Self-Care Behaviors of African Americans with Heart Failure: A Photovoice Project

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SELF-CARE BEHAVIORS OF AFRICAN AMERICANS WITH HEART FAILURE: A PHOTOVOICE PROJECT

by

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ABSTRACT
SELF-CARE BEHAVIORS OF AFRICAN AMERICANS WITH HEART
FAILURE: A PHOTOVOICE PROJECT

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The purpose of this dissertation study was to gain a better understanding of the subjective experience of low-income, urban dwelling, African Americans with heart failure. Outlining both the perceived facilitators and barriers related to engaging in heart failure self-care behaviors. The theoretical framework for this study was founded on the principles of education for critical consciousness. This study utilized a mixed methods descriptive research design and the photovoice methodology.

Ten low-income African Americans with heart failure were recruited from three public housing buildings. The participants' mean age was 67.5. Their average annual income was $13,537. Participants were provided with digital cameras and instructed to take photographs of what they do to take care of themselves, what makes it easy, and what makes it difficult. The participants and the researcher met for two hours per week for six weeks to discuss the photographs that were taken each week. Additionally, participants completed the Personal Health Questionnaire (PHQ-9) depression severity screening tool and the Self-Care of Heart Failure Index (SCHFI).

Commonly reported self-care maintenance behaviors included adhering to medications, following dietary restrictions, and participating in daily physical activity. Three themes emerged concerning the facilitators: *family support gives me the push I need, social interaction lifts me up, and support in my environment has allowed me to better my condition*. An additional sub-theme—*personal benefits of the environment*—was identified within the third theme. Four themes emerged as the barriers: *depression slows my heart down, interruption in health care provider, neglected environment, and dietary challenges*.

The findings from this study provide a deep understanding of the importance of social support from family, friends, and health care providers in improving self-care maintenance behaviors. Additionally, inescapable environmental constraints were identified as interfering with engagement. These findings may assist nurses in understanding the complexity of heart failure self-care among low-income African Americans living in urban settings. Understanding individual self-care behaviors, facilitators, and barriers of those with heart failure can lead to the development of appropriate patient-centered assessments and interventions.

ACKNOWLEDGMENTS

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Chapter 1

This chapter begins with the definition of heart failure (HF). The mortality and morbidity rates secondary to HF, the high health care costs associated with HF, and the documented need for this study are presented. The purpose and specific aims of this study are outlined and the chapter concludes with the significance to nursing posed.

Introduction

HF is a chronic, rapidly accelerating disease that currently has no cure (National Heart, Lung, and Blood Institute [NHLBI], 2010). HF is defined as a clinical syndrome caused by a variety of cardiovascular diseases that produce cardiac structural changes (Jessup et al., 2009). These cardiac structural changes result in cardiac dysfunction and eventually lead to the symptoms of HF. HF symptoms can include dyspnea, fatigue, exercise intolerance, and congestion (Jessup et al., 2009). In addition to the physical deterioration associated with HF, an individual may experience negative effects on their psychological and psychosocial well-being.

Currently, 5.8 million people in the United States are living with HF (Lloyd-Jones et al., 2010). Approximately 670,000 people are diagnosed with HF each year (Lloyd-Jones et al., 2010). HF is most common in people 65 and older, and is the number one reason older people are hospitalized (NHLBI, 2010; Thom et al., 2006). HF claims 300,000 lives each year (NHLBI, 2010). Fifty percent of people diagnosed with HF will die within five years (Roger et al., 2004). After HF is diagnosed, the survival rate is lower in men than in women, but fewer than 15% of women survive more than 8 to 12 years (NHLBI, 2010). The one-year mortality rate is high with one in five people dying

(NHLBI, 2010). Among people diagnosed with HF, sudden cardiac death occurs at six to nine times the rate of the general population (Fuster, Alexander, & O'Rouke, 2001).

When looking specifically at HF in the African American population, a disparity is evident. African Americans have higher percentages of HF at younger ages (Roger et al., 2011). Information from the 2011 Heart Disease and Stroke Statistics indicate that African Americans have the overall highest risk of developing HF (4.6%), followed by Hispanics (3.5%), Caucasians (2.4%), and Chinese Americans (1.0%) (Bahrami et al., 2008). In addition to having a higher prevalence and increased risk factors, African Americans are more likely than people of all other racial or ethnic groups to suffer more severe forms of HF (NHLBI, 2010). The psychosocial burdens of lower socioeconomic status lack of access to health care, decreased quality of health care, and the stress associated with years of racial discrimination may have influenced adherence to HF regimens and contributed to poor HF outcomes for African Americans (Barr, 2008; Mathew et al., 2005; Yancy, 2005). These identified psychosocial burdens within the African American culture (Yancy, 2005) must be acknowledged as a contributing factor to the disparity that exists.

Documentation of Need

The increases in morbidity and mortality rates for HF are associated with an increase in hospital admissions and health care costs. Hospital discharges for HF rose from 400,000 in 1979 to 1,106,000 in 2006 (DeFrances, Lucas, Buie, & Golosinskiy, 2008). Data from ambulatory care visits, physician offices, hospital outpatient departments, and emergency departments in the United States from 1999 to 2000 totaled

the number of visits for HF at 3.4 million. Over 29 billion dollars were spent on HF in

2006. The estimated direct and indirect costs for the treatment of HF in the United States

for 2010 were $39.2 billion (Lloyd-Jones et al., 2010). Results from epidemiological

studies support that African Americans are subject to increased hospital admissions and

costs, both results of being hospitalized seven to eight times more often for HF than

Caucasians (Davis, Liu, & Gibson, 2003).

Prevention of hospitalization and improvement of health outcomes can be

influenced by increasing the appropriate and consistent use of HF self-care behaviors

(Riegel, Moser et al., 2009). HF self-care is defined as a naturalistic decision-making

process that involves the choice of behaviors that maintain physiological stability (self-

care maintenance), the response to HF symptoms when they occur (self-care

management), and the confidence (self-care confidence) to engage in each phase of self-

care (Riegel, Lee, Dickson & Carlson, 2009). A systematic review by McAlister,

Steward, Ferrua, and Murray (2004) indicated that programs focused on increasing HF

knowledge and promoting self-care behaviors had a significant decrease in HF hospital

admissions and all hospital admissions in general. Results from the present study

emphasize the importance of understanding what facilitates and/or hinders an individual's

ability to perform HF self-care in order to develop appropriate nursing interventions.

There are several factors that may influence self-care behaviors in HF patients. In

reviewing the literature concerning the facilitators and barriers to engaging in HF self-

care, several constructs emerged. These included: knowledge, decision making skills,

social support, health status, socioeconomic status, race, ethnicity, and culture, and

personal beliefs, attitudes, and perceptions. These constructs and how they influence self-care behaviors will be presented and reviewed.

Currently, there are no studies that investigate the subjective experience of living with HF in relation to the facilitators and barriers for self-care specific to low income, urban dwelling African Americans. Understanding the subjective experience is an essential aspect in improving nursing interventions meant to promote such self-care behaviors. This research will address the factors that facilitate and impede self-care behaviors among this group.

Purpose of the Study

Although a disparity among racial and cultural groups is evident, less is known about the subjective experience of living with HF from African Americans specifically. The purpose of this research was to gain a better understanding of the subjective experience of low income, urban dwelling African Americans who are over the age of 50 and have been diagnosed with HF. This study will outline both the perceived facilitators and barriers related to engaging in HF self-care behaviors. The specific aims of this study include:

1) Describe the self-care behaviors of low income, urban dwelling African Americans with HF;

2) Render a more complete understanding of the facilitators that allow low income, urban dwelling African Americans to engage in HF self-care behaviors;

3) Render a more complete understanding of what barriers low income,

urban dwelling African Americans face when attempting to engage in HF self-care behaviors.

Significance to Nursing

This research study was an investigation into the subjective experience of self-care behaviors and the perceived facilitators and barriers that low income, urban dwelling African Americans face when engaging in HF self-care behaviors. In order to investigate the subjective experience, the photovoice methodology was used. The photovoice methodology is action-based research founded on Freire's theoretical work on education for critical consciousness. The photovoice method was employed in this study—using reflection and discussion—to assist in the participants' analysis of the facilitators and barriers associated with HF self-care. A solid understanding of these facilitators and barriers discovered in the present study can be used to develop future nursing interventions to increase engagement in HF self-care behaviors.

Self-care behaviors include a complex treatment regimen of multiple medications, dietary and fluid restrictions, daily weight monitoring, symptom recognition and management, and a unique balance of rest and exercise (Riegel, Lee et al., 2009). The results of this study contribute to nursing knowledge by providing specific information about HF as experienced by low income African Americans living in urban areas. It will alert health care providers to the unique obstacles present when engaging in HF self-care behaviors. Furthermore, recognition of the facilitators and barriers associated with HF self-care behavior will contribute to the development of more effective, targeted interventions. In order to provide appropriate care, health care providers must understand

the contextual and cultural influences that promote or inhibit individuals' engagement in HF self-care behaviors.

For many, a HF diagnosis marks the beginning of a downward trajectory of HF exacerbations and frequent hospitalizations. Research has found that African Americans, in contrast to other racial and ethnic groups, have an increased risk for poorer health outcomes (Davis et al., 2003; Roger et al., 2011). This study provides a more complete view of the subjective experience of low income African Americans living in an urban setting; it describes their engagement in HF self-care behaviors and examines the facilitators and barriers they face. A better understanding of the HF self-care facilitators and barriers may improve nurses' ability to assist HF patients to develop, implement, and evaluate patient specific interventions.

Chapter 2

Review of the Literature

This chapter begins with a discussion of the constructivist paradigm and the theoretical literature concerning the levels of consciousness, which guided this research study. HF self-care is defined and the disparity that exists between African Americans and other racial and ethnic groups with HF is presented. The author's assumptions are identified. The comprehensive review of literature focuses on the facilitators for and barriers to the engagement in HF self-care behaviors. The literature review also includes research studies that used nursing interventions to promote engagement in HF self-care behaviors. This chapter concludes with a summary of the gaps within the literature.

Philosophical Underpinnings

The constructivist paradigm provided the philosophical basis for this study and guided the investigation into the factors that variously facilitate and hinder engagement in HF self-care behaviors. Constructivists believe that knowledge is constructed and developed through human activity and is constantly changing (Guba, 1990). Within the constructivist paradigm, objectivity is not possible; this perspective posits that realities are subjective and uniquely formed within each individual (Guba, 1990). An individual's reality is holistic, social, and holds multiple, continually changing mental constructions (Guba, 1990; Palan-Lopez, 2007; Polit & Hungler, 1999).

According to the constructivist paradigm, research is inductive, holistic, grounded in experiences, flexible, qualitative, and in search of behavioral patterns among

participants (Polit & Hungler, 1999). The constructivist does not want to predict or control meaning, but rather strives to reconstruct meaning through the interpretations of the participants (Guba, 1990; Polit & Hungler, 1999). Because the reality of the phenomena of interest (HF self-care behaviors in the case of this study) exists within the minds of the participants, subjective interaction is the only way to access the participants' perspectives. Additionally, the constructivist beliefs can easily be adapted to the problem being studied and allow for new insights into an individual's perspective (Denzin & Lincoln, 2000). Hunt (2009) supports the use of the constructivist paradigm in research, acknowledging that its use assists the researcher to connect action to praxis and to develop practice-relevant findings. The constructivist paradigm aligns with the researcher's belief that the use of the photovoice method will bring about a better understanding of the subjective experience of the facilitators and barriers that low income African Americans face when engaging in self-care behaviors.

In order to analyze participant realities, the constructivist combines hermeneutics and dialectics (Lincoln, 1990). This combination is used to acknowledge multiple constructions and to identify those most prevalent or important to the group being observed. Hermeneutics is the process of analyzing written and spoken information; it is used to accurately interpret the participants' individual constructions (Lincoln, 1990). Dialectics compares and contrasts the individual constructions within a group of participants (Lincoln, 1990). In this study, the group interaction allowed for the emergence and analysis of the participants' mental constructions. This was accomplished by allowing the researcher to focus on the social processes of construction, reconstruction, and elaboration (Guba, 1990). This social process occurred during the

photovoice project through individual reflection (construction), group reflection, discussion, and sharing (reconstruction), and the discussion and clarification of identified conflicts or consensus on group themes (elaboration).

Theoretical Framework

The theoretical framework for this study is founded on the principles of education for critical consciousness as written by Paulo Freire. Freire (1973) proposed that three levels of consciousness affect the reality of behavioral responses: (a) magical, (b) naïve, and (c) critical. Magical consciousness arises when an individual simply "apprehends facts and attributes them to a superior power by which it is controlled and to which it must therefore submit" (Freire, 1973, p. 44). At this level of consciousness, an individual is trapped by assumptions and feels helpless and oppressed. Those who stay in the magical level believe that the trajectory of their life is based on fate and they have little control over how their life progresses. Life is accepted for what it is.

Individuals begin to visualize and interpret their own situation during the progression from the magical level into the naïve level of consciousness. A naïve consciousness sees "causality as a static, established fact, and thus is deceived in its perception" (Freire, 1973, p. 44). This is to say that while an individual becomes aware of his or her problem, concern, or issue, acceptance of the situation does not occur. Individuals associate responsibility for their problems—which are viewed as coincidences—with others and not themselves.

The final level of consciousness, critical consciousness, represents "causal and circumstantial correlations" (Freire, 1973, p.44). At the critical level of consciousness an

individual becomes aware of his or her choices; there is an acceptance of the current reality, as well as an acceptance of personal responsibility. With acceptance comes the belief that one can change. At this level there is a realization that they are responsible for maintenance and change; that is, with critical consciousness, action and change can occur. The individual accepts responsibility and makes the necessary decisions to integrate choices into his or her life (Freire, 1970/1973).

Movement through the levels of consciousness requires a time of reflection during which plans for the future can be made, and therefore lead to both action and change. There must be a recognizing moment in which an individual sees his or her present reality as a problem. In order to facilitate this movement through the levels of consciousness, Freire (1973) presented his subjects with coded existential situations. Here, a coded existential situation was a sketch that Freire chose and presented to his subjects. He used picture drawing to shift the power toward the participants. This allowed participants to transfer abstract meaning to concrete realities. Freire used these drawings combined with informal discussions to connect with people and gain entrance to their individual perceptions. He suggested that in order to investigate an individual's thinking and reality, the participants must be treated as co-investigators.

Heart Failure Self-Care

The Self-Care of Heart Failure Model is used to define HF self-care. The model includes self-care maintenance, self-care management, and self-care confidence as its central concepts (Riegel & Dickson, 2008). In this model, HF self-care is defined as a naturalistic decision-making process that involves a choice of behaviors aimed to

maintain physiological stability (self-care maintenance), a response to HF symptoms when they occur (self-care management), and the confidence to engage in each phase of self-care (self-care confidence) (Riegel, Lee et al., 2009). Naturalistic decision-making is used in everyday decision-making and consists of: (a) a focus that is process oriented, (b) matching decision rules to the situation and the action, (c) decision-making that is influenced by context, and (d) making practical decisions based on the empirical information available (Lipshitz, Klein, Orasanu, & Salas, 2001).

Self-care involves behavioral choices related to physical stability or maintenance behaviors, symptom management, and overall confidence (Riegel & Dickson, 2008). Self-care maintenance requires a person with HF to live a healthy lifestyle that includes taking medications, eating a low sodium diet, exercising, and actively monitoring symptoms (Riegel, Lee et al., 2009). Self-care management is a deliberate decision-making process that requires recognizing changes in symptoms, evaluating the symptoms, responding to symptoms by implementing a treatment remedy, and evaluating that treatment remedy (Riegel & Dickson, 2008). Self-care is process-focused, situation specific, and influenced by knowledge and experience (Riegel, Lee et al., 2009). This process is also influenced by self-care confidence, which is a moderator of self-care outcomes (Riegel & Dickson, 2008; Riegel, Lee et al., 2009).

Race, Ethnicity, Culture, and Heart Failure

Race is a social construct used to distinguish between groups of people. The concept of race as used in the United States originated in Western Europe, as explorers began to realize that people from different continents had strikingly different physical characteristics (Barr, 2008). Over time racial categories, like most labels, became

attached to and associated with certain stereotypes. Negative stereotypes of different cultural groups, which were initiated by the dominant cultural group, laid the foundation for racism and prejudice. Although there is no biological basis for the term race, race is a determinant of health status. For instance, African Americans have the highest risk for developing HF compared to all other racial groups (Bahrami et al., 2008).

It is evident that there is a disparity among health outcomes for African Americans when compared to other groups. African Americans have a higher incidence of being diagnosed with HF at younger ages (Bahrami et al., 2008; Davis et al., 2003). According to the NHLBI, the age adjusted incidence for HF indicated that African American men and women have higher incidences of HF compared to Caucasians (Loehr, Rosamond, Change, Folsom, & Chambless, 2008). Additionally, African Americans are more likely to die within five years of being diagnosed with HF compared to Caucasians, explaining why it appears that HF rates for African Americans are decreased after 75 years of age (Loehr et al., 2008). Currently African Americans are more likely than people of all other races to suffer from more severe forms of HF, have a more progressive disease trajectory, have increased hospital admissions, and consequently higher hospital and health care costs (Bahrami, et al., 2008; Davis et al., 2003).

Some researchers have attributed these poorer health outcomes to be related to the increased incidence of atherosclerotic heart disease, hypertension, and diabetes among African Americans. It is more likely that these disparities exist due to the psychosocial burdens present for some. These psychosocial burdens can include years of exposure to lower SES, lack of access to health care, and decreased quality of health care (Barr, 2008;

Matthew et al., 2005; Yancy 2005). Additionally African Americans are disproportionately exposed to both acute and chronic stress, often associated with racism (Clark, Anderson, Clark & Williams, 2013). Exposure to racism is among the factors related to negative health outcomes among African Americans (Clark et al., 2013).

As individuals experience stressful situations such as racism, low socioeconomic status, and lack of access to quality health care, the body makes ongoing attempts, (referred to as allostasis) to adapt to stressors and maintain stability (McEwen, 1998). The wear and tear that results from too much stress or from inefficient management of stress is referred to as allostatic load (McEwen, 1998). The chronic effects of allostatic load induced by chronic perceptions of racism have been associated with increased rates of hypertension (Klonoff & Landrine, 2003; Manuck, Kasprovicz, & Muldoon, 1990). These negative physiological affects related to allostatic load may help explain the differences in health outcomes. Further, it should be acknowledged that when controlling for socioeconomic status in patients with heart disease, the black/white differences in health disparities were reduced, but not eliminated (United States Department of Health and Human Services, 1998).

Assumptions

There are several assumptions that under grid this study. A mixed methodology was used for the present study. This approach was based on the assumption that the participants would honestly answer questions on the instruments used and concerning the questions about the photographs during the group discussion. Based on the poor health

care outcomes among African Americans, it was also assumed that there were unique and discoverable facilitators and barriers that influenced self-care behaviors.

Outline of Literature Review

The purpose of this section is to review the existing knowledge relevant to understanding the facilitators and barriers to engaging in HF self-care behaviors. The theoretical and empirical literature on HF is extensive. Due to the large number of research studies regarding HF, this literature review focused on studies addressing the facilitators and barriers to engaging in HF self-care behaviors. PsycINFO, Medline via OVID, and CINAHL databases were used to search for English research articles— between 1980 and January 2012—with the keywords "congestive heart failure," "chronic heart failure," "heart failure," "self-care," "obstacles," "barriers," "influences," and "facilitators." The criteria for inclusion were articles that positioned self-care as a main variable, analyzed facilitators and barriers, or identified these in the research results. Articles that used individualized nursing interventions aimed at increasing or improving engagement in HF self-care behaviors were also included. This resulted in 26 articles for analysis. Particular attention was paid to the demographics included in all studies so as to determine whether or not the information gathered could appropriately represent the African American population. When included, racial, ethnic, or cultural identity provided in the demographic sections of the reviewed literature is presented. The following sections present the literature identifying the facilitators and barriers to engaging in HF self-care and are followed by the literature pertaining to nursing interventions aimed at increasing or improving engagement in HF self-care behaviors.

Facilitators and Barriers to Engaging in Heart Failure Self-Care Behaviors

In reviewing the literature concerning the facilitators and barriers to engaging in HF self-care, four primary constructs emerged. These included knowledge, decision making skills, social support, and health status. Because health status is multidimensional, it was determined for the purposes of this study to only include physical and psychological well-being. In addition to these, a secondary set of less frequently identified constructs were identified. This set included: socioeconomic status, race, ethnicity, and culture, and personal beliefs, attitudes, and perceptions; all were determined to influence behaviors. This second set of constructs were not reported as frequently as the main constructs, but were identified as facilitators and barriers to engaging in HF self-care behaviors in several of the reviewed studies. What follows is a review of the literature of what is known about these facilitators and barriers and how they influence self-care behaviors.

Knowledge and decision making skills. Knowledge and decision making skills, although two separate constructs, were often found in the literature together and will be discussed in this section. HF knowledge can include possessing an understanding of HF, HF symptoms, signs of worsening symptoms, low sodium food selection, medication uses and actions, and the prevention of HF exacerbations (Artinian, Magnan, Sloan, & Lange, 2002; Moorhead, Johnson, Maas, & Swanson, 2008). Riegel, Lee et al. (2009) described that laypersons use naturalistic decision making when making decisions regarding how to respond to their symptoms. Naturalistic decision making is process-focused and is based on the information available at the time of decision making (Lipshitz et al., 2001).

Lack of knowledge and difficulty making self-care decisions were found to be common barriers to engaging in HF self-care in the literature. Although knowledge has been described as a necessary and influential aspect of developing decision making skills (Riegel & Dickson, 2008), HF knowledge is not a sufficient determinant of self-care behaviors (Clark, Freydberg, McAlister, Tsuyuki, Armstrong, & Strain, 2009). However, several studies have identified that individuals with more knowledge regarding HF are more likely to have better outcomes and fewer hospitalizations (Krumholz et al., 2002; Riegel et al., 2002). Adequate decision making skills are essential for people with HF (Riegel & Dickson, 2008). What is known about the influence that knowledge and decision making skills have on self-care behaviors is presented here.

The following studies found that people who lack HF knowledge also have difficulty instituting appropriate decision making skills regarding dietary restrictions (Gary, 2006; Reilly et al., 2009; Sheahan & Fields, 2008; Van der Wal, Jaarsma, Moser, Van Gilst, and Veldhuisen , 2010) medication uses and actions (Reilly et al., 2009; Van der Wal et al., 2010), and symptom management (Horowitz, Rein & Leventhal, 2004; Jurgens, Hoke, Byrnes, & Riegel, 2009; Riegel & Carlson, 2002). In Gary's (2006) qualitative descriptive exploratory study, with the purpose of describing the self-care behaviors of women with HF (n=32), Gary found a lack of knowledge regarding dietary restrictions. Data collected through semi-structured interviews revealed that 44% of the participants did not know that sodium and salt were synonymous. Eighty-seven percent misinterpreted food labels. Participants reported improperly choosing low calorie frozen dinners unaware of their high sodium content. In addition to reporting a knowledge deficit and improper decision making regarding dietary restrictions, the women

participants were reluctant to give up culturally influenced dietary practices. Although the data was not analyzed by race or ethnicity, almost half of the participants were African American (n=13), with 81% of the participants reporting an annual income at or below the poverty level.

Similar findings were reported by Sheahan and Fields (2008). This qualitative, descriptive study used semi-structured interviews to explore the experiences and decision-making process associated with the adoption of a sodium restricted diet. The study included 33 women aged 65-98, one third of the participants (n=11) were African American. These women were divided into three focus groups. A consistent theme among all three groups was "lack of knowledge." Participants reported lacking knowledge about dietary sodium in general; they did not know their sodium restrictions and how to interpret food labels, sodium alternatives, or how to locate the sodium contents within other salt alternatives. Participants in this study also reported that they did not receive dietary counseling from their health care providers. The participants of this study described being raised on "Southern foods" high in salt and fat, which they continued to consume. These findings suggest that a lack of knowledge about sodium and difficulty interpreting sodium restrictions hindered decision making ability to choose and cook sodium restricted foods. The results in this study were presented as aggregate findings.

In addition to this lack of knowledge regarding sodium restrictions, Van der Wal et al. (2010) also identified lack of knowledge as a barrier to medication adherence. In this qualitative study (n=15) conducted in the Netherlands, the patient's perspective for compliance was explored through semi-structured interviews. The focus of the interview

was the reasons for and barriers to compliance. Even though all participants had been diagnosed with HF for at least 18 months, and nine of the participants attended a HF management program, several knowledge deficits were identified. The most common knowledge deficit was the failure to know the uses and actions of their daily medications. Several participants did not know the amount of sodium in different food items and perceived that they could wash away or rid their sodium intake through urination. These examples demonstrate that a lack of knowledge increased the complexity of implementing proper decision making skills. An example of how a lack of knowledge contributed to difficultly making appropriate decisions is reflected in one participant's response that she added fruit to decrease the overall sodium content of her meal.

Reilly et al. (2009) conducted psychometric testing of the Atlanta Heart Failure Knowledge Test (A-HFKT), with the purpose of developing a standardized instrument for both clinical and research settings. This study revealed valuable information about people with HF. Only 50% of the patients, however, and 39% of the family members actually knew what the acceptable amount of sodium was. Both patients and family members identified difficulty discussing typical HF medication. Findings indicated that there was a correlation among an increase in knowledge, an increase in self-care, and a decrease in sodium ingestion. Higher scores on the A-HFKT were associated with increased number of days medications were taken correctly. The sample (n=116) included 67 African American dyads, consisting of a HF patient and a family member. Although findings were not analyzed by race or ethnicity, these findings support that many patients and family members may lack knowledge regarding dietary restrictions and medications. The findings suggest that those with increased knowledge may have

had better decision making skills regarding medications and dietary ingestion of sodium.

