

11-5-2014

# The Lived Experience of African American Caregivers Caring for Adult African American Patients with Heart Failure: A Phenomenological Study

Heather Marie Hamilton

*University of Connecticut - Storrs*, [heather.morrison@uconn.edu](mailto:heather.morrison@uconn.edu)

Follow this and additional works at: <https://opencommons.uconn.edu/dissertations>

---

## Recommended Citation

Hamilton, Heather Marie, "The Lived Experience of African American Caregivers Caring for Adult African American Patients with Heart Failure: A Phenomenological Study" (2014). *Doctoral Dissertations*. 631.  
<https://opencommons.uconn.edu/dissertations/631>

The Lived Experience of African American Caregivers Caring for Adult African American Patients  
with Heart Failure: A Phenomenological Study

Heather Hamilton, PhD, RN

University of Connecticut, 2014

Abstract

An estimated 5.7 million people in the United States are currently living with heart failure (HF); this population is expected to double in the next 25 years due to advances in modern medicine that have decreased the mortality rates for cardiovascular diseases. Because of the complex regimen required, the help of family members, friends or neighbors is crucial to adequately managing symptoms and preventing hospital readmissions. Descriptive phenomenology underpins this study. Formal interviews were used to explore African American caregivers' lived experience in caring for African American heart failure patients. Snowball sampling and purposive sampling yielded a total of 10 interviewed participants, which achieved data saturation.

The interviews were analyzed using Colaizzi's steps. Seven themes emerged:

(1) Juggling act, (2) Layers of support, (3) Realization of self-neglect, (4) Experiencing the "blues," (5) Connecting with healthcare provider, (6) Unmet financial needs and (7) Perception of non-adherence. Thorough information regarding the experience of African American caregivers of heart failure patients obtained through this research will enhance the resources available to healthcare professionals for delivering culturally competent support to African American caregivers, thereby improving quality of life for heart failure patients and their caregivers.

Key words: Heart Failure, African Americans, Caregivers, and Phenomenology

The Lived Experience of African American Caregivers Caring for Adult African American Patients  
with Heart Failure: A Phenomenological Study

Heather Hamilton, MSN, RN

B.A., Rutgers University, 2001

MSN. , Rutgers University, 2005

A Dissertation

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

at the

University of Connecticut

2014

Copyright by  
Heather Hamilton, MSN, RN

2014

APPROVAL PAGE

Doctor of Philosophy Dissertation

The Lived Experience of African American Caregivers Caring for Adult African American Patients  
with Heart Failure: A Phenomenological Study

Presented by

Heather Hamilton, MSN, RN

Major Advisor \_\_\_\_\_  
Cheryl Beck, DNSc, CNM, FAAN

Associate Advisor \_\_\_\_\_  
Xiaomei Cong, PhD, RN

Associate Advisor \_\_\_\_\_  
Juliette Shellman, PhD, RN

University of Connecticut  
2014

## Acknowledgement

I would like to thank God, my family, friends, and advisors who have helped me along this journey.

To God, thank you for the blessings you have bestowed upon me throughout my time as a student at the University of Connecticut, School of Nursing.

Dr. Regina Cusson, and Elizabeth Polifroni, thank you for your endless support to ensure my success in this program.

I would like to thank my advisor Cheryl Beck, my associate advisors Juliette Shellman, and Xiaomi Cong, and my readers Desiree Diaz, and Kelly Newlin Lew.

To my family and friends, thank you for your love and support. To my sisters, Semone Morrison, Stacy- Ann Lambert, and Nickesha Lambert, thank you for your encouragement and guidance when I needed it most.

To my husband Horace and my 5-year-old sunlight, Abigail, thank you for each sacrifice you have made to ensure my success in this program.

To my mother Betty-Ann, I wish you had the opportunity to share this moment with me.

## Table of Contents

Approval page	iv
Acknowledgement	v
Table of Contents	v
Chapter 1. Introduction to African American caregivers	1
Background	1
Purpose of the study	6
Research Question	6
Significance and Relevance to Nursing	6
Summary	8
Chapter 2. Review of Literature	9
African American Culture and its Caregivers	10
African American Caregivers vs. Caregivers from Other Ethnic Backgrounds	15
Caring for Patients with Conditions Other than Heart Failure.	
Caregivers of Heart Failure Patients	18
Caregivers' Role in Managing the Health of Heart Failure Patients	22
Caregivers Emotions	30
Chapter 3. Method of Inquiry	38
Research Question	38
Philosophy of Phenomenology	38
Research Design	45
Protection of Participants.	46
Recruitment of Participants	47
Data Collection	49

Data Analysis	51
Methodological Rigor	52
Conclusion	53
Chapter 4: Results	54
Sample	54
Table 1: Demographic Sample	55
Themes	56
Table 2: Significant Statements, Formulated Meanings, Themes and Sub-themes	57
Theme I: Juggling Act	65
Theme 2: Layers of Support	76
Theme 3: Realization of Self-Neglect	70
Theme 4: Experiencing the “Blues”	72
Theme 5: Connecting with the Health Care Provider	75
Theme 6: Unmet Financial Needs	77
Theme 7: Perceptions of Non-Adherence	79
Exhaustive Description	82
Chapter 5. Discussion of Findings	84
Implications for Nursing Practice	101
Implications for Nursing Education	104
Future Research	106
Limitations	108
Conclusion	109
Table 3: New York Heart Failure Classification	112
References	113
Appendix A: University of Connecticut IRB Approval Letter	125



Appendix B: Rev.com Privacy Policy	127
Appendix C: Informed Consent Form	129
Appendix D: Approval Letters from Sites	132
Appendix E: Recruitment Flyer	134
Appendix F: Demographic Table	135
Table 4: Heart Healthy Diets for African Americans	136

## Chapter I

### Introduction to African American caregivers

The purpose of this study was to investigate the lived experience of African Americans who have assumed the responsibility of caring for African American friends, neighbors or family with a diagnosis of heart failure. The African American community consists of many generations of African and Caribbean immigrants, as well as their descendants born in the United States (U.S. Census Bureau, 2012). In this chapter the necessity and purpose of the study are addressed along with an introduction to heart failure and discussion of the particular challenges faced by African American heart failure patients and the assistance they require in maintaining a healthy lifestyle, including the informal caregivers' role in this process.

### **Background**

Heart failure is a chronic, disabling syndrome characterized by systemic perfusion inadequate to meet the body's metabolic demands as a result of impaired cardiac pump function (Heart Failure Society of America (HFSA), 2010). An estimated 5.7 million people are currently living with heart failure in the United States; this population is expected to double in the next 25 years due to advances in modern medicine that have decreased the mortality rates for cardiovascular diseases (American Heart Association (AHA), 2012; AHA, 2014). However, quality of life for many heart failure patients is less than optimal (AHA, 2012; AHA, 2014; HFSA, 2010).

Debilitating physical symptoms, emotional distress, and impaired quality of life are prominent in the lives of heart failure patients. Additionally, they encounter repeated hospitalizations and, in some cases, premature death (Chen, Normand, Wang, &

Krumholz, 2011; Riegel, Moser & Anker, 2009; Zaya, Phan, & Schwarz, 2012). One in every 100 African Americans will develop heart failure by the age of 50, which is 20 times the rate for Caucasian Americans (Bibbins-Domingo et al., 2009). Currently 4.2 percent of the African Americans population, compare to 2.4 percent of the Whites population is living with a diagnosis of heart failure. (AHA, 2012). The American Heart Association (2012; 2014) states that African Americans are more likely to die from heart failure and related complications than Whites.

Historically, the majority of heart failure patients died within 5 years of being diagnosed (Bibbins-Domingo et al., 2009). Now, with new advancements in the treatment of heart failure, patients are living longer. However, many are unable to adequately care for themselves due to frequent symptom flare-ups or other co-morbidities. Many patients need help maintaining the complex regimen necessary to prevent exacerbation of their illness. The more severe the disease, the greater the likelihood for patients to neglect self-care routines and, consequently, patient quality of life suffers. The increased dependency of heart failure patients draws family members, friends and neighbors into the caregiving role - willingly or unwillingly (Humphrey, Kulich, Deschaseaux, Blackburn & Stromberg, 2013).

The role of caregiver has been studied with regard to cancer, dementia, and Alzheimer's patients, but only limited attention has been given to the heart failure population (Clay, Roth, Wadley, & Haley, 2008; Durant et al., 2013; Hamilton, 2013; Lahaie, Earle, & Heymann, 2012; Molloy, Johnston, & Witham, 2005; Molloy, et al, 2008; Rozario & DeRienzi, 2008; Saunders, 2008; Saunders, 2009; Saunders, 2012; Thornton & Hopp, 2011; Woodend et al., 2008). While the role of informal caregivers is

generally similar across a spectrum of illnesses, some characteristics are unique to those caring for heart failure patients; these differences need to be examined. For instance, heart failure patients have a higher incidence of repeated hospitalizations (Saunders, 2012). They also require more complex medical technology to maintain their health, and many heart failure patients need assistance in using such technology (Saunders, 2012; Woodend et al., 2008). This places greater demands on heart failure patients' caregivers compared to those caring for patients with other chronic conditions.

Among African American caregivers, research is available with regard to caregivers for patients with diseases such as Alzheimer's disease, cancer and dementia, but there is only limited knowledge of such individuals caring for African American heart failure patients. A literature review revealed two qualitative studies which address segments of African American caregivers caring for African American patients with heart failure: Thornton and Hopp's (2011) study of African American daughters caring for a parent with heart failure and Durant's et al. (2013) study of the significance of community health advisors providing social support to African American heart failure patients. Because of the chronic nature of heart failure, health determinants and the complex dynamics of African American families, specific research is needed on African Americans providing informal care for friends, relatives or neighbors with heart failure. This qualitative study begins to address that void.

Several studies have discussed the impact of caregivers upon the quality of life of heart failure patients ( Helleø, Eines & Fagermoen,, 2012; Luttik, et al.; 2007b; Luttik, Blaauwbroek, Dijker & Jaarsma, 2007a; Luttik, Jaarsma, Lesman, Sanderman & Hagedoorn, 2009; Molloy et al., 2008; Pressler et al., 2009; Thornton and Hopp, 2011).

Durant et al. (2013) and Thornton and Hopp (2011) are the only studies that focused exclusively on African Americans caregivers. All other studies had a low percentage of African American participants. To date, most studies on caregivers for heart failure patients have focused on spouses as caregivers (Molloy et al., 2005). This is problematic because, while research has shown married people are happier and experience less burden in the caregiver role (Luttik et al, 2007a; Martensson, et.al, 2001; Molloy et al., 2008; Molloy et al., 2005), these findings cannot be generalized to African American caregivers, because the majority of African Americans adults are unmarried (U.S. Census.gov, 2012). More information is needed on African American caregivers who care for African Americans with heart failure.

The Centers for Disease Control and Prevention's (2014) definition of Black or African American will be used in this study. The Centers for Disease Control and Prevention (2014) defines "Blacks or African Americans" as

people having origins in any of the Black racial groups of Africa. The Black or African American population includes people who marked their race(s) as "Black, African Am., or Negro" or reported entries such as African American; Sub-Saharan African (e.g., Kenyan and Nigerian); or Afro-Caribbean such as Haitian and Jamaican according to the US Census Bureau (CDC 2014, p.1).

For the purpose of this study the term "caregiver" refers to an unpaid or informal caregiver, typically a spouse, family member, neighbor or community member who provides services without financial compensation to an individual who is unable to care for him or herself (Family Care Alliance (FCA), 2012).

Services provided by informal caregivers are divided into two categories: activities of daily living (ADL) and instrumental activities of daily living (IADL). Activities of daily living refers to those daily activities necessary to meet one's basic needs, such as bathing, dressing, grooming, feeding and physically moving the patient. Instrumental activities of daily living complement basic physical needs, by helping a person to live as independently as possible. Examples of IADL include taking patients to doctors' appointments, picking up medications at the pharmacy, sorting and arranging medications and ensuring that the patient takes them at the proper time, grocery shopping, cooking and watching the patient's sodium intake (Clark, 2012; FCA, 2012).

In 2009, it was estimated that all services provided by informal caregivers would have cost \$450 billion in a formal setting, such as a nursing home or paid in-home care (FCA, 2012). All informal caregivers provide services that surpass those offered in formal settings. It is estimated that the informal caregiving community is comprised of 34% men and 66% women (FCA, 2012). The average age of an informal caregiver is 40. Women, on average, spend more hours per week than men providing such care. Women caregivers also tend to perform more demanding tasks, such as bathing the patient and providing in-home care. Therefore, the burden on female caregivers is proportionally greater. The same is true for individuals of either gender when caring for a spouse and also for those who spend more hours in the role and perform more challenging functions (FCA, 2012).

Studies consisting of participants from different ethnic groups with a diagnosis of dementia, Alzheimer's disease, and heart failure have shown that competent and effective informal caregivers are associated with better symptom management, less depression, improved quality of life, more efficient self-care, decreased hospitalization, and lower

mortality in patients (Clay et al, 2008; Haley et al, 2004; Hellesø et al., 2012; Humphrey et al., 2013; Luttik et al., 2007a; Pressler et al., 2009; Thornton & Hopp, 2011). Some studies have shown the caregiving role to produce positive emotions for caregivers and heart failure patients, which in turn causes decreased symptoms exacerbation in heart failure patients (Hellesø et al., 2012; Luttik et al., 2007b; Thornton & Hopp, 2011). Nauser, Bakas and Welch (2010) further suggested that the burden associated with caring for others often leads caregivers to neglect their own social, mental, and physical health. Nauser, et al. (2010) observed that such trends may cause these individuals to need caregivers of their own, while negatively affecting the health of those they are caring for.

### **Purpose of the study**

The purpose of this study was to explore and describe the experiences of African-American informal caregivers who provide care to adult African American heart failure patients. A descriptive phenomenological design was used to reach a deeper understanding of the participants' lived experience.

### **Research Question**

The research question was: "What is the lived experience of African- American caregivers caring for adult African Americans living with heart failure?"

### **Significance to Nursing Science**

Low participation in research has limited the information available to clinicians regarding culturally sensitive techniques that could help to optimize the well-being of African American caregivers and the health of heart failure patients. African Americans encounter numerous social, economic, financial, and educational barriers that must be addressed. Healthcare providers should take the African American culture into

consideration when providing direct or indirect health services to this population. For example, African Americans often lack the financial resources (such as health insurance and cash) needed to hire in-home help or to pay for services such as cardiac rehabilitation, physical therapy, and medications (Hamilton, 2013; Hellesø et al., 2012; Luttik et al., 2007b; Thornton and Hopp, 2011). The inability to pay for such services leads informal caregivers to assume the responsibilities of providing the services required to benefit the patient's health.

Thornton and Hopp (2011) stated that in African American communities, caregivers and care recipients are likely to reside in the same dwelling. As a result, they are likely to depend on intergenerational relatives to meet their health needs. Samuel-Hodge et al. (2000) attributed this dependency to increased time devoted to caregiving functions and limited financial resources available to African American caregivers.

Studies by Pressler et al. (2009), Luttik et al. (2007b), and Hellesø et al. (2012) have shown that effective caregiving helps to limit repeated hospital visits. According to Riegel et al. (2009), re-admissions are common among heart failure patients. All these studies asserted that effective instruments are required to accurately assess the needs of caregivers prior to patient discharge. They further argued that providing caregivers with a list of resources available to assist them with their caretaking duties should be an integral part of discharge planning for the heart failure patients. The concerns of the caregivers should be taken as seriously as those of the patients, because many patients will experience exacerbation of symptoms without adequate support from these individuals.

This study is intended to increase awareness of the issues affecting African American caregivers, and the impact these issues have on the African American heart



failure patients for whom they care. The insights obtained from the interviews will benefit other caregivers, and heart failure patients. Information learned as a result of this study can be shared with members of the healthcare workforce and help nurses provide appropriate guidance to their African American heart failure patients and caregivers. The information learned can be shared with the community as well, via churches and other local services. The findings of this study will improve the understanding of caregiver roles and their experiences when providing care to African American heart failure patients. It can also be tailored to other racial groups, as it will be culturally congruent and adaptable to meet the needs of those requiring services.

### **Summary**

This chapter introduced the principal focus of the dissertation, the aim of the study, and a brief overview of the research that supports the need for a research study on caregivers caring for African American heart failure patients. A more in-depth review of literature pertinent to the development of the study follows in Chapter 2. Chapter 2 focuses on African American caregivers, the role of caregiving among African Americans caring for patients with chronic conditions other than heart failure, those caring for heart failure patients, caregiver management of the heart failure patients, and caregivers' burdens. Chapter 3 discusses in detail the design and methods (descriptive phenomenology) used to guide the study. Colaizzi's (1978) phenomenology was used to guide, analyze, and arrive at the "essence" of the findings. Chapter 4 presents the results of the study, and Chapter 5 concludes with a discussion of the study's findings, limitations, implications and conclusions.

## Chapter 2

### Review of Literature

This chapter contains an in-depth review of both qualitative and quantitative literature pertaining to caregivers in general, African American caregivers, and individuals caring for patients living with heart failure. Because heart failure is chronic, progressive and long-term, reliable help is essential as the disease progresses. The particular needs and unique challenges faced by caregivers of heart failure patients are discussed in detail.

The goal of this study is to explore and understand the needs of African American caregivers providing support to members of their community, friends and family members with heart failure. To achieve this goal an analysis of findings from studies of individuals caring for patients with other conditions, such as stroke and dementia, was done. This analysis sets a foundation for assessing whether the dynamics observed among this population can be applied to African American caregivers caring for adult African American heart failure patients.

A search of the literature was conducted using the following databases: CINAHL, Academic Search Premier, Pubmed, Social Work Abstracts, PsycINFO and Knowledge Web. Search terms were “HF,” “heart failure,” “caregivers,” and “African Americans.”

The literature review is divided into five sections as follows:

- 1) African American culture and its caregivers. This section focuses on the characteristics, challenges, and barriers that are unique to the African- American culture, as well as their impact upon African American caregivers.
- 2) African American vs. White caregivers providing care to patients with conditions other than heart failure. This section compares and contrasts the effects of the

- caregiving role on African Americans vs. Whites caring for patients with chronic conditions other than heart failure.
- 3) Caregivers caring for heart failure patients. This section addresses those characteristics that are unique to individuals caring for heart failure patients.
  - 4) Caregivers' role in managing the health of the heart failure patients. The challenges and benefits of the caregiving role in managing the health of heart failure patients is discussed in this section.
  - 5) Caregivers' burden. This section provides an in-depth analysis of the burden placed on caregivers and how it affects their lives and the lives of heart failure patients.

