40. I don't understand my illness
- 41. My illness doesn't make any sense to me
- 42. I have a clear picture or understanding of my condition
- 43. The symptoms of my illness change a great deal from day to day
- 44. My symptoms come and go in cycles
- 45. My illness is very unpredictable

46. I go through cycles in which my illness gets better or worse
47. I get depressed when I think about my illness
48. When I think about my illness I get upset
49. My illness makes me feel angry
50. My illness does not worry me
51. Having this illness makes me feel anxious
52. My illness makes me feel afraid

Difficulties in Emotion Regulation Scale

Please indicate how often the following 36 statements apply to you by selecting the appropriate option from the scale below for each item. The choices are "Almost never (0-10%)," "Sometimes (11-35%)," "About half the time (36-65%)," "Most of the time (66-90%)" or "Almost always (91-100%)."

1. I am clear about my feelings
2. I pay attention to how I feel
3. I experience my emotions as overwhelming and out of control
4. I have no idea how I am feeling
5. I have difficulty making sense out of my feelings
6. I am attentive to my feelings
7. I know exactly how I am feeling
8. I care about what I am feeling
9. I am confused about how I feel
10. When I'm upset, I acknowledge my emotions
11. When I'm upset, I become angry with myself for feeling that way
12. When I'm upset, I become embarrassed for feeling that way
13. When I'm upset, I have difficulty getting work done
14. When I'm upset, I become out of control
15. When I'm upset, I believe that I will remain that way for a long time
16. When I'm upset, I believe that I'll end up feeling very depressed
17. When I'm upset, I believe my feelings are valid and important
18. When I'm upset, I have difficulty focusing on other things
19. When I'm upset, I feel out of control
20. When I'm upset, I can still get things done
21. When I'm upset, I feel ashamed with myself for feeling that way
22. When I'm upset, I know that I can find a way to eventually feel better
23. When I'm upset, I feel like I am weak
24. When I'm upset, I feel like I can remain in control of my behaviors
25. When I'm upset, I feel guilty for feeling that way
26. When I'm upset, I have difficulty concentrating
27. When I'm upset, I have difficulty controlling my behaviours

28. When I'm upset, I believe that there is nothing I can do to make myself feel better
29. When I'm upset, I become irritated with myself for feeling that way
30. When I'm upset, I start to feel very bad about myself
31. When I'm upset, I believe that wallowing in it is all I can do
32. When I'm upset, I lose control over my behaviours
33. When I'm upset, I have difficulty thinking about anything else
34. When I'm upset, I take time to figure out what I'm really feeling
35. When I'm upset, it takes me a long time to feel better
36. When I'm upset, my emotions feel overwhelming

Index of Coexistent Diseases

Take a moment to read through the disorders below and let us know, by selecting the appropriate option, if you experience any of these. The scale runs from 0 ("I don't have the disorder") to 3 ("I have the most severe form").

1. Ischemic heart disease
2. Congestive heart failure
3. Arrhythmias
4. Other heart disease
5. Hypertension
6. Cerebral vascular disease
7. Peripheral vascular disease
8. Diabetes mellitus
9. Respiratory disease
10. Malignancy
11. Hepatobiliary disease
12. Gastrointestinal disease
13. Neurological disease
14. Arthritis
15. Hematological disease
16. HIV/AIDS
17. Anticoagulation

Appendix B: Follow-up Survey

The Medical Outcomes Study Specific Adherence Scale

How often was each of the following statements true for you during the past 4 weeks?

The choices are "None of the time," "A little of the time," "Some of the time," "A good bit of the time," "Most of the time" or "All of the time."

1. I had a hard time doing what the doctor suggested I do.
2. I followed my doctor's suggestions exactly.
3. I was unable to do what was necessary to follow my doctor's treatment plans.
4. I found it easy to do the things my doctor suggested I do.
5. Generally speaking, how often during the past 4 weeks were you able to do what the doctor told you?
6. How often have you exercised regularly?
7. How often have you taken prescribed medication?
8. How often have you followed a low salt diet?

Negative Health Events

1. Hospitalized within the last 30 days?
 - a. Yes
 - b. No
2. If you answered "Yes" to the previous question...
 - a. What date(s)?
 - b. For how many days?
 - c. How many times?
3. Visited an emergency room within the last 30 days?
 - a. Yes
 - b. No

Appendix C: Medical Record Review

Clinical and Demographic Information

1. Patient Insurance
 - a. Medicare
 - b. Medicaid
 - c. Governmental (VA, Tricare)
 - d. Private
2. Left Ventricular Ejection Fraction
 - a. Documented LVEF?
 - b. Documented as non-sustained ejection fraction?
3. What is the patients' New York Heart Association Functional Classification?