Several studies identified that some people with HF lack knowledge about HF self-care management skills. It may be that some have difficulty cognitively processing their HF symptoms in order to make the appropriate decisions to be able to prevent, recognize, or respond to HF symptoms before emergent care is needed. Cognitive processing of HF symptoms includes acknowledging the symptoms, perceiving the seriousness of symptoms, and the perception of one's ability to control the symptoms (Burnett, Blumenthal, Mark, Leimberger, & Califf, 1995).

Horowitz et al. (2004) completed a grounded theory study (n=19) to render a better understanding of patient factors that serve as barriers to effective self-care management. Through qualitative analysis of semi-structured interviews, three dominant themes emerged. The first theme—*inadequate knowledge of causes, symptoms, and consequences of HF*—was supported by reports of a number of misunderstandings regarding self-care. Many participants did not have a clear understanding of HF symptoms. The second theme—understood as a *failure to link symptoms with procedures*—arose from participant reports of not recognizing their symptoms were related to HF and therefore did not implement the appropriate action to address the escalating HF symptoms. This inability to link symptoms to a HF exacerbation resulted in an inappropriate response or no response to HF symptoms. Participants did not realize they could minimize HF symptoms through specific self-care management behaviors. The third theme—*barriers to receiving care*—was derived when participants reported not knowing how to contact their physicians or how to receive care for worsening symptoms other than visiting an emergency department. The consequence of this lack of

knowledge, difficulty with cognitively processing symptoms, and difficulty instituting decision making skills resulted in a lack of symptom management and prevention of HF exacerbations. Less than half of the participants were identified as African Americans; additionally, data was not analyzed by race or ethnicity.

In a qualitative study, Riegel and Carlson (2002) reported that people with HF often did not recognize their HF symptoms, or they misinterpreted the importance of their symptoms. This study explored how HF influences patients' lives, how they perform self-care behaviors, and how life situations facilitate or impede HF self-care (n=26). Qualitative data from structured interviews identified that while some participants recognized classic symptoms of HF (dyspnea, swelling), many failed to notice their symptoms, noticed them to late, or delayed seeking treatment. Similarly, Gary (2006) reported that participants were unable to identify a change in symptoms and did not know how to respond to symptoms as they occurred. These findings indicate that people with HF may lack knowledge or have difficulty cognitively processing symptoms related to HF. This lack of knowledge or difficulty cognitively processing HF symptoms may have inhibited their ability to make appropriate decisions regarding when to seek treatment. Both of these studies presented their findings as aggregate data.

Lack of knowledge, difficulty cognitively processing symptoms, and difficulty making decisions regarding self-care management was reported by Jurgens et al. (2009). This mixed method study evaluated the factors related to symptom recognition and response among older adults hospitalized with decompensated HF (n=77). Participants completed the HF Perceptions Scale, Specific Activity Scale (SAS), the Response to Symptoms Questionnaire, and responded to open ended questions about the experience of

having symptoms. Results indicated that participants in this study did not know the

symptoms of HF and were unable to correlate the severity of their symptoms with the

need for treatment. Analysis of the Response to Symptoms Questionnaire identified that

56% of the participants were unaware they were experiencing HF symptoms and 80%

waited for the symptoms to resolve on their own. Fifty-four percent of the study

participants believed they had no control over their symptoms. Poor symptom

recognition in participants in this study resulted in almost half of the participants

reporting they had symptoms for three or more days before seeking care. It is unknown if

there were differences in symptom recognition and management between African

Americans and Caucasians due to the small percentage of African Americans (n=9)

included and aggregate analysis of the data.

These studies support that some individuals may lack HF knowledge, resulting in

incorrect decision makings skills to effectively engage in the self-care maintenance

behaviors of dietary (Gary, 2006; Reilly et al., 2009; Sheahan & Fields, 2008; Van der

Wal et al., 2010) and medication adherence (Reilly et al., 2009; Van der Wal et al.,

2010). Some people with HF have been found to have difficulty engaging in self-care

management behaviors (Horowitz et al., 2004; Jurgens et al., 2009; Riegel & Carlson,

2002). Lack of knowledge and difficulty cognitively process symptoms may make it

difficult to use appropriate decision making skills regarding how to adhere to treatment

regimens and respond to the symptoms of a HF exacerbation.

Five of the seven studies in this section were qualitative in nature. One study was

done outside of the United States. Five of the studies done within the United States

provided demographic information identifying racial and ethnic backgrounds of the

participants. None of the studies presented in the literature review thus far analyzed data by race or ethnicity, but the overall findings in diverse samples did support that a lack of knowledge, difficulty cognitively processing of symptoms, and difficulties using decision making skills exists for many people with HF.

Social support. While social support is a vital facilitator, lack of social support can be a sizable barrier in the lives of people with HF. Social support has been commonly defined as the perception of support one receives from others in the environment (Zimet, Dahlem, Zimet, & Farley, 1988). Social support can come as either formal or informal encouragement; both are broadly defined within the HF literature. Formal support is the perceived support provided by formal helping agents; this includes physicians, nurses, and other medical professionals (Cohen, Underwood, & Gottlieb, 2000). Informal support is the reliable assistance provided by friends, family, or colleagues (Moorhead et al., 2008). Social support can include the perception of having available informational (advise or guidance), instrumental (tangible, practical, physical, or material assistance), or emotional (expressions of understanding and encouragement) support (House, Umberson, & Landis, 1988). Informational, instrumental, and emotional support from family, friends, and health care providers has been identified as facilitating engagement in self-care behaviors (Riegel and Carlson, 2002). Definitions for the various forms of social support can be found in Appendix A.

Perceived social support has contributed to improved self-care behaviors among people with HF (Sayers, Riegel, Pawlowski, Coyne, and Samaha, 2008; Scotto, 2005). Adequate social support provides stress-buffering effects and positively influences health behaviors (Cohen, 1988; House et al., 1988; Wallston, Alagna, DeVillis, & DeVellis,

1983). According to Cohen and McKay (1984), perceived social support is thought to provide protection against stressful events. Social support from family members or friends may moderate the stress response and improve an individuals' ability to react to and cope with a stressful situation (Cohen et al., 2000). If one perceives they have social support the reaction to stress may be buffered or appear less threatening, decreasing the physiological response (Cohen & McKay, 1984). It is possible that adequate social support could make behaviors such as self-care seem less stressful, and thus decrease the negative cardiovascular effects associated with stress.

Supportive relationships promote health behaviors by providing information and reminders, tangible assistance, and emotional support (Sayers et al., 2008). The response to stress may be influenced by others who lend informational support by providing appropriate solutions to problems (Cohen & McKay, 1984). Adequate tangible support or receiving needed material resources from others may also influence health behaviors. Such as, if an individual receives assistance with medication administration and purchasing or cooking meals, it would seem that adherence would be easier. Emotional support may be perceived as love or esteem. The influence that social support has on emotions, cognitions, and behaviors has been linked to positive physiological and behavioral responses affecting the cardiovascular system (Cohen, 1988; Cohen et al., 2000). Additionally the positive impact that social support has on treatment adherence has been identified as decreasing rehospitalizations and mortality (Luttik, Jaarsma, Moser, Sanderman, & Van Veldhusien, 2005).

Several studies found familial and health care provider support as important facilitators for self-care maintenance behaviors. In a phenomenological study by Scotto

(2005) fourteen participants were asked to describe the experience of adhering to their prescribed HF regimen of care. Individuals reported that the involvement of significant others and health care professionals positively influenced their self-care maintenance behaviors, such as following dietary restrictions. Participants who had active, positive involvement from their health care providers reported that this support was helpful to maintain self-care behaviors. Those who did not feel support from either their significant others or their health care providers were more likely to stray from their diets and neglect their prescribed treatment regimens. Racial and ethnic demographics were not provided or analyzed in this study.

Sayers et al., (2008) used a cross sectional design to investigate the effects of social support among people with HF (n=74). This study also tested the hypothesis that those who were married and those living with others perceived greater levels of social support than those living alone, using race (black vs. white) as a moderator variable. Participants consisted of African Americans (55.4%), Caucasians (40.5%), and Native Americans (2.7%) all with low socioeconomic status. Several instruments were used in this study. Family involvement was measured with the Medical Care Questionnaire (MCQ). The Multidimensional Score of Perceived Social Support (MSPSS) assessed various types of support, including emotional and instrumental support. The Self-Care of Heart Failure Index (SCHFI) measured the self-care behaviors of the participants. Additionally medication and dietary adherence were assessed. Family members, including spouses, were identified as providing social support to all participants. Perceived social support was associated with increased engagement in self-care behaviors overall. Perceived emotional support was specifically associated with increased

medication and dietary adherence. Family members were found to be key factors in assessing the need for medical treatment. There were no significant differences in the perception of social support based on racial or ethnic backgrounds except in the instance of marital status and living situation. Single, Caucasian participants that lived alone had significantly lower levels of perceived support compared to the African American participants. Although overall performance of self-care behaviors among participants was poor, family members were noted as positively influencing how the participants made decisions to seek medical attention. These results display the important role family members and supportive relationships have in facilitating self-care behaviors.

Three studies examined how social support facilitates the development of HF knowledge and decision making skills (Crowder, 2006; Eldh, Ehnfors, & Ekman, 2006; Schnell, Naimark, & McClement, 2006). Crowder (2006) conducted qualitative ethnographic interviews (n=15) (Caucasian 86.7%, African American 13.3%) to describe how patients were referred to an outpatient HF clinic and why they continued treatment. Physician recommendations and support from family members were identified as facilitating factors for enrollment. Participants reported that they returned to the outpatient clinic for treatment because they perceived positive outcomes; they reported feeling stronger, normal, and younger. The participants viewed other people in the clinic as family, or another form of support. Conversations with peers were reported as increasing their knowledge about HF and improved their ability to make proper decisions when managing symptoms. The knowledge and decision making skills that were gained increased their ability to properly engage in symptom management. Results from this study support the importance of social support in the promotion of knowledge acquisition

and building decision making skills. Social support in the form of both informal and formal support, along with HF knowledge and decision making skills, were found to be important factors for improving coping with, and facilitating the acceptance a HF diagnosis. Although demographic information was provided, the findings were not examined or reported by racial or ethnic groupings.

Studies done outside of the United States also identified social support as a facilitator for engaging in self-care behaviors. Schnell et al. (2006) conducted a qualitative study to explore self-care experiences that enhance or impede self-care. Eleven Canadian participants were involved in semi-structured interviews. The major qualitative themes included: social support, satisfaction with care, and self-care decision-making behaviors. Eight participants identified their health care clinics as sources of support by providing information about self-care strategies; they also reported that patient-staff reassurance and guidance about symptom management increased their satisfaction with care. Five participants reported the importance and strength of their social networks in making self-care decisions to follow the suggestions made by their health care provider. Results indicated that informal support along with formal support—including the individualization of patient teaching plans and the frequent monitoring of symptoms—facilitated the improvement of self-care.

Although a phenomenological study by Eldh et al. (2006) had a small sample size (n=4), results were similar to other studies. The purpose of this study was to explore the phenomena of patient participation and non-participation in HF self-care behaviors as experienced by Swedish patients and nurses. Participants reported feeling that the nursing staff withheld valuable information from them. When nurses withheld

information, participants perceived that they did not have an equal or respectful relationship with the nurse. Participants reported that they needed the nurse to provide them with enough information or knowledge to take care of themselves. Participants succeeded more readily when they had a respectful relationship with their health care provider and were treated as individuals. According to Eldh et al., engagement in self-care was viewed as accepting responsibility for one's health in general.

In the literature reviewed concerning social support and HF four of the five studies were qualitative in nature, and two were conducted outside of the United States. Findings consistently support the notion that varying forms of social support facilitate engagement in HF self-care behaviors. A variety of racial and ethnic backgrounds were not represented in all of the studies. Crowder (2006) included African American participants in the sample, but did not analyze findings by race or ethnicity. Sayers et al. (2008) aimed to test if race was a moderator of perceived levels of social support and identified that strong family relationships facilitated engagement in self-care behaviors among African Americans. Sayers et al. also identified that single Caucasians living alone had lower perceived social support compared to African Americans. These findings indicated that social support positively influenced self-care behaviors for some people with HF, adding that kinship ties may be particularly important to African Americans. Further investigation is needed to understand the role of social support and its influence on self-care behaviors among people of different racial, ethnic, and cultural backgrounds.

Health status. Health status is multidimensional. For the purpose of this literature review health status includes a person's functional capabilities and the

symptoms associated with activities of daily living (ADL's) that affect both physical and psychological well-being (Myers et al., 2006). The following studies represent what is known about health status, both physical and psychological, and the influence health status has on HF self-care behaviors.

Physical well-being. The desire to maintain an optimal physical health status can be a facilitator for engaging in HF self-care behaviors. Although the HF regimen is difficult, the threat of worsening symptoms sometimes helps individuals acclimate to the many restrictions associated with the HF regimen (Van der Wal et al., 2010). Chris, Sheposh, Carlson, and Riegel (2004) completed a non-experimental, correlational study to explain which patients would be successful at HF self-care maintenance (n=66). Racial demographics were not provided, however 43.9% of the participants reported an average annual income of less than $20,000. Self-care maintenance was measured by a sub-scale of the SCHFI. Analysis of aggregate data identified predictors for self-care maintenance. Specifically, elderly men and those with fewer co-morbidities were most successful at self-care maintenance. Having multiple conditions was noted as challenging, and made it difficult to interpret symptoms. Those with fewer co-morbidities found it easier to monitor their symptoms and their health.

Living with multiple comorbidities and managing multiple symptoms has been found to be a barrier to self-care management. In the study by Riegel and Carlson (2002), described within the knowledge and decision making section, common challenges included physical limitations and multiple health conditions. These conditions made HF management complex when attempting to monitor multiple symptoms. Most participants

reported difficulty discerning if a particular symptom was related to HF. Others failed to notice symptoms, noticed to late, misinterpreted symptoms, or delayed taking action. These findings were consistent with Chris et al. (2004), as discussed previously, who reported that the management of multiple symptoms made self-care complicated.

   Psychological well-being.   Depression is also a major concern for people living with HF; depression has been identified as a barrier to engaging in HF self-care behaviors in the following studies. Friedmann et al. (2006) reported that thirty-six percent of people with HF have depression. Carels (2004) identified that the debilitating effects of HF have contributed to a perceived decreased quality of life in this population. Carels completed a descriptive investigation examining the impact that disease severity, functional status, and level of depression have on quality of life among HF patients (n=58). Participants completed the Beck's Depression Inventory (BDI), a 2-week daily assessment of quality of life diary (DAQL), and the Minnesota Living with Heart Failure Questionnaire that assessed physical and emotional quality of life. Results indicated that depression had a greater impact on quality of life than disease severity. HF patients that were depressed reported being less likely to take action to control their symptoms or to engage in activities that might improve their health. Participants that felt depressed also reported having additional physical symptoms, a decreased acceptance of their HF diagnosis, decreased coping, a lack of control, and feeling as though they were burdens to their families. Participants reported that when they experienced a HF exacerbation which may have included a deteriorating health status, physical limitations, and increasing symptoms, they were more likely to take medications and follow their treatment regimens. Racial or ethnic backgrounds were not identified or analyzed separately in this

study.

An additional study supported that poor psychological health along with poor physical health were barriers to engaging in HF self-care behaviors. This study, conducted in Sweden, indicated that people with HF who have experienced symptoms associated with deteriorating health status, such as fatigue and depression, were less likely to attempt change, engage in self-care, and adhere to HF regimens (Falk, Patel, Swedberg, & Ekman, 2009). Falk et al. (2009) conducted this descriptive study to examine the relationship between fatigue, anxiety, depression, and symptoms distress. HF patients (n=112) completed the Multidimensional Fatigue Inventory (MFI-21), the Hospital Anxiety and Depression Scale (HADS), and the Symptom Distress Scale. Results indicated that higher depression scores correlated with reduced physical activity, low motivational levels, and decreased functioning. The emotional distress reported, combined with the experience of fatigue, resulted in a decreased ability to cope, manage daily activities, and engage in HF self-care behaviors. Three of the four studies in this section did not provide demographic data; one was conducted outside of the United States. Although specific information related to race or ethnicity was not provided in these studies, it is likely that physical well-being, multiple co-morbidity management, and psychological well-being influence self-care behaviors across cultural groups.

Socioeconomic status. The following three studies indicated that HF patients with lower socioeconomic status had difficulty engaging in self-care behaviors. Results from Macabasco-O'Connell, Crawford, Stotts, Stewart, and Froelicher's (2008) descriptive, cross-sectional study revealed that 54% percent of the participants performed

poor self-care. The participants (n=65) consisted of 55% women, 86% unemployed, 52% indigent living in poverty, and 35% nonwhite defined as a combination of African Americans and Asians. A one-time semi-structured interview and the SCHFI was completed by each participant. Overall, self-care scores were low. Analysis of the qualitative data identified that lack of finances were the major obstacle to engaging in HF self-care. Financial concerns were reported as a lack of money saved for medications; furthermore, personal conflicts arose when deciding to use money for medications or to meet the needs of other family members. Lacking or having inadequate health insurance were also noted as a barrier to medication adherence and seeking medical treatment. Gary (2006) and Horowitz et al. (2004) (see previous sections for details of these studies) reported that HF participants who had limited financial ability to purchase medications had an increased number of hospital admissions.

The three studies mentioned above reported that inadequate insurance and a lack of money to purchase needed medications inhibited the participants' ability to properly adhere to prescribed treatment regimens. These three studies included 35-42% African American participants. Although the results were not analyzed by race or ethnicity, these findings indicate that low socioeconomic status poses additional and unique barriers to medication adherence and access to health care.

Race, ethnicity, and culture. Because health disparities among African Americans with HF have been identified, it was necessary to identify the known racial, ethnic, or cultural facilitators and barriers to engaging in HF self-care behaviors. Four studies were found that identified racial, ethnic, and/or cultural difference in self-care behaviors (Artinian et al., 2002; Gary, 2006; Schnell-Hoehn, Naimark, & Tate, 2009;

Sheahan & Fields, 2008). Artinian et al. (2002) completed a descriptive correlation study with 110 participants that examined the frequency of self-care behaviors and factors that affect self-care. The sample was 63% African American. Data was collected with the Revised Heart Failure Self-Care Behavior Scale and the Heart Failure Knowledge Test. Analysis of aggregate data identified that the top three frequently performed self-care behaviors were related to taking prescribed medications, while the least performed self-care behaviors concerned symptom monitoring or symptom management. With the analysis of the self-care behaviors by race, significant differences between the mean scores of 9 self-care behaviors were identified. When compared to Caucasian participants, African Americans were more consistent in seeking medical assistance when dyspneic, if they had increased fluid retention, or a loss of appetite. African American participants also reported believing they could adjust to HF more readily and had higher mean scores for monitoring fluid intake. In contrast, Caucasian participants were more likely to manage their medication regimen and use a pill reminder system. The exact reason for differences in self-care behaviors between African Americans and Caucasians was not identified. This study did not include subjective qualitative data.

Cultural barriers to engaging in HF self-care have been identified in two previously described studies (Gary, 2006: Sheahan and Fields, 2008). Gary (2006) reported that African American participants were reluctant to give up culturally-influenced practices that were not consistent with HF dietary restrictions. Sheahan and Fields (2008) identified that the older southern women, both African American and Caucasian, were used to eating "Southern Cooking" and that these women continued to eat foods high in salt and fat despite being instructed not to. These studies identify that

culture may influence dietary practices.

Although the study by Schnell-Hoehn et al. (2009) was conducted in Australia, cultural and ethnic differences were identified. The purpose of this cross-sectional study was to determine the self-care behaviors among people with HF living in Australia (n=65). Data was collected through chart reviews and completion of the SCHFI and the Kansas City Cardiomyopathy Questionnaire (KCCQ). Race and ethnicity were noted as being of European or Aboriginal decent. A unique finding was that self-care maintenance behaviors were significantly lower in aboriginal participants. Review of the qualitative data indicated that aboriginal participants adhered to traditional customs regarding diet and seeking guidance from elders with HF symptoms rather than participating in Western self-care behaviors. Even though the Aboriginal participants represented only a small portion of the participant sample, their responses were significantly different from those of European decent.

Racial, ethnic, and cultural differences have been identified. Artinian et al. (2002) also reported that African Americans were less likely to follow their medication regimens compared to Caucasians. This study did not include qualitative data to provide information as to why there were differences in medication adherence. Cultural practices linked to ethnic backgrounds have also been identified as influencing dietary choices. Examples included cooking most meals with salted meat despite being warned of the high sodium content (Gary, 2006; Schnell-Hoehn et al., 2009), and being reluctant to give up "Southern Style" cooking, which consisted mostly of high sodium and high fat foods (Sheahan & Fields, 2008).

In the previously mentioned cultural study, aboriginal participants from Australia

when compared to European participants had poorer symptom management due to their preference to seek elder guidance rather that Western self-care behaviors (Schnell-Hoehn et al., 2009). Because self-care involves a wide range of lifestyle behaviors, ethnicity, and culture may pose additional facilitators and barriers that have not yet been addressed in other research studies. These findings bring to light the importance of understanding how ethnicity and culture may influence the engagement of specific behaviors and corroborates the idea that different self-care behaviors exist between people with varying backgrounds.

Personal beliefs, attitudes, and perceptions. Personal beliefs, attitudes, and perceptions can influence an individual's ability to learn about HF and how willing they are to change health behaviors and engage in self-care (Stromberg, Brostrom, Dahlstrom & Fridlund, 1999). Studies that examined the influence of personal beliefs, attitudes, and perceptions on self-care behaviors are discussed here (studies have been reviewed in previous sections).

Several studies have identified that persons with HF may have negative attitudes and perceptions about the HF regimen (Crowder, 2006; Larsson et al., 2007; Macabasco-O'Connell et al., 2008; Riegel & Carlson, 2002; and Van der Wal et al., 2010). Van der Wal et al., (2010) reported participants had difficulty coping with HF treatment and that it remained an ongoing battle to adhere to HF regimens even after a routine had been established. Riegel and Carlson (2002) found that some participants were embarrassed about their high number of medications. These participants also reported skipping diuretic medications when going places in order to avoid using the bathroom frequently in public. While negative perceptions about the HF regimen have been a barrier to

engaging in HF self-care, Scotto (2005) identified that positive beliefs about the outcomes of following the HF regimen facilitated adherence. Participants in Scotto's study reported that they worked harder to engage in self-care if they valued the end results. Feeling normal and being in control also promoted positive self-care behaviors for some participants (Crowder, 2006). In general, these findings support that personal beliefs, attitudes, and perceptions influence how individuals engage in self-care. Similar to other studies, the studies in this section have not been analyzed by race or ethnicity.

Nursing Interventions that Facilitate HF Self-Care Behaviors

The aforementioned research studies addressed how different factors influenced self-care behaviors as either facilitators, barriers, or both. Riegel, Moser et al. (2009) have identified that skill development and behavior change can be effective interventions in promoting self-care behaviors. In this section nursing literature that used motivational and behavioral interventions, goal setting, and HF education to promote self-care behaviors are reviewed.

Motivational intervention. Self-care behaviors were improved in two studies that used a motivational intervention (Paradis, Cossette, Frasure-Smith, Heppell, and Guertin, 2010; Riegel et al., 2006). Paradis et al. (2010) conducted a randomized experimental pilot project to evaluate the use of motivational interviewing on self-care behaviors in HF patients living in Canada (control n=15, intervention n=15). Both the control and the intervention group completed the SCHFI. The intervention group received three motivational interventions: one in person and two via telephone. The nurse assisted with increasing conviction and confidence with a self-care behavior of the

participant's choice. As a result, the intervention group had significantly higher confidence in self-care behavior participation. Increased confidence scores correlated with improved self-care behaviors. The nurses in this study assisted the participants with a self-care behavior of their choice, individualized nursing interventions, and included the patient in the decisions regarding their personal self-care goals.

Similarly, Riegel et al. (2006) evaluated the effectiveness of a motivational intervention intended to improve self-care in hospitalized patients (n=15). Riegel et al. used a mixed methods, pre-test post-test design. More than half of the participants were African American (53.5%). The intervention included patients' family members and focused on motivation, self-care, skill building, and support. The motivational counseling in this study emphasized autonomy, goal setting, and self-efficacy. This allowed the participants to develop their own goals, values, and strategies to improve self-care. Self-care behaviors were assessed by using the SCHFI pre and post intervention. Self-care behaviors improved in 71.4% of the participants who received the interventions. Qualitative findings from this study identified that a lack of knowledge or misconception regarding dietary restrictions and symptom assessment were frequently reported among the participants. Reasons for change were often represented by the fear of a declining health status. The researchers found that listening, affirmation, and collaboration were essential for this intervention to be effective. The nurses that delivered the intervention paid particular attention to the participants' beliefs and behaviors that influenced self-care. They focused on helping the patients overcome their individual barriers. In addition to providing HF education, role-playing and practice situations were used to improve decision making skills. HF self-care must fit into the

patients' lives; heath care providers can assist with this transition.