### **African American Culture and its Caregivers**

African Americans, in general, have lower socioeconomic status, less education, and stronger cultural ties compared with the general population (U.S. Census.gov, 2012). The African American culture is highly complex, and members of this ethnic group often take a different view of the caregiving role than do many other groups. Unique cultural beliefs, practices, and levels of acculturation sometimes result in different needs. Kramer (1997) and Picot (1995) observed that African Americans frequently derive a sense of satisfaction from the caregiving role. The stronger the relationship between the caregiver and the care recipient, the more likely the former is to view the role as rewarding, resulting in less perceived stress (Rozario & DeRienzi, 2008). Social support and cultural traditions impact the role of the informal caregiver (Hinojosa, Zsembik, & Rittman, 2009). For example, the African American culture considers it taboo to place family members in a nursing home (Dilworth-Anderson, William & Gibson, 2002; Haley et al., 2004). African

Americans are socialized to accept caregiving responsibilities and view them positively (McCallum, Longmire & Knight, 2007; Thornton and Pratt, 2011).

African Americans disproportionately suffer from disease when compared to the general U.S. population (CDC, 2014), a situation that they themselves attribute to socioeconomic status rather than ethnic background (McCallum et al., 2007). Roth, Haley, Owen, Clay and Goode (2001) further observed that, despite African American caregivers' health problems, their depressive symptoms decreased, as they get older.

The Heart Failure Society of American (HFSA, 2010) and the American Heart Association (AHA, 2012) stated that African Americans are at a higher risk for hypertension, heart disease, diabetes, obesity and clinical depression than any other racial group. Dilworth-Anderson, Williams and Gibson (2002) attributed this to neglecting doctor's appointments, unhealthy eating, insufficient exercise, and lack of sleep. On the other hand, studies by Dilworth-Anderson et al. (2004) and Haley et al. (2004) suggested that church and religious activities help to alleviate stress and emotional burdens for African American caregivers.

Rotter's (1945) framework for a social learning theory of personalities examined a person's "locus of control," which is classified as either internal or external. Those characterized by the former believe that they are personally responsible for what happens in their lives, while those in the latter category attribute control to outside forces. Many African Americans believe that their lives are controlled primarily by a "higher power." African Americans who are responsible for the care of a family member often engage in religious activities, such as praying, singing, and reading the Bible, to help cope with the stresses of these responsibilities. However, these activities are often performed to the

exclusion of other, more formal means of support that could be helpful in alleviating some of the burden (Coogle, 2002), such as asking for assistance to pay for medical insurance premiums or to hire a paid caregiver to help to care for the heart failure patient, which would also give respite care to the caregiver.

A quantitative study by Rozario and DeRienzi (2008) using a sample size of 521 African American women, focused on African American cultural beliefs and their influence on individuals caring for dementia patients. Using a cross-sectional design, the authors looked for signs of stress and depression while controlling for personal factors. The study concluded that certain cultural beliefs and practices pertaining to the care of a sick relative are associated with increased psychological distress. Cultural beliefs and practices include, “familism” (relying on family members for support), the belief that the caregiving role is a responsibility that one must fulfill, and external locus of control (belief that a higher power set the course of one’s life). The study identified additional potentially adverse factors that can impact the care of patients, including educational level, relationship with the care recipient, general health of the caregiver, and level of employment of the caretaker. However, more research is needed to inform healthcare professionals about the caregiving role in terms of cultural beliefs, cultural barriers and the unique needs of African American communities. Having this knowledge will assist caregivers to deliver culturally congruent care.

The Institute of Medicine report on unequal treatment recommended getting the communities involve in eliminating health disparities (Smedley et al, 2003). The support of the community will help to decrease health disparities in marginalized communities and will help to breakdown cultural barriers, which are partly responsible for health disparities.

A recommendation for getting the community involved is to use the Community Health Workers Evidence Based Model. The Community Health Workers Evidence Based Model encompasses community health workers who are lay members of communities who work either for pay or as volunteers in association with the local healthcare system in both urban and rural environments and usually share ethnicity, language, socioeconomic status, and life experiences with the community members they serve. This model uses community health workers to “offer interpretation and translation services, provide culturally appropriate health education and information, assist people in receiving the care they need, give informal counseling and guidance on health behaviors, advocate for individual and community health needs, and provide some direct services such as first aid and blood pressure screening” (US DHHS HRSA, 2011, p. 4).

The use of community workers is ideal in helping to eliminate disparities for several reasons. They are usually culturally competent because they are from the same cultural /ethnic background. They tend to be respected and trusted members of their community and they are often a crucial liaison between healthcare provider/system and sick members within their community. This model has also been use and is successful in researching ways to prevent exacerbation of symptoms among minorities with diseases such as cancer, hypertension and diabetes. The use of community health workers within African American communities has resulted in an improvement of hypertension and diabetes control in some communities and increasing cancer awareness, thus increasing the number of people who participate in early screening for breast cancer detection (Brownstein, 2007). Because this model has been successful in decreasing symptoms exacerbation in people living with hypertension, diabetes and cancer, it could be significant

and beneficial for heart failure patients and their caregivers. Successful application of the Community Health Worker Model among heart failure patient could potentially decrease symptoms exacerbation and the use of community workers could relieve caregivers of some of the burden associated with caregiving.

(Durant et al. (2013) found that community workers provided social support for heart failure patients within their respective communities. The main purpose of the Durant et al. study was to assess the benefits of having community workers assist heart failure patients. Fifteen semi-structured interviews were conducted and analyzed using the grounded theory method. The community workers were trained to provide social support to the heart failure patients, including “informational, instrumental and emotional support” (p. 20). The community workers support was found to be beneficial because the heart failure patients often times had inconsistent support from family members, and, thus, they experienced difficulties meeting their daily needs. The support of community workers was effective in preventing symptoms exacerbation among this population, because they were able to provide heart failure education to these patients. They were able to inform them about community resources available to assist them. They were able to assist them with picking up medications and to communicating with health care services needed to improve their care. The community workers also provided companionship for the patients, thus easing some of the heart failure patients’ emotional burden and giving caregivers respite time.

### **African American Caregivers vs. Caregivers from Other Ethnic Backgrounds Caring for Patients with Conditions Other than Heart Failure.**

African Americans are more likely to provide care to an extended family member as opposed to a spouse (Thornton & Hopp, 2011; U.S. Census Bureau, 2012), while the opposite is true for Caucasian Americans (Molloy et al., 2005). Among all caregivers, spousal care is associated with higher levels of stress, often leading a spouse to seek institutional care for the sick patient (Covinsky et al., 2003).

Covinsky et al. (2003) study looked at five thousand six hundred and twenty-seven African American Dementia patients and their caregivers to “determine the patient and caregiver characteristics associated with depression among caregivers of patients with dementia” (Covinsky et al., 2003, p.1006). A cross-sectional design was necessary to arrive at a conclusion that states that more screening is needed for depressive symptoms that caregivers are exhibiting.

In comparing Whites and African American women caregivers who are caring for patients with different types of illnesses, Rozario and DeRienzi (2008), using the Center for Epidemiologic Studies Depression Scale, concluded that because African American women are socialized into the caregiving role, they tend to have fewer depressive symptoms associated with their responsibilities, despite the higher burden of dealing with their own health problems while caring for someone with a chronic illness.

In a study comparing Caucasian Americans and African Americans caring for dementia patients, Clay et al. (2008) examined factors such as social support (using a 12-item Social Support Questionnaire scale), depression (using The Center for Epidemiologic Studies Depression Scale), and general satisfaction with life (using the Life Satisfaction



Index Scale). Their study followed 166 caregiver-patient dyads (69 African American; 97 White) over a 5-year period. Data were obtained from 63.25% of participants at year 2; 40.96% provided data at year 3; 21.96% at year 4; and 14.46% at year 5. A linear random-effect regression model was used to examine the 5-year trajectories of the participants. The study concluded that social support decreased each year over the 5-year trajectory for both African- American and White study participants. However, African American and older caregivers had a higher level of satisfaction with their social support networks than Whites and younger caregivers. Caregivers who were satisfied with their caregiving role also had fewer depressive symptoms. While depressive symptoms among the African Americans in the study remained constant over the 5 - year period, these symptoms decreased among Whites during that time (Clay et al., 2008).

Studies by McCallum, et al. (2007) and Plant and Sachs-Ericsson (2004) using the same depression scale as the above mentioned studies, reported different results. While the literature cited above generally indicated lower levels of depression among African American caretakers due to greater satisfaction with their role, these authors concluded just the opposite: that Caucasian American caregivers actually experience fewer depressive symptoms owing to their higher willingness to seek counseling services. Plant and Sachs-Ericsson (2004) also concluded that African American caregivers suffer major depression due to a lack of the financial resources required to meet their basic needs.

Lahaie, et al. (2012) conducted a longitudinal study, which looked at the uneven burden on caregivers over a 12-month period. Among their findings were that African Americans, due to limited financial resources, have less access to professional services and, thus, the caregiving burden falls more heavily on the family members. They also

found that first generation immigrant caregivers were in poorer health and less educated and that those employed outside of their caregiving responsibilities tended to earn less income with fewer fringe benefits. Their study sample was 11.1 % Black, 77.8 % White, 6.2 % Hispanic, and 4.9 % other. McCallum et al. (2007) found that the majority of African Americans had low paying jobs, suggesting that they could not afford services that they may have known about, while Lahaie et al. (2012). suggested that immigrant caregivers are often unaware of the health and social services available to assist them. In addition, these immigrant caregivers are frequently terminated or forced to give up their employment due to an inability to meet their job requirements while carrying out their caregiving responsibilities.

Both Lahaie et al. (2012) and McCallum et al. (2007) concluded that the caregiving role negatively affects people due to increased emotional burden, while Lahaie et al. (2012) also indicated financial hardship associated with caregiving due to unpaid absences from work and job loss. All participants in the Lahaie et al.'s. (2012) study were immigrants, which may provide some insight into the experience of African Americans, of whom a large percentage are immigrants. On the other hand, only 11.1 % of Lahaie et al.'s sample were African Americans, so it is unclear if findings from that study can be generalized to all African Americans.

Hinojosa et al. (2009) examined 124 caregivers and 124 stroke patients over a period of 12 months. The caregiver group was paired with the stroke patients. The racial breakdown was as follows: 45 pairs were Whites; 49 pairs were Puerto Ricans; 28 pairs were African Americans; and 2 pairs were Asians. In comparing the pattern of informal support among Puerto Rican, African American and White stroke survivors, the

investigators noted that Puerto Rican patients had more informal support than the African Americans, who in turn had more informal social support than Whites. The study concluded that African Americans and Puerto Ricans were more likely to be unmarried and thus seek more support from extended family and friends. Comparing only African Americans and Whites, the study found that the former generally had a wider network of informal caregivers, including family, friends, neighbors, and church members. African Americans and Puerto Ricans were also found to have higher procreation rates, resulting in a greater likelihood of the caretaker being a child or grandchild of the patient. The authors also concluded that since it is common for extended family members to cohabitate in African American communities, the likelihood of the caregiver living with the care recipient was highest among this population.

During the 12-month course of the Hinojosa et al. (2009) longitudinal study, caregiver turnover was highest among African Americans. One-third of African American caregivers were replaced during the 12 -month period compared with one-fourth of the Puerto Ricans and one-tenth of the Whites. The most common reasons given for the change were that the caregiver became sick or died, or a replacement occurred with no reason disclosed.

### **Caregivers of Heart Failure Patients**

A 2011 quantitative prospective cohort study by Hwang, Fleischman, Howie-Esquivel, Stotts and Dracup examined the impact of heart failure on families. The study consisted of 76 heart failure patient-caregiver dyads who completed the Medical Outcome Social Support Survey, which assessed perceived availability of social support; the Control Attitude Scale, which measures perceived control of the patient's heart disease; and the

Caregiver Reaction Assessment Scale, which measures the impact on the caregiver of providing care to the heart failure patient. Depression and health status of the caregiver were also measured using the Patient Health Questionnaire and the Physical and Mental Component Summary Score, respectively (Hwang et al., 2011). Of the 76 heart failure patient-caregiver dyads, 66 % of heart failure patients and 63 % of caregivers were White; 11 % of patients and 9 % of caregivers were African American; 11 % of patients and 16 % of caregivers were Hispanic; and 9 % of both patients and caregivers were Asian. Eighty-seven percent of the caregivers resided with the care recipients, 74% of whom were spouses. The study concluded that heart failure patients often suffered from a lack of adequate informal care and that, among heart failure patients, social support was more critical after a period of hospitalization or exacerbation of the disease. Hwang et al. (2011) also indicated that caregivers for heart failure patients were frequently over-burdened, because of lack of social support and the severity of the patient's heart failure. The level of burden on the caregiver impacted their health and that of the heart failure patient.

Pattenden, Roberts, and Lewin's (2007) qualitative study, which used a cross sectional design, examined heart failure from the perspective of patients and caregivers. The study consisted of 36 patients and 20 caregivers, 17 of whom were spouses. Of all the participants, two were Afro-Caribbean's, six were of Asian descent and the other 18 were Whites. They identified six themes, three of which are discussed in this section. These are: 1) caregiver's adjustment to the new role; 2) caregiver's adjustment to a partner's heart failure; and 3) cultural differences between caregivers and recipients that arise from religious beliefs. Whittingham, Barnes, and Gardiner (2013) conducted a narrative review of quantitative studies on the quality of life and burden on caregivers that focused on

similar themes (the ethnicity of the study participants was not included in the authors' original texts), but which also included types and impacts of caregiving tasks, patient's condition, and perceived level of caregiver control. Both studies found that caregivers had difficulty adjusting to their new role of caring for a heart failure patient and that this negatively affected the caregiver's quality of life. This resulted in depression for many of the caregivers. Depressive symptoms were assessed using two scales, the "Beck Depression Inventory, Short Form (SF)-36, and the Center for Epidemiological Studies Short Depression Scale. The type and impact of the tasks, the caregiver's physical health and the level of social support that they received affected their perception of the caregiving role. As a result of the experiences that caregivers encounter, the written scientific statement by the American Heart Association (Riegel et al., 2009) emphasized the need for caregivers to participate in the education of heart failure patients. Participation inadvertently improves the caregivers quality of life because they are informed, they are able to quickly identify symptoms exacerbation and act appropriately and they are able to seek resources need to improve the heart failure patient life thus their quality of life.

Loss was a frequent theme discussed in Pattenden et al. (2007) and Whittingham et al. (2013). One common example was the loss of control related to managing the heart failure patient's care. The feeling of loss of control in managing the heart failure patient's symptoms and preventing symptom exacerbation often led to emotional distress for caregivers. Another type of loss that caregivers reported in other studies (Molloy et al., 2008; Pattenden, et al., 2007; Whittingham et al., 2013) was financial. Many caregivers decreased their work hours, took unpaid time off from work, or retired early. Others were terminated or had to give up their jobs because their caregiving interfered with their work.

Decrease in a caregiver's quality of life was often positively correlated with a lower socioeconomic status (Chung, Moser, Lennie & Rayens, 2009). Females were more likely than males to take on caregiving responsibilities, and they were also more likely to suffer from reduced finances associated with those responsibilities.

Thornton and Hopp's (2011) study, which consisted of seven African American daughters who cared for their parent who had stage III or IV heart failure with poor prognosis, provided another example of the responsibility of the female caregiver. This study consisted of in-depth, qualitative interviews and used an interpretative thematic approach to analyze the data. The study resulted in two themes, Caregiving Stressors and Caregiving Coping Strategies. In the first theme, the caregivers spoke about things that created stress in their life. The sources of stress for the caregivers were their parents' symptoms exacerbation, their duties as caregivers, anticipating the loss of their parents, putting their lives on hold to care for their parents, lack of trust in the health care system and financial issues related to paying for their parents' medical expenses. The second theme focused on how caregivers cope with the many issues that they encounter on a daily basis. Valuing the caregiving role was one of the most effective coping strategies for these daughters. In addition to valuing the role, they made sure that all their siblings were involved in the care to some extent, but it was usually the daughter, or one sibling, who was responsible for the majority of the caregiving duties. The caregivers also focused less on themselves and more on the suffering their parents were enduring as a result of the illness. The use of spiritual guidance was another important factor that helped each caregiver to cope. Despite these effective coping strategies, the researchers concluded that more could be done to support caregivers. They suggested that sharing the caregiving role

equally with other family members and seeking help from an outside agency would be beneficial in alleviating the stressors of these African American female caregivers

Overall, caregivers for heart failure patients experience numerous health problems and financial strain. Caregiving responsibilities include ensuring that the patient takes his or her medications as prescribed; providing social and emotional support; and assisting patients with all activities of daily living. Greater severity of the illness often increases the burden on the caretaker, including the associated emotional challenges. The complexity of caring for patients with heart failure has led many caregivers to seek assistance in coping with these challenges. They tend to view such support as necessary for maintaining the health of the heart failure patient. The needs of each caregiver and care recipient are complex and must be assessed independently. The long-term effect of the caregiving role should be taken into consideration, since the disease is chronic and progressive (Chung et al., 2009; Kang, Li & Nolan et al., 2011; Molloy et al., 2008; Pattenden et al., 2007; Whittingham et al., 2013).

### **Caregivers' Role in Managing the Health of Heart Failure Patients**

Having a caregiver as part of the management team is instrumental in maintaining the health of heart failure patients (Grady et al., 2000; Riegel et al, 2009). The American Heart Association Scientific Statement by Grady et al. (2000) concluded that management of heart failure patients outside of an acute care setting is essential to a positive health outcome. Several outpatient management programs were developed to decrease recidivism, but the programs were not able to address the social issues that arise with the heart failure patients. The complex nature of heart failure, socioeconomic issues, cultural issues and the family dynamics of heart failure patients necessitate individualized plans of care.

The progress in meeting the needs of informal caregivers has been slow, despite their significant contribution to society. Saunders (2008) reported that heart failure caregivers often feel unsupported by the patient's health care provider. Many of these unmet needs revolve around inadequate information needed to maintain and improve the health of the care recipient. Education of informal caregivers who are usually non-clinicians is essential.