Class	Functional Capacity
I	Patients with cardiac disease but resulting in no limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea or anginal pain.
II	Patients with cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea or anginal pain.
III	Patients with cardiac disease resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes fatigue, palpitation, dyspnea or anginal pain.
IV	Patients with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of heart failure or the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort increases.

Table content attributed to the American Heart Association (2014)

Negative Health Events

1. Died within the last 90 days?
 - a. Yes
 - b. No
2. If "Yes" to the previous question...
 - a. What date?
 - b. For what reason? (Heart failure, cardiac, or other)
3. Hospitalized within the last 90 days?
 - a. Yes
 - b. No
4. If "Yes" to the previous question...
 - a. What date(s)?
 - b. For how many days?
 - c. How many times?
 - d. For what reasons? (Heart failure, cardiac, or other)

5. Visited an emergency room within the last 90 days?
 - a. Yes
 - b. No
6. If "Yes" to the previous question...
 - a. What date(s)?
 - b. How many times?
 - c. For what reasons? (Heart failure, cardiac, or other)

Appendix D: Recruitment Materials

Screening Eligibility Checklist



SCREENING – ELIGIBILITY CHECK LIST: Start with Heart Study

Project: Emotion Regulation in African American Women with Heart Failure

Primary Investigator: Kelly Adams RN, MSN, PCCN, PhD; Michigan State University-College of Nursing

1. Patient Initials (Write in): _____
2. Setting (Check): () Sparrow () McLaren

Does patient meet the following pre-study criteria for eligibility? (Check yes/no)

3. Yes ____ No ____ Has heart failure class II-IV?
4. Yes ____ No ____ Is an African American woman?
5. Yes ____ No ____ Has clearly prescribed diet, exercise, and medications?
6. Yes ____ No ____ Can read and understand English?
7. Yes ____ No ____ 45 years of age or older? (Write in age in years) _____
8. Yes ____ No ____ Free of any major physical, psychiatric, or cognitive issues that would hinder participation?
9. Yes ____ No ____ Not discharged to long-term care or palliative care?

If patient answers “NO” to any question from questions 3 to 9 in the above section, the patient is NOT eligible for this study.

10. If not enrolled reason: _____

Completed by: _____ (Recruiter-Sign) Date: ____/____/____

Consent Form

START WITH HEART PATIENT CONSENT FOR RESEARCH

Print Patient Name: _____ **Date of Birth:** _____

Kelly Adams, Michigan State University College of Nursing
1355 Bogue Street - Room C300, East Lansing, MI 48824, Phone: 231-557-0270
Rebecca Lehto, Michigan State University College of Nursing
1355 Bogue Street - Room C344, East Lansing, MI 48824, Phone: 517-353-4757

You are being asked to take part in a research study because you are an African American woman with heart failure. This form gives you important information about the study. It describes the purpose of the study, and the risks and possible benefits. Please take time to review this form carefully. After you are done, you should talk to us and ask any questions you may have. You may also wish to talk to others (friends, family, or doctors). If you decide to take part, you will be asked to sign this form. Before you sign, it is important that you understand what the study is about.

This study will include 60 African American women with heart failure.

PURPOSE OF THIS STUDY: The purpose of this study is to learn about how feelings impact how patients live with their illness and use health services. Whether you choose to participate or not does not affect the healthcare you receive at any time.

WHAT THIS STUDY INVOLVES: If you choose to participate you will be asked to participate in two interviews. The interviews will be by phone. The first interview takes approximately 30 minutes to complete and the second takes about 15 minutes. The first interview will take place within a week of your decision to participate. The second interview will take place one month following the first. After the second interview we will look at your medical record for details about your heart health and your use of healthcare services. This medical record review will include information about your age, medical conditions, heart disease history including current and/or past discharge instructions, cardiac-related laboratory and test results, number and length of previous medical visits including hospitalizations, and cardiologist information.

POTENTIAL BENEFITS: There are no direct benefits to you for taking part in this study. The study will help us to develop programs to help patients with heart failure learn skills to stay healthy.

COMPENSATION: If you choose to participate and complete both interviews you will receive a \$20 gift card following the second interview.

POTENTIAL RISKS: You may feel uncomfortable answering some questions. If during the study, we find that you are having increased mental distress, we may contact your family, health provider or other authorities to keep you safe. We provide hotline numbers to help you in case of need.

CONFIDENTIALITY OF RESPONSES: Your privacy will be protected to the maximum extent allowable by law. No personal information will be used on the data collection forms. Only a unique identification number will be used on these forms. The research team and the Human Research Protections Program (HRPP) will have the only access to study materials. The study materials will be kept in a secured and locked file in a research office at the Michigan State University College of Nursing for 3 years after the close of the research project. Results of this project will not be provided to you. However, results may be presented at a scientific meeting or published in a scientific journal.