Behavioral intervention. Kodiath, Kelly, and Shively (2005) conducted a mixed methods study to evaluate the effectiveness of a behavioral intervention in improving self-management behaviors in HF patients (n=44). Racial demographics were not reported and data was not analyzed based on race or ethnicity. The interventions were designed to establish healthier behaviors and promote quality of life. This consisted of providing information about living with HF and managing HF, while also teaching behavior skills that improve quality of life. The behavior skills included exercise, weight loss, salt intake limitation, smoking cessation, and alcohol reduction or cessation. Qualitative analysis of the interventions found that participants were successful in choosing a behavior they wanted to change and setting personal goals, but were unable to sustain the change. Participant feedback identified that they lacked knowledge about HF symptoms. Additionally, a knowledge deficit regarding when and how to report symptoms of HF exacerbation surfaced. Participants reported confusion regarding when and how to access medical care. Knowledge deficits and difficulty making appropriate self-care management decisions may have contributed the participants' inability to sustain habits that lead to change. The results regarding knowledge deficit and decision making skills regarding symptom management are similar to findings of other studies (Gary, 2006; Jurgens et al., 2009).

Educational intervention. Educational interventions have also been effective in increasing self-care behaviors among people with HF (Shearer, Cisar, & Greenberg, 2007). Shearer et al. (2007) conducted a randomized control trial to examine the effects of a telephone-delivered empowerment intervention with HF patients. The empowerment

intervention included teaching and guiding the participant to develop and attain goals, use and develop self-management skills, and improve functional health. The sample consisted of 87 participants (control n=45, intervention n=42), 2.3% were African American. Telephone interventions were conducted by a nurse who called the participant at home 1-3 days post hospital discharge and on weeks 2, 4, 6, 8, and 12. The intervention included support and education from a nurse clinician in order to facilitate participation in self-management. Teaching instructions for following treatment plans such as daily weights, diet restrictions, and evaluation of lower extremity edema were provided. The follow up phone calls focused specifically on self-management, goal attainment, and functional health. All participants completed the Power as Knowing Participation in Change Tool VII (PKPCT), which was used to operationalize one's ability to participate in goal attainment. The SF-36 was used to assess functional health and the Self-Management of Heart Failure Scale (SMHF) was used to assess one's ability to make decisions in response to signs and symptoms of HF. Repeated measures analysis of variance was used to evaluate the intervention's effectiveness. The intervention group had significantly higher self-management scores from pre-test to post-test when compared to the control group. The intervention group was able to manage their HF with self-care behaviors such as checking daily weights, edema, and eating a low-sodium diet. The nurses in the telephone delivered intervention assisted patients to purposefully participate in their health care decisions and self-management of HF. Similar to the results presented by Kodiath et al. (2005), Paradis et al., (2010), and Riegel et al. (2006), the nurses helped participants create their own goals and solutions involved in achieving their goals. These findings supported the importance of individualized nursing

interventions.

Research done outside of the United States found educational interventions to be effective in improving self-care behaviors. Mohammadi, Ekman, & Schaufelberger (2009) completed a descriptive intervention study to evaluate adherence to Angiotensin Converting Enzyme Inhibitors after receiving individualized medication counseling with trained nurses. The Satisfaction With Information About Medications Scale and the European Heart Failure Self-Care Behaviour Scale were completed at baseline and when the targeted blood pressures were reached by HF patients in Sweden (n=88). Participants received both written information and verbal reinforcement regarding their medications. Participants were encouraged to share their perceptions of the medications they were taking and all questions were addressed. Medication adherence was measured by systolic and diastolic blood pressure. There was a positive relationship between lower blood pressure, better self-care, and increased satisfaction with medication information. The supportive nurse relationship facilitated participant adherence in their prescribed medication regimen. Advanced HF was also seen as a motivating factor for medication regimen adherence. As the illness of these participants became more debilitating, the participants began to more strictly follow their medication regimens. The combination of social support, personal perceptions, and desire to maintain health status facilitated an increase in self-care for this population. Additionally, the intervention from the nurses provided patient-specific teaching to meet their individual needs.

Mutual goal setting and supportive-educative intervention. Mutual goal setting is defined as an active decision making process that involves the patient and the nurse working together in the goal setting process (Scott, Setter-Kline, & Britton, 2004).

A supportive-educative nurse intervention is a process that teaches self-management strategies while providing additional information and support needed by the patient (Setter-Kline, Scott, & Britton, 2007). The following section will provide results from studies that used mutual goal setting and supportive-educative nursing interventions.

Meyerson and Setter-Kline (2009) conducted a qualitative analysis of anecdotal records made by a nurse interventionist during the implementation of mutual goal setting interventions to identify factors influencing self-management. The racial and ethnic background of the participants (n=88) was not provided. Through content analysis four themes emerged. The first theme—*competing priorities*—was supported by common concerns for dealing with comorbidities. The second theme—*self-efficacy related to HF self-management*—was supported by the participant reports of insufficient confidence in their ability to make appropriate decisions to manage HF symptoms. If participants believed their actions would result in a desired outcome, they were more likely to overcome barriers and work toward those goals. *Activity level* was a common goal for the participants. Participants reported wanting to maintain independence and remain at home. When individuals identified the goal of staying out of the hospital, they were more likely to learn about HF and how to manage it. The final theme—*psychosocial adaptation*—was common among participants as they struggled to come to terms with their diagnosis. Social support, both informal and formal, was reported as a critical component in goal attainment. According to Meyerson and Setter-Kline, assistance with goal attainment contributed to improved HF self-management and better health outcomes for people with HF. This goal setting process helped the nurse understand the perspective of the patient, and helped promote appropriate self-care behaviors by

providing individualized assistance.

Scott et al. (2004) evaluated mutual goal setting, a supportive-educative nursing intervention, and a placebo in an experimental repeated measures design study. The racial and ethnic identity of the participants (n=88) was not reported. All participants completed the Mental Health Inventory (MHI-5) to assess mental health. Quality of life was assessed by the cardiac version of the Quality of Live Index (QLI). All groups received routine nursing interventions in which nurses from the mutual goal setting group assisted patients in an examination of their values and the development of their goals. The supportive-educative intervention group was taught about self-care management. This group had significantly improved mental health and quality of life scores over the six-month intervention period. Nursing interventions that focus on goal setting at the onset of diagnosis prevented mental health deterioration and frequent hospitalization, as well as improved symptom management.

A secondary analysis completed by Setter-Kline et al., (2007) of the above study evaluated the interventions' ability to increase HF knowledge and self-efficacy. The supportive-educative group that received individualized education demonstrated a significant increase in self-efficacy while managing HF symptoms. Results indicated that there were increased HF knowledge, decision making skills, and self-efficacy in HF management. These findings supported that developing HF education that focuses on strategies to improve self-efficacy lead to improved outcomes.

In conclusion, motivational, behavioral, educational, mutual goal setting, and supportive-educative nursing interventions have been found to promote behavioral changes that increased engagement in self-care behaviors. Findings continue to support

the importance for nurses to familiarize themselves with the HF patient and to assess their individual needs and goals; this brings to light the important role nurses have in providing personalized support. The support given by nurses must include interventions that are tailored to meet the specific needs of the population the nurse serves. Of the eight studies reviewed two were completed outside of the United States. Two of the studies completed within the United States provided racial demographics however, both reported aggregate results. None of the studies presented in this section of literature review analyzed data by race, ethnicity, or culture, but the overall findings did support that individualized interventions completed by supportive nurses facilitated engagement in self-care behaviors.

Summary of Facilitators and Barriers for African Americans

Two studies reviewed used race as a variable for comparison of self-care behaviors (Artinian et al., 2002; Sayers et al., 2008). It was found that African Americans had higher perceived social support when compared to Caucasians (Sayers et al., 2008). In Sayer et al's (2008) study perceived emotional support was associated with increased medication and dietary adherence. Additionally, Artinian et al. (2002) compared nine self-care behaviors of African Americans and Caucasians. African Americans were identified as being less likely to manage their medications and use a daily pill reminder system. In regards to symptom management African Americans were more consistent in seeking medical assistance when dypsneic, had increased fluid retention, or a loss of appetite (Artinian et al., 2002). Qualitative data identifying the possible explanations of these differences was not provided.

Most of the studies did not report findings by racial, ethnic, or cultural backgrounds however, barriers to engaging in self-care behaviors were identified. Studies that included African Americans and those of low socioeconomic status indicated that a lack of money was a barrier to purchasing medications and that a lack of insurance hindered people from seeking the necessary medical treatment, contributing to poor self-care behaviors (Gary, 2006; Horowitz et al., 2004; Macabasco-O'Connell et al., 2008). These research studies identified that the barriers to engaging in self-care may be different among those of lower socioeconomic status.

Several studies identified that many individuals with HF lack knowledge regarding dietary restrictions (Gary, 2006; Reilly et al., 2009; Sheahan & Fields, 2008) and medication actions and uses (Reilly, et al. 2009). Results from several studies indicated that there was a lack of knowledge, difficulty cognitively processing HF symptoms, and difficulty making decisions regarding symptom recognition and management (Gary, 2006; Jurgens et al., 2009; Horowitz et al., 2008). It appears that if an individual does not know what to eat or is unable to connect their symptoms to a HF exacerbation, it would be expected that decision making in response to these factors would be difficult. Identifying the areas where people with HF lack knowledge, and understanding how they use decision making skills to engage in HF self-care is important for nurses to assess and develop appropriate interventions. In addition to lack of knowledge and difficulty making decisions, the management of multiple co-morbidities has been described as making symptom management a difficult task (Chris et al., 2004; Riegel & Carlson, 2002). Also participants who perceived feeling depressed were less likely to take actions to control their symptoms or engage in activities that promoted

health (Carels, 2004).

In summary, while lack of knowledge and limited decision making skills was a barrier to engaging in HF self-care, participants with increased knowledge demonstrated increased decision making skills regarding sodium ingestion (Reilly et al., (2009). Perceived social support was identified as a facilitator for medication (Sayers et al., 2008) and dietary adherence (Sayers et al., 2008; Scotto, 2005). Supportive family members, friends, and health care professionals were identified as increasing knowledge about HF and improving decision making skills regarding symptom management (Crowder, 2006). This information regarding the facilitators for and barriers to engaging in HF self-care can assist nurses in completing proper assessments and developing accurate interventions.

Gaps Within the Heart Failure Literature

The examination of the literature on facilitators and barriers for African Americans as they engage in HF self-care behaviors led to the discovery of several gaps. These gaps include that African Americans were underrepresented in the qualitative literature, no studies were located that were specific to African Americans, and studies include varying percentages of African American participants with the majority of the results reported as aggregate data. The presentation of the gaps in the literature is what follows.

First, despite the poor health outcomes for African Americans with HF, this population was underrepresented in the qualitative HF research literature in the United States. Of the 26 research studies reviewed, 8 were conducted outside of the United

States; the reviewed studies were from Canada (2), Australia (1), and the European countries of Sweden (3) and the Netherlands (1). These studies may or may not have accurately represented self-care behaviors of those from various racial, ethnic, or cultural backgrounds residing in the United States.

Second, none of the studies located were specific to HF self-care behaviors of African Americans. The existing research has included varying percentages of African American participants. Eleven of the 19 studies conducted within the United States provided information about the racial background of the participants. Recent studies including African American participants ranged from 2.3%-63%; these included Artinian et al. (2002) 63%, Crowder (2006) 13.3%, Gary (2007) 41%, Horowitz et al. (2008) 42%, Jurgens et al. (2009) 11.7%, Macabasco-O'Connell et al. (2008) 35% nonwhite, Sayers et al. (2008) 55%, Sheahan and Fields (2008) 33%, Shearer et al. (2007) 2.3%, Reilly et al. (2009) 57.8% and 58.8%, and Riegel et al. (2006) with 53.3%. The percentage of African American participants in most of the studies can be equated to the general African American population in the United States at 12.6% according to the 2010 Census Bureau. Because African Americans have the highest risk of developing HF compared to those from other racial or ethnic backgrounds (Bahrami et al., 2008), there is a need for research studies with higher percentages of African American participants.

Although the aforementioned studies included African Americans, only two of the studies analyzed or reported their results based on the racial or ethnic backgrounds of the participants (Artinian et al., 2002; Sayers et al., 2008). With a lack of studies that focus on or specifically analyzed data from African American participants, it is difficult to determine how the identified facilitators and barriers are present in this population.

Without accurate information, the ability of nurses to develop culturally appropriate assessments and interventions is hindered. It was also identified in the literature that nursing interventions are effective and beneficial in improving self-care, but again these studies do not include adequate representation from the African American population.

Generally, the literature identified a broad range of facilitators and barriers. However, the self-care behaviors of low income, urban dwelling African Americans have not been examined in detail. Likewise, scant research was done to understand the facilitators and barriers specific to the ability of African American patients with HF to follow their complicated regimens of medication, dietary sodium and fluid restrictions, daily weight monitoring, exercise, and symptom management. Overall, the research that focuses on the needs of HF patients has not identified the specific facilitators and barriers present for African Americans, and has neglected to include the voice of African Americans with HF.

The present study provided African Americans with a voice in the discourse on HF self-care. Given this gap in the literature, the focus will settle on the subjective experience of African Americans with HF in order to identify the facilitators for and barriers to their engagement in HF self-care behaviors.

Chapter 3

Research Design and Method

This chapter will describe the photovoice methodology and the rationale for its use. Also presented are the criteria for inclusion along with the recruitment and retention plan for the study's participants. The photovoice project is described including the instruments used and the weekly procedure. A detailed plan for data analysis, maintaining methodological rigor, management, and the protection of human rights is explained. The chapter concludes with a summary of the potential benefits and risks of participation and the limitations of the study.

Research Design and the Photovoice Method of Research

This study used a mixed methods descriptive research design. Photovoice, a participatory action research method, was used to render a more complete understanding of the subjective experience of low income, urban dwelling African Americans over the age of 50 diagnosed with HF. This included the discovery of perceived facilitators and barriers related to engaging in HF self-care behaviors.

The photovoice method of research is built upon Freire's (1970/1973) theoretical literature on education for critical consciousness. Freire used picture drawings to enable people to think critically about social and political influences in their everyday life. This was facilitated by the discussion of a visual image Freire presented (Freire, 1973). In the photovoice method, the researcher provides cameras to people in the community so they may visually represent and communicate to others their experiences (Wang & Buris,

1994). Through this method, participants serve as the experts on their own lives.

Photovoice is a means of exploration in which photographs provide visual records of what the participant perceives as a benefit or potential problem. The photographs offer visual documentation of what needs to be changed, strengthened, and/or maintained. This can be an environmental concern, health condition, or social issue. Taking photographs facilitates critical dialogue (participant discussion and reflection) by helping participants express things that may otherwise be difficult to vocalize.

Photovoice research projects begin with discussion. The participants of a photovoice study take photographs based on a topic provided by the lead researcher, the participants, or a combination of both. The participants then discuss the photographs with a group of other participants and researchers. The group discussions provide the participants with the opportunity to share their worldviews and the events that have shaped their lives (Wang & Burris, 1994). Participants then have time to reflect on the photographs and the discussions that occurred during their group sessions.

The use of participant photography, discussion, and reflection facilitates a gathering of knowledge that creates a means to share information, find solutions, enact change, and promote health. The ultimate goal is to allow this activity to result in personal change (Wang & Burris, 1994). In a literature review by Catalani and Minkler (2010), 60% of photovoice projects resulted in an action that addressed the identified issues. Ninety-six percent of these projects resulted in a public photo exhibition organized to share participant photographs and findings with the greater community (Catalani & Minkler, 2010). The organization of a photo exhibition further engaged the participants and aided in the dissemination of their findings (Valera, Gallin, Schuk, &

Davis, 2009). The use of the photovoice method in the present study allowed African Americans with HF to discuss and reflect on the subjective experience of living with HF and engaging in self-care behaviors.

Rationale for Using the Photovoice Method

Photovoice was the method of choice for this population due to the ease of implementation, the opportunity to transfer power to the participants, the ability to bring a community of people together and empower them, and to advocate for personal and community change. Photovoice has also been identified as a method that allows culturally-specific information to emerge more naturally. The following sections will provide the rationale for the use of the photovoice method within the present study.

Easily implemented. Photovoice is a method that can be easily implemented. Wang and Burris (1997) suggest that almost anyone can be taught to use a camera. An individual does not need to be able to read or write in the dominant language in order to select a scene and take the picture (Wang & Burris, 1997). As such, photovoice can be a powerful tool for people of different cultural backgrounds, people who are vulnerable or stigmatized, and those who are unable to read or write. Researchers provide cameras to people who may not otherwise be equipped with a tool to capture and record issues within their lives and communities. Additionally, it may be easier for an individual to take a picture of something that they have difficulty discussing or vocalizing. Because photovoice can be used easily across age groups, educational levels, and cultures, it was chosen for the method in this study.

Transfer of power. Within the photovoice method, the researcher transfers

power to the participants by allowing the participants to control what they take pictures of. This transfer of power acknowledges that the participants are the experts and authorities on their own health conditions within their communities. Shifting the power from those most often in control to a disempowered group is a common objective of both the photovoice method and Freire's work. In the present study, the photovoice method was used to help establish an environment for people with HF to share their knowledge, personal perspectives, and personal expertise with those traditionally thought of as being in the position of power. The photovoice method assisted in providing the opportunity for this vulnerable population to share their personal beliefs and perspectives.

Empowering participants. In addition to the shift of power that results from using the photovoice method, active participation empowers the participants further. In previous research studies, photovoice participants reported feeling empowered by the realization that they had opinions and that these opinions were valued by others. Others have also found photovoice to be an enjoyable, beneficial, and meaningful experience (Foster-Fishman, Nowell, Deacon, Nievar, & McCann, 2005; Necheles, Chung, & Hawes-Dawson, 2007; Strack, Magill, & McDonagh, 2004; Streng et al., 2004; Wang & Burris, 1997; Wilson et al., 2007). The use of cameras to tell a story promotes a sense of pride and ownership (Wang & Burris, 1997), and the participants are encouraged to claim authority over their lives (Rhodes, Hergenrather, Wilkin, & Jolly, 2008). Empowerment was identified as a benefit in 44% to 60% of studies that used the photovoice methodology (Catalani & Minkler, 2010). Photographs allow participants to tell a story from their perspective, which then allows participants to advocate for their own well-being (Wang & Burris, 1997). Using photovoice encourages participants to present their

lived experience though images, language, and context; and ultimately, the group discussions provide participants an opportunity to reflect on the personal and community aspects—both facilitators and barriers—involved with engaging in HF self-care behaviors.

Promoting consciousness. Promoting consciousness through group discussion is one of the goals of the photovoice method (Wang & Burris, 1997). The use of the photovoice method empowers individuals to explore and identify issues through the use of photographs and critical dialog; this leads to the appropriation of knowledge and public consciousness about the topic at hand (Foster-Fishmnan et al., 2004; Wang & Burris, 1994). This consciousness allows for future plans to be created and acted upon (Freire, 1973). Carlson, Engelbretson, and Chamberlain (2006) used the photovoice method with low-income African Americans; they reported that by providing an opportunity for reflection, critical thinking, and action there was not only an increase in participant empowerment but also a higher level of critical consciousness. According to Freire (1970/1973), those who achieve the critical level of consciousness are more able to accept responsibility, take action, and enact change. Promoting critical dialogue and the achievement of critical consciousness may increase the ability for people to make appropriate decisions regarding HF self-care.

Culturally specific. The photovoice method was used to identify culturally specific topics regarding health. There were no photovoice studies found that included HF participants; one photovoice study reported the perceptions of cardiovascular health among Asian immigrants (Fitzpatrick et al., 2009). Findings from that study revealed common themes relating to cardiovascular health such as diet, exercise, and stress. In

addition to these common themes the study also provided relevant cultural examples such as the importance of drinking tea and massaging feet with stones to prevent death (Fitzpatrick et al., 2009). Providing individuals with cameras to take pictures of how they manage their cardiovascular health proved useful to identifying culturally specific findings. Traditional research methods may not have located these relevant findings. Because of the fact that African Americans have been underrepresented in the HF self-care literature—despite being a vulnerable population—the photovoice method was chosen to allow for the emergence of culturally specific facilitators and barriers to HF self-care behaviors.

Although there were no photovoice studies used with the HF population, the photovoice method was successfully implemented in the African American community. Photovoice studies have revealed culturally specific information about the African American population's unique health conditions, needs, and assets of individuals and communities. Wang, Cash, and Powers (2000) used the photovoice method with the homeless in Ann Arbor, Michigan. One participant took a picture of a clock that displayed the time as well as the Dow Jones. This photograph was taken to represent that people in shelters often work two or three jobs, a fact that the participant felt many people did not know. In a photovoice study aiming to understand African American men's perceptions of racism, photographs of abandoned buildings and cars led to discussions regarding the lack of investment in historically African American neighborhoods (Ornelas et al., 2009). Photographs of liquor stores represented how these men felt that unhealthy products were often specifically marketed to African American men. Strack et al. (2004) identified ways to improve neighborhood conditions. A

photograph of an abandoned building was taken by a 14 year old participant. The building, according to many adults, was viewed merely as an empty building; but to the youth in the neighborhood the place was a fun, yet dangerous place to hang out and get away from parents. This photograph alerted community members of the dangers present in the neighborhood.

The findings from the aforementioned studies provided new information that resulted in action and change. Studies have found that photovoice is an effective method for sharing, learning, enhancing respect and knowledge, and facilitating change (Hergenrather, Rhodes, Cowan, and Bardhoshi, 2009). Photovoice was used in the present study because of its proven ability to facilitate entry into communities that may otherwise be restricted or neglected.

<div align="center">**Photovoice Project**</div>

Participants

African Americans were specifically selected to participate in this study due to the major health disparities that exist among African Americans when compared to other racial and ethnic groups. The inclusion criteria for this study was as follows: English speaking, self-identified African Americans over the age of 50 with a self-identified diagnoses of HF; the participants also needed to be willing to attend group meetings for two hours per week for six weeks. The age inclusion criteria were chosen for several reasons: the risk for developing HF is 1 in 5 after the age of 40 (NHBLI, 2010); for people aged 60-79 the incidence of HF is 10 per 1000 (NHBLI, 2010); and convenience. Participants had to be able to use a digital camera and live in one of the three pre-selected

low-income public housing complexes. The participants did not have to be able to read.

Based on the Mini-Cog score, persons with dementia would be excluded. Persons with

mild cognitive impairment, however, were able to participate. Whitlatch, Feinberg, and

Tucke, (2005) reported that people with mild cognitive impairments are able to express

values and preferences regarding the care needed and received. Studies that have used

the photovoice method have had varying sample sizes. Small sample sizes have been

supported as the only way to allow entrance into communities that may have historically

avoided participation (Catalani & Minkler, 2010). Ten participants were selected for this

study based on the sample sizes of other photovoice and qualitative studies, as well as

prior research experience with the photovoice method.

Recruitment and retention. Participant recruitment was coordinated with the

nursing and social work case managers who were employed within three low-income

senior public housing complexes in a large metropolitan city. Initially, the key staff

members of the case management organization were contacted and permission was

granted to recruit participants. The primary investigator (PI) consulted with the staff of

the housing complexes about the best strategies for sharing information relevant to the

study with residents. The case managers within the housing complexes were available

for consultation on an ongoing basis.

The case managers were instrumental in participant recruitment. Case managers

asked potential participants if they were willing to have the PI contact them to discuss the

study. The PI contacted all agreeable potential participants to describe the study and

inquire about participation. While recruiting participants, the research team attempted to

develop trusting relationships with the participants and stressed the importance of the

participants' contributions. The research team was present during organized bingo games, health clinics, free monthly food distribution, and other regularly scheduled activities in their community room. During this time the potential participants were encouraged to ask questions in order to gain an understanding of the research study and to grasp the possible benefits the study may have for them, as well as other African Americans with HF. Recruitment continued until the sample size of ten participants had been acquired. All but one of the potential participants contacted agreed to participate. All participants that agreed to participate completed the six-week program. This resulted in three groups participating in the six-week photovoice project.

The PI and research assistant (RA) made every effort to retain the research participants. Due to the need for weekly meetings and the potential for including participants with deteriorating health statuses, the PI decided to hold the meetings within their building of residence. The meeting times and location within the buildings was based on convenience for the participants. The participants were given time to discuss any questions or concerns they had regarding the research study or personal matters. Additionally, a small selection of healthy snacks and beverages were provided at the weekly meetings. All of this was done with the intention to decrease attrition and increase comfort among the participants.

Instruments

Several data collection forms and instruments were used in this study. A demographic form was used to collect age, gender, relationship status, health history, daily medications, and length of HF diagnosis for each participant (Appendix B). The

Mini-Cog was used for descriptive purposes regarding the cognitive function of participants and to exclude those with dementia (Appendix C). Additionally, the PI assessed each participant using the New York Heart Association (NYHA) Functional Classification prior to beginning the research (Appendix D). The Self-Care of Heart Failure Index (SCHFI) (Appendix E and F) and the Patient Health Questionnaire (PHQ-9) (Appendix G) were also completed prior to the first photovoice session. The SCHFI and the PHQ-9 were used for descriptive demographic purposes.