Washington, Meadows, Elliott and Koopman's review of literature (2011) consisted of sixty- two studies of which 18 were from the United States and the others were from Australia, Canada, Europe and the Middle East. Washington et al (2011) study concluded that caregivers are looking for "types of information and timing of information provision" (p. 37). Types of information were classified as general or specific. General information included "basic detail resources necessary for survival" (p.38), which covered basic knowledge regarding the disease, how to improve availability of services, and how to overcome barriers to access to services. Once caregivers were comfortable with the basic detail resources, they found it easier to care for the heart failure patient. The timing of the provision of the information was crucial to the caregiver's mastery of basic information and recognition of their need to expand their knowledge. When informational needs were met, the burden on caregivers decreased, as they were able to plan time off from work or arrange schedules in advance. Further complicating the provision of adequate information, the educational needs of both patients and caregivers changed constantly, as the health of the patient fluctuated (Washington et al., 2011).

Similar themes were identified within all the studies, suggesting that discharge information given to patients was not individualized, even though caregivers wanted and



required information tailored to their specific needs. Because the needs of each patient being cared for differ according to individual physical challenges, other health concerns, and economic status, having both the patient and the caregiver present for discharge planning was beneficial to the well-being of both (Washington et al., 2011). Washington et al. (2011) blamed poor discharge planning for frequent (on average every 90 days) hospital readmissions. The American Heart Association scientific statements by Grady et al. (2000) and Riegel et al (2009) also cited poor discharge planning, including failure to start patient education in a timely manner and to include the caregiver and other support staff who will be providing care for the heart failure patient.

The caregiver plays an essential role in the patient's adherence to the outpatient regimen. It is the informal caregivers who often recognize the signs and symptoms of heart failure exacerbation. Early recognition of these signs and symptoms could delay or prevent hospitalization and ultimately reduce the burden on caregivers (Washington et al., 2011). Hospitalization of the heart failure patient often increased the caregiver's stress. Change in routine and lack of communication with healthcare providers in the hospital were also sources of frustration for caregivers (Saunders, 2008).

The conclusions of Grady et al. (2000), Saunders (2009) and Washington et al. (2011) supported the existing body of literature that states that the caregiver's needs may differ from those of the patient and, therefore, should be addressed separately. The one providing the care generally needs more in-depth information to communicate with healthcare providers regarding the needs of the heart failure patient.

In another American Heart Association Scientific Statement, Riegel et al. (2009) defined self-care as a “naturalistic decision-making process that patients use in the choice

of behaviors that maintain physiological stability (symptom monitoring and treatment adherence) and the response to symptoms when they occur” (p.1441). Co-self-care is necessary to maintain the health of heart failure patients (Siabani, Leeder & Davidson, 2013), but due to the debilitating nature of heart failure, many patients depend on their caregiver to perform “self-care” for them, which can lead to poor self-care among heart failure patients. Co-self-care is the caregiver performing or assisting with all the tasks that the heart failure patient should be doing if they were capable of performing their self-care. The scientific statement (2009) cited the following as signs of poor self-care: lack of adherence to a medication regimen; inadequate symptom management, including failure to recognize signs and act appropriately; inconsistency in following dietary guidelines; fluid restriction; alcohol consumption and smoking; improper use of over-the-counter medications; and failure to follow appropriate exercise guidelines. In addition, other illnesses, including depression and anxiety, can lead to further physical disability adding to the barriers to consistent self-care (Riegel et al., 2009; Siabani et al., 2013).

Siabani et al. (2013) conducted a meta-synthesis of “Barriers and Facilitators to Self-care in Chronic Heart Failure,” which included 23 articles that addressed the cases of 477 patients whose ethnicity was not identified. The studies examined in this meta-synthesis included formal and informal caregivers. The results demonstrated that the barriers experienced by heart failure patients were inability to carry out an effective self-care regimen, because of lack knowledge on how to perform self-care and cultural practices. For example, ethnic food choices may interfere with preventing symptoms exacerbation, while cultural beliefs about the origin of heart failure emphasize stress as opposed to lifestyle habits and genetic predispositions. Finally, they found that social

isolation presents an environmental barrier to adequate self-care. Although the aim of this meta-synthesis was to discuss barriers and facilitators, the researchers focused minimally on facilitators that could potentially improve the heart failure patient's quality of life. The facilitator that they focused on was that the heart failure patient should accept their diagnosis because acceptance of the diagnosis serves as an effective coping strategy. This study serves to highlight the need and the necessity of a caregiver in the life of a heart failure patient. The role the caregiver plays in the life of a heart failure patient has the ability to decrease some of the barriers experienced by heart failure patients (Albert et al., 2009; Durant et al., 2013; Jaarsma et al., 2013; Kang et al., 2011; Riegel et al., 2009; Saunders, 2008, 2009 and 2012; Sebren and Woda, 2012).

In the 2009 American Heart Association Scientific Statement, Riegel et al. identified the benefits of family support in maintaining a healthy self-care regimen. In managing a heart failure patient's disease, the caregiver plays a dual role that impacts both parties differently. For example, a heart failure patient may be unable to sleep due to diuretics and the fear of waking up short of breath. The caregiver may be unable to sleep because of constant worry about the heart failure patient in respiratory distress and the fear of being asleep when the patient needs help. Although the reasons are different, sleeplessness affects both.

The physical demands of caring for a heart failure patient are significant. These may include monitoring the fluctuation of symptoms and the patient's self-care routine, as well as the use of medical devices. The impact of providing care sometimes results in depression. Changes in sexual activity and sleep patterns among both caregiver and patient are additional concerns (Molloy, Johnston & Witham, 2005). Knowing the challenges

presented to caregivers of heart failure patients is essential to providing appropriate care to this population.

Jaarsma, Brons, Kraai, Luttik and Stromberg (2013) reviewed the literature concerning heart failure management and home care in the United Kingdom included 70 articles covering heart failure interventions geared towards the following five components: “a multidisciplinary team, continuity of care, care plans, optimized treatment according to guidelines, education and counseling of patients and caregivers” (Jaarsma et al., 2013, p. 230). This review is important because it confirms that home interventions have been instrumental in decreasing repeated hospitalizations of heart failure patients (Jaarsma et al., 2013). Of the 70 articles in the Jaarsma et al. review, 24 pertain to informal caregivers of heart failure patients, with the remainder focused on professional caregivers. Eighty-seven percent of the articles included in the review addressed education of patients and their caregivers. The ethnic backgrounds of the study participants were not listed, but the information obtained seems consistent with the American Heart Association’s scientific statements by Grady et al. (2000) and Riegel et al. (2009) regarding the management of heart failure patients. The five components addressed are essential to decreasing morbidity and mortality in heart failure patients; caregivers are the key to achieving this goal (Jaarsma et al., 2013).

The 2000 American Heart Association’s scientific statement (Grady et al. (2000) to healthcare professionals regarding heart failure patients’ care focused on all aspects of heart failure care: etiology, treatment and management of heart failure from an acute stage to a chronic stage, and the role of informal and professional caregivers. Though not a research study, the statement provided a comprehensive view of heart failure and its

impact. The report focused mostly on professional caregivers but also highlighted the important role of the informal caregiver in providing continuous care to heart failure patients. The report concluded that caregivers should be a part of the education and discharge process. Jaarsma et al. (2013) supported this finding.

The most recent American Heart Association scientific statement stated, “the goal of education and counseling is to assist patients in compliance with the therapeutic regimen, to maintain clinical stability and function, and to improve quality of life” (Riegel et al., 2009, p. 1159). This is best achieved when healthcare professionals partner with the heart failure patient and his or her caregiver to ensure that the latter has sufficient knowledge to confidently care for the heart failure patient.

In 2005, Molloy et al. conducted a review and analysis of heart failure caregivers in the United Kingdom, which considered 13 quantitative studies and three qualitative studies. The ethnicity and the race of the participants in each study were not identified in this review and analysis. Rather, the focus was specifically on the impact of heart failure on family members and their roles in managing the disease. The themes that emerged from this review are significant in the lives of caregivers and informative for healthcare providers. These include: difficulties that caregivers encountered in managing the complex medical needs of the heart failure patient; frequency of hospitalization; and sleep patterns of the patients and their emotional impact on the caregiver. The study focused on those aspects of the caregiving role that affected these individuals negatively, thus impairing their management of the heart failure patient.

Molloy et al. (2005) expressed an important caveat concerning the conclusions of their review, as the majority of the methods used by the research studies they considered

were inconsistent and lacked rigor. Nonetheless, their analysis does suggest trends relevant to my study. One finding was that heart failure patients who resided with their caregivers were more likely to maintain their treatment regimen. Molloy et al. (2005), like others cited above, noted the significant role that the caregiver plays in the patient's life and stressed that educating both is instrumental in delaying and preventing repeated hospitalizations. Ensuring that caregivers receive the support and assistance they require is critical to maintaining the health of the heart failure patient (Molloy et al., 2005).

Molloy's et al.'s (2005) observations were corroborated in a 2011 study by Hwang et al., which asserted that the needs of each caregiver and care recipient are complex and that health care providers should assess the caregivers' and the heart failure patients' needs on an individual basis. Due to the chronicity of heart failure, patients need strong social support. Finding resources for the caregiver is essential to maintaining the health of the patient and the well-being of the caregiver (Hwang et al., 2011).

Washington et al.'s (2011) meta-synthesis consisted of 62 studies focusing on the informational needs of informal caregivers caring for older adults with chronic health conditions. Eighteen of the 62 studies were conducted in the United States. Thirty-three percent of the chronic conditions looked at in this composite were listed as unspecified; only two were named as cardiac disease (types of cardiac disease unknown). All caregivers in this analysis were aged 50 or above, but the ethnicity and race of the participants in the studies considered were not identified by the authors. Although both the AHA (2012) and HFSA (2010) stated that the majority of caregivers in the African American community are younger than 50 years old, Washington et al. (2011) nonetheless provided valuable insights into the informational needs of individuals responsible for the care of patients with

chronic conditions. These insights are necessary to assess whether the informational needs of the general population of patients with chronic health conditions and their caregivers can be applied to African American heart failure patients and their African American caregivers. Still, further research is needed on this specific population to determine its unique cultural demands.

### **Caregiver Emotions**

This section discusses the emotions that caregivers experience, specifically, the emotional burden on those caring for the heart failure population. It also discusses the differences in emotions due to the caregiver's race, ethnicity, and gender, and factors associated with the onset and types of emotions that arise.

Financial hardship due to job loss and reduction in work hours resulting from caregiving responsibilities imposes a severe emotional burden on caregivers. The caregiver is sometimes responsible for co-payments on medication as well as providing groceries and transportation for the care recipient. Another emotional burden is the social isolation caused by increased caregiving responsibilities due to both direct factors, for example, the demanding and time-consuming tasks associated with caregiving, and indirect ones, such as a fear of leaving the patient alone. Many caregivers also feel guilty when they take time off to tend to their own personal needs (Covinsky et al., 2003; Dilworth-Anderson et al., 2002; Hwang et al. 2011; Lahaie et al., 2012).

Non-spousal caregivers, such as adult children, have less perceived social support and thus feel more burdened by obligations outside of caring for the sick, such as providing care for their children and working.

The satisfaction that many people derive from their caregiving role may decrease over time among those caring for the heart failure population due to the chronicity of the disease (Covinsky et al., 2003; Dilworth-Anderson et al., 2002). In order to optimize the health of both the caregiver and the heart failure patient, it is important to assess the caregiver's social support needs and routinely screen for depression. Numerous studies (Lahaie et al., 2012; McCallum et al., 2007; Plant and Sachs-Ericsson, 2004; Rozario and DeRienzi, 2008) highlighted the need to incorporate the culture of both the patient and the caregiver into the plan of care for heart failure patients.

Calderon and Tennstedt's (1998) qualitative study used ethnographic interviews and content analysis to analyze the interviews. The study illustrated how caregivers of different races express their burden while caring for patients with various chronic illnesses, such as Alzheimer's and severe mental illness. They concluded that African Americans tend to cope more effectively with caregiving responsibilities, thus experiencing less depression and perceived burden (Calderon & Tennstedt, 1998; Covinsky et al., 2003;), and that Blacks, Whites and Puerto Ricans experience burden equally but express it differently. The study consisted of 18 caregivers (4 Whites, 6 African Americans and 8 Puerto Ricans) who provided, on average, 49.9 hours of care weekly. Many of the African American subjects reported feelings of frustration, anger, and somatic complaints. They also described their roles as "time-consuming and demanding" (p. 167). Yet, their commitment to the role and their cultural values allowed them to cope. The Whites in the study frequently described their roles as difficult. They were frustrated and angry, and experienced difficulty sleeping. Like Whites and African Americans, Puerto Ricans also expressed feelings of anger, frustration, and somatic complaints, but they were committed



to the caregiving role and experienced some level of satisfaction. The positive attitude and feeling that they had no other choice but to provide care helped African American and Puerto Rican caregivers cope with their burdens. Calderon and Tennstedt's (1998) results were the opposite of Kaufman's study (2010), which consisted of caregivers caring for patients with dementia. This study also indicated that there was no difference in social support based on race. However, many African American caregivers perceived their own health to be poorer than that of Whites. This may account for the greater physical burdens felt by African American caregivers. Depressive symptoms were measured in almost half of all the participants using the Center for Epidemiologic Study Depression Scales. This study echoed the sentiments of many of the other studies that suggested that caregivers are prone to experiencing depressive symptoms regardless of their ethnicity.

Studies by Luttik et al., 2009; Hellesø et al., 2012; and Thornton and Hopp, 2011 indicated a greater burden on those caring for patients afflicted with heart failure compared with other conditions, due to the inability of this population to care for themselves. In Hellesø et al., (2012) qualitative study which assess the benefit of informal caregivers managing information for heart failure patients, they concluded that an informal care giver is an important element in maintaining the health of heart failure patient. The study consists of 14 participants, eight women and 4 men. The study used in depth semi structured interviews to ask heart failure patients about their perspective of the necessity and the benefits of having an informal caregiver one week after they were discharge from the hospital. Data were analyzed using content analysis. Additional results obtained from the study resulted in two main themes, " first information ambivalence, is related to the background of the informal carer, whether or not their informal carer had a health care

background. The second phenomenon, information ambivalence, is related to the relationship between the patient and the informal carer with regard to information management at home” (Hellesø et al., 2012, p.495). This study results highlights the importance of nurses ability to accurately assess and identify, the needs of the heart failure patient and their caregiver prior to and after discharge. Accurate assessment of the heart failure patient and their caregiver needs can help to decrease caregiver burnout.

Thornton and Hopp (2011) chronicled the experience of African American daughters caring for parents with heart failure, providing some valuable insight into the cultural challenges faced by this population. Some challenges are lack of education, inequality in employments and job benefits, lack of financial resources and mistrust of the healthcare system. The study discussed effective coping strategies within African American communities. Stressors were prevalent among caregivers, yet they were able to function in that role due to skills they had developed. Among the stressors mentioned were progression of the disease, insufficient assistance from others, emotional sacrifices, and conflicting responsibilities, such as young children and gainful employment. The high cultural value placed on the caregiving role, spiritual belief, and having siblings who shared the responsibilities were factors that lessened the stress that caregivers encountered.

Luttik et al. (2007b) used a cross-sectional design to identify mental health risk among caregivers of heart failure patients. The study consisted of 357 participants: 75 % were female and 96% were married, but ethnic background was not identified. The Caregiver Reaction Assessment Scale was used to assess risk to spouses, while caregiving tasks were examined to measure the caregivers’ perceived burden. Women were more likely than men to report an elevated burden in the caregiving role due to a lack of social

support. Hwang et al.'s (2011) study findings were similar, suggesting that female caregivers experience more physical and emotional burden than male caregivers.

Kang, Li and Nolan's (2011) meta-synthesis consists of 10 studies with a total of 134 participants, of which 39 were male and 95 were female. A meta-ethnographic method was used to analyze the studies used in the Meta synthesis. Similar to the other meta-syntheses, the race or ethnic backgrounds of participants were not identified in this study.

Kang et al (2011) study determined that that some caregivers had difficulty adjusting to their new role. Despite frequent physical limitations associated with their own health issues, the caregivers were responsible for performing household duties, assisting the heart failure patient with activities of daily living, managing the patient's physical limitations, medical management of heart failure, and being a source of companionship.

Anxiety in new caregivers was prevalent for various reasons, including adjustment to the heart failure diagnosis and fear of making mistakes in carrying out their new responsibilities, such as purchasing, picking up, and administering medication. Anxiety also resulted from social isolation due to the time-consuming tasks that prevented the caregiver from leaving the heart failure patient and also the fear and guilt of leaving the patient alone or giving someone else the responsibility (Kang et al., 2011; Thornton & Hopp, 2011).

Another theme to emerge from the literature was conflict, which resulted from caregivers' struggling with recipients over adherence to their treatment plans (Kang et al., 2011). While the majority of patients reported that they received great support from informal caregivers, caregivers did not feel adequately supported by doctors, who, they believed, did not have the necessary time to teach them. Out of respect for the doctors'

time, caregivers reported that they were not assertive in asking for help. The most important finding from Kang et al. (2011) was that caregivers did not feel that they were well informed. Some reported having limited knowledge; others felt they lacked the formal knowledge necessary to appropriately manage the heart failure patient.

In both the Kang et al. (2011) and Thornton and Hopp (2011) studies, the caregivers described the close union that they formed with the care recipient as a result of spending a significant amount of time with the patient. Caregivers also reported being more proactive about their health because they were aware of the strain and burden associated with caring for someone with a chronic illness. They carved out time to exercise, meditate, and improve their own self-care routines, and actively sought support when necessary in order to best care for the heart failure patient.

The coping skills used by caregivers in the Kang et al. (2011) are similar to those identified in the McCallum et al. (2007) and Thornton and Hopp (2011) studies that found that African Americans' cultural beliefs and positive attitude towards caregiving help them to cope with the role despite their own actual or perceived poor health. Kang et al. studied 35 African American and 35 White female caregivers, and compared and contrasted the coping mechanisms between the two groups. Findings revealed that the strong familial ties between the African American caregivers and care recipients negatively impacted the caregivers' health, since they were more likely to neglect their own physical needs to provide care to the patient with a chronic illness. Mental health outcomes were similar between the two racial groups, but coping mechanisms were different. This information is essential for health care providers to keep in mind when interacting with caregivers, who

must be routinely assessed in order to optimize their social, physical, and mental well-being when caring for someone with a chronic illness (McCallum et al., 2007).