VOLUNTARY PARTICIPATION: Your participation in this study is voluntary. You may choose not to answer any questions that make you feel uncomfortable. Also, you may change your mind and chose to withdraw from this study at any time without any change in the services that you receive. You also do not need to take part in this study to receive health services. If you choose to tell the researchers why you are leaving the study, your reasons for leaving may be kept as part of the study record.

COSTS: There is no cost for participating in this study. Compensation for participation includes a \$20 gift card for completing the study.

QUESTIONS: If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the researcher: Kelly Adams RN, MSN, PCCN, PhD(c), at: 231-557-0270, or email Kelly.Adams@hc.msu.edu or regular mail at Michigan State University College of Nursing 1355 Bogue Street - Room 300, East Lansing, MI 48824. If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or email irb@msu.edu or regular mail at 408 W. Circle Dr. 207 Olds Hall, MSU, East Lansing, MI 48824.

CONSENT: By signing the Statement of consent below, you are identifying that you have read and received a copy of the explanation of the study and consent form. You will be given a copy of this consent form to keep.

I VOLUNTARILY AGREE TO PARTICIPATE IN THIS RESEARCH STUDY

Patient Name (please print)

Signature of Patient

Date

Recruiter Name

Date

PROVIDE COPY TO PATIENT

Appendix E: Approvals and Permissions

IRB Approval

MICHIGAN STATE UNIVERSITY

August 26, 2014

To: Rebecca Lehto
422 West Fee Hall

Re: **IRB# 14-612M** Category: EXPEDITED 5, 7
Approval Date: August 25, 2014
Expiration Date: August 24, 2015

Title: Emotion regulation in African American women with heart failure (CGA134195)

The Institutional Review Board has completed their review of your project. I am pleased to advise you that **your project has been approved**.

This approval letter is being re-issued from the previously released letter dated 08/25/2014 due to an editing error.

This protocol falls under the Reliance agreement between MSU and McLaren Healthcare System. This study will be conducted at the following McLaren sites: McLaren Greater Lansing

This protocol falls under the Reliance agreement between MSU and Sparrow Hospital. YOU MAY NOT BEGIN THIS PROJECT AT SPARROW UNTIL YOU RECEIVE AN ACCEPTANCE LETTER FROM THE SPARROW IRR.



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East Lansing, MI 48824
(517) 355-2180
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This approval also notes that if/when the PI identifies additional personnel who will be engaged in the study you must submit a revision application(s) via the online system for review and approval before implementation.

The committee has found that your research project is appropriate in design, protects the rights and welfare of human subjects, and meets the requirements of MSU's Federal Wide Assurance and the Federal Guidelines (45 CFR 46 and 21 CFR Part 50). The protection of human subjects in research is a partnership between the IRB and the investigators. We look forward to working with you as we both fulfill our responsibilities.

Renewals: IRB approval is valid until the expiration date listed above. If you are continuing your project, you must submit an *Application for Renewal* application at least one month before expiration. If the project is completed, please submit an *Application for Permanent Closure*.

Revisions: The IRB must review any changes in the project, prior to initiation of the change. Please submit an *Application for Revision* to have your changes reviewed. If changes are made at the time of renewal, please include an *Application for Revision* with the renewal application.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects, notify the IRB office promptly. Forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office.

MSU is an affirmative-action,
equal-opportunity employer.

Good luck in your research. If we can be of further assistance, please contact us at 517-355-2180 or via email at IRB@msu.edu. Thank you for your cooperation.

Sincerely,

A handwritten signature in cursive script, appearing to read "Ashir Kumar".

Ashir Kumar, M.D.
BIRB Chair

c: Kelly Adams, Barbara A. Given

**Initial IRB
Application
Approval**

Permissions for Scales

Table of Scale Citations and Copyright information

Table 27.

<i>Scale Citations and Copyright Information</i>		
Scale	Primary Citation	Copyright Information
Perceived Stress Scale (PSS)	(S. Cohen et al., 1983)	Free to use for research. http://www.mindgarden.com/documents/PerceivedStressScale.pdf
Hospitalized Anxiety and Depression Scale (HADS)	(Zigmond & Snaith, 1983)	Requires payment and registration with www.gi-assessment.co.uk Countersigned agreement from GI-assessment.
Attention Function Index (AFI)	(Cimprich et al., 2011)	Email permission from Dr. Cimprich. AFI is public domain.
Illness Perception Questionnaire – Revised (IPQ-R)	(Moss-Morris et al., 2002)	Email permission from Dr. Moss-Morris.
Difficulties in Emotion Regulation Scale (DERS)	(Gratz & Roemer, 2004)	Free, not copyrighted http://www.nctsn.org/content/difficulties-emotion-regulation-scale
Medical Outcomes Study – Specific Adherence Scale (MOS-SAS)	(DiMatteo et al., 1992)	Email permission from Dr. Hays.
Index of Coexistent Disease (ICED)	(Miskulin et al., 2001)	Email received from Dr. Miskulin, ICED is in the public domain.