Mini-Cog. Cognitive status was assessed by using the Mini-Cog, which can be completed in 3 minutes. It consists of a three-item recall and a clock drawing test (CDT) (Borson, Scalan, Brush, Vitaliano, & Dokman, 2000; Borson, Scanlan, Chen, & Ganguli, 2003; Borson, Scanlan, Watanabe, Tu, & Lessig, 2005). One point is given for each correctly recalled word after the CDT. In the event of a zero score, or if a participant scores 1-2 and the CDT is incorrect, the test indicates a positive result for dementia or a cognitive impairment. A score of 1-2 and a correct CDT, or a score of 3, indicates a negative result for dementia or cognitive impairment (Borson et al., 2000). The Mini-Cog's diagnostic ability to discriminate between demented and non-demented participants is not affected by education or language (Borson et al., 2000; Borson, et al., 2005). The Mini-Cog has acceptable levels of sensitivity (99%), specificity (93%), and diagnostic ability (96%) in identifying cognitive deficits (Borson et al., 2000). The Mini-Cog is a valid and reliable tool, and is able to identify both dementia and cognitive deficits despite participants' educational levels. The Mini-Cog was the instrument of choice due to its ease of completion and its short duration. The Mini-Cog tool, with instructions for administration and scoring, can be found in Appendix C.

New York Heart Association Classification. The NYHA assesses an individual's functional capacity. It is used to classify the severity of HF symptoms in simple daily activities. Classification ranges from Class I (mild), to Class IV (severe). Individuals classified as Class I have no symptoms, while those placed in Class IV are unable to carry out physical activities comfortably and efficiently (Committee for the New York Heart Association, 1994). The assessment of the NYHA was based on the PI's objective assessment of participants' functional status and on subjective reports of symptoms. The PI, who is experienced with assessing HF patients, assessed the NYHA classifications of all participants. This was done to diminish the possibility of error in scoring participants. Participants within HF studies are frequently classified using the NYHA Classification I-IV. The NYHA classification assisted in describing the disease severity of the participant sample. The NHYA was used because of its administrative simplicity, as well as its brief completion time (Appendix D).

Self-Care of Heart Failure Index. The scores from the SCHFI were used in this study to describe the HF self-care behaviors of the participants. The SCHFI measures the process of individual decision-making about stability maintenance, ongoing symptom management, and overall confidence related to self-care (Riegel & Dickson, 2008; Riegel, Le et al., 2009). More specifically, the SCHFI v.6 is a 22-item tool that measures self-care maintenance (*Cronbach's alpha* = .71), self-care management *(Cronbach's alpha* = .83), and self-care confidence (*Cronbach's alpha* = .93) (Sebern & Riegel, 2009). There is no learning effect associated with the repeated administration of the SCHFI and the social desirability is minimal. Construct validity was supported by factor analysis (Riegel, Lee et al., 2009). Overall model fit of the SCHFI is adequate.

Triangulation was completed to confirm, cross-validate, and corroborate findings (Riegel, Lee et al., 2009). Cameron, Worrall-Carter, Driscoll, and Stewart (2009) completed an analysis of the psychometric properties of instruments used to assess self-care in HF. Of the 14 articles reviewed, only 2 instruments were identified as reliable and valid tools for the measurement of HF self-care. These included the SCHFI and the European Heart Failure Self-Care Behaviour Scale. The SCHFI was chosen because of its ability to assess self-care behaviors and the ease of administration. See Appendix E for a copy of the SCHFI and Appendix F for scoring instructions.

   Personal Health Questionnaire Depression Scale 9. Five percent of Americans 12 years of age and older have experienced depression (Pratt & Brody, 2008). The rate of depression is higher among poor persons when compared to those with higher incomes (Pratt & Brody, 2010). Depression is also a common problem for people with HF. Friedmann et al. (2006) identified that thirty-six percent of people with HF have depression. Depressed individuals have been identified as being less likely to engage in HF self-care behaviors (Falk, Swedberg, Gaston-Johansson, & Ekman, 2007). To identify participants with depressive symptoms the PHQ-9 was administered. PHQ-9 scores can range from 0 to 27. The interpretation of scores is as follows: a score of 0-4 represents no depressive symptoms, 5-9 mild depressive symptoms, 10-14 moderate depressive symptoms, 15-19 moderately severe depressive symptoms, and 20-27 severe depressive symptoms. A score of greater than ten requires initiating a treatment plan that may include counseling and/or medication intervention (Kroenke & Spitzer, 2002). A PHQ-9 score of >10 has a sensitivity of 88% and a specificity of 88% in diagnosing major depressive symptoms (Kroenke, Spitzer, &WiIliams, 2001). The results from this

instrument were used to describe the levels and frequency of depressive symptoms within the study participants. Individuals that were identified with depressive symptoms were referred to the social work and nursing case managers that were employed within the public housing buildings. The PHQ-9 was the instrument of choice due to its ease of completion and short duration. The PHQ-9 is a valid and reliable tool, with the ability to identify depressive symptoms in participants. The PHQ-9, with instructions for scoring, can be found in Appendix G.

Procedure

The procedure for this study followed the guidelines as recommended by Wang, Yi, Tao, and Caravano (1998). Suggestions for implementing the method included: photovoice training with assistants and participants, devising themes or topics for taking photographs, photographic instruction for participants, and the facilitation of group discussions (Wang et al., 1998). The PI and RA engaged the photovoice participants as co-investigators. The research team comprised of the PI—a Caucasian, master's-prepared nurse with more than 10 years of experience working with people who have HF—an African American RA who was an undergraduate nursing student, and the 10 participants. The 10 participants were divided into three groups according to their residence. This consisted of 4, 4, and 2 participants respectively. Each group met for approximately one to two hours a week for six weeks.

Prior to beginning the photovoice meetings, consent was obtained, demographic data collected, and the Mini-Cog, SCHFI, and PHQ-9 were administered. The PI assessed each participant's NYHA classification (I-IV) at that

time. This was done on an individual basis with only the PI and participant present.

All forms were read to the participant and the PI collected the data. The PI explained

all forms and answered any questions the participants had. Once the participants had

consented, a mutual time was scheduled to conduct the first photovoice meeting. All

of the group meetings took place in a private room within the public housing building.

The PI, RA, and participants met for one to two hours each week for six weeks. The

weekly photovoice procedure for each group is presented below. See Appendix H for

a copy of the participant consent form.

     Week 1. The first week consisted of introductions and instructions. The PI and

RA led each weekly meeting with the assistance of the participants. Each session was

audio recorded by the PI and transcribed by the RA or PI. The PI and RA took field

notes during the team meetings and the large group discussions. The PI provided

education about safety, power relationships, and the ethics of taking photographs of other

people. Participants were taught how to use the cameras and given instruction on

photographic techniques. Instruction on how to approach people for photographs and

how to obtain written consent was also discussed (Appendix I). Participants were

instructed to provide each person photographed a small card with information regarding

the purpose of the project, notification that their photograph may be used in a public

display or a publication, and the PI's contact information (Appendix J). See Appendix K

for a copy of the consent to be photographed. The initial team conversations involved an

introduction about the photovoice method, a discussion of the goals for the project, and a

brainstorming session for ideas on how to take pictures for the photo assignments.

Participants were asked to take pictures of anything including but not limited to people,

objects, activities, or something that represents to them the topic assigned that week. For the first week, participants were instructed to "take photographs of images representing what you do to take care of yourself." This was done to identify self-care behaviors among the participants. Participants received a $5.00 grocery gift card at the end of each session in weeks 1 through 5.

Week 2. The process of downloading photographs, group reflection, and discussion began. The participant photographs were downloaded onto the PI's computer before the group discussions began. The photographs were projected on the wall for all participants to see. Participants were asked to describe why he or she took the photograph and what it meant to them. The SHOWeD method was introduced to the group and was intended to facilitate photograph reflection and discussion (Appendix L). SHOWeD is an acronym for what do you **S**ee here?; what is really **H**appening here?; how does this relate to **O**ur lives?; **W**hy does this situation, concern, or strength exist?; and what can we **D**o about it? (Streng et al., 2004). The SHOWeD acronym was difficult for all participants in each group to use. Participants reported that they did not feel that the discussion points assisted in the discussion of their photographs. The SHOWeD acronym was referenced each week as a resource to use for discussion. Although rarely used in its entirety, discussion was prompted by questions such as: "What does this mean to you?"; "How does this affect your health and your heart?"; and, "Does this make it easier or more difficult for you to take care of your health and your heart?" An additional list of potential prompts and probing questions used is available in Appendix M. These questions were used to stimulate discussion when needed. Questions were also used to clarify participant statements such as: "My daughter provides me with support" or "I

don't know how to do that." Questions such as: "What kind of support does your daughter provide?" or "What do you know about that?" were used. Participants were reminded weekly not to discuss photographs or topics if they felt uncomfortable. The PI provided information regarding HF or HF self-care when directly asked, or if discussion involving these topics consisted of incorrect information or misconceptions regarding HF and HF self-care. The AHA HF guidelines (Appendix N and O) were used as a resource when needed.

At the close of each session the cameras were returned to the participants, who were given their next photovoice assignment. At the end of this session the participants were instructed to "take photographs of what makes you want to, or what makes it easy to take care of yourself and your HF." This was asked in order to identify facilitators present for engaging in HF self-care behaviors. Transcripts were reviewed after each session (beginning with this session) to develop follow up questions for clarification or additional prompts that may have been needed.

Week 3. The process of downloading photographs, group reflection, and discussion was repeated. Clarification and follow up of previous topics and themes occurred. At the end of the session the cameras were returned and the participants were instructed to "take photographs of what barriers you have to overcome, or what makes it difficult for you to take care of yourself and your HF." This question was asked in order to encourage the participants to take photographs of the barriers present when attempting to engage in HF self-care behaviors.

Week 4. The process of downloading photographs, group reflection, and discussion was repeated. Clarification and follow up of previous topics and themes

occurred. At the end of the session cameras were returned and the participants were instructed to "take photographs of the previous topics or of anything you want to express or feel is important and relates to how you take care of your HF." This was done to allow the participants an opportunity to take additional photographs of previous topics that they may not have identified during the week the topic was assigned. This also allowed the participants to take photographs of anything else they may have viewed as important in their lives and that they would like to share with the group and/or the research team.

Week 5. The process of downloading photographs, group reflection, and discussion was repeated. Clarification and follow up of previous topics and themes occurred. This session concluded with asking the participants to begin to think of names or themes for photographs they had taken and to reflect on those themes over the next week.

Week 6. Final reflection, discussion, and clarification of themes and photographs took place. All photographs that were taken were developed and spread out on a table. Participants were asked to group like pictures together. They were then asked to give a name, topic, or theme to the group of pictures. Discussion among the participants occurred until a consensus on a topic or theme occurred. If there was not a consensus among the participants several themes were assigned to a group of pictures. This process occurred for groups one, two, and three. After the participants in group two had assigned themes to their photographs, the photographs with the identified themes from group one were introduced. At this point group two could then move their photographs into some of group one's themes or vice versa. The same sequence of events occurred for group three. After group three developed their themes for their photographs, the photographs from

group one and two with the assigned themes were introduced. This group was also able to move pictures to various themes and comment on the previous groups' themes. At the completion of each group's six-week session all cameras were returned to the PI or RA and participants received a $35.00 grocery gift card for their time and effort.

Data Analysis

This section describes the analysis of data. The following focused on meeting the specific aims of this research study. The specific aims as previously listed are:

1) Describe the self-care behaviors of low income, urban dwelling African Americans with HF;

2) Render a more complete understanding of the facilitators that allow low income, urban dwelling African Americans to engage in HF self-care behaviors;

3) Render a more complete understanding of what barriers low income, urban dwelling African Americans face when attempting to engage in HF self-care behaviors.

Quantitative data analysis. Descriptive statistical analysis was performed using the Statistical Package for Social Sciences (SPSS). Descriptive statistical analysis was completed on the demographic information, PHQ-9, and SCHFI. The mean, median, and range were analyzed for all demographic data. PHQ-9 mean, median, and standard deviation scores were analyzed. The three self-care sub-scales of the SCHFI (maintenance, management, and confidence) were analyzed independently to identify the participants' self-care maintenance, self-care management, and self-care confidence

scores. Self-care management scores were only recorded and analyzed if the participant had reported HF symptoms within the last six weeks. Analysis of this data included mean, median, and standard deviation scores. Scores from the SCHFI range from 0-100, a score of less than 70 on one of the three scales reflects inadequate self-care in that domain (Riegel & Dickson, 2008). These scores were used to describe the engagement in self-care behaviors among the study participants.

Qualitative data analysis. Analysis of the qualitative data included data collection, data reduction, data display, and conclusion. Several matrices were developed to assist with the organization and analysis of the transcribed data. The process used for data analysis is as follows.

Data reduction. Data reduction is the process of selecting, focusing, simplifying, abstracting, and transforming data from field notes and transcripts (Miles & Huberman, 1994). Following the recommendations from Miles and Huberman (1994), data reduction began at the initial encounter with the participants and continued through the conclusion of data analysis. The PI and RA entered the participants' environment as observers. The PI and RA carried themselves with attitudes of understanding and took on the role of deciphering a living "code" (Freire, 1973). After each photo discussion, the PI and RA documented body language, behavior, and general impressions. Data reduction began as the weekly field notes and transcripts were reviewed for details that needed follow up or clarification at the next photovoice group meeting. The PI wrote a brief report that was reviewed and discussed with the RA. At the following photovoice meeting, these preliminary findings were discussed with the participants to confirm their accuracy and to make modifications weekly. This allowed the researcher to validate the

participants' perceptions on certain occurrences or situations and contradictions that became evident.

Next, the PI listened to the audio taped group discussions and took additional notes to identify any recurrent patterns. The audiotapes were transcribed by the RA and PI. The PI verified the transcripts by reviewing them while listening to the audiotapes. After the group discussions were transcribed and verified, the reading for broad categories began. Initial analysis consisted of reading through the transcripts to organize into topic codes. The transcripts were read three times with topic codes written in the margins. Topic coding is used to find all of the data about a particular topic or experience being studied (Richards & Morse, 2007). These topic codes included the facilitators and barriers of self-care maintenance, self-care management, and self-care confidence. As previously defined, self-care is defined as a naturalistic decision-making process that involves the choice of behaviors that maintain physiological stability (self-care maintenance), the response to HF symptoms when they occur (self-care management), and the confidence (self-care confidence)to engage in each phase of self-care (Riegel, Lee et al., 2009). These topic codes were used to prepare for the development of a matrix that allowed for further analysis of the data.

Data display. Miles and Huberman (1994) explain that data display goes beyond data reduction to provide an organized, compact assembly of information that can allow for analysis and conclusion drawing. Data displays allow the researcher to begin to distinguish patterns and interrelationships. Data displays help researchers understand what is happening, so as to allow for further analysis or result in an action based on the understanding gained from the display. At the display stage, additional higher order

categories or themes emerge from the data that go beyond those discovered during the initial process of data reduction (Miles & Huberman, 1994).

Three checklist matrices have been developed and used to organize the participant data in this study. The three matrices used are titled: Matrix #1 for Facilitators and Barriers of HF Self-Care, Matrix #2 Refined Codes, and Matrix #3 HF Self-Care New Concepts. Checklist matrices are often used for exploring a new domain and are useful if some initial variables or components have been identified (Miles & Huberman, 1994). A checklist matrix is systematic, and allows for verification and comparison (Miles & Huberman, 1994). The checklist matrix was used to assist in the identification and display of facilitators and barriers of self-care maintenance, self-care management, and self-care confidence.

During the third reading of the transcripts, direct quotes from the transcripts were entered into the first checklist matrix titled Matrix #1 for Facilitator and Barriers of HF Self-Care (Figure 3.1). Direct quotes that represented HF self-care maintenance were sorted and entered into the correct column of the matrix. These included discussions of the facilitators or barriers a person with HF may face when attempting to live a healthy lifestyle, such as: taking medications, eating a low sodium diet, exercising, and actively monitoring HF symptoms (Riegel, Lee et al., 2009). The response to the symptoms of HF refers to self-care management. Direct quotes that identified facilitators or barriers to recognizing a change in symptoms, evaluating the symptoms, responding to symptoms by implementing a treatment remedy, and evaluating the effectiveness of that treatment remedy (Riegel, Lee et al., 2009) were entered into the self-care management columns. Direct quotes that referenced or implied confidence to engage in self-care maintenance or

self-care management behaviors were entered into the appropriate columns. Analysis of

the matrix included noting patterns, themes, making contrasts, and comparisons (Miles &

Huberman, 1994).

Figure 3.1 *Matrix #1 for Facilitators and Barriers of HF Self-Care*			
Heart Failure Self-Care	Facilitators of Self-Care	Barriers of Self-Care	Self-Care Confidence
Self-Care Maintenance Behaviors			
Self-Care Management Behaviors			
Figure 3.1. Matrix used to identify facilitators and barriers to self-care maintenance and self-care management and self-care confidence in these behaviors.			

The next step of data analysis consisted of reevaluating Matrix #1. This analysis focused on taking the broad topic codes and developing more refined codes. In order to correctly code the data, a reading guide was created by the PI (Appendix P). This reading consisted of sorting data into predetermined topics that had been previously identified in the literature review as facilitators and barriers to engaging in HF self-care behaviors. Portions of direct quotes were placed into the Matrix #2 Refined Codes (Figure 3.2); these topics included the following: knowledge and decision making skills, social support, health status, socioeconomic status, race, ethnicity, and culture, personal beliefs, attitudes, and perceptions, and any additional facilitators or barriers. This matrix was used to support or refine the current identified factors and to identify new facilitators and barriers of self-care.

Figure 3.2 *Matrix #2 Refined Codes*			
Heart Failure Self-Care	Facilitators to Self-Care	Barriers to Self-Care	Self-Care Confidence
Self-Care Maintenance Behaviors			
Knowledge and Decision Making			

Social Support
   Informal Support
   Formal Support			

Health Status			
Socioeconomic Status			
Race, Ethnicity, and Culture			
Personal Beliefs, Attitudes, and Perceptions			
Other			
Self-Care Management Behaviors			
Knowledge and Decision Making			

Social Support
   Informal Support
   Formal Support			

Health Status			
Socioeconomic Status			
Race, Ethnicity, and Culture			
Personal Beliefs, Attitudes, and Perceptions			
Other			
Figure 3.2. Matrix used to refine codes within Matrix #1, based on reading guide in Appendix P.			

During the analysis of the data within Matrix #2 Refined Codes new concepts emerged. The next step consisted of developing a third matrix. This matrix included the addition of columns for the newly developing concepts. In order to correctly organize and analyze this data, a second reading guide was developed (Appendix Q). The three new concepts developed by the PI were based on direct quotes from the participants. This new matrix titled Matrix #3 of HF Self-Care New Concepts (Figure 3.3) included the new concepts: counterbalance, pleasant activities, and self-management of illness. Counter balance was viewed as both a facilitator and a barrier. Discussions coded as counter balance included the discussion around topics that were viewed as potential barriers one example included daily medications. Participants had many negative comments about medications including that taking them was stressful. In the same instance medications were described as the most important part of their day, and if they did not take them they could experience negative effects, even death. To the researcher this was viewed as counter balance, and in the end these barriers were outweighed as facilitators. Pleasant activities included any activities that were described as positively influencing a participant's health status. Self-management of illness differed from the concept of self-care management in that self-management of illness included making therapeutic, behavioral, and environmental adjustments that were not specific to treating HF symptoms. Definitions for the new concepts with examples are found in the reading guide in Appendix Q.

Finally, Matrix #3 was analyzed again. Portions of quotes within the matrix were analyzed for accuracy within their columns and moved as necessary. Particular attention

was paid to patterns. These patterns were identified by bold headings within the respective column. Data was also clustered within these patterns. The quotes that had been identified as part of the "other" category were analyzed again to see if they fit within one of the newly established columns. No changes were made to the original definitions within the previous matrices. Analysis of this matrix included noting patterns, identifying themes, making contrasts and comparisons, and clustering and counting (Miles & Huberman, 1994). The final themes developed through the analysis of these three matrices include the facilitators for self-care maintenance behaviors: *family support gives me the push I need, social interaction lifts me up*, and *support in my environment has allowed me to better my condition*, and one sub-theme *personal benefits of the environment.* Themes that emerged as the barriers to engaging in HF self-care maintenance include: *depression slows my heart down, interruption in health care provider, neglected environment*, and *dietary challenges.* One theme, *lack of knowledge and decision making skills*, emerged as a barrier to self-care management behaviors. These themes are presented in chapter 4.

Figure 3.3 *Matrix #3 HF Self-Care New Concepts*

Heart Failure Self-Care	Facilitators to Self-Care	Barriers to Self-Care	Self-Care Confidence	Counter-balance	Pleasant Activities
Self-Care Management Behaviors					
Knowledge and Decision Making					
Social Support Informal Support Formal Support					
Health Status					
Socioeconomic Status					
Race, Ethnicity, and Culture					
Personal Beliefs, Attitudes, and Perceptions					
Self-Care Maintenance Behaviors					
Knowledge and Decision Making					
Social Support Informal Support Formal Support					
Health Status					
Socioeconomic Status					
Race, Ethnicity, and Culture					
Personal Beliefs, Attitudes, and Perceptions					
Self-management of Illness					
Other					

Figure 3.3. Matrix used to add additional concepts from Matrix #2, based on reading guide in Appendix Q.

Methodological Rigor

To ensure validity and increase credibility within this study, the following guidelines suggested by Maxwell (2005) were used: (a) long-term involvement; (b) rich data; (c) respondent validation; (d) searching for discrepant evidence; and (e) triangulation.

Long-term involvement and rich data. Long-term participant observation can provide more complete data than other methods. Long-term involvement with research participants enables researchers to collect rich, detailed data. This research study lasted for one to two hours a week for six weeks. During these six weeks, the PI observed how the participants interacted with each other and listened to their discussion of photographs. This six-week time frame provided *long-term involvement*, observation, and participation in the detailed discussions of participant-chosen topics. In-depth group discussions that occurred with multiple participant encounters, transcripts, field notes, and participant-identified themes and photographs provided plentiful, *rich data.*

Respondent validation and discrepant evidence. Respondent validation consists of systematically and continually seeking feedback regarding the researcher's data and conclusions regarding the participants being observed. This is the simplest way to rule out the misinterpretation of data. Asking for participant feedback enabled the researcher to check personal biases and assumptions, and to identify discrepant evidence. *Respondent validation* of data occurred on a continual basis. The transcripts of the group meetings were analyzed for qualitative themes. Each week, the themes were identified by the PI and were presented for clarification and validation to the group the following

week. The themes developed by the PI were compared and contrasted with the themes developed by the participants, no discrepancies were found. Researcher bias and assumptions would have been assessed at this time if *discrepancies* among themes had been found.

  Triangulation. Triangulation refers to the collection of information from a range of individuals and settings, while using a variety of methods. Throughout all the meetings, participants were provided an opportunity to clarify, change, and add any themes they felt were most representative of the facilitators and barriers to engaging in HF self-care barriers. These themes were supported with the participant-taken photographs. The use of the participant-identified themes, photographs, weekly notes, transcripts, and data from the SCHFI were used in the *triangulation* of the data.

  Researcher bias. In addition to following the strategies for maintaining validity, the PI addressed credibility through continual assessment of researcher bias. The PI acknowledges that as a white researcher, nurse educator, and a medical-surgical nurse, previous experiences may influence the interpretation of data. The PI is aware that cultural mistrust and previous misinformation from health care providers are barriers to recruiting and retaining African Americans as research participants (Corbie-Smith, Thomas, Williams, Moody-Ayers, 1999; Kennedy & Burnette, 2007; Marcantonio et al, 2008). The PI has lived in the selected city the majority of her life and has previous experience working with the African American community. The PI's nursing career has included wide experience in a large metropolitan hospital with diverse client base, as well as two years as a home care nurse with a largely African American patient population. The PI is aware that being a Caucasian researcher may be a barrier for collecting data

from a differing racial group. To increase the comfort level of the participants, an African American undergraduate nursing student worked as a RA and assisted with all of the photovoice meetings. The PI identified personal assumptions and beliefs prior to beginning the research study. The PI controlled for these biases by identifying them and continually reevaluating throughout the study. The PI and the RA attempted to avoid body language, tones of voice, or leading questions that might have skewed participant discussion toward the research team's opinions.

Plan for Data Management and Protection of Human Rights

Institutional Review Board (IRB) approval was received from Marquette University prior to beginning recruitment. The consent form is included as Appendix H. Once participants were selected, all were assigned an alias in order to conceal their identity from the transcripts. The alias was not the same as another participant's given name. These names were known only to study participants, the researcher, and the research assistant.

Measures were taken to maintain participant confidentiality. During the study, the participants' photos were downloaded onto the PI's laptop into a password-protected file. Photographs were organized into files labeled with the participants' alias and the dates the photographs were taken. Photographs, original recordings, and electronic copies of transcribed group meetings—with identifiers removed—were stored in a password-protected file on the PI's computer. Upon completion of the study, each participant received printed copies of their photos. Consent forms and questionnaires are kept in a locked file cabinet in the PI's office. Consents, demographic questionnaires,

and original electronic recordings of the group meetings will be kept for three years and then destroyed. Photographs that were discussed during the study had identifying features removed and are saved in a separate file. All other photos were deleted from the laptop at the end of the study. The identification-cleaned database, transcripts, and photos will be kept indefinitely in a password protected file on the PI's computer in her locked office and may be used in future studies or used for student instruction.