There are positive and negative effects of the caregiving role. Low socio-economic status, poorer overall health, and use of less formal support, often put African-American caregiver at risk for greater burden. However, some of these burdens are often mitigated by a belief in an external locus of control and the use of their large informal networks, such as extended families and church members. African Americans' socio-economic status and the multiple cultural backgrounds of the various groups in the African American communities make the role of the African American caregiver caring for the African American patient living with heart failure and other chronic health issues extremely complex (Brummett et al., 2012; Calderon & Tennstedt, 1998; Clay et al., 2008; Durant et al., 2013; Hwang et al., 2011; Lahia, 2012; Thornton & Pratt, 2011).

In summary, the majority of the studies available on caregivers for heart failure patients relied on small samples of African Americans, thus making it difficult to generalize the findings to the wider African American population. This study addresses this weakness, by providing information specific to African American caregivers caring for African American heart failure patients. The condition of African Americans with heart failure health outcomes is usually worse than that of their White counterparts, and, as a result, they are more likely to need caregivers. More research is needed to understand the full experience of African American caregivers. Thus, this study also explores the root causes of why African American caregivers fail to seek the help of mental health professionals. This study also provides information on the eating habits of the African American caregivers and their influence on the heart failure patients' eating habits. In

addressing this particular gap in the existing literature, this study provides insights for health care professionals and caregivers on how to provide culturally congruent care, and for researchers who plan to develop intervention studies to address the eating habits of this community.

This study aims to fill several gaps in the literature concerning African American caregivers caring for African American heart failure patients. As noted above, there are only two studies which focus solely on African American caregivers caring for African American heart failure patients (Durant et al., 2013, and Thornton and Hopp (2011), but these studies cannot be generalized to all African American caregivers, because one focuses on daughters caring for their parent and the other focused on the community health advisor's role as a caregiver. This study provides detailed information on the full range of experiences that African American informal caregiver encounter.

## Chapter 3

### Method of Inquiry

Chapter three presents a detailed description of the research methodology in this study. This chapter specifically addresses the following areas: research question, research design, sample, procedure, protection of research participants, data analysis and methods to ensure research rigor. The descriptive phenomenology method of Colaizzi (1978) was chosen to analyze the research data, which allowed the experience of the African American caregiver caring for an adult African American patient living with heart failure to surface.

#### **Research Question**

The research question of this study is: “What is the lived experience of African American caregivers caring for adult African American heart failure patients?”

#### **Philosophy of Phenomenology**

Phenomenology is a philosophical movement that began in Germany, as philosophers became curious about exploring the concept of “consciousness.” Phenomenology observes, interprets, defines and distinguishes the meaning of the phenomena. Husserl (1999) defined phenomenology as a science of “pure phenomena” and how “each phenomenon manifests itself to consciousness” (p. 248). To understand phenomenology, Husserl used and explained important concepts, such as *objectivity*, *epoche*, *bracketing*, *reduction*, *natural attitude*, *life world*, *essence*, *consciousness*, *intentionality*, and *transcendental ego*. Of all the concepts, *epoche* and reduction are the principal ones that allow for phenomenology to be a philosophical research method (Husserl, 1931). Within Husserl’s philosophy of phenomenology, concepts such as these are necessary to capture the meaning or essences of the phenomena being studied.

Through the epoche a new way of experiencing, of thinking, of theorizing, is open to the philosopher; here, situated above his own natural being and above the natural world, he loses nothing of their being and their objective truths and likewise nothing at all of the spiritual acquisitions of his whole life or those of the whole historical communal life (Van Manen, 2014 p.219).

Van Manen (2014) states that, regarding epoche, Husserl wrote,

This is not a “view,” an interpretation bestowed upon the world. Every view about... every opinion about “the” world, has its ground in the pregiven world. It is from this very ground that I have freed myself through the epoche; I stand above the world, which has now become for me, in a quite peculiar sense, a phenomenon (Husserl 1970b, p.152, as cited in Van Manen, 2014, p.219).

Epoche is the opening of one’s self to experience the phenomenon under investigation. Epoche is also known as bracketing. To fully understand and to arrive at the *essence* of the phenomenon under investigation, the researcher must apply concepts such as epoche, bracketing and reduction to be able to describe the participant’s experience, which permit the essence of the phenomenon to appear. When researchers open themselves to an experience, they have to suspend their presuppositions and preconceived ideas about the phenomenon under investigation (Husserl, 1931; Van Manen, 2014).

Bracketing is a cognitive process that includes all conscious experiences; it allows an individual to set aside personal beliefs in order to hear or observe the experience of another without assumptions or judgments. It focuses on the experience within the mind and suspends the experience of the world as we know it to be. It enables an individual to interpret information with as little interference as possible from his or her own life world,



or life experiences, thus allowing the true meaning of the phenomenon under investigation to be uncovered (Husserl, 1970a). Bracketing does not change one's mind but allows the truth to reveal itself without the intrusion of assumptions from one's consciousness.

Bracketing allowed for enhancement of meaning. Husserl believed that awareness of the content of consciousness is necessary for one to get the full understanding of life.

Reduction is acknowledging the experience and keenly identifying the memory of the experience. The memory of the experience can be a smell, a word, a feeling or a thing. According to Van Manen (2014), "Husserl insists that phenomenological reduction is not a function of facts but rather of essence" (p. 217). He also (2014) states, "reduction is an attentive turning to the world when in an open state of mind, effectuated by the *epoche*" (2014, p.218). To achieve this reduction bracketing must occur, as must the suspension of one's "natural attitude" which is one's most basic interpretation of the world.

Van Manen wrote, Phenomenological reduction is the method of leading phenomenological vision from the natural attitude of the human being whose life is involved in the world of things and persons back to the transcendental life of consciousness and its noetic- noematic experiences, in which objects are constituted as correlates of consciousness (Heidegger, 1982, p.21, as cited in Van Manen, 2014, p. 220). Phenomenological reduction is a procedure initiated by *epoche*. It allows for a more accurate description of each participant's experience. It refers to the researcher's ability to suspended assumptions, purge the mind, and alter conscious thinking so that philosophical inquiry can occur. With phenomenology, every part of each participant's experience must be assessed and analyzed to allow each one's experience to be told. Husserl described the process of reduction as "transcendental reduction" (Husserl 1970, p. 151) and bracketing as

“transcendental epoché” (Husserl 1970, p. 151). Transcendental reduction rests on the belief that within one’s consciousness, there is an ability to separate beliefs, thus allowing for “true phenomena” to be recognized.

*Life world*, used interchangeably with “lived experience,” is a concept essential to Husserl’s philosophy of phenomenology. It is the foundation for understanding all human experiences. “Lived experience means that phenomenology reflects on the prepredicative and prereflective life of everyday existence” (Van Manen, 2014, p. 222). It refers to the meaning that people apply to their experiences and what defines the uniqueness of their lives. The sum total of a person’s experiences or encounters is what defines his or her life world. To follow the norms of phenomenology, the researcher’s “life world” needs to be bracketed, meaning that all the experiences that shape who they are must be acknowledged, set aside and taken into consideration when collecting and analyzing data (Husserl, 1970a).

*Essence* is the inner central aspect of something that makes some thing what it is. Essence is universal to all experience. Essence is not a result of insight; it is the result of scrutinizing and thinking about an experience to identify its core. Essence is isolated by epoche and phenomenological reduction.

Husserl (1970A) stated, “ I am present to myself continually as someone who perceives, represents, thinks, feels, desires and so forth; and for the most part herein I find myself related in present experience to the fact-world which is constantly about me” (p. 94). The notion of natural attitude is essential here, because it allows for a subject to uncover his or her true essence without the natural attitude of the researcher interfering with the view of that subject’s consciousness. Phenomenological reduction is pure

phenomena, which allows the true essences of one's experience to emerge.

*Consciousness* represents an awareness of things within an individual's world: how one views oneself, how a person views another person and how each individual views everything that they encounter in their lifetime or within a specific moment of their lifetime, otherwise known as the phenomena under investigation. These phenomena consist of memories and experiences that influence the way in which one perceives and interprets their experiences, the experiences of others and things with which they have contact. Whether the experience is real or imagined, it impacts one's consciousness. To think about one's lived experience or that of another consciousness is necessary. Thus, at the end of Husserl's bracketing is the *transcendental ego*, "*the true self*," the consciousness required to understand a particular phenomenon. It is the relationship between the individual's consciousness (what is being experienced) and that of the world (the way in which one experiences the world).

According to Husserl (1970), *intentionality* is the core of consciousness. Intentionality also refers to an individual's direct awareness of a thing, such as an event or object (Husserl, 1970a). Objects are seen as intentional because, depending on the context, their meaning is subject to multiple interpretations. An object's relation to other objects, as well, will determine the interpretation of its meaning. Husserl claimed that an intentional relationship exists at all times with the things that make up experience on a daily basis. Shared experience is subjective in nature and related to individuals' interpretation and perception of their world; thus, each participant's experience will be different, and the researcher must strive to understand the phenomenon from each participant's experience.

Martin Heidegger studied the philosophy of phenomenology under Husserl, but

eventually developed different principles to support his philosophical perspective on it. Instead of focusing on essences, Heidegger focused on human existence and human “being,” in particular the discovery of “being.” Heidegger stated, “Being is found in thatness and whatness, reality, the objective presence of things [*Vorhandenheit*], subsistence, validity, existence [*Daesein*] and in ‘there is’ [*es gibt*]” (Heidegger, 1962, p.5). While Husserl thought that one must suspend his or her presuppositions to arrive at the true essence of another’s experience, Heidegger stated that phenomenological reduction was not possible. Heidegger believed that one should not suspend his or her presuppositions, because interpretation is necessary to understanding “being” (Heidegger, 1962). He also believed that we exist by “having to do with something, producing something, attending to something and looking after it, making use of something, giving something up and letting it go, undertaking, accomplishing” (Heidegger, 1962, p.83). As a result, reflection is necessary to understand one’s life world.

The French philosopher Maurice Merleau-Ponty’s work on phenomenology was influenced by both Husserl and Heidegger. Merleau-Ponty used both the philosophy of essences (Husserl) and existences (Heidegger) and the concept of bracketing, which Husserl and Heidegger had used, but he focused on *embodied consciousness*. He stated that bracketing “. . . places in abeyance the assertions arising out of the natural attitude, the better to understand” (1962, p. vii) the participants. Merleau-Ponty’s interpretation of reduction differed from Husserl’s. While Husserl thought it was impossible to have complete reduction (Husserl, 1931), Merleau-Ponty (1956) argued that one should be aware of his or her connection to the world, that is, where they are in the world and the positions of others in the world. By being aware of their presuppositions, a researcher can

then directly address and analyze them, further increasing their understanding of their subjects' lived experience.

Colaizzi (1978) derived his approach to descriptive phenomenology as a systematic method for analyzing data from Husserl's phenomenological philosophy. This occurred because Colaizzi believed that the philosophy on its own was inadequate as a research method. Colaizzi's descriptive phenomenology focuses on describing the essences of experience. He insisted on viewing individual experience as "already in the world" (p. 52), rather than an internal perspective (what is within). Colaizzi (1978) believed that how we view the world, our place in the world, and whom we interact with within our world form the essences of our being.

For researchers to recognize and understand the essence of another being, they must be self-reflective, empty their consciousness of previous experiences (reduction), and bracket what is left in order to present the phenomenon being studied in its purest form. Bracketing allows for a state of neutrality in one's consciousness, which is necessary to maintain the standard of scientific rigor required when conducting a descriptive phenomenological study. The researcher must have some experience of the phenomenon being studied. It is also essential for the researcher to have "imaginative listening" skills and that he or she be "present" and observe every nuance of each participant as the interview is being conducted.

In summary, phenomenology draws from the ideas of Husserl, Heidegger, and Merleau-Ponty to establish a framework for articulating and interpreting human experiences with a rigorous process to try to prevent bias. *objectivity, epoche, bracketing, reduction, natural attitude, life world, essence, consciousness, intentionality, and*

*transcendental ego* underpin the researcher's attempts to learn and understand the events and feelings that make up an informant's lived experience. They allow the researcher to remain cognizant of his or her beliefs and notions, yet the ability to bracket those belief, notions and assumption to allow for recruiting participants, collecting and analyzing data (Husserl, 1970a; Husserl, 1931; Merleau-Ponty, 1956; Van Manen, 2014).

The use of descriptive phenomenology is appropriate for this project, because the goal is to reveal the participants' experiences as they lived them. The life world examined in this study was the experience of the African American caregiver caring for an adult African American patient living with heart failure.

### **Research Design**

Phenomenology as a method has a variety of approaches, including the descriptive and interpretative approach. This is as a result of philosophers who deviated from Edmund Husserl's beliefs (Husserl, trans, 1931, 1970a, 1970b and 1999), because they did not completely agree with his concept of "bracketing." Colaizzi's (1978) descriptive phenomenology varied from Husserl when describing bracketing. Heidegger's (1962) philosophy varied from Husserl beliefs, because he focused on interpretive phenomenology when illustrating the concept of bracketing.

This research study used Colaizzi's method because of it defines steps that allow a researcher to describe human experiences. Objectivity, is usually the focus of natural science research (measurable things) and human experience is often ignored (consciousness experience by all humans). Colaizzi (1978) and Husserl (1931) viewed human experience as involving part of the external world, not just what is internal. Most important is the way we encounter the world and others within our world. Colaizzi stated

that one must scrutinize their presuppositions and biases regarding a phenomenon prior to collecting data and during data analysis. This type of reflection is essential for accurate description to occur. During this process of reflection, “imaginative listening” (p. 62) is key. Imaginative listening is the attentiveness to the participants’ gestures, speech and uniqueness, and the researcher’s being aware of themselves and the taping and transcribing of the interview. All these qualities are necessary for individual’s lived experience to surface.

The research literature on the lived experience of African Americans is sparse. Because health disparities among African Americans are not well understood, the use of Colaizzi’s descriptive phenomenological method to explore the lived experience of African American caregivers is ideal.

### **Protection of Participants.**

Approval to conduct this study was received from the University of Connecticut Institutional Review Board (see Appendix A). Privacy and confidentiality of all the participants’ information was ensured during transcription by using Rev.com. (Rev.com is a transcription company that specialized in transcribing voice-recorded data. See Appendix B for rev.com privacy policy). The transcripts were checked for accuracy and to ensure that no participant’s identifiable information was present. Any such information found was promptly removed. Only the researcher and her advisor were able to identify the participants through a coding system. Research records were labeled with codes derived from a sequence of five letters followed by three numbers. The letters consisted of the abbreviation for caregivers and heart failure patients (CGHFP) and a sequential three-digit number that reflected the number of people enrolled in the study. A master key linking

names and codes was maintained in a separate location from the data and secured. All computers and electronic files (e.g., electronic recorder, database, spreadsheets, etc.) containing identifiable information were password-protected, and only the researcher and her advisor have access to passwords. All files will be destroyed 3-years after the completion of the study.

Participants were given as much time as they needed to decide if they wanted to participate and sign the consent form. In order to evaluate potential participants' ability to consent to participate in the study, the researcher asked them to describe the study's purpose, foreseeable risks, and the voluntary nature of participation. If repeated accurately, participants were asked to sign the consent form (see appendix C). If they were unable to repeat accurately, the session was ended and they did not participate in the study. Prior to the interview each participant verbalized the study's purpose, foreseeable risks, and the voluntary nature of their participation. After accurate verbalization, written consent was obtained. The consent signing and the interview took place in a quiet setting in a closed room. The consent forms were stored in a secure envelope.

### **Recruitment of Participants.**

Recruitment of study participants was conducted primarily at two sites: a predominantly African American church and an inner city senior center ( see appendix D). Ninety percent of the congregation consists of African American from the Caribbean and the other 10 percent were born in the United States of America. The senior center consist of mostly African American and Hispanics, ranging from the age of 58-94 years. The members of the center typically visit the center for lunch, activities and to socialize. Two recruitment methods were used: word of mouth communication to the general public and a flyer



handed out to members of the church and each member of the community center. Those who met the study criteria were given information regarding its purpose and asked whether they would like to participate. The ability to express one's thoughts clearly and effectively was required for inclusion in the study. The message on the flyer (see Appendix E), which is identical to the one communicated orally in the "word of mouth" recruitments, reads:

You are invited to participate in a study regarding African American caregivers' experiences in caring for adult African American heart failure patients. The purpose of this study is to explore and describe African American caregivers' experiences caring for adult African Americans with heart failure. Your participation in this study will last approximately one hour. Study participants must be English-speaking African American adults (aged 21 years or older) caring for someone with a primary diagnosis of heart failure. The caregiver must reside with the HF patient and or assist the HF patient with [activities of daily living] ADLs and [instrumental activities of daily living] IADLs.

As it is often difficult to recruit African American participants, snowball and purposive sampling were used to recruit study participants.

Snowball sampling [is] as a technique for gathering research subjects through the identification of an initial subject who is used to provide the names of other actors. These actors may themselves open possibilities for an expanding web of contact and inquiry. Faugier and Sargeant, 1997" (Lewis-Beck, Bryman and Liao, 2004, p. 1).

Snowball sampling is one of the most effective methods for recruiting study participants among populations that have historically posed challenges for researchers.

Purposive sampling, where the researcher deliberately selects subjects with certain diverse characteristics (Sadler, Lee, Lim and Fullerton, 2010), such as racial background and caretaking responsibilities, and knowledge about the phenomenon under study, allows a thorough, in-depth analysis of such phenomena. Combining these sampling methods, 10 participants consented to interview for this study.

Inclusion criteria were:

- 1) Participants must be English-speaking African American adults, aged 21 years or older.
- 2) Must self-report that they are caring for an adult African American diagnosed with heart failure.
- 3) The caregiver must reside with the heart failure patient and or assist the heart failure patient with ADLs and IADLs
- 4) Be willing and able to articulate their experience.
- 5) Participants should not be cognitively impaired.