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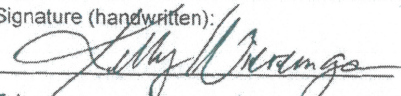
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S. Green 17/11/2015

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Title: <u>Ruth Z. Kirschstein National Research Fellow</u>	
Company/Organisation: <u>Michigan State University</u>	
Date: <u>11/1/15</u>	

Permissions for Use of AFI

Re: Permission to use the AFI

Bernadine Cimprich [cimprich@umich.edu]

Sent: Monday, November 02, 2015 8:25 AM

To: Kelly Adams

Attachments: Attention Function Index.doc (28 KB)

Dear Kelly,

I did publish the instrument in the PsychoOncology journal and that is now in public domain. However, I do have a newer Likert type version which is easier to score. I have attached it for you.

I appreciate hearing what your results were and if you publish anything using it, since it helps with a later review. By the way who is your faculty advisor?

Best regards
Bernadine Cimprich

Permissions for Use of IPQ-R

[Reply](#) [Reply All](#) [Forward](#)

Re: Permissions for use of IPQ-R

Moss-Morris, Rona [rona.moss-morris@kcl.ac.uk]

To: Kelly Adams

Friday, October 30, 2015 11:43 AM

No permissions needed
BW
Rona

Permissions for Use of MOS-SAS

[Reply](#) [Reply All](#) [Forward](#)

Re: Permissions to use the MOS specific adherence scale

RONALD HAYS [drhays@ucla.edu]

To: Kelly Adams

Cc: hays@rand.org

Attachments: hays_j_behav_med_1994.pdf (733 KB) [Open as Web Page]

Friday, October 30, 2015 11:25 AM

http://www.rand.org/health/surveys_tools.html

"All of the surveys from RAND Health are public documents, available without charge. Please provide an appropriate citation when using these products. In some cases, the materials themselves include specific instructions for citation. Some materials listed are not available from RAND Health. Those links will take you to other websites, where you will find instructions for use. There are no further permissions necessary."

Permissions for Use of ICED

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RE: Permissions for use of ICED

Miskulin, Dana [dmiskulin@tuftsmedicalcenter.org]

To: Kelly Adams

Monday, November 02, 2015 9:39 AM

It is in the public domain.

Appendix F: Descriptive Data

Table 28.

Descriptive Statistics of Illness Perception and Emotion Regulation Subscales

Characteristic (Total scale range of scores)	Overall sample N = 54 mean $\pm$ SD or %	Results Range
Illness Perception Questionnaire		
<i>Psychological Causal attribution (6-30)</i>	14.5 $\pm$ 4.3	6-26
<i>Risk Causal attribution (7-35)</i>	20.0 $\pm$ 4.4	13-30
<i>Immune Causal attribution (3-15)</i>	7.7 $\pm$ 1.9	4-11
<i>Chance Causal attribution (2-10)</i>	4.6 $\pm$ 1.4	2-10
<i>Illness identity (0-14)</i>	4.8 $\pm$ 3.4	0-14
<i>Timeline acute/chronic (6-30)</i>	20.8 $\pm$ 4.8	10-30
<i>Timeline cyclical (4-20)</i>	12.4 $\pm$ 3.2	4-19
<i>Consequences (6-30)</i>	22.1 $\pm$ 4.0	14-30
<i>Personal control (6-30)</i>	23.4 $\pm$ 3.3	13-30
<i>Treatment control (5-25)</i>	18.3 $\pm$ 2.8	10-25
<i>Illness coherence (5-25)</i>	15.9 $\pm$ 4.1	8-25
<i>Emotional representations (6-30)</i>	17.8 $\pm$ 5.0	6-29
Emotion Regulation (36-180)	65.7 $\pm$ 19.3	36-122
<i>Non-acceptance of emotional responses (6-30)</i>	10.2 $\pm$ 4.6	6-24
<i>Difficulties engaging in goal-directed behavior (5-25)</i>	10.7 $\pm$ 5.3	5-25
<i>Difficulties with impulse control (6-30)</i>	9.0 $\pm$ 3.7	6-19
<i>Lack of emotional awareness (6-30)</i>	13.4 $\pm$ 5.4	6-26
<i>Limited access to emotion regulation strategies (8-40)</i>	13.3 $\pm$ 5.2	8-29
<i>Lack of emotional clarity (5-25)</i>	9.1 $\pm$ 3.6	5-17

Note. All scales reported here are the original scales with all items included reporting the total scale and subscale information.

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