Even though privacy and confidentiality were maintained within the group setting to the greatest extent possible, confidentiality could not be guaranteed outside of the group. Measures were taken to promote confidentiality both outside and within the group meetings. Participants were reminded that by being involved in this study they allowed other people in their community to know that they have HF. The participants were informed prior to each group meeting that it was not necessary they answer questions or share information they would prefer to remain private. Participants were reminded that their identity would be protected on the questionnaire and the tape recordings of the meetings. However, the researchers could not protect participant identity within the group. Again, the participants were reminded to withhold information they would rather not share with the group. Participants were also encouraged to refrain from taking any photographs that they would not like to share with the group. The researchers discouraged them from taking any photographs that may put them in uncomfortable or dangerous situations. The participants were also asked not to share the content of the group discussions outside of the group meetings.

Potential Benefits of Participation

Participation in a photovoice study offered many benefits. Initially, the research team transferred power to the participants, this transfer of power allowed them to express the subjective experience of living with HF and the facilitators and barriers faced when engaging in HF self-care behaviors. Because there is an immense sense of control and power in the photographer's hands (Lopez, Eng, Robinson, & Wang, 2005; Wang & Burris, 1997), participants were in control of what they photographed and what they discussed. Power and control is a major benefit of using photovoice. This power led to benefits that include empowerment and the promotion of health (Wang & Pies, 2004; Wilson et al., 2007). Individuals began to understand they have a voice and they could enact change. Participants in the photovoice project were able to increase their awareness of HF self-care through group discussion. The increased awareness, and thus knowledge, could result in action and change.

Potential Risks of Participation

There were minimal risks involved in this study. Participants may have felt uncomfortable talking about their chronic illnesses and the ways in which they engaged in self-care behaviors. Some participants may not have felt confident or comfortable with taking photographs. Participating in this study announced to the others in their community that they were diagnosed with HF. A negatively judging attitude might have surfaced when participants decided which photos to take and which to share with the group. Because the participants were in control of what they photographed they had the opportunity to seek out, and at times avoid, photographs of certain topics (Lopez et al.,

2005; Wang & Burris, 1997). While it was easy for the participants to take photographs, it may have been difficult for some to express or summarize their thoughts when reflecting on the pictures they had taken (Wang & Burris, 1997).

Limitations

Several study limitation were noted. Purposeful selection was limited to participants that were African American, had HF, and were over the age of 50. Participants were allowed to engage in the study regardless of their NYHA classification; results could have differed depending on the severity of HF. NYHA classifications and Mini-Cog results were reported but not analyzed beyond their descriptive purposes. Participants were accepted with a self-reported diagnosis of HF; this may have resulted in participants with heart disease but who have not been diagnosis with HF by a primary care practitioner.

Final collective analysis of all photographs did not occur with the entire group of participants. A collective discussion on themes may have resulted in an alteration of some of the group's identified themes. This study also eliminated the perspectives of individuals who did not have the ability or dexterity to use a camera, as well as those who did not volunteer to participate.

Chapter 4

Results

As discussed in chapter three, the researcher examined both transcribed and photographic data in order to understand the self-care behaviors themselves and the facilitators and barriers associated with African American engagement in HF self-care. This chapter presents the findings in two parts. The first section includes the demographic and descriptive participant characteristics; the demographic characteristics include age, gender, marital status, and monthly income. The descriptive data on disease severity includes the number of daily medications, length of years with HF, co-morbidities, and the NHYA classification. Depressive symptoms are presented with the results of the PHQ-9 and the SCHFI findings are used to describe the self-care behaviors of the sample. The second section provides the qualitative results concerning each of the research questions. Also included are the self-care behaviors as described by participants. This chapter concludes with the themes that represented the facilitators and barriers to engaging in HF self-care behaviors for low income, urban dwelling African Americans.

Participant Characteristics

Demographic and Descriptive Data

Ten self-identified African American males and females living with HF consented and completed the six photovoice sessions. The participants each lived alone in a one

bedroom apartment in one of three preselected government-owned low income public housing buildings. Residents of these buildings were required to be low income and over the age of 50. While some were disabled, all residents needed to be able to independently care for themselves. In each building social worker and nursing case management services were offered. The facilities were all equipped with a lunch room, television room, exercise room, health room, library, and many common areas. Participants were not asked to report their annual incomes; demographic data from the housing authority reported an average yearly income of less than $13,537. Participants reported their income as being not enough (n=5) or just enough (n=5).

Table 4.1 summarizes frequencies of the demographic and descriptive information for the participants. The average age of participants was 67.5 years. Seven participants were female. At the time of the study each participant lived alone, four had never been married, four were divorced, and two were widowed. One of the ten participants was in a current relationship; his significant other lived in the same building. Participants took an average of 8 daily medications, which had an average cost of $80 per month. All participants reported co-morbidities. Some of these co-morbidities included chronic pulmonary disease, diabetes, hypertension, and peptic ulcer disease. Two participants reported a diagnosis of depression. Length of years living with HF ranged 4-9 years; two participants did not know how long they had been diagnosed with HF. Seven participants were classified as NYHA class I or II, while three participants were class IV.

Table 4.1
Baseline Demographic and Descriptive Characteristics (n=10)

Characteristic	Mean (*SD*), Median (range)
Age	Mean 67.5 (5.7) years Median 65 (62-77) years
Length of years with HF N=8	Mean 5.63 (1.7) years Median 5.5 (4-9) years
Daily Medications	Mean 8 (3.5) medications Median 8 (2-14)
Monthly Medication Costs	Mean 79.8 (150.4) dollars Median 25 (0-500) dollars

Gender: Female	7
Marital Status	
Single	4
Divorced	4
Widowed	2
Monthly Income	
Not enough	5
Just enough	5
Co-Morbid Conditions	
Cardiac Arrhythmias	1
Chronic Pulmonary Disease	6
Depression	2
Diabetes	3
Hypertension	9
Peptic Ulcer Disease	4
NYHA Functional Classification	
Class I	3
Class II	4
Class IV	3

Note: Demographic and descriptive data collected at baseline. The New York Heart Association Functional Classification (NYHA) was taken from Committee for the New York Heart Association, 1994. Length of years with HF (n=8), as two participants did not know length of diagnosis.

Depressive Symptoms

The severity of depressive symptoms was assessed using the PHQ-9. PHQ-9 scores can range from 0 to 27. The interpretation of scores is as follows: a score of 0-4 represents no depressive symptoms; 5-9 mild depressive symptoms; 10-14 moderate depressive symptoms; 15-19 moderately severe depressive symptoms; and 20-27 severe depressive symptoms. A score greater than ten requires a treatment plan that may include counseling and/or medication intervention (Kroenke, & Spitzer, 2002). Depressive symptom scores are presented in Table 4.2. One participant was undergoing treatment for severe depression at the time. This participant scored a 21 on the PHQ-9. Because this high score elevated the mean scores ($M = 5.3$), analysis of median scores presented a better representation of the depressive symptoms of the group. The median score was 2.0, which indicated that overall, participants at the time of the study had no depressive symptoms.

Table 4.2

Depressive Symptoms

	M (SD) Median
PHQ-9 (n=10)	5.3 (6.3) 2

Note: The personal health questionnaire (PHQ-9) was taken from Kroenke & Spitzer, 2002.

Self-Care Behaviors

Self-care behaviors were assessed using the SCHFI. A score greater than or equal to 70 was used as the cut-point to judge self-care adequacy. Scores that fell below 70 in one of the three self-care subscales indicated inadequate self-care in that domain (Riegel, Lee et al., 2009). The scores from the SCHFI are reported in Table 4.3. Self-care maintenance scores were adequate. Self-care management and self-care confidence scores were all below the cut-point. Self-care management could only be assessed if a participant reported ankle swelling or trouble breathing in the last six weeks. Six participants reported symptoms; because of this their self-care management was assessed with the sub-scale.

Table 4.3

Self-Care of Heart Failure Index

	M (SD) Median
Self-Care-Maintenance (n=10)	71.9 (12.1) 69.9
Self-Care Management (n=6)	64.1 (21.5) 55
Self-Care Confidence (n=10)	65.6 (16.3) 62.2

Note: Self-Care of Heart Failure Index (SCHFI) taken from Riegel, Lee et al., 2009. SCHFI scores of less than 70 indicate inadequate self-care in that domain.

Qualitative Findings

Data analysis of the final matrix focused on developing themes and meeting the specific aims of this research study. The following section presents self-care behaviors as described by the participants, as well as the themes found to be representative of the facilitators and barriers to engaging in HF self-care. The first section describes self-care behaviors; the second section presents the study themes.

Themes emerged during group discussions that focused on the photographs taken by the participants. One hundred photographs were taken in total. This analysis resulted in the emergence of seven themes and one sub-theme regarding the facilitators and barriers to engaging in HF self-care maintenance; one theme surfaced as a barrier for self-care management. The chapter concludes with self-care confidence. Several themes emerged from the photograph discussions that were not necessarily represented in the content of the photographs. Participant quotations are presented to provide support for the themes. Any names herein have been changed to protect participant identity and privacy.

Reported Self-Care Maintenance Behaviors

Self-care maintenance requires the person with HF to live a healthy lifestyle that includes taking medications, eating a low sodium diet, monitoring fluid intake and daily weights, exercising, and actively monitoring symptoms (Riegel & Dickson, 2008). The participants in this study demonstrated adequate self-care maintenance. This was supported by a mean self-care maintenance score higher than 70 ($M = 71.9$). Although the median score ($Mdn = 69.9$) was slightly below the cut off score of 70, further

evidence of self-care maintenance behaviors was provided in verbal reports stimulated

through group discussion about the photographs taken. Participants reported the most

common ways that they engaged in self-care maintenance behaviors included: taking

their medications, following their prescribed diet, and participating in some daily

physical activity. The self-care maintenance behaviors of the participants are presented

below.

Medications. Each participant expressed a negative perception of taking

medications. Four photographs of medications were taken – one in each of the three

groups. Brenda took a photograph of her medication and stated, "I keep them by the

garbage can and sometimes I want to throw it all in the garbage," (see Figure 4.1).

Another participant reported, "I didn't feel bad at all after missing one day." Five

participants explicitly stated they do not like taking pills; others expressed that taking

multiple medications each day is stressful, frustrating, and depressing.

Although each participant reported some dislike for taking medications,

medication adherence was consistently reported among the participants. Medication-

taking was reported as an instrumental daily activity: "It's the most important part of my

day." It was also noted as a necessity: "I just take them because I have to"; "Helps my

blood pressure stay normal"; and, "It's the only thing that keeps me going." Participants

noted that if the medications were not taken daily they could experience negative effects

such as "I could throw a clot" and "I have to keep my blood thin enough to go through

that valve." Medication adherence was seen as an important daily routine for the sake of

maintaining good health. A pillbox or similar reminder system was used by all

participants to "Make life easier."

Figure 4.1. Photograph of Medications

Dietary restrictions. Each participant reported following a healthy diet. Participants described that a healthy diet consisted of limiting the intake of dietary sodium, high fat and fried foods, and alcohol. Following a healthy diet also required that they replace non-healthy food items with fresh fruits and vegetables. Attempting to maintain a healthy weight was also voiced as being important. All participants reported the frequent intake of foods high in salt, cholesterol, and fat in previous years. They reported a difference in cooking once diagnosed with hypertension, heart disease, HF, or diabetes. Angela said, "You need to watch what you eat, eat healthier." Reba said, "I try to keep my weight down and not to gain weight." Others echoed this with comments like: "I try to eat healthy, eat vegetables, keep the heart healthy" and "It's better to eat healthy." Leonard added, "I do not read food labels, but I don't use processed foods at all." All participants reported avoiding fast food restaurants, but admitted that their convenience and low cost is tempting.

Physical activity. Daily exercise of at least 30 minutes was reported by more than half of the participants. Although three participants verbalized that they were physically unable to participate in 30 minutes of exercise due to their poor functional status, these participants reported a desire to exercise. All participants reported engaging in some form of physical activity each day. The most common forms of activity included walking around the hallways in the apartment building, attending building activities, and doing their own house cleaning. Rhonda stated she could no longer exercise for a prolonged period of time due to severe degenerative joint disease in her knees, said, "I wish I could." While several participants stated they could not engage in 30 minutes of daily exercise, all but one of the participants attended regularly scheduled activities within the building – activities such as bingo, card games, and monthly new resident cake and coffee sessions. These in-building events encouraged individuals to get out of their apartments and walk in the halls.

Facilitators to Engaging in HF Self-Care Maintenance Behaviors

Photographic and qualitative data analysis within the three matrices produced three themes and one sub-theme relevant to the concept facilitators for engaging in HF self-care maintenance behaviors. Social support was the primary component within the themes that were identified. Twenty-six photographs representing social support were taken by participants. These photographs included pictures of family members, friends, support groups, and one of the nurses working within the public housing buildings. Additionally, eleven photographs were taken that included the exercise equipment, health information, and health educational materials available within the health and exercise

rooms. The nurses and social work case mangers helped to obtain and maintain the exercise equipment and health information that was available to all residents in the building.

The following themes for engaging in HF self-care maintenance behaviors are identified using portions of direct quotes from the discussions of the participants. These themes include: 1) family support gives me the push I need, 2) social interaction lifts me up, and 3) support in my environment has allowed me to better my condition. An additional sub-theme involving the personal benefits of the environment was identified as part of the third theme. These themes – identified as facilitating engagement in HF self-care maintenance behaviors – are described below.

Family support gives me the push I need. The most commonly reported facilitator for engaging in HF self-care maintenance was support from others. All of the participants except Herb reported their immediate family (brother, sister, children, and grandchildren) as the main source of informational, instrumental, and emotional support. Herb no longer had contact with his family but was in a relationship with another resident in the building and was close to his significant other's family. Herb viewed his girlfriend's family as a source of support to both himself and his girlfriend. Examples of instrumental support from family members included physical assistance such as: "She helps me clean"; "She takes me to church"; and, "She cooks me dinner." Family members were described as always being available. Reba stated, "I could call one of them and they would come get me, whatever I need." Family members were also helpful in providing informational support, such as frequent reminders for medications and dietary restrictions: "She be on me"; "Remind me of my medications and the food that I

am eating"; "My do's and don'ts of food and activity"; and, "She checks to see what I am cooking." Jeanine discussed Figure 4.2, and described the type of support her daughter provides:

> She visits every day, sometimes two or three times. She inspects the kitchen for food items I shouldn't have. She be on me, she helps me. This makes me want to do the right things. When she don't come around I am calling her because I need that push.

Figure 4.2. Photograph of Daughter
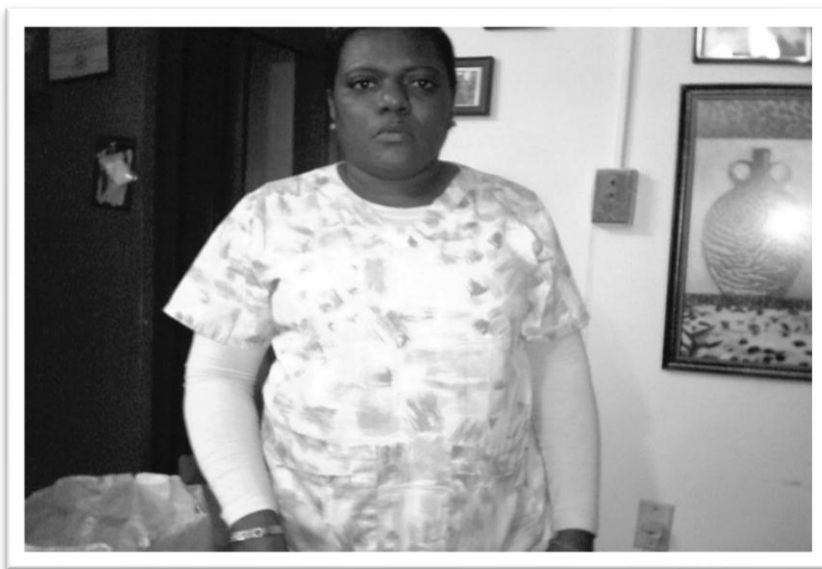
In addition to providing informational and instrumental support, family members also offered emotional support. Grandchildren were especially important to the female participants. While discussing Figure 4.3, Jeanine described the relationship with her granddaughter:

> My granddaughter puts a highlight in my life, especially when I am feeling down.

She always makes me feel better, and being with her takes away a lot of the stress.

She gives me the push I need to do better.

Jeanine also mentioned that other family members call to remind her to take her

medications and make sure she is eating properly and within her dietary restrictions.

Brenda's only child is in prison but reported her brother as a main source of support.

Brenda described her brother saying, "He calls twice a week to ask how I am doing, and

how I am feeling, and see what I am cooking." The relationships with these family

members also instilled hope for maintaining health. Discussions about emotional familial

support revealed that the relationships cause such sentiment as: "Makes me want to

survive"; "Just to make it to see a great-grandson"; and, "Helps me want to take care of

myself." Family members provided a "Push to live."

Figure 4.3. Photograph of Granddaughter

Social interaction lifts me up. Additional facilitators to engaging in self-care

maintenance were positive social interactions such as friendly companionship. Five photographs of friends were taken. Companionship was described as playing cards, bingo, watching television, or listening to music with friends. Spending time with friends was described as both uplifting and relaxing. All participants acknowledged that friendly companionship was important for promoting conversation and laughter: "If you're under depression, it relaxes you if you around other peoples" and "We laughed and talked, this relaxes you and you won't get so tense." Accessibility to friends with whom to talk and spend time was reported as beneficial: "It's good to talk to someone else and get their view point on some things"; "Being around somebody who is laughing and talking has helped me"; and, "You won't get so stressed out when you are around somebody." These friendships were described as being able to "Lift you up" and "Lift your spirit." Knowing that a friend would be there when needed was described as important.

Support in my environment has allowed me to better my condition. Although there was limited discussion regarding health care providers, it was visible that the participants valued the informational, instrumental, and emotional support received from the nurses and social worker case managers within the public housing buildings. Brenda stated, "She is helping me keep track of my weight and my blood pressure." The case management staff also provided frequent health clinics and screenings to all residents. Beyond providing the health education materials to the residents, case managers also encouraged people to read the materials and ask questions if needed. The nurses and social work case managers knew the majority of the residents by their first names and new personal details of their lives. Each participant reported having a respectful, supportive relationship with at least one of the nurse or social worker case managers

within their building. Leonard identified the importance of listening to their suggestions: "I don't always follow their advice, but I want to know about it. I want to know about it and I want to make the decisions. It's my life; it's my body."

The case managers were at the center of the discussion about health education and exercise. Pictures of health education included models of hearts, posters detailing exercises, and operational exercise equipment. The health room in the public housing buildings contained a plethora of information. Reba said that residents could "Read for themselves, and if you don't understand, you can go to somebody and ask them. They may explain to you what it means." Felicia said she woke at 5am every day to ride her mountain bike (see Figure 4.4). She said she was "grateful" there was an exercise room available. If the weather was bad, she would use the stationary bike in the exercise room. Felicia's reason for exercising everyday was to "Better my own condition." Two female participants from two different buildings who could not use the exercise equipment due to physical limitations took a picture of the hallway within their buildings. Both participants described how they walked the long hallways daily.

While discussing these photographs, the participants acknowledged that the nurses and social workers were responsible for posting the health information. The residents were encouraged to maintain healthy behaviors and to use the exercise equipment that was available. The case managers offered instruction when residents found it necessary. As such, the case managers were actively involved in the lives of the residents; they were a constant form of support.

Figure 4.4. Photograph of Bicycle

Personal benefits of the environment. The constant presence and efforts of the case managers promoted exercise, improved health, and substantiated the subtheme related to the personal benefits of the environment. While discussing the photographs of exercise equipment, all participants acknowledged that using the available exercise equipment would improve cardiovascular health. This was supported by the following comments: "Makes me stronger"; "My lungs gonna get better"; and, "The more weight you put on the worse it is on your heart." The fear of death was a reason for one participant to engage in daily exercise; Herb said, "I don't ever want to have heart surgery; I never want to have a heart attack. I want to live as long as I can." Another participant agreed that the thought of having heart surgery or "Ending up dead or like a vegetable" encouraged daily walks in the neighborhood. In addition to the cardiovascular benefits of exercise, mental health improvements were noted. Leonard described exercise as helping the heart and mind focus: "The heart affects everything. If the heart is happy, everything else calms down." Exercise was valued to provide energy, improve

strength, and be "Good for my heart."

Barriers to Engaging in HF Self-Care Maintenance Behaviors

Analysis of the photographic and qualitative data within the three matrices revealed four themes relevant to the concept barriers involved with engaging in HF self-care maintenance behaviors. These themes were based on participant comments within the qualitative data. Themes representing barriers to engaging in HF self-care maintenance are as follows: 1) depression slows my heart down, 2) interruption in health care provider, 3) neglected environment, and 4) dietary challenges.

Depression slows my heart down. Conversations regarding the barriers to self-care maintenance suggested that feeling depressed was the primary reason participants did not engage in taking their medications, following their prescribed diets, and/or participating in daily physical activity. Two of the participants were diagnosed with depression. One was diagnosed with major depression and was under frequent psychiatric treatment on both an inpatient and outpatient basis. Although only two were diagnosed with depression, all of the participants reported having intermittent episodes of feeling depressed. While none of the photographs depicted depression blatantly, twenty-eight photographs demonstrated how individuals avoided feeling depressed or lifted themselves out of a state of depression. Photographs showing how an individual avoided or self-managed depression included pictures of a radio (2), television (2), fish and plants in fish tanks (15), potted plants (4), books (4), and card playing (1). During the related discussions, all participants described how these activities relaxed them, eased their minds, and improved thinking. Leonard stated, "If you improve your mind, your heart

can improve." The terms "lift spirits" and "uplifting" were used frequently throughout all three groups to describe the affect these activities had on an individual.

Depression was talked about very openly in all three groups. When the participants felt depressed they reported, "I don't do anything"; this included not leaving their apartment or exercising. Jeanine said, "I don't come out the apartment when I'm depressed, I'm just there. I don't answer the phone, I don't answer the door." Depression also influenced medication adherence and following prescribed diets: "Depressed people are not eating right and taking their pills." Another participant stated, "I can't eat, I don't want to eat." Several participants reported feeling cardiovascular effects from depression: Jeanine said, "When I'm depressed I feel like mine [heart] is just slowing down"; Brenda added, "I'm slowing down and my heart's slowing me down." Another participant reported, "I feel so down until I think I need to go to the emergency room."

Interruption in health care provider. Two out of the ten participants described a less than supportive relationship with their health care provider – specifically their primary physician. There were no pictures to represent this lack of formal support from physicians, but conversations arose due to a photograph of the nurse case manager. Herb described his physician:

I was taking seventeen pills and an aspirin. She wanted to give me another pill. I told her "You're tryin' to kill me, put that prescription pad down." She didn't explain nothin'. We do not have a good relationship. She did not explain my meds to me like she should and she got all offended when I asked.

After this incident, Herb sought care from a different physician. Similarly, Betsy felt that

her physician was "Telling me less and less," which resulted in Betsy changing physicians. Betsy further explained that she would "Take better care" of herself if she was provided with the appropriate information; as a patient, she said, you must "Advocate for yourself." Leonard felt slighted that more health education was not provided when he was younger. He expressed that at his age and with all of his medical problems it was too late for him to regain much of his health. He said, "If there was more emphasis on health education, there would be less problems now." Although the majority of participants reported strong supportive informational and emotional relationships with their physicians, the two participants that did not feel supported both decided to seek care from a different physician. While searching for a new physician, both participants had a period of time without medications. Betsy didn't know what medication she had been prescribed and stopped taking all medication until she saw a new physician. Herb felt he was being over prescribed with his eighteen medications; he, too, discontinued medications until evaluated by a new physician.

Neglected environment. Participants in one of the three groups took photographs of their outside environment. These photographs included a vegetable garden, flower garden, and a trash receptacle. The discussion around these photographs focused on the stress and frustration experienced by the residents of this particular building; these stressors were associated with aspects of their immediate environment. The vegetable garden was planted and maintained by one of the residents in the group, and while it was intended to provide free healthy food to residents of the building, members of the community at large repeatedly burglarized the garden. Furthermore, the flower gardens in the front of the building were replaced with bushes by the building

management. This made the residents feel that the building was less beautiful than it had been. The participants were attempting to work with management in hopes of improving the beauty of the building and finding ways to protect the garden.

The photograph of the trash receptacle, Figure 4.5, led to conversations about poor building maintenance and general disregard many of their neighbors showed toward their home. Brenda stated that when she looked at the photograph she saw "A lot of disease, infections, and viruses." Jeanine stated, "I stay here, you know, and it just makes it look messy for us. It is stressful. It is dirty." The lack of support on the part of the management staff resulted in "stress" and "frustration." Stress was understood to have negative effects such as: "Stress can make you feel really bad" and "Stress about things is not good for your body, your heart, or your mind." These four participants reported feeling higher a heart rate and blood pressure while their stress levels increased. Their physicians had told them to avoid stress, but the nature of their immediate environment made this difficult.

Dietary challenges. Photographs of fast food restaurants (2), vending machines (1), and canned vegetables (1) sparked conversation about the challenges the participants encountered when attempting to follow their prescribed diets. All of the participants described the importance of following a strict diet of low sodium, cholesterol, and fat. Two residents identified that the cost of healthy food is a barrier: "I can't afford to buy healthy food" and "Fried food is not good for you. I know that, but that's cheap." Others said they gave things up in order to afford the healthy choices, even when more expensive. Angela did this; she said, "I want to stay healthy and strong so I cut back on

Figure 4.5. Photograph of Trash Receptacle

something and I get me some bananas, apples, grapefruit and oranges." Several participants discussed the problems with having vending machines (see Figure 4.6) in the building. Jeanine went on further to explain the temptation that the vending machines caused:

> They don't have any diet stuff in the vending machine. I sit here all day looking at that machine. It [vending machine] is right here in my face. It's enticing to us. Eventually you find yourself getting something that you don't need.