### **Data Collection.**

The interview between the researcher and the participant was recorded and transcribed. The researcher practiced bracketing prior to and during the data collection process as much as humanly possible. To ensure bracketing, after each interview, the researcher wrote her thoughts and feelings related to the interview to help isolate them from those of the participants. As discussed earlier, bracketing is an essential form of presupposition reduction that involves identification of any thoughts or feelings (presuppositions) held by the researcher that may interfere with recruitment, data collection, and data analysis. It is necessary to reveal the researchers' presuppositions to

avoid the possibility of their influencing the researcher's interpretation of the participants' transcripts during data analysis (Husserl, 1970a). In this case, the following presuppositions were identified:

- 1) Caregivers will perceive their family members as a burden.
- 2) Caregivers will feel that the healthcare providers do not listen to them.
- 3) The lack of resources available to African American caregivers is a source of frustration.
- 4) Caregivers feel that the role is burdensome.

All participants were informed that the survey would be confidential and that their participation was voluntary. After signing the consent form, participants were asked, "Describe your experience of caring for an African American living with heart failure. Please describe all of your thoughts, feelings and emotions as completely as possible." Based on the participant's responses, the researcher might probe for additional information with open-ended phases, such as "Tell me more," or "How would you summarize your experience?" to enrich the interview response. This helped the participants talk more freely without guidance or influence from the researcher, thus allowing for an in-depth exploration of their caregiving experience. Upon completion of each interview, each participant was asked to complete a questionnaire consisting of demographic questions (see Appendix F).

The interviews took place at quiet, private locations of the participants' choosing, for example, their home, a library and a restaurant. Participants were given the option to stop the interview at any time. The interviews last approximately one hour and were recorded electronically.

### **Data Analysis.**

Data analysis began with the first interview and continued with each additional interview. Data saturation was assessed after each transcript was analyzed. Colaizzi's steps (Colaizzi, 1978, pp. 48-71) for qualitative phenomenological research to guide data analysis were used. These are:

- 1) Reading and rereading of transcripts to gain a feeling for the content.
- 2) Extraction of significant statements that were pertinent to the phenomena under investigation.
- 3) Formulated meanings were identified. Formulated meaning refers to the identification of the meaning of each significant statement. The formulated meaning allows for the discovery of the hidden meaning within each significant statement.
- 4) Organizing the formulated meaning into clusters of themes that are universal to all participants.
- 5) Validating the clusters of themes by checking each against the original transcript, which allows for verification that the description was consistent with the transcription. Data that did not fit (that is when the researcher's conclusion did not match the participant's transcript) were not ignored.
- 6) Integrating the findings to produce an exhaustive description of the phenomenon under investigation.
- 7) Member checking, or asking participants to compare the findings with their experiences.
- 8) Making final changes to the exhaustive description if necessary based on the

participants' suggestions. Then that final product is called the fundamental structure.

### **Methodological Rigor.**

The purpose of rigor is to maintain the accuracy of the research by ensuring appropriate collection and analysis of the data, thereby revealing the participants' true experiences (Lincoln and Guba, 1985). Methodological rigor was addressed by establishing data accuracy, dependability, transferability, confirmability, and credibility.

Credibility is "confidence in the truth of the data and interpretation of them" (Polit & Beck, 2012, p. 585). Credibility was enhanced throughout the research process via reflective journaling. Each transcript was checked after each verbatim transcription. Themes and subthemes were reviewed with five participants to verify the congruence of the researcher's findings with the participants' experiences, also known as "member checking." Five of 10 participants verified the congruence of the researcher's findings. Following Colaizzi's procedural guidelines when analyzing the caregivers' experience also ensures credibility.

Confirmability and dependability, which refer to the trustworthiness and stability of the data (Polit & Beck, 2012), were addressed through maintenance of audit trails for all steps of the study (i.e., recruitment, interviews, and data analysis) as well as the researcher's thoughts (as per the bracketing process described above).

Transferability measures how well the study results can be generalized to another population (Polit & Beck, 2012). To increase the transferability of the findings, snowballing and purposive sampling were used to identify potential subjects. The participants who took part in the study are reflective of the African American population in

some ways and non reflective in other ways. Regarding their health, all participants had one or more risk factor for heart disease, 70% of the sample was overweight, and 60% of the participants had other health issues. The majority of the participants were between the ages of 31 and 64years. Given that these statistics are similar to African Americans within the United States, these results may be generalizable to other Africa Americans with similar characteristics. The majority of the sample was married, but this is not reflective of the statistics regarding marriage among African Americans in the United States. This sample of participants had more education than the average African American living in the United States, which may affect transferability.

### **Conclusion**

Phenomenology has provided the framework for this study. During the research process, the researcher was able to bracket her experiences to allow for the participants' true experiences to be shared. Data were analyzed using Colaizzi's steps, which allowed participants' experiences to surface. Along with bracketing, journaling and Colazzi's steps, rigor was maintained and achieved. All of these methods are essential for understanding the participants' experiences.

The next chapter discusses the results obtained as a result of interviewing participants for the study.

## Chapter 4

### Results

This chapter describes the results of this phenomenological study. The demographics of the study participants, and the themes that emerged are described.

#### **Sample**

The sample included 10 participants, each of whom self-identified as an African American providing care to an African American heart failure patient. The participants' ages ranged from 24 to 68 years old. The mean age of the participants are 46.3, (SD=14.6), The sample included both African Americans born in the U.S. and first and second-generation immigrants from the Caribbean islands. Sixty percent were women (n=6) and 40% (n=4) were men. Eighty percent (n=8) of the participants reported two or more years of college education. Eighty percent (n=8) of the participants co-resided with the heart failure patient. Fifty percent (n=5) worked full-time hours outside of the house. On average, caregivers had spent 3.8 years and 11.9 hours per day providing care to the heart failure patient. See Table 1 for additional demographic information.

**Table 1**  
**Demographic Sample**

Age range	< 30yrs = 20%	31-64yrs = 60%	> 65yrs = 20%
Sex	Male = 40%	Female = 60%	
Education Level	High School= 20%	2 or more years of college = 80%	
Marital status	Married = 60%	Unmarried = 40%	
Relationship to patient	Spouse = 20%	Children = 70%	Friend = 10%
Co-reside	Yes = 80%	No = 20%	
Adequate social support	Yes = 80%	No = 20%	
# of co-morbidities	None = 40%	One = 30%	Two to five = 30%
# of hours worked outside the home	FT = 40%	PT = 40%	Retired = 20%
House spent providing care	0-5 hrs = 20%	6-10 hrs = 40%	>11hrs = 40%
# of years spent providing care to the heart failure patient	< 1 year = 40%	1-5 years = 30%	>5 years = 40%
Does the heart failure patient's HCP communicate effectively with you?	Yes = 90%	No = 10%	
Felt prepared to care for the heart failure patient	Yes = 50%	No = 50%	



## Themes

The sample consists of 10 participants who were interviewed. The 10 interviews yielded 159 significant statements along with their formulated meanings, clusters of themes and sub-themes. The significant statements and their formulated meanings evolved into seven prominent themes (see Table 2). The themes derived from this qualitative study of African American caregivers' lived experience caring for adult African American heart failure patients are:

- 1) Juggling act
- 2) Layers of support
- 3) Realization of self-neglect
- 4) Experiencing the “blues”
- 5) Connecting with the health care provider
- 6) Unmet financial needs
  - a. Losing the breadwinner
  - b. Job loss/ hours reduction
- 7) Perceptions of non-adherence.

The lives of the caregivers and of the heart failure patients are intertwined. Caregivers are unable to make decisions about their own lives without thinking about the effect they will have on the heart failure patient. In addition, caring for a heart failure patient is increasingly complex because of all the co-morbidities he or she may present, to say nothing of the comorbidities that the caregiver might have. These complications made caregiving a very difficult task to accomplish, and eventually affected the physical and emotional well-being of the caregivers.

Table 2

## Selected Significant Statements, Formulated Meanings, Themes and Subthemes

## Theme 1: Juggling Acts

Significant Statements	Formulated Meanings	Themes	Subthemes
<p>They found a calcification in my breast. Okay, and so, I mean, that knocked me down. I never told my mom about it, though.", "Now think about this:</p> <p>have the radiation in the morning, come home and eat something and get in the car and go to take care of her.</p> <p>And they came and had to rush him to the hospital. I also had to go with him to the hospital, make sure that he ... that they stabilized him and then I had to leave him there and then rush to go to work and then immediately after work, I had to rush back to the hospital to make sure he was okay.</p> <p>And then there were some times when I'd come home from work and have to get in my car and drive to see my mother because something was going</p>	<p>Another participant discuss her health at the same time maintaining the health of her mother</p> <p>Participant spoke about caring for his dad and making sure he was on time for work to fulfill his job obligation and to make sure his dad did not feel neglected</p> <p>A participant spoke about taking care of her mother while tending to her personal needs</p>	Juggling Acts	

---

on with them [both her mother and father were diagnosed with heart failure]or someone had to go to the hospital. I can very well remember going in for a conference and having my sister call me and say that my mom had to be hospitalized because she had congestive heart failure and that she couldn't breathe and they didn't know whether she would make it through the night."

---

## Theme 2: Layers of Support

Significant Statements	Formulated Meanings	Themes	Subthemes
I would worry about it [i.e., the drive to my mother's town], especially in October where the days start getting shorter and I'm older, and I couldn't see that well, so my daughter would always say, "Mom," you know, and I knew she was tired too. She said, "I'll go with you."	A participant voices her concerns about traveling during the cold winter months to care for her mother. She also recall the support she received from her daughter	Layers of Support	Emotional Support
He would try to lift my spirit by talking to me and telling me how he went through the same thing with his mother." Another said, "Thank God I have friends that would call me and pray with me.	The emotional support was important in alleviating stress and giving her the strength to move forward		Physical Support
It was helpful to ha-			

---

have someone, I have a dear friend that would come over every night and stay with us. She [meaning her mother] was extremely heavy to lift and I needed someone there with me. I don't know what I would've done without this person because, um, he would come at eight o'clock at night and he would stay with me until maybe 8 o'clock in the morning.

A participant spoke about a friend who assisted her with ADL's consistently and how grateful she was for the support

---

### Theme 3: Realization of Self -Neglect

Significant Statements	Formulated Meanings	Themes	Subthemes
Virtually, my sister and I were living down there, you know, just staying in the house. We would alternate, you know, alternate	Sharing ADL's and IADL's was important in decreasing the burden	Realization of Self - Neglect	
I can just shoot the breeze or watch something that makes me ... happy and joyful. It makes me feel good. Something that keeps my mind off stuff. I need stuff like that. Even I do - I need to go back to reading books. I used to read books to get myself out of stress.	Realization that they had to do things outside of caring for the heart failure patient to maintain their health (such as exercising, spending time with friends and following up with their health care providers), so they would avoid needing a caregiver.		
I found I wasn't a super woman. I found that, yes, in fact, I do get tired. Yes, in fact, I do get frustrated. Uh. Yes, in fact, my blood pressure was out of, getting out of whack.	A caregiver realized that it's impossible to do everything on her own, at the expense of her health		

---

And a lot of it had to do with emotional stuff, you know, that was going on. Um, I found that, um, I really didn't take care of my health the way that I should

---

Theme 4: Experiencing the “blues”

Significant Statements	Formulated Meanings	Themes	Subthemes
I've been in a, uh, black mood. Talking about death all the time. I really still think I'm gonna die shortly. And it has an emotional effect, because I know my father has it. [He was talking about his father diagnosis of heart failure.] And, I thought to myself a couple days ago, well-uh-guess we gonna both go together.	Participant admits to depressive symptoms, but did not seek help. They felt informal support was necessary, not formal counseling. The informal support appeared to be inadequate to alleviate the depressive symptoms long-term	Experiencing the “blues”	
I remember one time, too, and my doctor told me that, um, it was a lot of emotional stuff going on. All of a sudden, I broke out in like, I had pimples. It felt like hives. It felt like hives all over me, you know. And, um, I, I came back home and I went to the doctor's and had him check it out, but it was nerves.	Participant exhibit physical symptoms of depression, which are unexplainable medical symptoms		
I did make several mistakes on my because I was so worried about him back here. Worrying about how he's making out. Worrying	Some depressive symptoms that affect everyday life are worry, anxiety, frustration and inability to focus. Many of the participants experience these emotions on a daily		

---

if he's living, if he's all right. And I couldn't concentrate a hundred percent on my job. But, emotionally it was breaking me down. You know, I was wondering, "what man, wh, what's going on in my life?"

basis but did not seek the required help. Living with depressive symptoms was the norm.

---

Theme 5: Connecting with the Healthcare Provider

Significant Statements	Formulated Meanings	Themes	Subthemes
<p>You really have to advocate, you know? You really have to have somebody that's going to, you know, talk for you. And if somebody, you don't like what they say, just, um, really question them about their answer. If they said something that I didn't like, I would really question them about it.</p>	<p>Advocating for the heart failure patient, attending the doctor's appointment and visiting the, hospital are important for the heart failure patient's health outcomes</p>	Connecting with the Healthcare Provider	
<p>I mean ... I-I just thought the doctors was tryin' to get more money out of him.</p>	<p>Lack of trust still exists between African Americans and their health care providers.</p>		
<p>The doctors treated me with respect and dignity.</p>	<p>Communication has improved between the caregiver and the healthcare providers. Participants felt respected and felt comfortable communicating with their health care providers</p>		

---

## Theme 6: Unmet Financial Needs

Significant Statements	Formulated Meanings	Themes	Subthemes
I mean it was a big transition and it was scary too, it really was, 'cause he is like the main breadwinner, I don't know... just being alone and if anything happened to him, heaven forbid it was really scary. It really was.	The fear of losing the main breadwinner in the family was frightening for the participants, because they did not know how they would pay the bills for the home.	Unmet financial Needs	Losing the Bread Winner
I didn't have as much money to spend and to pay my bills. But, um, when your family's sick, even though it might be a financial strain on you, you know you're going to sacrifice, and, you know, do what you have to do to get them better. It was hard but I didn't really, I wasn't really upset about losing the money. I was more upset about him.	The main breadwinner's hospitalization resulted in loss of income forcing the caregiver [the patient's wife] to work extra hours at her job to balance their household budget.		Job loss/ hours reduction
Well, because of, because of his situation and we [he and his wife] had to lose time from work; it was taking a toll on our finances because if you don't get regular	Giving up work and reducing job hours were necessary for the caregiver to provide safe and effective care to the heart failure patient.		

work, you know, people who work 40 hours a week, we wouldn't be able to pay our own bills and our expenses. So whenever we had to take time off and take him to the doctor for doctor visits and stuff like that, we had it hard making ends meet because we don't get to, uh ... our full salary.

I have to help him get to the doctor. I ... when I had to take off time from my job and take him to his doctor's appointments and things like that, and we were just trying to make ends meet and we have to pay our bills and, you know, we have mortgage and take care of our finances and things like this, buy gasoline and you know.

Taking time off from work was important in order to care for the heart failure patient. Taking time off from work resulted in the patient taking home less wage. Less wage resulted in inability to pay for their daily expenses. This decision created financial hardship.

---

#### Theme 7: Perception of Non-Adherence

Significant Statements	Formulated Meanings	Themes	Subthemes
We knew it was coming because of the way he ate, over the years. So it wasn't surprising; it bothered me because he is my father. And I felt like, he can do better but ... it's hard because, it's hard to teach old dog new tricks. And ... for him to learn how to eat differently at his age, it-it-he probably-he feels like, what difference does it make?	It's difficult to teach someone who thinks that their ways are the best. The heart failure patient's failure to follow the necessary medical regimen created stress in the life of the caregiver	Perception of Non-Adherence	
	Giving up work and		

---



I try to recommend food, but that's difficult because he likes buyin', chitlins and stuff like that--highly salty food. And, he buy yogurt here and there.

He was in a drunken state when I saw him and I, you know, I found out he took double of his blood pressure medicine than what he was supposed to and I just chewed him up. I mean, he's hard-headed, the guy's hard-headed, I mean, really, really, truly hardheaded.

reducing job hours were necessary for the caregiver to provide safe and effective care to the heart failure patient.

Caregivers were constantly trying to get the heart failure patient to do the right thing, but their efforts were unsuccessful

### Theme 1: Juggling Act

Each caregiver interviewed spoke about their personal life and the life of the heart failure patient as a juggling act. Some were responsible for self, husband, children, work, and the needs (both ADLs and IADLs) of the heart failure patient. One participant spoke about her health issues and the need to continue caring for her mother. When she finally took some time to tend to her own health and visited the doctor, she was given an unexpected diagnosis of breast cancer. She said, *“They found a calcification in my breast. Okay, and so, I mean, that knocked me down. I never told my mom about it, though.”* Despite receiving this diagnosis, undergoing surgery to remove the lump and subsequently going for radiation, she had to continue caring for her mother. She stated, *“Now think about this: have the radiation in the morning, come home and eat something and get in the car and go to take care of her.”*

Although this interviewee was receiving radiation treatment, she still had to provide care for her mother, since her mother was unable to care for herself and had no one but her daughter to care for her. Despite her feelings, this interviewee had to perform her mother’s ADLs and IADLs, because her mother was unable to do any activity because of the severity of her heart failure.

Another participant spoke about working and caring for his dad. He said: *“And they came and had to rush him to the hospital. I also had to go with him to the hospital, make sure that he ... that they stabilized him and then I had to leave him there and then rush to go to work and then immediately after work, I had to rush back to the hospital to make sure he was okay.”*

He also said, *“I did make several mistakes on my job because I was so worried about him back here.*

This participant described the effect of rushing. For a period of time he was rushing to work and after work he was rushing home to his dad. While at work he worried about his dad and when he was home with his dad he worried about mistakes made on the job. This juggling act affected his thought process. Being responsible for too many things at the same time can affect a person ability to concentrate, thus undermine their ability to perform at optimal level. Increased responsibility with increasing time constraints can lead to caregivers’ burnout. It also can lead to emotional neglect of the caregiver’s other family members and friends. This caregiver also spoke about neglecting his wife to care for his father. He had no other choice: that was his father and he had to care for him.

Still another interview subject spoke about leaving work to drive to another state after hearing that her mother was back in the hospital. She said: *“And then there were some times when I'd come home from work and have to get in my car and drive to see my mother because something was going on with them [ both her mother and father were diagnosed with heart failure]or someone had to go to the hospital. I can very well remember going in for a conference and having my sister call me and say that my mom had to be hospitalized because she had congestive heart failure and that she couldn't breathe and they didn't know whether she would make it through the night.”*

In speaking about her role as a caregiver, one interviewee provided a vivid description of an event that shed some light on the daily sacrifices that caregivers make to ensure that heart failure patients’ needs are met. She stated: *“I got someone to come down to sit with her and I said, "Mom, I'm going across the street to Subway." Well, I was walking and I*

*stumbled over something and fell and hit my head. And- you know what I did? I kept on going. I didn't go back and I went to the Subway and ordered the sandwich and the man said to me, "Um, lady, you're bleeding. . . . And, uh, I said, "Oh, okay, uh, can you just give me this sandwich?" And I went back. And so, like, sometimes it seems that I was in, uh, a cloud because I had so much on my mind. I'm worried about my mother and I had so much on my mind. Plus I had to give her her medicine on time."* Here is an individual who was juggling so many things that she was also neglecting her health. All the participants echoed the same sentiments.