The high cost of vending machine foods was also discussed.

All of the participants denied eating regularly at fast food restaurants, but they did discuss the ease of and resulting temptation in the proximity of fast food restaurants. One of the public housing buildings was directly across the street from a popular fast food restaurant. The other two buildings had fast food restaurants within walking distance. None of the three buildings had a grocery store to which residents could walk. The

Figure 4.6. Photograph of Vending Machines

participants discussed how often their neighbors would walk to the restaurants and offer to return with food for them. They discussed a major temptation in the ease of buying fast food, as opposed to cooking. Jeanine commented, "It's easy to order pizza." Felicia said, "[It's] cheap to get a hamburger." The majority of the participants expressed that they preferred home cooking and often shared meals with other residents in the building. Several participants reported opting for fast food or something from the vending machine when tired or not feeling well.

An additional barrier to following a prescribed diet was described as the free food that was provided each month to the low-income residents from a local non-profit agency. Those who met the low income requirements received a large, monthly box of food. These boxes were filled with canned foods, cereals, and other nonperishable processed food products. The participants described this as a constant struggle. They understood that they should have avoided much of this food, but by making use of the

nonperishable items they were able to save money. Most of the participants could use only half of the food items in the box when attempting to pick out the food with the least amount of salt. The unused food was then given to family members or other residents in the buildings.

Barriers to Engaging in HF Self-Care Management Behaviors

Self-care management is a deliberate decision-making process that requires recognizing changes in symptoms, evaluating the symptoms, responding to symptoms by implementing a treatment remedy, and evaluating the response to that treatment remedy (Riegel & Dickson, 2008). There was limited discussion about self-care management among all groups. Additionally, self-care management scores were below the cut point of 70 ($M = 64.1$, $Mdn = 55$). Two female participants discussed their familiarity with HF symptoms and how to respond to their symptoms. Others had limited or incorrect responses contributing to the theme "lack of knowledge and decision making skills."

Lack of knowledge and decision making skills. There were no photographs that fit into the category of self-care management. Conversations about Herb's dissatisfaction with his previous physician, however, led to Herb's description of a HF exacerbation:

> I didn't know what was happening. I thought I was dying, lying up there trying to sleep, can't breathe. I turned a fan on my face. Somethin' is wrong, but I kept goin' to work for a week. Then I started swelling up, feet, ankles, and stuff. Aw, it's time to go the hospital.

Leonard had two syncopal episodes. He didn't go the emergency department or call his physician or nurse for advice until the third syncopal episode that was followed by an

episode of chest pain. When asked why, Leonard responded:

> Being male I sorta procrastinated. I waited till the third time. Being male, first
>
> time was an accident, we will wait and see what happens. The second time ahh,
>
> third time I was like I gotta go, I was getting chest pains, I was like I gotta go.

Both participants identified having symptoms, but ignored them until the severity of their

symptoms resulted in needing to go to the emergency room. Neither participant

recognized that their symptoms were related to their HF. Leonard also discussed that he

tended to diagnose himself with the help of medical websites. He acknowledged, "If the

symptoms last more than a week I will usually go to the hospital."

Self-Care Confidence

Self-care confidence is the confidence to engage in self-care maintenance and

self-care management behaviors (Riegel, Lee et al., 2009). Although self-care is best

represented by the self-care maintenance and management scores, the self-care process is

influenced by self-care confidence, which is a moderator of self-care outcomes (Riegel &

Dickson, 2008; Riegel, Lee et al., 2009). The self-confidence scores for the participant

sample were below 70 ($M = 65.6$, $Mdn = 62.2$).

There were no photographs taken to fit into the category of self-care confidence.

Analysis of the qualitative data indicated that the participants had confidence in the three

most frequently performed self-care maintenance behaviors – medication adherence,

following dietary restrictions, and daily physical activity. Analysis of the individual

questions within the self-care confidence sub-scale indicated that participants were most

confident when following the treatment advice they were given, and recognizing changes

in their health if they occurred. Participant comments that supported confidence in self-care maintenance included descriptions of how they succeeded in following medical advice about medication adherence. All the participants were able to explain the medications they were taking each day, the importance of taking them daily, and how they used reminders to ensure adherence. Participants also discussed the many challenges associated with following their diet. They brought up ways to overcome some of these challenges. Participants also expressed the importance of exercise; they shared how they engaged in daily physical activity despite some of their physical limitations. Those who believed they were unable to engage in thirty minutes of exercise said that they consistently participated in activities in the building and walked the halls every day.

Self-care confidence was not evident in self-care management behaviors. According to the self-care confidence sub-scale participants were least confident in keeping themselves free of HF symptoms, doing something to relieve symptoms, and evaluating the effectiveness of a remedy. Participants were not directly asked questions regarding self-care confidence. The lack of direct questioning by the PI may have resulted in limited discussion about those behaviors.

Conclusion

In conclusion, the participants of this study displayed adequate self-care maintenance; as indicated in the qualitative data and supported by the SCHFI self-care maintenance scores. The participants reported regular engagement in the self-care maintenance behaviors of taking daily medication, following prescribed diets, and engaging in daily physical activity. Because a score of less than 70 in one or more of the

three scales reflects inadequate self-care in that domain (Riegel, Lee et al., 2009), the findings from this study may indicate insufficient self-care management and self-care confidence. The lack of qualitative data regarding self-care management may suggest that self-care management is a difficult and challenging task. It may also be that further exploration is needed in these areas of self-care.

Facilitators for engaging in HF self-care focused around social support. Family members and friends were the primary source of informal social support within this sample. The formal support provided by health care professionals within the participants' immediate environment also facilitated the engagement in HF self-care maintenance. The desire to maintain health and live a long life was prompted by their perceived support from others and was also identified as facilitators for engaging in self-care maintenance behaviors.

Several barriers to engaging in HF self-care maintenance were identified. The primary barrier identified was depressive symptoms; the participants discussed their perception that feeling depressed negatively influenced participation in self-care maintenance. The lack of formal support from physicians for two participants resulted in dissatisfaction with care and eventually led to a lapse in physician care and medication adherence. The physical appearance of the participants' immediate environment also increased stress and frustration for some, causing them to feel adverse cardiovascular effects. The low cost, easy access, and temptation of non-healthy food choices acted as barriers to following the prescribed diet of low sodium, fat, and cholesterol that HF patients are directed to follow.

Little discussion that could be coded as self-care management occurred; scores in

this area on the SCHFI were also below the cut point. Furthermore, it was identified that

a lack of knowledge, the inability to recognize HF symptoms, or a lack of decision

making skills resulted in a trip to the emergency room for two of the study participants.

Similarly, self-care confidence scores were below the cut point, indicating inadequate

self-care confidence and – as with self-care management – limited discussion coded as

self-care confidence occurred. However, unlike self-care management, qualitative data

did indicate adequate self-care confidence in self-care maintenance behaviors.

Interpretations of these results are presented in Chapter 5.

Chapter 5

Discussion

The findings in this study add to the body of knowledge regarding HF self-care behaviors and challenge some of the material previously described in the literature. This chapter presents an interpretation of the key findings of this study. The interpretation and relationship to previous research will focus on self-care behaviors and the facilitators and barriers to engaging in self-care maintenance and self-care management. Self-care confidence is also discussed. An evaluation of the photovoice method and Freire's theoretical framework for this research follows. The importance of the qualitative and quantitative findings and the limitations of the study are described as well. This chapter concludes with suggestions for future nursing research and the implications for nursing practice with this vulnerable population.

Self-Care Behaviors

The present study identified the three most common self-care maintenance behaviors as medication adherence, following dietary restrictions, and participating in daily physical activity. Participant-taken photographs and discussions regarding consistent engagement in these self-care maintenance behaviors supported this. Analysis of the SCHFI scores also indicated self-care maintenance scores were adequate ($M = 71.9$, Mdn = 69.9).

Similar studies have also found medication and dietary adherence as commonly performed self-care behaviors. Schnell-Hoehn et al. (2009) identified that medication adherence and following a low sodium diet were the most frequently performed self-care

behaviors. Reilly et al. (2009) reported that participants who understood their treatment regimen decreased their sodium intake and improved medication adherence. Although participants in the present study reported that they currently adhered to a low sodium, fat, and cholesterol diet, they identified that it was difficult to begin when first instructed to follow new dietary restrictions. This response was similar to the findings of Artinian et al. (2002), Scotto (2005), and Van der Wal et al. (2010), who found that dietary adherence became easier as the patients became more familiar with the restrictions.

Some of the findings from the present study did not support other previously reported findings. In three studies, African Americans were identified as having decreased medication adherence (Artinian et al., 2002; Bagchi et al., 2007; Wu et al., 2008). This was not evident in the present study, where verbal reports and adequate self-care maintenance scores indicated medication adherence. Participants in the present study were knowledgeable about their medication uses and actions. They also used good decision making skills to develop reminder systems to endure daily adherence. Overall, participants indicated that taking their medications was the most important part of their day.

In other studies, participants reported that knowledge deficits regarding medications and dietary restrictions were persistent in their everyday lives (Artinian et al, 2002; Riegel & Carlson, 2002; Van der Wal et al., 2010). Gary (2006) and Sheahan and Fields (2008) reported that participants did not know how to read food labels and continued to eat high sodium food items. Van der Wal et al. (2010) reported that participants with knowledge deficits regarding sodium restrictions did not monitor their dietary sodium intake. Contrary to the aforementioned studies, the participants in the

present study verbally described the differences between the foods they should eat and the ones they should avoid. Participants also took photographs of canned food, vending machines, and fast food restaurants to illustrate their knowledge of unhealthy, inappropriate food choices for someone with HF. Although the participants in the present study possessed knowledge regarding their dietary restrictions, the barriers present made it difficult at times to make proper decisions regarding what food to eat.

Participants in the present study voiced engaging in daily physical activity to maintain health. In addition to the personal health benefits of exercise, participants described how health care providers, family members, and friends either reminded them to exercise or of the importance of exercise. Similarly, other studies have reported that social support from family members (Gallagher, Luttik, & Jaarsma, 2011) and peers (Clark, Whelan, Barbour, & MacIntyre, 2005; Petter, Blanchard, Kemp, Mazoff, & Ferrier, 2009: Schutzer and Graves, 2004) correlated with increased physical activity. Tierney et al. (2011) found that the interaction with relatives and professionals prompted participants to be active. Tierney also reported that most participants described their engagement in exercise as walking, which was similar to the present study's participants. Tierney's study differed in that participants reported that they could not participate in walking due to inclement weather which included heat, ice, rain, and cold temperatures. Participants in the present study reported engaging in some form of physical activity year round. The building was temperature-controlled in all common areas, including the hallways and exercise rooms.

Participants repeatedly described adherence to their medication regimens, their dietary restrictions, and participation in some form of daily physical activity. Possible

explanations for these self-care maintenance behaviors included that all participants described receiving dietary and medication counseling from their health care providers. Participants also verbalized that their pharmacists provided them with further medication counseling. An additional reason for adherence may have stemmed from the support they perceived from the staff within the public housing buildings. Health education materials and exercise equipment were readily available. The case managers working within the public housing buildings frequently scheduled health presentations from nursing and medical students. Several other non-profit agencies frequently provided health education and screenings. These presentations were open to all residents. The participants voiced that the health education provided was often general health information focusing on diet and exercise. There were also education sessions that focused on the signs and symptoms of heart attack, stroke, and various forms of cancer. Because most of the available resources focused on diet and exercise, this may have influenced the self-care maintenance behaviors of the participants.

Facilitators for Engaging in HF Self-Care Maintenance

Self-care maintenance involves engaging in behaviors to maintain physiological stability. This requires the person with HF to live a healthy lifestyle that includes taking medications, eating a low sodium diet, exercising, and actively monitoring symptoms (Riegel, Lee et al., 2009). Social support was identified as the primary facilitator for engaging in HF self-care maintenance behaviors. This section will demonstrate how perceived social support facilitated the self-care maintenance behaviors of medication adherence, following dietary restrictions, and participating in daily physical activity.

Social support, which is the perception of support one receives from others in the environment (Zimet et al., 1988), was described as the primary facilitator for engaging in self-care maintenance. Social support was comprised of formal and informal support. Formal support is the perceived support provided by formal helping agents; this includes physicians, nurses, and other medical professionals (Cohen et al., 2000). Informal support includes reliable assistance provided by friends, family, or colleagues (Moorhead et al., 2008). Please refer to Appendix A for the definitions of the various forms of social support.

Although social support was not formally measured in the present study, verbal reports identified that immediate and extended family members were the primary sources of social support, followed by friends and health care providers. These individuals were described as providing informational, instrumental, and emotional support. These findings were consistent with Sayers et al. (2008) who used a similar participant sample consisting of mostly African Americans with low socioeconomic status. Sayers et al. reported strong kinship ties among the African American participants. According to Sayers et al., participants with perceived social support from a significant other, other family members, or friends demonstrated better medication and dietary adherence.

The strong and loving relationships—especially those involving supportive family members—were described as instilling a desire to maintain a healthy life style by the participants in the present study. It may be possible that these desires to maintain a functioning health status and to live a long healthy life facilitated self-care maintenance behaviors. Previous studies revealed similar findings of wanting to live long, healthy lives with family members to be a facilitator for medication adherence (Gary, 2006; Van

der Wal et al., 2010). Previous studies also reported that the fear of death or the threat that other family members would have to care for them prompted their interest in taking care of themselves and increasing their engagement in self-care maintenance behaviors (Macabasco-O'Connell et al., 2008; Sheahan & Fields, 2008).

Friendly companionship was identified as the second most important facilitator for self-care maintenance by the present study participants. Friendly companionship was specifically important for the provision of emotional support. This emotional support was described as involving conversations with friends that evoked laughter and feelings of relaxation and happiness. This interaction also was described as providing distractions and improving one's mood. Being around others may have assisted in alleviating depressive symptoms. Having friends within the same building encouraged individuals to leave their apartments and join activities in the community room, ultimately promoting physical activity and healthy socialization. Participants stated that they often played bingo and cards with their friends and other residents. In a study completed by Gary (2006), participants also reported receiving support from friends while talking on the phone. In these ways, friendly companionship has been identified by participants as improving engagement in self-care behaviors in the present study and by others (Gary, 2006; Sayers et al., 2008).

Formal support was also identified as a facilitator. Participants described receiving formal support from nurses, physicians, pharmacists, and social workers. Support from health care professionals included education regarding medical problems, completing physical assessments, listening to problems, and understanding health care needs. Participants in the present study described that a supportive relationship with their

health care provider needed to be individualized and respectful. These participants described their own positive, supportive relationships, and the knowledge gained from health care providers as promoting their engagement in the self-care maintenance behaviors. It is likely that this involvement from the case managers also improved their decision making skills. The above findings from the present study were consistent with Crowder (2006), Eldh et al. (2006), Riegel and Carlson (2002), and Scotto (2005).

Participants in the present study voiced the influence that positive social support had on their self-care behaviors. The findings from this study were consistent with several other studies. Participants described how social support from health care professionals, family, and friends contributed to more effectively engaging in self-care maintenance. Others have reported that social support was associated with increased medication adherence (Larsson, 2007; Sayers et al., 2008), dietary adherence (Sayers et al., 2008; Scotto, 2005), and increased physical activity (Schnell et al., 2006; Scotto, 2005).

In a meta-analysis, DiMatteo (2004) found that support, which included instrumental and emotional support, had a greater influence on adherence than support based on an individual's living arrangements. In other words, strong, supportive, quality relationships may be more valuable than simply having an individual present, such as a spouse or living with another family member. The value of quality social support was visible among the participants in the present study. Although each of the participants lived alone, they all reported having strong social support from family members, friends, and health care professionals that provided informational, instrumental, and emotional support. The strong importance of friendly companionship in this sample may have

stemmed from the fact that the participants lived in close proximity to other people similar in age and with chronic health problems. Additionally, the case managers in the public housing buildings promoted socialization among the residents by organizing group outings, bingo, card games, and other group activities. Social support that provided informational, instrumental, and emotional support to this vulnerable population were reported by participants as being essential to their ability to successfully engage in HF self-care maintenance.

Barriers to Engaging in HF Self-Care Maintenance

Several barriers to self-care maintenance were identified within this study. Some of these barriers were similar to those in other studies. These barriers included perceived feelings of depression, lack of formal support from physicians, environmental stressors, and difficulty adhering to dietary restrictions.

During the present study, the majority of participants scored between 0-4 on the PHQ-9, indicating they currently did not have depressive symptoms. Although the participants were not depressed at the time of data collection, all participants reported intermittently feeling depressed. Participants described depressive symptoms and depression as an illness that intermittently surfaced. Feeling depressed or having depressive symptoms was described by the participants as the primary barrier to engaging in HF self-care maintenance. Depressive symptoms were described as negatively impacting the ability to engage in self-care maintenance behaviors similar to Gary's (2006) findings. Participants in the present study reported that feeling depressed negatively impacted medication and dietary adherence; many reported not taking their

medications, eating, or eating food that was not appropriate for their dietary restrictions simply because they did not care or have the energy to choose healthy options. Participants related that when they felt depressed, they secluded themselves from others. They also reported feeling fatigued and as if their hearts were slowing down. Participants described depression as being detrimental to engaging in self-care maintenance. This is similar to other studies that have found that those suffering from depression were less likely to engage in self-care behaviors (Carels, 2004; Falk et al., 2009; Falk et al., 2007).

The lack of formal support from health care professionals was identified as a barrier to medication adherence in both the present study and by other studies (Schnell et al., 2006; Scotto, 2005; Riegel & Carlson, 2002). Although the present group reported overall medication adherence at the time of the study, two participants described that lack of formal support from their physicians resulted in a period of time without medical supervision and medication adherence. Two participants in the present study perceived that their physicians addressed health problems by prescribing additional medications instead of taking time to find the root cause of the problems. Scotto (2005) identified similar perceptions from participants regarding medication prescriptions and that a lack of physician support or physician involvement in the patient's plan of care acted as a deterrent to adherence. The two participants from the present study who sought new physicians had a period of time when medications and medical supervision ceased. Although participants reported a lapse in medication adherence, these participants reported abandoning their current medical regimen because their original physicians would not take time to explain their treatment plan to them. These two participants sought out new physicians for the purpose of gaining an improved relationship, which

they perceived would result in improved personal health.

The participants in this study identified environmental barriers to include a lack of support from the building management to provide a flower garden, the disrespect from neighboring residents who burglarized the vegetable garden, and other residents who piled their trash outside the building. These environmental factors resulted in participants verbalizing that they were not able to follow their physicians' recommendations of maintaining a stress-free lifestyle. Although they attempted to avoid the stressful situation, participants reported that it was impossible because the stressors were a constant in their immediate environment and therefore inescapable. Because participants expressed how the lack of support from the building manager along with other environmental factors had negative physical and emotional effects, these findings reinforced the importance of social support and its stress-buffering affects (Cohen, 1988; House et al., 1988; Wallston et al., 1983). The significance here lies in the fact that when the participants felt a lack of support from the management in their building and the people in their neighborhood, they perceived the biological markers of stress and elevated blood pressure. Although these participants knew they should avoid stress, it appeared that they lacked the decision making skills to avoid or alter the situation. Alternatively, it may have been that the environmental constraints present were too large to overcome.

Lack of money was a similar barrier reported by Macabasco-O'Connell et al., (2008). Macabasco-O'Connell et al. found that participants lacked money for medications and medical insurance. Instead, participants in the present study reported a limited budget to purchase food items. Although all the participants reported following their dietary restrictions, they did identify that the lack of money and the availability of

non-healthy food choices in their immediate environment were barriers to following dietary restrictions. Participants expressed that the high cost of food items forced the low-income participants to continually evaluate and manage their budget. Participants in the present study were provided with free food each month from a local non-profit agency. The food was described as consisting of items with high sodium and high fat content. Similar to Artinian et al. (2002) and Gary (2006), low income participants relied heavily on canned food, despite knowing they should avoid high sodium foods. The ease of nearby fast food restaurants and a vending machine within their residence were considered constant temptations for the present study participants. Temptation was a similar barrier reported by Scotto (2005). Glanz, Sallis, Saelens, and Frank (2005) referred to the problem experienced by the present study participants as a problem caused by the general environment, and is based on distribution of food items.

Glanz et al. (2005) developed the Model of Community Nutrition Environments based on the ecological model of health behavior. Glanz et al. identified that the amount of healthy versus non-healthy food products in near proximity affect the odds of an individual consuming healthy verses non-healthy food items. The environmental constraints present in this model were supported in the present study. For example, participants purchased food from the vending machines, went to fast food restaurants, and consumed the items from their free food box, despite knowing they should avoid these items. These barriers made it difficult for low income patients with HF to follow their dietary restrictions.

The Environment and the Ecological Model of Health Behavior.

Through the analysis of the qualitative data it emerged that there were several environmental facilitators and barriers present. The ecological model of health behavior was explored because the model has been used to design individual models and to explain behaviors. The ecological model can also be used to develop appropriate behavioral interventions when there may be multiple determinants of health behavior. According to Sallis, Neville, and Fisher (2008), the ecological model of health supports that there are many factors that influence health behaviors. The principles of the ecological model combine the environmental and policy contexts of behavior with the social and psychological influences. This can include intrapersonal (biological, psychological), interpersonal (social, cultural), organizational, community, physical environmental, and policy (Sallis et al., 2008). Sallis et al. describes that there are four core principles of the ecological model of health behavior:

1). There are multiple influences on specific health behaviors (intrapersonal, interpersonal, organizational, community, and public policy);

2). Influences on behavior interact across different levels;

3). Ecological models should be behavior-specific and identify the most relevant potential influences at each level;

4). Multi-level interventions should be most effective in changing behavior (p. 446, 2008).

The ecological model of health has been used to help researchers understand how people interact in their environments. According to Sallis et al. (2008) motivating and providing the skills to change behavior is not enough if the environment makes it hard for individuals to choose healthy behaviors. This was most evident in the present study

when participants identified that free food, vending machines, and the accessibility of fast food restaurants were barriers. Stress within the participants' environment was also described as a barrier to healthy behaviors. When using the ecological model of health one must acknowledge that the role of behavioral influence operates at multiple levels, which was evident in this study.

Using the principles of the ecological model to view the present findings assisted in identifying that strong social support (informational, instrumental, and emotional) within their immediate environment facilitated engagement in self-care maintenance. The public housing environment included supportive case managers, group activities, peers living in close proximity, health education materials, and exercise equipment. Analyzing these findings from an ecological perspective highlights how these multiple influences (intrapersonal, interpersonal, organizational, and community) interact at different levels, influence health behaviors, and, in the case of this study, self-care maintenance behaviors.

Barriers to Engaging in HF Self-Care Management

Self-care management is the response to HF symptoms once they occur (Riegel, Lee, et al., 2009). Self-care management is a deliberate decision-making process that requires recognizing changes in symptoms, evaluating the symptoms, responding to symptoms by implementing a treatment remedy, and evaluating the response to that treatment remedy (Riegel & Dickson, 2008). The self-care management scores of the SCHFI range from 0-100, scores of 70 and highter indicate adequate self-care management. In this study self-care management was only assessed if a participant

reported ankle swelling or trouble breathing in the last six weeks. Six participants

reported these symptoms, thus completing the self-care management sub-scale. Scores

on the self-care management sub-scale ($M = 64.1$, $Mdn = 55$) identified inadequate self-

care management behaviors. Other studies have found that people with HF generally

have low self-care management scores (Macabasco-O'Connell et al., 2008; Schnell-

Hoehn et al., 2009), difficulty recognizing symptoms of HF (Artinian et al., 2002;

Horowitz et al., 2004; Jurgens et al., 2009; Riegel & Carlson, 2002), and often do not

seek care for acute symptoms (Gary, 2006). The lack of discussion regarding symptom

recognition, symptom management, and the low self-care management scores may

suggest that participants did not understand the symptoms of a HF exacerbation, the

strategies to use in response, and the decisions to make based on their symptoms.

Jurgens et al. (2009), Macabasco-O'Connell et al. (2008), and Riegel and Carlson

(2002) reported that progressive symptoms of a HF exacerbation were not perceived as

important reasons to seek medical treatment. Similarly, two male participants of the

present study described instances when they ignored their HF exacerbation despite the

escalating symptoms. These participants were in two different discussion groups. During

the discussion about a HF exacerbation, symptom recognition and management, the rest

of the participants did not add to the discussion. The exact reason for the lack of

discussion regarding self-care management behaviors was not identified within this

group. Because of the limited discussion, it was difficult to determine the reasons for

poor self-care management scores.

Other studies have found that many patients delayed contacting their physician for

progressing HF symptoms (Gary, 2006; Horowitz et al, 2004). This could be related to a

lack of knowledge and difficulty with decision making skills or a lack of familiarity with these types of symptoms and how to respond. Horowitz et al. (2004) and Jurgens et al. (2009) reported that family and friends were often responsible for recognizing symptoms and the need for medical attention. This was not discussed by the present study participants. This lack of discussion could partially be due to the fact that all participants lived alone and did not have family members constantly available to assess their symptoms. According to Jurgens et al. 56% of participants did not know HF symptoms or recognize their importance, this was supported by qualitative data revealing that over half did not know what caused the symptoms. Jurgens et al. found participants' responses to symptoms to be either absent or incorrect. Symptom monitoring and symptom management have been reported as the least performed self-care behaviors (Artinian et al., 2002). Participants have also described symptom recognition as difficult (Van der Wal et al., 2010).

Mean and median scores from the SCHFI suggested poor self-care management among the participants in the present study. Upon completion of the study it was difficult to determine the overall self-care management behaviors of the group due to the limited discussion that occurred. During the group discussions, participants described ways in which health care providers explained medications, dietary restrictions, and the importance of engaging in physical activity. Verbal reports from participants suggested that health care professionals did not focus HF instructions on symptom recognition and management. A health and exercise room was located within each of the three buildings that contained many posters that promoted proper diet and exercise. As mentioned previously, members of non-profit organizations and nursing and medical students

frequently presented health topics to the residents. It may have been that the signs and symptoms of a HF exacerbation were not discussed within these presentations. Another possible explanation is that health care providers focused on self-care maintenance by promoting medication and dietary adherence but lacked a focus on symptom identification and management. It may also be that these participants had difficulty initiating appropriate decision making skills to engage in self-care management behaviors once symptoms began.

Self-Care Confidence

Self-care confidence is defined as the confidence to engage in self-care maintenance and self-care management (Riegel, Lee et al., 2009). The self-care confidence scores for the participant sample were below the cut-point of 70 ($M = 65.61$, $Mdn = 62.28$). In the present study the participants were not directly asked questions regarding self-care confidence. Although the overall self-care confidence mean and median scores were below 70, analysis of the individual self-care confidence questions and the qualitative data suggested that the participants were confident that they could follow their treatment advice. Even though the participants in this study identified environmental constraints, verbal reports indicated that they were most confident in the areas of medication adherence, following dietary restrictions, and participating in daily physical activity. Participants were also able to easily identify the facilitators and barriers for engaging in these three specific behaviors. According to the self-care confidence sub-scale, participants were least confident in keeping themselves free of HF symptoms, taking action to relieve symptoms, and evaluating the effectiveness of a remedy. This

was supported by the comments of two male participants, which suggested that the participants lacked self-care confidence to engage in self-care management behaviors. It would also seem that if one lacks knowledge and decision making skills related to self-care management behaviors, he or she would also not hold the confidence to engage in those behaviors.

Other studies that have evaluated self-care confidence found that male participants reported being more confident in interpreting HF symptoms and initiating treatment (Riegel, Dickson, Kunh, Page, & Worrall-Carter, 2010). The female participants in Riegel, Dickson et al.'s (2010) study described uncertainty of HF symptoms and would not initiate any treatment without prior consultation with their physician. Heo, Moser, Lennie, Riegel & Chung (2008) identified that the female participants with higher self-confidence and a decreased functional status correlated with better self-care behaviors. At that completion of the study it was difficult to accurately present the participants' level of self-care confidence due to a lack of discussion and specific probing questions about this topic.

Methodological Importance

This study was the first of its kind to use the photovoice method to identify the facilitators and barriers to engaging in HF self-care for low income African Americans living in an urban area. The photovoice method was appropriate to use with this population and was effective in meeting the specific aims of the study. The use of this method assisted in the identification of the themes that represented the facilitators and barriers to engaging in self-care. Using photovoice also allowed entry into the

participants' personal lives, their immediate environment, and provided supplemental benefits to the participants.

The participants needed minimal instructional assistance with the digital camera. Each of the participants had used a similar camera in the past. In total, the participants took one hundred photographs, which proved to be effective visual props to facilitate dialogue within the group. Visualization and discussion of the photographs promoted collaboration. Each participant was given time to share their perspective on how they interpreted the photograph, which added to the discussion. The participants needed minimal prompting by the PI or RA. In this study, the photovoice method was used in conjunction with open-ended questions during discussion sessions, which easily promoted individual reflection, group collaboration, and group discussion.

The use of the photovoice method was beneficial in the ability to identify self-care behaviors, facilitators, and barriers to engaging in HF self-care maintenance. Participants took photographs of people, places, and things that were identified as making engagement in self-care easy or difficult. Participants also took photographs of activities that they described as being effective to decrease depressive symptoms and feelings of depression. While viewing the photographs participants described how participation in these activities affected their mood as well as their cardiovascular system. These photographs provided a visualization of the facilitators and barriers that were present. The participants did not take photographs that represented self-care management or self-care confidence. The exact reasons for the lack of these types of photographs were not identified.

The photographs allowed the PI and RA to see a portion of the participants' lives.

The majority of the photographs taken were within the public housing buildings and outside on the building grounds. Many participants wanted to discuss how their family members were important to facilitating self-care. If they were not going to see their family members during the time of the study, they used the digital camera to take a photograph of previously taken pictures of their family members. Three photographs that were taken outside of the buildings included a church, a fast food restaurant, and a park. Because the majority of the photographs were taken within their apartments, this method allowed the researcher to visualize and gain a better understanding of the facilitators and barriers within the participants' immediate environments. These aspects of their lives may not have been uncovered or discussed using a different method.

Overall, the photovoice project was reported as a good experience by the participants. Each of the participants reported that they enjoyed being a part of the study describing it as "fun" and "interesting." Participants reported a better understanding of HF treatment and how to overcome some of the barriers presented through group discussion. One participant stated she would participate in anything that would help her learn how to take care of herself better. Others described it as "a learning experience" and "educational." Several participants asked the PI to contact them again for future studies. Another possible reason the participants found the photovoice method enjoyable was because this method promoted social interaction; the participants gathered with a group of their peers and discussed how they participated in self-care.

Although the photovoice method worked particularly well, there were a few things that could have been altered in practice. Specific questions regarding self-care management and self-care confidence could have resulted in more photographic and

qualitative data to represent these behaviors. Additionally, the use of the SHOWeD method to promote group discussion proved difficult for the participants. The SHOWeD prompts did not fit well with the topic studied, likely due to the fact that the study's focus was on an individual level verses a societal level. Refining the prompts for the discussion would be beneficial for future projects.

Theoretical Importance

The photovoice method is a participatory action research method derived from Freire's concepts of education for critical consciousness (Freire, 1970/1973). As discussed in Chapter 2, Freire (1970/1973) proposed that three levels of consciousness affect the reality of behavioral responses: (a) magical, (b) naïve, and (c) critical. It is at the level of critical consciousness that an individual realizes that he or she is responsible for maintenance and change. The individual accepts responsibility and makes the necessary decisions to integrate choices into his or her life (Freire, 1970/1973).

During the group discussion, it was evident that the participants were at a level of critical consciousness regarding the self-care maintenance behaviors of medication adherence, following dietary restrictions, and participating in daily physical activity. Participants' comments supported that they understood these three aspects of their treatment regimen and made a constant effort to take responsibility for their health by engaging in appropriate self-care maintenance behaviors. With respect to self-care management behaviors, the PI acknowledged that self-care management behaviors are difficult for many individuals. The limited discussion regarding self-care management made it difficult to determine the level of consciousness among all of the participants at

the time of the study. Comments made by two of the participants suggested that they may be in the naïve level of consciousness. An individual in naïve consciousness becomes aware that he or she has a problem, concern, or issue, but does not take responsibility for the situation. Blame is placed on coincidence or on others (Freire, 1973). Comments such as "waiting for it to get better," or placing blame on "being a man, and a procrastinator," are consistent with the naïve level. It may be that it is difficult to achieve a level of critical consciousness regarding self-care management. This could be due to a lack of knowledge or that decision making skills regarding HF symptoms and symptom recognition may be difficult for some.

This study supports the use of Freire's theory in providing a framework for the development of the appropriate nursing assessments and interventions that include the many determinants of health behavior; these determinants may involve the personal, social, economical, and environmental factors that influence health (HealthyPeople.gov). This study supports the notion that there are many factors that influence an individual's self-care behaviors. Understanding one's level of consciousness may also assist in developing interventions appropriate to the person's perspective on HF and HF self-care behaviors.

Importance of Qualitative and Quantitative Findings

The quantitative data supported the qualitative findings and assisted in developing a better understanding of the self-care behaviors of the participants. The analysis of the transcripts and photographs taken by the participants supported the adequate self-care maintenance scores. The lack of photographs and limited discussion regarding self-care

management were congruent with the low mean and median self-care management scores. The self-care confidence sub-scale measures confidence to engage in each phase of self-care. Although the self-care confidence scores were low, analysis of transcripts suggested that participants were confident with medication adherence, following dietary restrictions, and engaging in daily physical activity. Further analysis of the questions within the self-care confidence sub-scale indicated that participants were most confident following the treatment advice they were given.

Further analysis of the qualitative data supported that the participants in this study possessed the knowledge and decision making skills to adhere to their medication regimen and participate in daily physical activity. In the present study the participants were also knowledgeable about dietary restrictions and the importance of decreasing stress in their lives. Some were also able to identify HF symptoms. Although these participants had adequate self-care maintenance scores and adequate knowledge, these participants may have had difficulty making appropriate decisions in the areas of dietary adherence, stress reduction, and symptom management.

Mean scores from the SCHFI indicated that the participants had adequate self-care maintenance behaviors. Qualitative examples of this included the ability of the participants to verbalize and take photographs of the types of foods they should avoid. Participants were also able to describe the barriers they faced when trying to adhere to their dietary restrictions. Despite having this knowledge it appeared that the participants were unable to avoid the temptation of vending machines and fast food restaurants. These participants also had difficulty deciding what to do with the free high sodium, high fat food they received. Although one might assume this is due to their inability to make

appropriate decisions, the environmental constraints likely played a larger role in their decisions to ingest food items not recommended for HF patients.

Several environmental factors were described as barriers to maintaining a stress free lifestyle. Although all of the participants were able to describe stress causing situations and the importance of avoiding stress, it appeared that they had not yet been able to decrease stress in their environment. It was difficult to determine if this inability to find ways to decrease stress was due to their lack of decisions making skills or from the lack of support from the building management to assist the participants with the flower, vegetable garden, and trash collection areas.

In regards to symptom recognition, six participants completed the self-care management subscale; only those who identified having HF symptoms of ankle swelling or trouble breathing within the last six weeks completed this scale. Mean and median self-care management scores were below 70 indicating that the group did not adequately engage in HF self-care management behaviors. Limited discussion regarding symptoms, symptom recognition, and symptom management existed. Two participants were able to identify they were having symptoms and described how they treated their symptoms. One described putting a fan on his face, another visited internet websites. Neither sought professional care until their symptoms became emergent. These findings indicate that that these participants knew they were having abnormal symptoms, they also made decisions to treat their symptoms. Unfortunately they made decisions that were ineffective in treating their symptoms of HF.

It was overwhelmingly obvious that the participants in the present study had adequate knowledge for engaging in self-care maintenance behaviors. Despite having

this knowledge, in some areas the participants did not make appropriate self-care decisions. What was not obvious was whether this lack of appropriate decision making was due to a lack of decision making skills or from the environmental constraints that each of the participants faced. Due to the limited discussion regarding self-care management further exploration in this area would be needed to assess their knowledge of self-care management, the decision making process to engaging in self-care management, and how the environment influences self-care management behaviors.

Limitations of the Present Study

As described in chapter 3, several study limitations were noted. Purposeful selection was limited to participants that were self-identified African American, had HF, and were over the age of 50. Participants were allowed to engage in the study regardless of their NYHA classification; results could have differed depending on the severity of HF. NYHA classifications and Mini-Cog results were reported but not analyzed beyond their descriptive purposes. Participants were accepted with a self-reported diagnosis of HF; this may have resulted in the inclusion of participants with heart disease but who had not been diagnosed with HF by a primary care practitioner.

Final collective analysis of all photographs did not occur with the entire group of participants. A collective discussion on themes may have resulted in an alteration of some of the group's identified themes. This study also eliminated the perspectives of individuals who did not have the ability or dexterity to use a camera, as well as those who did not volunteer to participate.

Upon completion of the analysis of the data, several other limitations were noted. Participants in this study who were not at a level of critical consciousness related to their HF may not have been able to achieve that level within a six-week time-frame. Level of consciousness was also subjectively implied and assessed in the qualitative data by the PI but was not analyzed further. Limited discussion occurred regarding self-care management and self-care confidence. Participants may have found it difficult to take photographs of HF symptoms, how they responded to those symptoms, and their confidence in engaging in these behaviors. Limited discussion regarding both self-care management and self-care confidence may have resulted from the unintentional lack of probing questions in relation to this topic. Self-care confidence was often implied but not specifically stated by participants. Also the PI did not ask the participants to specifically take photographs of self-care management behaviors or their self-care confidence to engage in these behaviors. It was difficult to ascertain if this was a limitation of the photovoice method or the researcher's procedure.

Although the participants appeared to speak very openly about their behaviors, it is possible they withheld some of their feelings, perceptions, and behaviors during the group discussions. Participants could have responded in a way they thought was desirable to the researcher and caution should be used when interpreting this self-reported data. The findings were limited to the data collected and were based on the participants' ability to discuss and describe their personal self-care behaviors.

Although typical for qualitative studies, the small sample size is another limitation of this study. The study was not designed to be generalizable, but to render a more complete understanding of the self-care behaviors, facilitators, and barriers to engaging in

HF self-care as described by low income, urban dwelling African Americans. Results from this study can be used to alert health care providers about specific issues that this population might experience. Health care professionals may use these results to tailor interventions and assist this population to improve engagement in self-care behaviors.

Suggestions for Future Research

Due to the fact that several environmental barriers were identified it would be appropriate to engage these participants in a community based participatory action research project, aimed at decreasing the environmental barriers. In addition to this several other areas were identified as needing further examination. Due to the limited discussion regarding self-care management behaviors that occurred in the present study, qualitative research is needed to render a more complete understanding of these self-care behaviors. Additional research that asks specific questions in regard to self-care management may be helpful to identify the specific facilitators and barriers to managing HF symptoms. Identifying specific facilitators and barriers may result in the development of more effective nursing interventions.

Findings in the present study also indicated that the participants had adequate knowledge regarding several self-care behaviors. What wasn't evident is how they made decisions to engaging in HF self-care. Further exploration regarding how decisions to engage in self-care behaviors are made is needed. Additionally, research regarding how the environment influences self-care decisions may also be beneficial.

Future research into the facilitators and barriers present for those engaging in HF self-care who do not live in public housing or in poverty would provide a beneficial

comparison. Individuals who are not as socially active as those in the present study or those who have limited support from others may have additional facilitators and barriers not identified in this study. Future research with a sample including married individuals and of those living alone in the community may provide an additional perspective. Due to the multiple factors influencing self-care, the ecological model of health behavior may be helpful to understanding how these multiple factors influence specific health behaviors, and ultimately support the need for further exploration with this model to develop nursing interventions for the HF population.

Implications of the Research for Nursing Practice with Vulnerable Populations

The purpose of this study was to render a more complete understanding of the self-care behaviors, facilitators, and barriers to engaging in HF self-care among a vulnerable population of low income, urban dwelling African Americans. The qualitative findings in the present study have implications for nursing practice. This section will provide suggestions for how nurses may be able to promote self-care behaviors for this vulnerable population. Based on the findings from this study, it appears that assessing self-care management behaviors and the decision making skills of HF patients are important first steps.

It was previously identified in the literature review that adequate knowledge and decision making skills are needed to improve engagement in HF self-care behaviors. For some of the present study participants, lack of knowledge and/or a difficulty initiating appropriate decision making skills were identified as a barrier to symptom recognition and management. Results from the SCHFI indicated that the participants had inadequate

self-care management behaviors. Additionally, limited discussion regarding self-care management occurred, which made it difficult to accurately assess knowledge and decision making skills involving self-care management behaviors of the participants. Participants had adequate knowledge of self-care maintenance behaviors but had difficulty making appropriate decisions when barriers were present. Participants also had insufficient self-care management behaviors. These findings may suggest that current teaching sessions with patients skip the steps of decision making in both self-care maintenance and self-care management. A teaching session that begins with an overall assessment of the patient's self-care behaviors including self-care management behaviors could be informative. This may assist in identifying the patient's knowledge level and the decision making process that is used to recognize changes in symptoms, evaluate the symptoms, respond to symptoms by implementing a treatment, and evaluate that treatment.

Self-care confidence was also inadequate based on the SCHFI mean scores. Further analysis suggested that the participants were confident that they could follow their treatment advice. Additionally, participants were less confident that they could keep themselves free of HF symptoms, do something to relieve symptoms, and evaluate the effectiveness of a remedy. It would also seem that if one lacks knowledge or has difficulty using decision making skills to engaging in self-care maintenance or self-care management behaviors, one would also not be confident to engage in those behaviors. This may indicate the need for additional assessments of a patient's knowledge and decision making skills, in addition to assessing how confident he or she is when engagement in these behaviors is necessary.

Knowing that the participants in this study had low self-care management and self-care confidence scores plays an important role when developing nursing interventions. Previous studies have identified that individualized nursing interventions that focused on self-care management and goal setting were effective in improving self-care confidence (Paradis et al., 2010). Increasing confidence levels is a predictor for positive self-care behaviors (Meyerson & Setter-Kline, 2009; Schnell-Hoehn et al., 2009), thus supporting that nursing interventions should be designed to increase confidence to engage in both self-care maintenance and self-care management behaviors. Focused interventions have increased patients' quality of life (Scott et al., 2004), self-efficacy in managing symptoms (Setter-Kline et al., 2007), and overall medication adherence (Mohammadi et al., 2009). Social support, both informal and formal, were described as critical in goal development (Meyerson & Setter-Kline, 2009). Nursing interventions that included family members resulted in improved self-care management behaviors (Shearer et al., 2007) as well as overall self-care (Riegel et al., 2006). These findings support the importance of individualized nursing interventions and collaborative goal setting to promote self-care behaviors.

Individualized nursing interventions have been found to improve self-care behaviors. It is also presumed that there are many factors that act as facilitators and barriers present for those engaging in HF self-care. The use of interventions based on the ecological model is thought to be most effective when targeting change at several levels of influence (Sallis et al., 2008). It would appear after further examination that the ecological model of health behavior would be beneficial to use while developing nursing interventions that promote self-care behaviors; this is due to the multidimensional factors

that are present as individuals engage in self-care. The use of the ecological model promotes the identification of the most relevant influences at each level, but multiple interventions are needed. It is likely that patients similar to the participants in the present study would benefit from interventions that are multidimensional and comprehensive. The following paragraphs include additional suggestions for nursing practice based on the facilitators and barriers described in this study.

Informal social support was identified as facilitating positive self-care maintenance behaviors in this sample. Participants reported that support from friends and family members was extremely beneficial in facilitating self-care. Assessments may evaluate patient's support system, inquiring who the patient lives with, who helps them with their health needs, and how that person helps them. It may be necessary for nurses to acknowledge that the patient's main form of social support could be a close friend or an extended family member. Encouraging family members and/or friends to come to medical appointments and be included in the patient's plan of care may result in additional social support for the patient. Because friends and family members have been identified as instrumental in promoting self-care maintenance, it would seem that including them in the development of interventions, goals, and teaching sessions would provide benefits for the patient.

Special acknowledgement was given to the nurses and social work case managers that were employed in the public housing buildings. The case managers were identified as providing support within the participants' immediate environment; the provided support was described as aide that made it easier for the participants to maintain health and to better their condition. Unfortunately, these types of services are not available to

the majority of patients with HF. It may be beneficial to assess if referrals to home care agencies that provide nursing and social work case management are available to some patients. Also, knowing that supportive relationships between nurses and patients have facilitated self-care behaviors in this sample may encourage nurses to take time to develop a therapeutic relationship. Asking the patient how the nurse can assist him or her with self-care behaviors might be an important step as well.

The majority of participants in the present study verbalized engaging in exercise for at least 30 minutes each day. Many participants took photographs of their own exercise equipment and the equipment in the common exercise room. Three participants verbalized that they could not participate in 30 minutes of continuous exercise due to their limited functional status, but did verbalize walking or participating in some other form of physical activity each day. Nurses can assess what type of exercise their patients are participating in. Nurses can help patients understand the importance of exercise and instruct them about what type of exercise would be appropriate. Additionally, alternative types of exercise such as chair exercises and implementing a walking program for patients may be beneficial.

Several barriers to engaging in self-care maintenance behaviors were identified in this study. These included feeling depressed, interruption in provider care, environmental stressors, and dietary challenges. Intermittent episodes of feeling depressed were described as the primary barrier to engaging in HF self-care maintenance. Participants reported that when feeling depressed, they often did not leave their apartments. Furthermore, they reported not taking their pills and either failing to eat anything or eating foods inappropriate for their dietary restrictions. It is important that patients have

continued dietary and medication adherence; neglecting parts of a HF treatment regimen often results in worsening HF. It may be beneficial for nurses to assess all patients with HF for depressive symptoms. Open discussions about depression may encourage patients to share whether or not they are experiencing depressive symptoms. Nursing interventions that focus on ways to alleviate or prevent depressive symptoms could be helpful and need to be explored further.

In this study, supportive relationships with health care providers were described as promoting self-care behaviors, while poor relationships with health care providers were identified as a significant barrier. For some, medication and medical supervision ended when the patient perceived that their health care provider was not providing a supportive relationship. This poor relationship was described as occurring when their physicians addressed their needs with another medication prescription instead of further discussion or investigation into the patients' symptoms or complaints. This poor relationship led participants to seek care from a different health care provider that would take time to listen to their concerns and address their needs regarding medication management. This highlights the importance of the provider-patient relationship. Findings from this study support the notion that active involvement in medication assessment and teaching helps improve the perception of a supportive relationship. Intermittent medication teaching that includes verbal and written instruction, medication teaching with new prescriptions, and evaluation of the teaching session may all improve provider-patient relationships and medication adherence.

Stress-inducing situations in the immediate environment were also noted as a barrier to engaging in HF self-care behaviors. A few participants described several

stressors within their environment. Stressors included: a lack of support from management to build and maintain a flower garden, neighbors who burglarized the vegetable garden, and garbage in common areas. These particular barriers were not previously identified in the literature review. These environmental stressors contributed to feelings of increased blood pressure. Participants reported these stressors as concerning because they were instructed by their health care providers to avoid stress or situations that elevated their blood pressure. Nurses who acknowledge stressors and show genuine concern may help improve the therapeutic nurse-patient relationship. This improved relationship may promote discussion. Open discussion about the stressors within a patient's environment may help patients develop decision making skills that can be used to decrease the stressors. Putting these individuals in touch with additional resources such as case managers, the public health department, and the sanitation department may decrease some of the environmental factors that are described as stressors. Additionally, nurses can provide information on how to promote discussion among other residents, which may lead to the formation of a small group of residents with common concerns. Although nurses may not be able to change the patient's current living situation, the nurse can provide the patient with interventions that may decrease stress. Interventions may include teaching relaxation techniques, deep breathing exercises, and guided imagery. Information about the negative effects stress can have on the cardiovascular system may be provided as well. Nursing interventions that teach patients how to deal with stress, how to eliminate or decrease stressful situations, and how to promote relaxation may be beneficial.

Although the study participants reported having followed their dietary restrictions,

they acknowledged that they had to overcome constant barriers. Barriers within their immediate environment included the free high sodium food products they were given monthly, the temptation of vending machines available within the buildings, and the close proximity of fast food restaurants. Keeping this in mind, it is not enough just to assess a patient's knowledge regarding dietary restrictions. It is important to evaluating a 3 day dietary recall, and assess how and where a patient gets his or her food products. This will help identify the typical foods a patient is eating and how they are deciding what to purchase. Due to the many dietary challenges noted, referrals to food assistance agencies may be beneficial. Nurses may be able to assist in other ways by assessing what foods their patients enjoy. Nursing interventions could include teaching patients how to purchase and prepare less expensive meals that meet their dietary requirements. For patients similar to the participants in the present study, it is recommended that nurses provide education so patients not only know what types of food to purchase but how to incorporate appropriate foods into their diet when they have limited access to grocery stores or have a limited budget. A strategy to avoid the temptation of purchasing food from vending machines may be as simple as eating a healthy snack before going to areas in the building that have vending machines. Planning meals ahead of time or with other residents may also decrease temptation to go to fast food restaurants.

Conclusion

Being part of the photovoice project allowed me, a white female researcher, to enter into and observe the environment of a small group of African Americans with HF. Because the method employed using participant taken photographs and small group

discussions, I was able, as the researcher, to see intimate details of the participants' lives. The photographs provided me with a visual reproduction of their self-care behaviors.

The photographs also provided a visual explanation of the facilitators and barriers to engaging in HF self-care behaviors within their immediate environment. As I had suspected, family members were identified as the primary facilitator for engaging in self-care maintenance behaviors. I did not expect to find support from friends, nurses, and social worker case managers in their residence as another extremely important facilitator. Having friends constantly available within the building was connected to increased laughter, happiness, and participation in group activities. These activities were perceived as decreasing depressive symptoms. It was a unique, added benefit to these individuals that they had nurses and social worker case managers within their immediate environment 3-5 days per week.

I was surprised to find that there were many environmental constraints present for the participants in this study. A lack of a successful vegetable and flower gardens were significant sources of stress. These stressors caused great frustration for the participants to such an extreme that they reported experiencing increased blood pressures. Other barriers included the free food that was received each month, vending machines, and fast food restaurants. Although one might imagine that receiving free food would be a benefit, the free food consisted of high sodium food items that were harmful for a HF patient. Additionally, vending machines in the buildings and nearby fast food restaurants offered constant temptation to the participants, especially when participants did not feel well or were too tired to prepare meals. Although these barriers were present, all participants in this study expressed how they attempted to overcome these barriers for the

sake of promoting and maintaining optimum health status.