The caregiver role resulted in much life interruption for this particular participant, and life interruption was experienced by all (N=10) of the caregivers. The interruptions mostly affected the caregivers ability to work their full-time equivalent budgeted hours. The juggling act increased the caregiving workload for the caregivers and created many other issues, which emerged in the remaining themes.

Despite the juggling and stress associated with the multifaceted caregiving role, the caregivers' commitment to the caregiving role was apparent. They were always anticipating the next time they had to be there for the heart failure patient. Throughout this theme, caregivers were needed in two places at the same time. They had a sense of obligation to be there for the heart failure patient. The consequences of losing time from work, which created financial difficulties, and the distance they had to travel to see the heart failure patient, were not deterrents to the caregivers fulfilling their caregiving duties.

## **Theme 2: Layers of Support**

All participants, with the exception of one, reported that they had support. After analyzing all the information they provided regarding that support, it was apparent that

support can be divided into two categories. First is emotional support: all participants except one felt they had emotional support. They all had individuals with whom they could share their concerns and frustrations. Someone was always available to talk.

Participants spoke about the emotional support they received, one fondly recalling the emotional support she received from her children. She spoke about her trip to visit her mother some evenings after work (a two-hour drive). She said, *"I would worry about it [i.e., the drive to my mother's town], especially in October where the days start getting shorter and I'm older, and I couldn't see that well, so my daughter would always say, 'Mom,' you know, and I knew she was tired too. She said, 'I'll go with you.'"*

Regarding her son, this informant added, *"Now he wasn't able to go as much as my daughter, but when I would come back home, he would make a point, being a chef. 'I'm going to make everything that you like, to make you smile'."*

Another participant spoke about emotional support that she received from a dear friend. She said, *"He would try to lift my spirit by talking to me and telling me how he went through the same thing with his mother."* Another said, *"Thank God I have friends that would call me and pray with me."*

Second is physical support, which can be divided into two parts: (1) having assistance with IADLs of the heart failure patient and (2) having assistance with the ADLs of the heart failure patient. Forty percent (n=4) of participants spoke about receiving help with IADLs necessary for the heart failure patient to have a good quality of life. Examples of IADLs are assisting with picking up medications from the pharmacy, taking the heart failure patient to a doctor's appointment, etc. However, 50% percent (n=2) of the 40% did not receive consistent help with IADLs. Eighty percent (n=8) of caregivers stated that they

needed more assistant with ADL's. Of that 80% only 16% (n=2) of participants stated that they had consistent and reliable help. One participant spoke about his wife helping him with his dad's ADLs, but stated: *"My wife helps sometimes, but sometimes it was stressful for her and she did not really want to help. It was causing a problem in my relationship, because it was my dad and I had to take care of him."* The stress of caring for a sick father affected this participant's relationship with his wife, who appeared to have a difficult time with the new co-caregiving role that was thrust upon her.

One participant spoke about having consistent help from a friend who made it his duty to assist her with her mother's ADLs at night, in particular with the difficult task of transferring an overweight heart failure patient from a chair to bed. The participant described her experience: *"It was helpful to ha- have someone, I have a dear friend that would come over every night and stay with us. She [meaning her mother] was extremely heavy to lift and I needed someone there with me. I don't know what I would've done without this person because, um, he would come at eight o'clock at night and he would stay with me until maybe 8 o'clock in the morning."*

One participant spoke of her experience of sharing the caregiving role (ADLs) with her sister. She said, *"Virtually, my sister and I were living down there, you know, just staying in the house; we would alternate, you know, alternate."* This interviewee was the weekend caregiver, and her sister was the one who lived with the mother Monday through Friday because she was retired. When this participant came to relieve her sister on Friday night, she returned to her own home (2.5 hours away), but would come back to her mother's on Sunday afternoon so that her sister could leave to go home to prepare for work.

One participant spoke about receiving help with ADLs from a nursing agency. She said *“I had someone from an agency to come in to bathe my mother, uh, in the morning. And I had someone else come in at night and bathe her.”*

Another participant spoke about the lack of support from family members, observing, *“I feel like if I don't do it for him, no one else in the house [will] do it for him.”* Another participant spoke about his family's willingness to provide emotional support and their unwillingness to provide the physical support he needed to help him care for his dad. As the activity intensified (providing ADLs for his father), support diminished and was less consistent. He said: *“I got frustrated. Because, you know, I'm, I'm only human being. So one time I remember I got so mad because he had some sisters in another country and he had some brothers in the Islands. I got, I got so frustrated one time that I, I, I, call them up and ask them, is there any way to relieve me from this situation? Because I couldn't take it anymore.”* Everyone declined to relieve him of the stress associated with caring for his dad, and though he declined to reveal the reasons why they did not help, the fact remained that the physical help that he needed the most was not available.

### **Theme 3: Realization of Self-Neglect**

The participants all had an epiphany: they remembered the exact moment when they realized that if they did not start caring for themselves, they were also going to need caregivers. Below are caregivers expressing the moment they decided that while it was important to care for the heart failure patient, it was more important to maintain their own health.

One participant said: *“But you also have to take that, what you learn, what you experience, and, um, make it into something positive, make it into something that may look,*

*um, I had my little brush with death so, you know, now, I've got to start eating right, I've got to start exercising, I've got to do this, and I've got to do that."*

With the exception of three participants, all the other interviewees (n=7) had one or more comorbidities: breast cancer, heart failure, hypertension, asthma, diabetes, and/or obesity. Another participant spoke about neglecting her own ADLs, because caring for her mother was a 24-hour job, and for a 3-month period she had had no escape. She said, *"It was stressful; I started to neglect myself. I could not do my nails, I could not do my hair. I had to leave. I was so glad to leave. Now my brother is living with her."*

Another participant spoke about neglecting herself and eventually realizing that she is not indispensable. She said: *"I couldn't, I tried. And I did think at one point that I was a super woman, and then I was knocked down very, very fast, and saying no, you're not. I found I wasn't a super woman. I found that, yes, in fact, I do get tired. Yes, in fact, I do get frustrated. Uh. Yes, in fact, my blood pressure was out of, getting out of whack. And a lot of it had to do with emotional stuff, you know, that was going on. Um, I found that, um, I really didn't take care of my health the way that I should."*

Another participant realized she was not taking care of herself, observing that *"...physically, I uh, it- it took a toll 'cause I was tired. I didn't get the proper amount of rest."* Still another, speaking about the need to take time for himself, discussed the activities that helped him to cope. *"If I can just shoot the breeze or watch something that makes me ... happy and joyful. It makes me feel good. Something that keeps my mind off stuff. I need stuff like that. Even I do - I need to go back to reading books. I used to read books to get myself out of stress."*



Although it was difficult, when a participant realized that taking care of his dad was taking a toll on his relationship with his wife, he decided to place his dad in a nursing home, because it would be best for his dad and also for his relationship with his wife. He spoke about the effects of this decision on his relationship with his wife: *“You know, like life began to come back the way it used to be with our relationship because he wasn't there, you know, and, you know, so we started seeing things falling back into place, the way it used to be.”*

#### **Theme 4: Experiencing the “Blues”**

All the participants experienced depressive symptoms. One participant spoke about caring for his dad, who had been diagnosed with heart failure 2 years earlier and who was non-compliant with his medical regimen, and had multiple comorbidities. This participant's health was similar to his dad's. He had been diagnosed with heart failure 7-years earlier, and also had a diagnosis of hypertension and diabetes. According to the participant, his dad was noncompliant and, thus, regularly in the hospital. The participant described his own mood as a result of his own illness and his father illness, expressing a bleak outlook on his life and that of his father: *“I've been in a, uh, black mood. Talking about death all the time. I really still think I'm gonna die shortly. And it has an emotional effect, because I know my father has it. [He was talking about his father's diagnosis of heart failure.] And, I thought to myself a couple days ago, well-uh-guess we gonna both go together.”*

The participant's and his father's heart failure diagnoses helped to increase the depressive symptoms that the caregiver was exhibiting. The participant was so depressed,

he was preoccupied with thoughts of death. He was unable to see any good in his life; he was hopeless and did not have any interest in mental health services.

Another participant stated: *“Well it was depressing for her and depressing for me, too. Um ... I- I couldn't get out unless I had someone to stay.”* Another observed: *“And, it was just really depressing, just to have everyone know, you know, that this heart attack reminded us of that, he could die at any time.”*

All the participants had depressive symptoms, but none sought any professional help; they only spoke to friends to help alleviate the stress. Other participants' descriptions of events provided evidence that they were exhibiting depressive symptoms: *“I remember one time, too, and my doctor told me that, um, it was a lot of emotional stuff going on. All of a sudden, I broke out in like, I had pimples. It felt like hives. It felt like hives all over me, you know. And, um, I, I came back home and I went to the doctor's and had him check it out, but it was nerves.”*

This participant was having somatic symptoms of depression and was unaware that the physical symptoms that she exhibited were indicative of depression. Another participant stated, *“Sometime I break down, um, it was hard, it was hard.”* Crying is another symptom of depression. This caregiver was unable to see this symptom as a sign that she may be depressed. Another commented: *“Emotionally it was breaking me down. You know, I was wondering, what man, who, what's going on in my life”?*

Another, reflecting on how her caregiving affected her schoolwork, said: *“I look back now and noticed that, ah, I could have done better or, you know, maybe if I hadn't been sleeping so much because of my depression, that maybe I would have been able to put more effort into the things that I wrote for my finals.”*

This participant echoed the same sentiment as other caregivers. Having the opportunity to express themselves verbally during the interview segment created an opportunity for caregivers to self reflect. Self-reflection resulted in caregivers' having a retrospect look at their roles and how they performed. From this retrospection, caregivers identified areas in their lives that needed improvement, things they could have done to alleviate their depressive symptoms. One participant was able to identify that she was depressed. Feelings of lack of motivation, inability to give their all to an activity due to fatigue and mental stress of caring for the heart failure patient were all depressive symptoms identified by the caregivers.

All the participants (N=10) exhibited depressive symptoms related to caring for the heart failure patient. A majority (n=7) of the caregivers, however, did not recognize signs of depression in themselves. Three participants acknowledged that they were depressed, but only one considered going to a mental health care provider. Although the depressive symptoms were affecting all aspects of the caregivers' lives, they did not seek professional help. They coped by discussing their burdens with close friends or loved ones. However, this coping mechanism was generally ineffective because they all continued to experience depressive symptoms. Caregivers also coped by rotating the caregiving role between siblings and other family members. This method was effective, and removing themselves from the caregiving role was an integral part in decreasing depressive symptoms among the caregivers. While this coping mechanism was effective most caregivers (n=8) did not have the ability to rotate or share their responsibility of caring for the heart failure patient.

### Theme 5: Connecting with the Health Care Provider

Effective communication between the caregivers of heart failure patients and health care providers is important and necessary to decrease rehospitalization and length of stay among heart failure patients. Ineffective communication resulted in feelings of frustration and perceptions of inadequate care and mistrust. Thirty percent (n=3) of participants made negative comments about their health care providers. One participant said: *“So I asked the doctor about that. ‘Oh, uhh, no, that’s just, you know, she is retaining water, she’s retaining water.’ What can we do about that, you know? That particular doctor, I did not get the kinds of answers that I wanted. So therefore, what I did was I pulled my mother away from her, you know.”* This caregiver was frustrated with the lack of communication, but she was proactive and changed the health care provider because she was not happy with the service she was receiving.

Another interviewee believed that the doctor was trying to get more money from his dad, and that he was not thinking that his dad needed care. He commented, *“I mean ... I-I just thought the doctors was tryin’ to get more money out of him.”* This participant did not trust the health care providers, and felt that every time his dad was admitted to the hospital something happened that resulted in his father’s having a longer stay. This recurring issue resulted in the caregiver’s feeling frustrated and helpless, thus validating his feelings of mistrust of health care providers.

Lack of effective communication between healthcare provider and caregivers often resulted in decrease continuity of care, where patients had to switch health care providers. As a result patients and their caregivers felt frustrated and disempowered to make good choices.

Despite these negative comments about the health care providers, the majority (n=9) of the participants stated that they were satisfied with the care the heart failure patient received. They felt they could trust the health care provider, and that they could voice their opinions. Their comments revealed that as a caregiver's knowledge of heart failure increased, the communication between the provider and the caregiver improved. This communication allowed the caregiver to develop a rapport with the health care provider. One participant stated: *"I was in the medical field, so I knew the appropriate questions to ask them. And, and if I wasn't satisfied with their answer, I would question them about it."* Another participant spoke about the importance of being an advocate and asking questions, because this was necessary to keep the heart failure patient from experiencing symptom exacerbation. One participant said: *"You really have to advocate, you know? You really have to have somebody that's going to, you know, talk for you. And if somebody, you don't like what they say, just, um, really question them about their answer. If they said something that I didn't like, I would really question them about it. . . . Well, um, you have to, um, be up front and tell, you know, talk to these care providers and don't let them just, you know, tell you anything and you don't understand it. You know, ask them to explain it to you."*

Another participant echoed: *"The doctors treated me with respect and dignity."* This suggests that as caregiver and care provider established an effective pattern of communication, the following pattern emerged: As the caregiver was able to ask appropriate questions, advocate for the heart failure patient, and understand the discharge instructions and the regimen set forth by the health care providers, the caregiver's satisfaction with the health care team improved. An improvement in the heart failure

patient's health and a decrease in symptom exacerbation were evidenced. Effective communication between health care providers and caregivers is one of the essential elements needed to improve the health of heart failure patient, and to improve the support caregivers need, thus decreasing their burden of care.

### **Theme 6: Unmet Financial Needs**

**Losing the breadwinner.** Fear of not having enough was a prominent part of all the caregivers' lives: they feared losing the breadwinner: Forty percent (n=4) of the people interviewed noted that the heart failure patient was the breadwinner of the family. The fear of losing the salary created panic and unrest regarding how they would support themselves. One caregiver explained: *"I mean it was a big transition and it was scary too, it really was, 'cause he is like the main breadwinner, I don't know... just being alone and if anything happened to him, heaven forbid it was really scary. It really was."*

Another echoed the same sentiments: *"I didn't have as much money to spend and to pay my bills. But, um, when your family's sick, even though it might be a financial strain on you, you know you're going to sacrifice, and, you know, do what you have to do to get them better. It was hard but I didn't really, I wasn't really upset about losing the money. I was more upset about him."*

**Job loss/ hour's reduction.** Another participant spoke about issues on the job: *"I did make several mistakes on my job because I was so worried about him back here. Worrying about how he's making out. Worrying if he's living, if he's all right. And I couldn't concentrate a hundred percent on my job."* As a result, this participant worried about losing his job because of the mistakes that he had made. The stress, worry, lack of sleep, and limited time to rest or rejuvenate associated with caring for a sick father were

starting to take a toll on his performance at work. He thought about decreased income, his inability to pay his bills, and he shared in the interview that: *“Well because of, because of his situation and we [he and his wife] had to lose time from work, it was taking a toll on our finances because if you don't get regular work, you know, people who work 40 hours a week, we wouldn't be able to pay our own bills and our expenses. So whenever we had to take time off and take him to the doctor for doctor visits and stuff like that, we had it hard making ends meet because we don't get to, uh ... our full salary.”*

This participant was not a salaried employee; he was paid hourly. If he did not work, he did not get paid, and it was the same for his wife. They were both taking time off to take his dad to his doctor's appointments, or to stay with him because he was very unsafe. This participant spoke about an incident that took place one night that led him to make the decision to put his dad in a nursing home. Because he had to work and he had to pay his bills, he could not stay home with his dad any more. He said: *“Sometimes he would put on the stove and in his sickness he would forget that the stove is on and go up in the bed and things like that. I came from work a few times and again he forgot the water on in the face basin and you know, flood the bathroom up, you know because he forgot he had it on. And he ... one time he had put something in microwave and he had set the microwave at too many minutes for how it's supposed to be heated up and it almost caused a fire.”*

This man had to place his dad in a nursing home because it was unsafe for him to be home alone. Caring for his father was also affecting his relationship with his wife and his financial life. Not having enough money to pay household bills created stress and tension between him and his wife.

Another participant echoed these concerns: *“I have to help him get to the doctor. I ... when I had to take off time from my job and take him to his doctor's appointments and things like that, and we were just trying to make ends meet and we have to pay our bills and, you know, we have mortgage and take care of our finances and things like this, buy gasoline and you know.”*

One interviewee spoke about deciding to put her job on hold to care for her mother. Because of her profession she had to travel to other countries. She stated that *“It affected work in the sense of I had to ... Because I'm artist and I needed to travel, but could not. So therefore, I couldn't go.”* She added, *“I had to put my life on the back burner.”* She also spoke about other people's lack of understanding. They did not understand why she would take time off from work to care for an ailing mother. She constantly had to explain and justify why she was taking time off, and, eventually, she gave up trying to make people understand her role. She concluded: *“Not all people, how should I say it? Not all people love their parents the way that I do, OK? And not all people understand that, oh you're going to not be able to go simply because your mother is, you know, ill. And I got to the point where I was getting very frustrated and then trying to tell people that. You know? And I said, I just ... I'll just leave it alone.”*

This participant suffered some financial loss, but the loss was not significant because she is an artist and makes a living from selling her artwork. She was also married and had the financial support of her husband.

### **Theme 7: Perceptions of Non-Adherence**

One of the greatest sources of stress and frustration for caregivers are their perception of the care recipient's non-adherence to the medical regimen for heart failure



care. All of the participants spoke about the frustration and stress associated with trying to educate the heart failure patient about diet and exercise. Participants spoke about the time it took to research and prepare healthy meals for the heart failure patient, only to have the patient order out or go to the store and buy unhealthy meals.

One-care giver stated: *“We knew it was coming because of the way he ate, over the years. So it wasn't surprising; it bothered me because he is my father. And I felt like, he can do better but ... it's hard because, it's hard to teach old dog new tricks. And ... for him to learn how to eat differently at his age, it-it-he probably-he feels like, what difference does it make”?*

This participant also had unhealthy eating habits that were difficult to break. The patient was aware of the consequences of eating unhealthy foods, yet that did not deter him. The participant's father's lack of regards for his own health was taking an emotional toll on his son. This resulted in feelings of helplessness on the part of the caregiver. This level of frustration led to some of the depressive symptoms experience by the caregivers. Caregivers also had the perception that the heart failure patient had given up, that they were not interested in fighting the disease, and they thus were burdened with the thought that their efforts were futile.

Another caregiver spoke about a care recipient's non-adherence to his medication and diet regimen and his lack of exercise. He said: *“I try to recommend food, but that's difficult because he likes buyin', chitlins and stuff like that--highly salty food. And, he buy yogurt here and there.”*

Caregivers expressed their frustration with the heart failure patients. Many wanted to give up helping, because their help was not appreciated and because care recipients

often perceived the caring gestures and concerns as nagging. One caregiver said: *"It does not matter what I do or say. He is going to do whatever he wants."* Another echoed this feeling: *"The first time I convinced him to go for a walk, it was more like, I think it was more like my mom convincing him where she- ... she would nag him about it and then I would reinforce that nagging by saying, 'You know, Dad, you're going to end up back in the hospital'."*

Another said: *"And you remind them of these things and they keep falling back to the same old same old and then there's other people who just going back to the hospital and they still don't take a lesson of, you know, of what they're seeing there and a lot of problems, they just continue on with the bad habits they're continuing, you know, just not taking care of themselves."*

Another explained: *"He was in a drunken state when I saw him and I, you know, I found out he took double of his blood pressure medicine than what he was supposed to and I just chewed him up. I mean, he's hard-headed, the guy's hard-headed, I mean, really, really, truly hardheaded."*

One hundred percent of the caregivers perceived that they were being helpful by researching what was best for the heart failure patient, by cooking healthy meals, and encouraging the heart failure patient to eat healthy, to exercise regularly and to take their medication as prescribed by the doctor. However, the perception that their efforts were seen as nagging was also discussed by all of the caregivers. It seemed that the caregivers' attempts to help the care-recipient were having a negative effect. The heart failure patients were rebelling in terms of eating healthy food, exercising and taking their medication as prescribed.

### **Exhaustive Description**

All the caregivers spoke about how their lives were intertwined with those of the heart failure patients. Separating their lives was impossible because all the actions of the caregiver directly or indirectly affected the heart failure patient and vice versa. Despite their frustrations, all the caregivers loved caring for the heart failure patient and were happy to do so, yet the stress associated with the caregiving tasks was unbearable at times. Daily routines tasks, such as bathing, dressing, and feeding the heart failure patient, were difficult. The type of social support that would be most beneficial was not readily available, and the caregiver often bore the burden alone. Caregivers often felt guilty, and if they had to take time off from work or from caregiving, they worried that something might go wrong with the heart failure patient while they were out caring for themselves. Thus, they did not take the time necessary for self-care.

Emotional support is just as important as physical support, as it provides caregivers with a coping mechanism, an outlet for them to break away from their depressive symptoms. The caregivers wanted to please the care recipients to the extent that, in some instances, when care from an agency, such as a home health nurse, was available, the heart failure patient would refuse outside help. The caregiver would comply with the care recipient's wishes despite the added emotional and physical burden on him or herself. Over time, caregivers stated, they began learning and understanding that they needed to take control of their own health and their lives, and to set boundaries that would enable them to maintain a healthy lifestyle.

All the caregivers had to juggle their own health issues, those of their immediate families and the needs of the heart failure recipient. This juggling act created stress,

frustration, depressive symptoms, and financial issues that negatively impacted all the caregivers. However, the juggling act caused the caregivers to examine their own health and lives. They had to come to terms with the fact that, in most instances, the heart failure patient had the ability to make wise decisions about their health but still chose to do what was most appealing to them. From the point of view of the caregivers, it appears that heart failure patients neglected the fact that the caregivers experiences the stresses associated with frequent readmission due to exacerbation of the heart failure patient's symptoms, creating life disruption for both the caregiver and the patient. A key finding of the interviews was that the participants had an epiphany about the need to care for themselves, lest they also need a caregiver, or they die, leaving the heart failure patient without a caregiver.

Chapter 5 discusses the research findings, and compare and contrast the findings with previous research. The implications for nursing practice and nursing education are discussed. Recommendations for future research and a discussion of the study's limitations and its conclusion complete Chapter 5.

## **Chapter 5**

### **Discussion of Findings**

This chapter discusses the findings presented in Chapter 4. Determinants of health were used as a guide to discuss the findings of this research study. This chapter also discusses the implications for nursing practice and nursing education in the context of social determinants and health outcomes. Suggestions for future research, study limitations, and the conclusions will also be included in this chapter.

Determinants of health are

factors that contribute to a person's current state of health. These factors may be biological, socioeconomic, psychosocial, behavioral, or social in nature. Scientists generally recognize five determinants of health of a population: Biology and genetics, Individual behavior, Social environment, Physical environment and Health services (CDC, 2014, p. 1).

Social determinants of health are “shaped by the distribution of money, power, and resources throughout local communities, nations, and the world” (CDC, 2014, p.1). The root problems of health inequality and health disparities lie in social determinants and result in lack of health equity. Many African Americans are at a disadvantage for positive health outcomes, because they are more likely to live in areas that have challenges and more social determinants issues. African Americans living in poorer neighborhoods have difficulty with access to healthy food, transportation and quality education. African Americans encounter discrimination when seeking care, education and work. They are more likely to be underinsured and uninsured. These social determinant issues play an important role in the health of African Americans. Unless more is done to help achieve

equality among different racial groups, health equity cannot and will not be possible (CDC, 2014).

All the caregivers interviewed for this study spoke about juggling the heart failure patient's needs, work, family, friends and self. The time involved in caring for others left no time for caregivers to maintain their own health. Juggling was seen in all the themes. Depression was intertwined with a lack of physical support. Alleviation of depression, when it occurred, did so through social support from family and friends. The caregivers shared stories of trying to make time for self, to spend time with friends, and to care for the heart failure patient. Stories of frustration regarding the lack of assistance with difficult tasks, and caregivers' inability to get the heart failure patient to maintain a healthy diet all intertwined with neglecting themselves, although they eventually realized the need to take care of their own bodies.

All the themes discussed in Chapter 4 are intertwined and involved attending to multiple concerns at one time. This burden is seen in other studies, such as Hwang et al. (2011), where caregivers felt overwhelmed because of their daily task of caring for the heart failure patient. The study by Hwang et al. (2011) included 11% African American subjects. Kang et al. (2011) revealed that caregivers were losing their social lives. This theme is significant, because it shows that caregivers are burdened by multiple obligations, and these burdens affect their social well-being and every other facet of their lives. Kang et al. (2011) and Molloy et al. (2005) conducted a meta-synthesis and review and analysis, respectively; thus, they did not mention the race of all the participants included in their studies.

The findings in the above-mentioned studies revealed a juggling act similar to what the African American caregivers in this study spoke about. The consequences of juggling many responsibilities are the same, in most instances, for African Americans as for other ethnic groups. African Americans, Whites, Hispanics and Asians experience depression, caregiver burnout, issues with social and financial support. However, African Americans disproportionately experience more depression, caregiver burnout and financial hardship than Whites. African Americans tend to have more informal supports than Whites, while Whites tend to have more formal social support. Because African American caregivers are more likely to be uninsured, and more likely to report poor health, they have greater burden as a caregiver. African Americans are less likely to seek mental health services because of the stigma associated with seeking mental health services, such as not wanting to be perceived as weak. African Americans are less likely to hire help, because they cannot afford to pay for the services, and because, due to cultural ties, they feel it is their responsibility to be the caregiver.

The African American participants in this study reacted differently to obstacles that they encountered. Their thought process in arriving at decisions regarding the heart failure patient was often different because of cultural beliefs and socioeconomic issues, such as finances, living arrangements and level of social support. This study highlights African Americans' reaction to issues, such as depression, caregiver burnout, and lack of adequate social and financial support.

Participants in the studies reviewed by Hwang et al. (2011), Kang et al. (2011), and Molloy et al. (2005) all experienced juggling, but they coped by making time for friends and participating in activities other than caring for the heart failure patient. If African

Americans actively participated in such activities, it might help alleviate some of their burden.

Pattenden et al.'s (2007) study showed that there is a correlation between caregivers' burdens, depressive symptoms, their quality of life, and their health (see also Brummett et al., 2012; Riegel et al., 2009; Saunders, 2009). Interruptions in the routine care, such as additional doctors' appointments and hospital visitations, have affected most of the caregivers, which has resulted in financial losses. Financial instability creates stress and other difficulties for the caregivers. Creating a balance in the lives of caregivers is important for their mental, physical, emotional, and financial well-being.

In this study, caregivers found that they received a lot of emotional and social support, but received physical support sparingly. With tasks that were the most difficult, such as bathing and feeding, caregivers found that most of the time they received inconsistent help or no help. This contributed to periods of frustration between the caregiver and the heart failure patient, and between the caregiver and other family members who were unwilling to help. However, caregivers also derived a sense of satisfaction from knowing that they were able to help meet the needs of the heart failure patient. This finding is similar to Saunders' (2008) that Whites (76% of Saunders' sample) had same difficulties with ADL's as the participants in this study, but they experienced significant higher level of burden than the other minorities in the study. African Americans viewed the caregiving role more positively than Whites. Therefore, it appears that one's attitude and approach to a particular task is indicative of the positive benefit they will derive from the experience regardless of the difficulties associated with the task. Knight's (2007) study comparing mental health and physical health of African American (n=62)



and White (n=40) caregivers of dementia patients, unlike this study, found that there was no statistically significant difference in the mental health of African American and Whites related to the caregiving role, although African Americans were more likely to have poorer physical health outcomes.

The level of care needed for a heart failure patient depends on several factors: the classification of the patient's heart failure, level I-IV (see Table 3), the heart failure patient's comorbidities, and the frequency of symptom exacerbation (Molloy et al., 2005). Additional support is needed for the family during the heart failure patient's hospitalization and immediately after discharge.

Saunders (2008) stated that compared to African Americans and Hispanics caregivers, Whites caregivers experience a higher burden when caring for heart failure patients. However, Lahaie et al.'s (2012) study concluded that minorities with more social determinant issues have a greater burden in terms of their caregiving role directly and indirectly. While Saunders (2008) discussed the actual care, such as ADL's provided by caregivers, Lahaie et al. (2012) discussed the care that the caregivers provided (ADL's and IADL's), and all the social issues of inequality that minorities encounter when having a dual role as an employee and a caregiver. Due to the many variables discussed in Lahaie et al. (2012), it is safe to conclude that caregiver burdens are greater for minorities than they are for Whites, in part due to inequality.

There are many programs available to assist heart failure patients, such as outpatient heart failure management programs and cardiac rehabilitation. However, many African Americans are not able to participate in these programs because they are uninsured or underinsured. Community outreach programs tend to be more beneficial to African

Americans because they are free. One such model used in community outreach programs is the Community Health Workers Evidence Based Model (U.S. Department of Health and Human Services Health Resources and Service Administration (DHHS HRSA, 2011), which was used by Durant's et al. (2013). The use of this model has been successful in helping minorities to be compliant with their medical regimens.

Durant et al.'s (2013) study on social support for African Americans with heart failure suggested that community health advisors would be instrumental in providing social/emotional support and instrumental activities of daily living support. Although, Durant et al. (2013) did not discuss activities of daily living, such as bathing and the time spent with the heart failure patient, ADL's could be implemented as a part of the Community Health Workers Evidence Based Model to help alleviate African American caregivers of some of the burden associated with their caregiving role.

Clay et al. (2008), similar to other studies (see Kang et al., 2011, Lahaie et al., 2012, Saunders et al., 2008, and Sebern and Woda, 2012), reported that more African American caregivers found the caregiving role more fulfilling than Whites. However, Clay et al.'s (2008) study on dementia caregivers found that caregivers who had conflicts with the care recipient or the people whom they relied on for social support were at risk for poor psychosocial outcomes. Many of the participants were either frustrated with the care recipient or a person they depended on to provide social support to them. All the caregivers in this study expressed frustration with the heart failure patient. Realizing the negative impact poor social support has on caregivers, teaching caregivers how to cope with their frustration is important to maintaining their mental health.

The results of this study indicate that the participants' experiences are similar to those of other African American caregivers and to those of White caregivers caring for White heart failure patients. Research examining levels of social support that would be most beneficial for African American caregivers caring for African American heart failure patients is essential and needs further exploration. Hwang et al. (2011) concluded that caregivers who had better social support noticed a reduction in the number of times they had to visit the emergency room. Teaching the caregivers to reach out to support groups may help to improve their willingness to seek social support

Caring for heart failure patients is very demanding and consequently little to no time is available for the caregivers to care for themselves. The caregiving role caused caregivers to delay seeking medical and mental health care. Lack of time also resulted in caregivers not having time for social life, daily grooming, sleeping, eating healthy, or maintaining their health. As a result, some caregivers' health deteriorated (Lahaie et al., 2012).

Exercising, eating right, and maintaining one's health and social connections are important aspects of well-being. Hwang et al.'s (2011) study stated that social support is important in the life of caregivers. This current study, unlike Hwang et al.'s, evaluated and analyzed the types of support that each caregiver received and concluded that caregivers are not receiving the type of help that they need in order to maintain their health. Because of the demands they were experiencing, they chose to neglect their health. Eventually, something life threatening occurred, such as changes in the patient's health, changes in the caregiver's health, or social changes in their family, which caused the caregiver to start the process of caring for themselves. Empowering the caregiver is also an important process of

the caregiver caring for him or herself. If the caregiver's health is not maintained, this will adversely affect the health of the heart failure patient (Kang et al., 2011).

This study's participants all exhibited depressive symptoms. Factors associated with depressive symptoms in this study included: feelings of helplessness, the declining health of the heart failure patient, the ADL's of the heart failure patient and the health of the caregiver. The restrictions placed on caregivers' lives because of their responsibilities and the lack of support caused African American caregivers to be depressed. Siabani et al.'s (2013) meta-synthesis of mostly White caregivers attributed depressive feelings to the care recipient's feeling depressed. Those feelings of helplessness put the caregiver in a depressed mood; their inability to prevent the stress and the discomfort associated with the disease deepened the depressive symptoms.

The results found in this current study are similar to Knight's et al. (2007) regarding depression in African American caregivers caring for dementia patients. Knight et al (2007) used the "Center for Epidemiologic Studies' Depression Scale (Radloff, 1977)" (p.541), while this study used a rich descriptive analysis to arrive at the same results. However, Clay et al.'s (2008) study regarding dementia caregivers suggested that African Americans display fewer depressive symptoms. As mentioned before, the burden of caring for heart failure patient was greater due to the progressive decline in the disease process and the increase in care that is needed. Though this current study is only about African Americans, like Knight et al. (2007), it suggests that African Americans are less likely to seek treatment for their depressive symptoms. For example, one participant stated that she should have sought professional help but that at the time she did not know that help was available. The African Americans in this study had similar health issues to those

of the heart failure patients they were caring for; thus the added burden of their personal health was creating depressive symptoms in the caregivers. This is similar to Knight et al.'s (2007) findings on caregivers for dementia patients, suggesting that African American caregivers experienced more health issues than their White counterparts.

The participants coped with their depressive symptoms with distraction and by talking to friends and family members, suggesting that they did not think the depressive symptoms were severe enough to seek professional help. The findings also suggest that some participants were not aware of mental health services and others did not feel comfortable seeking help from a mental health professional. All the participants had depressive symptoms but did not seek professional help; they looked at depression as a part of the process of caring for the heart failure patient.

Much of the history of the relationship between health care and African Americans is centered on mistrust. One particular instance is the Tuskegee study, in which treatments for syphilis were deliberately withheld from African American males with the disease (Gamble, 1997). Mistrust, reports of unequal treatment, lack of access to health care, being uninsured or underinsured, language, culture barriers, levels of health literacy and lack of effective communication are many of the issues that arise when African Americans seek care (Gamble, 1997; Phillips and Malone, 2014; Smedley et al, 2003; Sullivan, 2004). These issues also present themselves when caregivers are seeking knowledge on behalf of the heart failure patient. This has been the trend for the last 100 years. One of the presuppositions bracketed was the researcher's belief that the caregivers would have difficulty trusting and communicating with health care providers. After analyzing the data, three participants had negative comments about their health care providers. One participant

made comments suggestive of the fact that he did not trust his healthcare provider. Two other participants were not comfortable with a specific incident that took place. One felt that their physician was not attentive to her family because he was busy filming a video about his profession, while the other felt that the doctor was not attentive enough in general.

The statements made by the three participants are similar to findings in other studies conducted with African Americans regarding their perceptions of health care (Gamble, 1997; Jacobs, Rolle, Ferrans, Whitaker and Warnecke, 2006; Thornton & Hopp, 2011). Though the three participants and the aforementioned studies confirmed a degree of mistrust and poor communication, the majority (80 percent) of the participants in this study were happy with the care the heart failure patient received and their interaction with their health care providers. The caregivers felt that they connected with their health care provider. They felt they were respected and that the information provided by the health care providers was honest and adequate to care for the heart failure patient. These findings suggest that our healthcare system may be changing, as the communication between African American caregivers and healthcare providers is improving.

Jaarsma et al. (2013) and Reigel et al. (2009) stated that communication with healthcare providers is essential to heart failure patient's health. In this study the African American caregivers were knowledgeable and assertive in asking appropriate questions. They were comfortable interacting with their health care providers. They stated that establishing a relationship with the health care providers was key to the heart failure patient's transition from home to the hospital and back to home or a rehabilitation center. The participants were proactive; they sought knowledge from the Internet, from nursing

friends within the healthcare systems, and from their medical doctor. These proactive approaches allowed them to be more knowledgeable about heart failure, and they felt empowered and, as a result, were able to communicate effectively with the health care providers.