Some of the barriers identified in this study were not previously identified in the literature review. I did not expect to uncover these barriers when I began exploring why people have difficulty engaging in HF self-care. These findings call into question whether these participants lacked decision making skills when faced with barriers or if the environmental constraints were too large to overcome.

Either way these findings emphasize that the environment has an inherent and direct influence on self-care behaviors. For these participants, having friends and case managers within their residence promoted positive self-care behaviors. Although social support was available, other inescapable barriers continued to exist. It is likely that these barriers were not specific to African Americans, but more general barriers present for all those living in low income, urban settings. Because many of the identified barriers were specific to the participants' environmental surroundings, it is imperative that nurses take time to explore the facilitators and barriers specific to the patients under their care.

At the conclusion of this study I returned to each of the low income, public housing buildings to display the photographs taken by the participants. Several of the photographs were enlarged and placed on a poster board with the themes the participants had assigned to them. These photographs were displayed for other residents within the public housing building to view. During this viewing I provided a teaching session on HF for all who attended. The teaching session included signs and symptoms, risk factors, and how to prevent and manage HF. A question and answer session also occurred. The participants from the study were present during the presentation and shared their photographs and stories with the residents of the building.

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APPENDICES

Appendix A

Definitions of Social Support

Type of Support	Definition	Reference
Social Support	Perception of support one receives from others in the environment.	Zimet et al., 1988
Formal Support	Perceived support provided by formal helping agents; this includes physicians, nurses, and other medical professionals.	Cohen et al., 2000
Informal Support	Reliable assistance provided by friends, family, or colleagues.	Moorhead et al., 2008
Forms of Support	Definition	Reference
Emotional Support	Expressions of understanding and encouragement.	House et al., 1988
Instrumental Support	Includes tangible, practical, physical, or material assistance.	House et al., 1988
Informational Support	Advice or guidance.	House et al., 1988

Appendix B

Demographic Data

DEMOGRAPHIC DATA **(Please take a few moments to answer these questions)**
Sex:
Age:
Marital or relationship Status:
Do you feel your monthly income is: Not enough_____ Just enough_____ More than enough_____
Please list the medications you take each day.
How much money do you spend each month on medication?
When were you diagnosed with Heart Failure?
What have you been told to do to stay healthy with Heart Failure?
Who told you this?
What other diseases or chronic illness do you have?
Who helps you manage your chronic illnesses?
Please share any additional comments, questions or concerns about Heart Failure or any of your other chronic health conditions:
Please return questionnaire to: Aimee Woda

Appendix C

The Mini-Cog

Instructions for Mini-Cog
1. Instruct the patient to listen and remember 3 unrelated words. Ask the participant to repeat the words:
    a. Apple
    b. Penny
    c. Watch
2. Give the participant a piece of paper with a blank clock; this is the Clock Distracter Test (CDT). Instruct them to draw the hands of the clock on a specific time. Instructions may be repeated, but no additional instructions may be provided. This task is a distracter.
    a. Draw the hands of the clock on at 35 minutes past one o'clock.
3. Ask the participant to repeat the 3 words previously stated.

Mini-Cog Scoring Algorithm
One point is given for each correctly recalled word after the CDT.
Score
0   Positive for dementia or cognitive impairment

1-2   If CDT is also incorrect then positive for dementia or cognitive impairment

1-2   If CDT is correct then negative for dementia or cognitive impairment
3   Negative screen for dementia, the score of the CDT is not needed

Appendix D

New York Heart Association Classification

Functional Capacity	Objective Assessment
Class I. Patients with cardiac disease but without resulting limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea, or anginal pain.	**A.** No objective evidence of cardiovascular disease.
Class 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.	**B.** Objective evidence of minimal cardiovascular disease.
Class 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.	**C.** Objective evidence of moderately severe cardiovascular disease.
Class 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 is increased.	**D.** Objective evidence of severe cardiovascular disease.

*The Criteria Committee of the New York Heart Association. *Nomenclature and Criteria for Diagnosis of Diseases of the Heart and Great Vessels*. 9th ed. Boston, Mass: Little, Brown & Co; 1994:253-256.

Appendix E

SELF-CARE OF HEART FAILURE INDEX

All answers are confidential.

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

SECTION A: Listed below are common instructions given to persons with heart failure.

How routinely do you do the following?

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

SECTION B: Many patients have symptoms due to their heart failure. <u>Trouble breathing and ankle swelling</u> are common symptoms of heart failure.

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

    0) No

    1) Yes

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

(circle **one** number)

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

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

(circle **one** number for each remedy)

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

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

(circle **one** number)

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

SECTION C:

In general, how confident are you that you can:

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

THANK YOU!

Appendix F

Self-Care of Heart Failure Index Scoring Instructions

Updated February 17, 2009

There are 3 summary scale scores within the Self-Care of Heart Failure Index (SCHFI). Each scale score is standardized to a 0 to 100 range.

1. Self-care maintenance (Section A)

Self-Care Maintenance Score. Note that if you are using the 10 item scale, there is a reverse scored item (# 8). First reverse code item #8. That is, 4=1, 3=2, 2=3, 1=4. After reverse coding, the lowest possible raw scale score is 10. The raw score indicating the best self-care maintenance is 40. Thus, for raw scores of 10 to 40, use the following formula to compute a standardized self-care maintenance scale score:

$$((\text{sum of Section A items})-10)*3.333$$

If you are using the 5 item version, the lowest possible raw scale score is 5. The raw score indicating the best self-care maintenance is 20. Thus, for raw scores of 5 to 20, use the following formula to compute a standardized self-care maintenance scale score:

$$((\text{sum of Section A items})-5)*6.667$$

Note: More than half of the items in this section should be answered for the scale to be an adequate measure of self-care maintenance. If all items are not answered, you will need to adjust the math using the following general formula: sum of items minus lowest possible raw scale score divided by the range of scores and multiply by 100. The phrase "range of scores" refers to the difference between the lowest possible raw score and the highest possible raw score.

2. Self-care management (Section B)

Score this scale only if the patient said **yes (1)** to having trouble breathing or ankle swelling in the past few months. Otherwise, ignore responses, even if the patient answers the items. Note that this first item (In the past month, have you had trouble breathing or ankle swelling?) is used only for this purpose and not in the scale score.

Code the responses to the rest of the items in Section B as 1 to 4 except for the first (How quickly did you recognize it as a symptom of heart failure?) and last (How sure were you that the remedy helped or did not help?) items in the section. These items have a true 0 possible.

Self-care Management Score should also be standardized. The highest possible raw score is 24, and the lowest possible raw scale score is 4. Thus, use the following formula:

$$((\text{sum of Section B items})-4)*5$$

Note: A commonly skipped item is "Take an extra water pill." If the patient is not taking a diuretic, this item can be skipped. Just adjust the total possible items when standardizing the score. Other items are rarely missing. If they are, they can be assumed to reflect the lowest score possible (0 or 1). Note that at least 2 of the 4 possible remedies (items 12-15) must be answered for the scale to be an adequate measure of self-care management.

3. Self-care confidence (Section C)

Self-care Confidence Score should be standardized as described above. The highest

possible score is 24, and the lowest possible scale score is 6. Thus, please use the following formula:

$$((\text{sum of Section C items})-6)*5.56$$

If you are using the 4 item version, the lowest possible raw scale score is 4. The raw score indicating the best self-care confidence is 16. Thus, for raw scores of 4 to 16, use the following formula to compute a standardized self-care confidence scale score:

$$((\text{sum of Section C items})-4)*8.333$$

Note: More than half of the items in this section should be answered for the scale to be an adequate measure of self-care confidence.

DO NOT SUM THE THREE SCALE SCORES; USE THEM AS SEPARATE SCORES.

Appendix G

Personal Health Questionnaire Depression Scale (PHQ-9)

Name _____ Date _____

Over the *last 2 weeks*, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

(For office coding: Total Score ____ = ____ + ____ + ____)

Appendix H

Consent Form for Photovoice Participants

Protocol Number: HR-2179

Human Subject Consent Form
MARQUETTE UNIVERSITY
AGREEMENT OF CONSENT FOR RESEARCH PARTICIPANTS
Photovoice Intervention Group
Aimee Woda, Principal Investigator
College of Nursing

You are invited to participate in a research study. Before you agree to participate, it is important that you read and understand the following information. Participation is completely voluntary. Please ask questions about anything you do not understand before deciding whether or not to participate.

PURPOSE: I understand that the purpose of this study is to develop an understanding about what motivates African Americans with Heart Failure (HF) to perform HF self-care. HF self-care involves making choices regarding behaviors involving physical stability or maintenance and symptom management.

PROCEDURES: I understand that I will be asked to complete two questionnaires about self-care activities involving heart failure, demographic data, a cognitive test and I will be assigned functional classification. I understand that I will meet in a group with five to six other people with HF. This group will meet for two hours per week for six weeks in a private location within the building I reside. I will be asked to take pictures of things that motivate me and things that make it difficult for me to perform HF self-care. I understand that I will be asked to talk about the pictures I have taken and what they mean to me. I understand that notes will be taken by the researchersand that the group meetings will be recorded. For confidentiality purposes my name will not be used, only a name I select for this project. I understand that I may choose which pictures I discuss each week as well as which pictures can be used in a public display. I understand that I will be invited to attend an optional meeting with all of the research participants to organize a public showing of the photographs taken for this study. I understand that this meeting is not required.I understand that I will be invited to the public showing of the photographs taken by myself and the other participants. I understand that there may be other participants, their family members and friends, community member and health care professionals in attendance.

DURATION: I understand that I will meet with the group for two hours per week for six weeks. An optional meeting at the conclusion of the study may be attended, as well as the photo showing. I understand that there is no minimum requirement for the number of pictures I take each week, and that I will take pictures independently in my free time.

RISKS: I understand the risks associated with participation in this study. I may feel uncomfortable talking about my chronic illness. I understand that by participating in this project other people will know that I have HF. I understand that I do not have to answer questions or share information that I would rather keep private. I may withhold information that I would rather not share with the group. I understand that I should refrain from taking any photographs that may put me in an uncomfortable or dangerous situation.

Protocol Number: HR-2179

BENEFITS: I understand the benefits associated with participation in this study. I will have the opportunity to explore and discuss what helps motivate me to perform HF self-care, as well as obstacles that I face. I may learn more about Heart Failure through group discussion.

CONFIDENTIALITY: I understand that all information I reveal in this study will be kept confidential. All my data will be assigned an alias name rather than using my name or other information that could identify me as an individual. I understand that my identity will be protected on the questionnaire and the tape recordings of the meetings. However, the researchers cannot protect my identity within the group. I understand that my identity and that I have HF may be disclosed to others in the public display. When the results of the study are published, I will not be identified by name. Photos, original recordings, electronic copies of transcribed group meetings with identifiers removed, will be stored in a password protected file on principal investigator's computer. Informed consents and questionnaires will be kept in a locked file cabinet in the principal investigator's office. Consents, demographic questionnaires and original electronic recordings of the group meetings will be kept for 3 years and then destroyed. Photos that were discussed during the study will be de-identified and saved in a separate file. All other photos will be deleted from the laptop computer at the end of the study. The de-identified database, transcripts and photos will be kept indefinitely and may be used in future studies or used to teach students about research. My research records may be inspected by the Marquette University Institutional Review Board or its designees, Sigma Theta Tau International and (as allowable by law) state and federal agencies.

COMPENSATION: At the close of each of the sessions 1-5, I will receive a $5.00 grocery gift card. Upon completion of the week six photovoice session, the second survey and return of the digital camera, I will be given a $35.00 grocery store gift card. I understand that I will not be compensated for the optional meeting that invites all of the study participants to help organize and plan the photo display. I understand that if I choose to attend this meeting I will be provided with a bus ticket for transportation to and from the meeting. I also understand that I may attend the public photograph display. I understand that I will not be compensated and I will not receive transportation to attend the public photograph display.

EXTRA COSTS TO PARTICIPATE: I understand that I will not have to travel outside of my building to participate in any of the photovoice discussions week 1-6. The group discussions will take place in a private room within the public housing building in which I reside. At the completion of all the group meetings I may attend an optional meeting to organize the public showing. Should I need to travel to this meeting, compensation for a bus ticket will be provided to and from the group meeting. If I choose to attend the public showing of the photographs, and it is not located within the building I reside, I will be responsible to find my own transportation to attend this event.

INJURY OR ILLNESS: I understand that Marquette University will not provide medical treatment or financial compensation if I am injured or become ill as a result of participating in this research project. This does not waive any of my legal rights nor release any claim I might have based on negligence.

Page 2 of 3

Protocol Number: HR-2179

VOLUNTARY NATURE OF PARTICIPATION: I understand that participating in this study is completely voluntary and I may withdraw from the study and stop participating at any time without penalty. If I withdraw from the study, the photographs and information I provided will not be used in the study's results. I may skip any questions in the group meetings or on the questionnaire that I do not want to answer. I may feel uncomfortable talking about things that affect my health. I do not have to answer questions or share information that I would rather keep private. During the group meetings, I am free to respond in my own way. I understand that the researchers cannot protect my privacy or identity within the group. I will be asked to maintain one another's privacy. However, it cannot be guarantee that other members in the group will maintain my privacy. The group will be reminded not to share comments or information with others outside of this group. I also understand that at any time I can withdraw my photographs from the public display.

CONTACT INFORMATION: If I have any questions about this research project, I can contact Aimee Woda 288-3865 or aimee.woda@marquette.edu. If I have questions or concerns about my rights as a research participant, I can contact Marquette University's Office of Research Compliance at (414) 288-7570 or orc@marquette.edu.

I HAVE HAD THE OPPORTUNITY TO READ THIS CONSENT FORM, ASK QUESTIONS ABOUT THE RESEARCH PROJECT AND AM PREPARED TO PARTICIPATE IN THIS PROJECT.

_____   _____
Participant's Signature   Date

_____
Participant's Name

_____   _____
Researcher's Signature   Date

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Appendix I

Procedure for Obtaining Photo Consent

1. Read the information card to the person you would like to photograph.
2. Ask the person(s) if you could take their picture and describe the general idea for the photograph. For example, "I would like to take a picture of you talking on the phone."
3. Give them the consent to be photographed. Explain that you have to have their written permission to take their pictures. Tell them that you will be talking with other people on the research team about how the picture represents something that influences how you take care of your heart failure. The picture may be shown to others in a public photo show or included in a written article about the study. You will not give out their name but they may be recognized by people who know them.
4. If the person(s) is under 18, ask to speak with a parent or guardian. Repeat steps one through three with the parent/ guardian.
5. Have the minor and the parent/guardian sign the consent form. EXCEPTIONS: The consent will not be explained to children under 2, the parent must sign the consent form. Children aged 2-5 will be explained why their picture is being taken and asked for permission. Parental written consent will be gathered for children aged 2-5.
6. Place the consent form in an envelope and seal it. Write photo consent on the outside and return it to the researcher at the next group meeting.
7. If they are willing to have their picture taken, and after they sign the consent, you may take their picture.

Appendix J

Photovoice Information Card

I am a part of a research study. We are doing a research project with a nursing instructor from Marquette University. We want to learn about what makes it easy or difficult for people to take care of their heart failure.

We are taking pictures of images that remind us of things that make it easy or difficult to take care of our heart failure. We will use some of the pictures in a public photo display about heart failure.

In the future, we hope the information we learn from this study will help other people who have heart failure.

If you have any questions about this study, please contact Aimee Woda MSN, RN (414) 587-0129.

Appendix K

Consent to be Photographed

Protocol Number: HR-2179

Human Subjects Consent Form
MARQUETTE UNIVERSITY
AGREEMENT OF CONSENT FOR RESEARCH PARTICIPANTS
Aimee Woda, Principal Investigator
College of Nursing

Assent/Consent to be Photographed

I agree to have my picture taken for the *Motivation in African Americans with Heart Failure: A Photovoice Intervention* research project being done by people living with heart failure and Nurses from Marquette University. I understand that the participants and nurses who are working on this project will be talking about how the pictures show things about taking care of heart failure. I will not be identified by name in these conversations. I agree that my photo may be used in a public display of photos or included in a written article about things that make it easy or difficult to take care of heart failure and my name will not be used. I understand that even though my name will not be included when my picture is shown, that people may recognize me from the picture. I understand I will not be paid.

I have read this consent form and I agree to be photographed for the *Motivation in African Americans with Heart Failure: A Photovoice Intervention* research project.

_____   _____
Signature   Date

_____
Name (please print)

I am 18 or older (circle one)   Yes   No

If under 18, a parent or guardian must also sign this consent form.

Parent signature (for those in the photo under 18 years old).

I have read this consent form and I agree to allow my child to be photographed for the *Photovoice* research project.

_____   _____
Parent Signature   Date

_____
Name (please print)

Appendix L

SHOWeD Acronym used for Photovoice Group Discussions

SHOWeD is an acronym for:

What do you **S**ee here?
What is really **H**appening here?
How does this relate to **O**ur lives?
Why does this situation, concern, or strength exist?
What can we **D**o about it?

Appendix M

Prompt Questions for Group Discussion

Tell me more about that.
How does that affect your how you take care of yourself?
How do you follow your treatment advice?
You said……can you explain what that means?
What do you do when faced with that obstacle?
Why do you see that as an obstacle?
You said that (someone) provides you with (support, knowledge, etc).
How does that person do that?
What does that person do?

Appendix N

What is Congestive Heart Failure?

If you have congestive heart failure, you're not alone. About 5.0 million Americans are living with it today. In fact, it's one of the most common reasons people 65 and older go into the hospital. It can take years for heart failure to develop. So if you don't yet have it but are at risk for it, you should make lifestyle changes now to prevent it!

Normal Heart — Left ventricle

Heart Failure — Enlarged heart
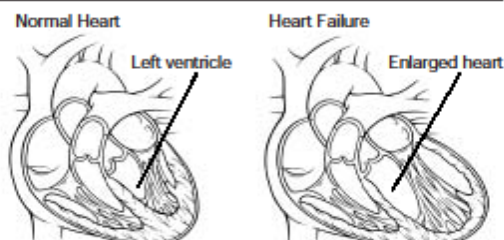
Heart failure symptoms usually develop over weeks and months as your heart becomes weaker and less able to pump the blood that your body needs. Heart failure usually results in an enlarged heart (left ventricle).

Does your heart stop?

When you have heart failure, it doesn't mean that your heart has stopped beating. It means that your heart isn't pumping blood as it should. The heart keeps working, but the body's need for blood and oxygen isn't being met.

Heart failure can get worse if it's not treated. It's very important to do what your doctor tells you to do. When you make healthy changes, you can feel a lot better and enjoy life much more!

What can happen?

- Heart does not pump enough blood.
- Blood backs up in veins.
- Fluid builds up, causing swelling in feet, ankles and legs. This is called "edema."
- Body holds too much fluid.

- Fluid builds up in lungs, called "pulmonary congestion."
- Body does not get enough blood, food and oxygen.

What are the signs?

- Shortness of breath, especially when lying down
- Tired, run-down feeling

- Swelling in feet, ankles and legs
- Weight gain from fluid buildup
- Confusion or can't think clearly

What are the causes?

- Clogged arteries don't let enough blood flow to the heart.
- Past heart attack has done some damage to the heart muscle.
- Heart defects present since birth.

- High blood pressure.
- Heart valve disease.
- Diseases of the heart muscle.
- Infection of the heart and/or heart valves.

Appendix O

How Can I Live With Heart Failure?

About 5 million Americans are living with congestive heart failure today. In fact, it's one of the most common reasons people 65 and older go into the hospital.

Fortunately, heart failure can be treated. Getting good medical care, following doctor's orders and learning about heart failure will help you lead a comfortable life.

You can help by taking your medicine as your doctor tells you, and by following your eating and exercise plans.

What medicine might I take?

Here are some examples:

1. Angiotensin Converting Enzyme (ACE) Inhibitor — lowers blood pressure and decreases the heart's workload.

2. Angiotensin Receptor Blocker (ARB) — lowers blood pressure.

3. Diuretic — helps your body get rid of extra water and sodium.

4. Beta-blocker — lowers blood pressure and slows heart rate.

5. Digoxin — helps your heart pump better.

6. Vasodilator — lowers blood pressure by relaxing blood vessels and allowing them to open (dilate).

What will help me get better?

- Visit the doctor and follow his or her advice.
- Read food labels and avoid foods high in salt or sodium.
- Start an aerobic exercise plan as your doctor advises.
- Keep up your interests and be upbeat!

My doctor's advice

Ask your doctor to fill in the blanks with recommendations that will help you recover.

Medicine Notes: _____

Diet Notes: ___Example: No salt allowed_____

Exercise Notes: _____

Appendix P

Reading Guide for the Matrix of Refined Codes

To complete the Matrix #2 Refined Codes, the Matrix #1 for Facilitators and Barriers of HF self-care was reread and direct quotes were copied from the original matrix and entered into the Matrix #2 Refined Codes. Matrix #1 was read in sequential order: first for knowledge and decision making, then for social support—both formal and informal—health status, socioeconomic status, race and culture, self-efficacy, personal attitudes, and finally beliefs. A final reading was done to identify any additional codes that had not yet been identified. The following identifies the topic codes with examples of potential acceptable participant responses. The responses were then copied and placed in the appropriate facilitator or barrier code based on characteristic self-care maintenance or self-care management behaviors.

Self-Care Behaviors

Self-care maintenance reflects behaviors used to maintain physiologic stability, symptom monitoring, and treatment adherence. This involves following a treatment plan and living a healthy life. These may include taking medications, eating a low sodium diet, monitoring fluid intake and daily weight, exercising, and actively monitoring HF symptoms (Riegel, Lee et al., 2009). Self-care management is the decision making response to symptoms as they occur: recognizing a status change, evaluating the change, taking action, implementing treatment, and evaluating that treatment (Riegel, Lee et al., 2009). Self-care confidence is the confidence to engage in each phase of self-care maintenance and self-care management (Riegel, Lee, Dickson, & Carlson, 2009).

HF knowledge and decision-making. HF knowledge can include possessing an understanding of HF, HF symptoms, signs of worsening symptoms, low sodium food selection, medication uses and actions, and the prevention of HF exacerbations (Artinian et al., 2002; Moorhead et al., 2008). Naturalistic decision-making is process-focused and is based on the information available at the time of decision-making (Lipshitz et al., 2001). This included any participant comments regarding their knowledge of treatment regimens or response to symptoms, ways to increase their knowledge, or lack of knowledge. Comments included the decisions that were made, or how they made decisions to engage in self-care behaviors.

Formal support. Formal support is defined as the appropriation of formal helping agents; this includes physicians, nurses, and other medical professionals (Cohen et al., 2000). Examples of formal support included healthcare provider instructions for following treatment plans, assessments, discussions, follow ups, and so on. Also noted was the various lack of the aforementioned activities.

Informal support. Informal support is the reliable assistance provided by friends, family, or colleagues (Moorhead, Johnson, Maas, & Swanson, 2008). This included participant comments that discussed support from a family member, friend, or colleague that provided them with some benefit. It also involved social interaction and conversation that encouraged participants to follow their treatment plans by providing instrumental, informational, or emotional support, etc.

Health status. Health status is defined as a person's functional capabilities, symptoms associated with activities of daily living (ADL's), and physical or psychological well-being (Myers et al., 2006). Participant comments that discussed any

physical or psychological ailment were included. This may include verbalization of how one's health affects participation in self-care, or how self-care affects health.

Socioeconomic Status. This included any comments by participants that made reference to their income or lack thereof, education, or social standing.

Race and Culture. This included any comments made about being "African American" or "Black." Comments also included topics of racism and discrimination. Comments about traditions or cultural practices that may have influenced self-care behaviors were also included.

Personal beliefs, attitudes, and beliefs. Comments that described a belief in being in control over one's own health were included. This section also included personal beliefs or attitudes about any of the self-care behaviors, or a description of how these attitudes and beliefs influenced self-car behaviors.

Miscellaneous. Participant comments that presented a facilitator or barrier that did not fit in the defined categories above were entered into the miscellaneous section, and therefore require further analysis.

Appendix Q

Reading Guide for Matrix #3 HF Self-Care New Concepts

During the analysis of the Matrix #2 Refined Codes, it became evident that additional columns needed to be added for newly-identified concepts. The Matrix was again analyzed, quotes were moved into the three newly-identified concepts of counterbalance, pleasant activities, and self-monitoring (described below). Particular attention was paid to patterns. These patterns were identified by bold headings within the respective column. Data was also clustered within these patterns. The quotes that had been identified as part of the "other" category were analyzed again to ensure they fit within one of the newly-established columns. No changes were made to the original topic codes within the previous matrix.

Counterbalance. Counter balance was viewed as both a facilitator and a barrier. Quotes that described potential barriers, while being outweighed as facilitators, were placed in this column. Examples of this included quotes describing the dislike, yet need, for medications, or the reasons why the participants continued to take them. Quotes also included the barriers to eating a low sodium, low fat diet and the reasons why they choose to eat healthy.

Pleasant activities. This included any quotes that discussed activities that positively influenced patients' health status. Examples included listening to music, watching TV, gardening, plant maintenance, caring for pets, socializing during card games or bingo; patients discussed along with these topics the perceived affects they had on their health status. This included relaxation, decreased stress, and decreased

depressive symptoms.

  Self-management of illness. Self-management included making therapeutic, behavioral, and environment adjustments. Quotes that reflected participant descriptions of adjustments made within their life to treat new symptoms were included. This included symptoms that could be associated with depression, HF, or other chronic illnesses.