Siabani et al. (2013) stated that there is a correlation between insufficient knowledge and lack of adherence to a medical regiment. This study found, however, that caregivers who established a relationship with the heart failure patient's health care providers were more likely to have those providers seek them out to provide information regarding the prognosis or the plan of care for the heart failure patient. This also suggests an improvement in the caregiver-provider relationship. The finding of this current study opposes Walden et al.'s (2001) and Washington et al.'s (2011) conclusions, which stated that heart failure patients and their caregivers perceived that they received inadequate information. The findings from this study confirm what Martennson et al.'s (2001) qualitative study revealed: involving caregivers in heart failure patient care has a positive outcome. It is also similar to Reigel et al.'s, (2009) finding that caregivers, along with the heart failure patient, should receive discharge instructions.

The majority of the caregivers in this study communicated effectively with their healthcare provider. Though there were improvements in the caregiver-provider relationship, it is important to know that all the participants in my study were from middle class communities, with educations ranging from high school to advanced degrees. The majority had completed at least 2-years of college. There may be a connection between the education level and their ability to interact with the providers. As of today, although the number of minorities receiving higher education is improving, the participants' education

level in this study is not reflective of the African American population's education level in general (U.S. Census, 2012). Thus their experience may be different from that of the general African American population. However, the information learned can be a useful tool for developing interventions to teach other African American caregivers how to communicate effectively with their healthcare providers.

Research has indicated that African Americans are being diagnosed with heart failure at a younger age (Bibbins-Domingo et al., 2009). In this study, the heart failure patients whom the caregivers were caring for ranged from 36 to 87 years of age. Seventy percent of the heart failure patients were below the age of 65 and were contributing to the work force in the United States. They were also the main breadwinners in their families. The lack of income that followed their diagnoses caused additional stress for the caregivers and the heart failure patients' families. The inability to work contributed to the social determinants that affect the lives of many minorities.

There is a significant gap between African American and White children in K-12 and also in higher education. African Americans are at a disadvantage in every facet of life, having started out from an unequal place in life. Many African Americans are born into less desirable living conditions, their education achievement is below standards, they earn less income than Whites, they are more likely to have fewer fringe benefits than Whites, and they are more likely to be underinsured, uninsured and in poor health. Health inequality is linked to economic and social status. People of low socio-economic status are generally sicker than people of a higher socio economic status, and African Americans, in general, are less healthy than Whites. The burden of illness affects African American greatly, and because of inequality, they are more likely to resign or get fired from a job



because of health issues. Equality in benefits, such as paid time off, may not be available to African Americans. They are more likely to be in lower paying jobs with fewer benefits than Whites, because of lack of education. Lack of education results in lower wages and benefits package that impact every area of the African American communities (Meyer, Yoon & Kaufman, 2013). Participants in this study spoke about the issues that arose as a result of them being sick and their inability to meet household expenses. The caregiver's household experienced major financial loss because the heart failure patient was hospitalized. The caregiver had to care for the heart failure patient in addition to helping to provide financially for their household

The fear of hour reduction and job loss weighed heavily on the minds of the caregivers. A majority of the caregivers were gainfully employed working full-time or part-time hours. As a result they had to work while dealing with the demands of the heart failure patient who needed their help. There were times, especially when the heart failure patient had symptom exacerbation that required medical attention. The caregivers were forced to leave work early and/or take time off to be there for the heart failure patient. Employers were sympathetic and gave them the time off that they needed. However, it was time off without pay. This negatively affected their ability to “make ends meet,” and this economic burden created stress that affected their personal lives. The mistakes they made on their jobs and their inability to be present at all times due to the needs of the heart failure patient made the caregivers feel that they could easily be replaced, because they were not functioning at their optimal best.

The findings in this study and Lahaie et al. (2012) indicated that women and first generation immigrants have less access to vacation time. This study also indicated that

when these individuals had access to time off, they did not take it or were unwilling to take it because it was not paid time off, or the paid time off would result in a significant decrease in their take home wage. Unlike Lahaie's et al.'s (2012) study on immigrants, which showed that workplace culture was unsupportive, 90% of the participants in this study felt supported by the workplace. Yet, similar to participants in Lahaie et al.'s (2012) study, caregivers had to reduce their hours temporarily in order to care for the heart failure patient. However, this study highlighted that the caregivers voluntarily reduced the job hours, even though making the decision to decrease job hours created a perception of instability and fear of job loss on the part of the caregiver. It is important to know that in this study employers did not reduce job hours or roles as a result of the caregiver role but rather showed empathy and were willing to accommodate the caregiver. This study also confirms Lahaie et al. (2012), which found that individuals with a college degree had better job outcomes when balancing the dual role of employment and caregiving.

According to Albert (2009), African American heart failure patients had greater problems with compliance issues and consequences related to poor management of heart failure. Walden et al. (2001) found non-compliance was an issue with participants who were mostly Caucasians. Caregivers were frustrated with the heart failure patient's non-compliance with physicians' orders. In a review of literature, Kang et al. (2011) and Reigel et al. (2009) found non-compliance issue as well among heart failure patients. African Americans, similar to other ethnic groups, had difficulty complying with doctors' instructions.

Eating unhealthy food was the main contributor to non-compliance issues in this study. There are several possible reason for this trend, one of which is the lack of cardiac

food choices that are appealing to African Americans. Most of the information available about healthy eating has food that appeals to the White population, as are most cardiac diets in healthcare facilities. This contributing factor is partly responsible for the poor eating habits among African American heart failure patients. Most of the research conducted on nutrition for heart failure patients is based on a majority sample of Whites. However, there are heart failure diet geared towards African Americans that are endorsed by the U.S. Department of Health and Human Services: National Institute of Health, National Heart Blood and Lung Institute (2008). Table 4 provides a list of heart healthy diets that are geared towards African Americans. Implementing these diets in health care facilities could be beneficial to African American patients. Having African American heart failure patients and their caregiver adhere to diets such as listed in table 4, could result in

The heart healthy menu that African American patients receive in the hospital, nursing homes, and the heart healthy menu included in their discharge instruction are not appealing to their palate, because it is not culturally familiar food. In addition to the foods being unfamiliar, eating healthy is expensive. Many African Americans, because of low paying jobs, lack of education, disability due to illness or lifestyle and minimal government support, cannot afford to buy healthy food. Another issue that African Americans encounter is lack of access to healthy food, either because their neighborhood does not have grocery store or there is a lack of transportation to areas where they can buy fresh vegetables (U.S. Census Bureau, 2012).

K-12 education in African American communities also needs improvement. This will help to increase the numbers of students who graduate from high school, and are academically prepared to enter higher education and, once they enter higher education, be

successful, graduate and be gainfully employed. Equal opportunity for employment and wages and benefits is needed for minorities. With better wages, African Americans are more able to care for themselves, live in better conditions and live a healthier lifestyle. Having a heart healthy menu that is culturally congruent is necessary to increasing compliance among African Americans. Having equality and health equity are necessary to change some of the habits of African Americans, in general, and of African American caregivers and heart failure patients, in particular.

Lack of adherence to the doctor's regimen caused great frustration among the caregivers in this study. They recognized the association between unhealthy eating habits and poor self-care and the heart failure patient's probability for readmission. Caregivers took the responsibility of educating heart failure patients, but it appeared as if the heart failure patients did not welcome the education. In fact, the heart failure patients experienced the caregivers' concerns as nagging. The information conveyed by the caregiver was not what the heart failure patients wanted to hear.

Also, caregivers had difficulty coping with the noncompliance issues of the heart failure patients. Reaching out for social support and additional resources might have been helpful in these cases. According to the American Heart Association Scientific Statement (Riegel et al., 2009), encouraging the heart failure patient to maintain compliance is necessary. Failure to maintain compliance can result in frequent hospitalization and increased progression of the disease. Still, heart failure patients were non-compliant despite the caregivers' pleading with them to follow the prescribed regimen. Heart failure patients tended to depend a lot on their caregivers once their disease progressed, yet they were unwilling to comply. In a previous study by Hamilton (2013), the heart failure

patients stated that their caregiver brought “junk” and other unhealthy food into the home, and that they tried to eat healthy but eventually they stopped, because eating healthy was difficult because the support was not there.

Kang et al. (2011) also found that caregivers felt a burden because they had to eat the same food as the heart failure patient. In this study, caregivers cooked healthy meals for the heart failure patient but also cooking more appealing meals (meals that were not heart healthy) for themselves. The food habits of both the caregiver and the heart failure patient created frustration for both parties. Health issues and risk factors for cardiovascular disease in many of the participants make it important for the caregivers to eat healthy to maintain their health and also, at the same time, motivate the heart failure patient to be compliant.

Kang et al. (2011), Molloy et al. (2005) and Sebern and Woda (2012) all stated that interventions that targeted both the caregiver and the heart failure patient were important in maintaining the health of the heart failure patient. Observations made during this study determined that all the heart failure patients were overweight and that 70% of the caregivers were also overweight, suggesting that the eating habits of the caregiver were similar to those of the heart failure patient. Thus, having the caregiver and the heart failure patient both make an effort to eat right could be instrumental in decreasing one of the many issues surrounding non-compliance among heart failure patients. To increase compliance, caregivers may need to actively change their own eating habits and their way of life to a healthy lifestyle. One participant spoke about cooking healthy meals for the heart failure patient, but also that she made a “nice” meal (a meal that was not heart

healthy) for herself and the kids. Though the gesture was thoughtful, it showed lack of support and made it difficult for the heart failure patient to be compliant.

Lack of adherence to the heart failure regimen resulted in frequent exacerbation of symptoms and repeated hospitalizations for the heart failure patient (Riegel et al., 2009). It also caused disruption in the caregiver's life and added to the burden that they experienced. In this study, the habits of caregivers concerning meal preparation, for the most part, were not beneficial to the heart failure patients that they cared for. These findings suggest that caregivers must be instrumental in the heart failure patients' adherence to their medication.

### **Implications for Nursing Practice**

If health care providers were more informed about the differences between different cultures and ethnic groups, they would be able to identify these differences in their African American population. They could then screen patients and caregivers more effectively and provide the types of support that would be most beneficial to them. It is important that nurses and other health care providers teach caregivers to take time for themselves; inform caregivers of resources available to them and their rights; and encourage them to ask for help or to seek professional and informal help, especially with tasks that are difficult (Molloy et al., 2005). Taking time away from the heart failure patient is also necessary for caregivers' emotional well-being. Additional alternative mental health treatment options should be introduced to African American caregivers to help them cope and to alleviate their depressive symptoms.

It is important that health care providers recognize depressive symptoms in caregivers and refer them to the appropriate health professionals, because depression is strongly associated with cardiovascular disease (Brummett, 2012). It is also important to

have caregivers who are free of depressive symptoms because there is a correlation between untreated depression in caregivers and decreased quality of life among the heart failure patients whom they are caring for (Wittingham, et al., 2013). Nurses who recognize depressive symptoms are important for improving the mental health of the caregiver and the quality of life for the heart failure patient.

All heart failure patients in Hamilton's (2013) study had comorbidities. The caregivers (N=10) in this study also had at least one risk factor for heart disease, and 70% (n=7) had at least one comorbidity, suggesting that the health of heart failure patients and their caregivers is reflective of the general African American population's health (U.S. Census Bureau, 2012). Currently all health care institutions are family centered; thus, it is important for the profession of nursing to explore the possibility of screening caregivers for risk factors of heart disease and, if they meet the criteria, to provide education on self-care and refer them to a health coach for a free consultation.

The discharge instructions geared toward the caregiver should include information on the association between risk factors and the development of heart failure. The correlation between diet, exercise and the development of risk factors for heart disease or some of their comorbidities should be an emphasis. There is a need for the discharge instruction to be reinforced post-discharge. Nurses should be sent to patients' homes to reiterate discharge instructions and confirm that patients and caregivers understand the discharge instructions that were provided. There also needs to be an assessment of the environment to see if it is conducive to compliance on the part of the heart failure patient and their caregiver. Following such a visit, the nurse will have to make an assessment and refer the home to an appropriate health care agency, if needed.

One might say that this is an expensive venture, and ask who will pay for it, but the cost of the follow-up visit would be less expensive than treating a patient for another episode of heart failure exacerbation. Overall, informing patients and their caregivers about the connections between eating habits, exercise habits, living environment, risk factors, comorbidity and heart disease is the most important step in getting people to make appropriate changes necessary to maintain their health.

Having a health liaison dedicated to caregivers is also necessary. It is important that the health of the caregiver be maintained, as they are an important and integral part of the heart failure patient's health. The health liaison should be available to focus solely on the caregiver's needs and to refer them for help. As mentioned above, including the caregiver in the discharge instruction is important because caregivers exhibit many of the same depressive symptoms that heart failure patient exhibit. Crying, feeling depressed, bleak moods, frustration and sadness are some of the feelings that caregivers express. Having a health liaison to screen for depressive symptoms in caregivers and to make appropriate referrals is important in maintaining the health of the caregiver.

Information learned in this study will promote the delivery of culturally competent care. Registered nurses will have an in-depth knowledge of the needs of African American caregivers caring for African American heart failure patients. They will know that the heart failure patient and their caregiver are a dyad and the needs of both must be met in order for consistent care to be provided to the heart failure patient. Every heart failure patient-caregiver dyad is the same regarding the diagnosis; however, socio-economics, cultural issues, and nuances make African Americans a unique population that requires additional attention, in particular discharge instruction that are personalized to meet the needs of the



dyad, which will allow for a higher probability that the instructions provided will be followed. It will also allow the nurse to know if the instructions given are clear and if they articulate an attainable goal for the heart failure patient-caregiver dyad.

Registered nurses who are in contact with caregivers have the ability to connect these caregivers to each other. Creating a support group for caregivers could be instrumental in their ability to cope and possibly share the burden of caregiving. Caregivers connecting will allow for shared knowledge of resources available and also information regarding how to care for the heart failure patient.

The caregiver role is critical in the lives of heart failure patients, as is the role of the registered nurse. Nurses interact the most with the caregiver-heart failure patient dyad, more than any other health professionals. Over time, nurses build and develop trust within this population, and they have the ability to suggest and implement changes that could be beneficial to the lives of caregivers caring for heart failure patients. Direct interaction with caregivers and heart patients offers time for nurses to assess the needs of the caregiver and make appropriate referrals, because during that period of transition more support is needed.

### **Implications for Nursing Education**

Another problem that affects the health of the African American population is the lack of diversity in nursing workforce. It is estimated that minorities will be the majority by 2040, but the prospect for an increase in the number of minority nurses seems bleak. The Institute of Medicine report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* (Smedley, Stith and Nelson, 2003) and the Sullivan Commission report, *Missing persons: Minorities in the Health Professions* (2004) stated that in order to

decrease health disparities between Blacks and Whites, more minority health professionals are needed in the workforce, because they will provide culturally competent care and can train other registered nurses and other health professionals on how to provide and deliver culturally competent care, care that is free of ethnocentric biases and stereotypes.

The two above-mentioned reports stated that nurses and health professionals who treat patients from the same background as themselves are more likely to be sensitive to the needs of those patients, because they understand the way of life in a particular culture. Having more minorities in the nursing workforce could be instrumental in teaching other health care professionals how to appropriately screen for cultural issues that impact the care of the patients, and see the needs of the caregivers at risk for not following through on the heart failure patients' regimen and also their need of respite care.

Lack of minority faculty in nursing institutions is partially responsible for the under-representation of minorities in the nursing profession. Social determinants, such as K-12 schools in minority neighborhoods are among the major reasons for the lack of nurses in the health profession and lack of minority faculty in health care teaching institutions. Lack of minority faculty is a barrier to recruiting and retaining minority students in health professions. Having minority nursing faculties is more likely to bring awareness to health issues affecting minorities. Minority faculties are more likely to conduct research on minorities, and to guide students toward addressing the issues that many minority patients encounter when they become part of the health care system.

Many minority nursing faculty members are frustrated in their positions because they are often faced with workload, promotion and salary inequities. They also encounter, overtly and covertly, forms of racism that are very stressful. Despite these challenges,

many minority-nursing faculties continue in this profession, because they are underrepresented. Leaving a faculty position would mean that minority faculty will move from underrepresented to missing. It is imperative to have minority faculties in schools of nursing, so that they can assist with recruiting and retaining minority students in the nursing workforce. Increasing recruitment and retention of minority students in nursing programs will increase the numbers of qualified minority nurses within the nursing workforce. Having qualified minority nurses can help to decrease the health disparity gap between Blacks and Whites (Stanley, Capers, & Berlin, 2007; Smedley, 2003; Sullivan, 2004).

### **Future Research**

Although only two caregivers spoke about staying awake to hear if the heart failure patient was having difficulty breathing, or staying awake anticipating the heart failure patient needs. Sleep deprivation in heart failure patients and their caregivers is an interesting concept that needs further exploration. Difficult ADLs, such as bathing, dressing and feeding the heart failure patient, are known to place a higher burden on the caregiver. However, African American caregivers were not willing to seek help. Studies are needed to identify the barriers that prevent caregivers from seeking the help that would be the most beneficial to them. Intervention studies are also needed that teach caregivers how to be more assertive and how to seek and accept help. This research would be an important step toward improving quality of life of caregivers and heart failure patients alike. It could help to alleviate some of the caregivers' burdens related to caring for the heart failure patient.

The depressive symptoms associated with the caregiving role were apparent in all the caregivers in this study, yet none sought professional help to deal with them. Further research is needed on the coping skills that African American caregivers use to deal with depressive symptoms. Intervention studies are also needed that will assess African American caregivers' knowledge of depression before and after providing education on depression. Raising awareness of depressive symptoms in African Americans is essential to treating depression in this population. Many are unaware that depressive symptoms are not normal and that help is available for them. The effectiveness of African American coping mechanisms needs further exploration. Barriers to African Americans' seeking mental health care also need to be addressed.

Non-compliance issues on the part of the heart failure patients and contributing factors of the caregivers in this role need to be explored. Hamilton's (2013) study on the lived experience of African American heart failure patients revealed that heart failure patients' difficulty with maintaining a healthy diet was partly a result of the caregivers' inconsistency in preparing health meals. This study also showed that the caregivers were frustrated with the heart failure patients' inability to eat healthy despite the education given on healthy eating, and despite the time they spent preparing healthy meals. As a result more research is needed to explore eating habits of heart failure patients and their caregivers and their effect on both the health of the heart failure patients and their caregivers.

An intervention study that is culturally relevant is needed to assess the myths regarding healthy foods among African Americans as well as their knowledge of foods that are appropriate for their health. Since all the caregivers in this study had one or more risk

factors associated with heart disease, healthy eating habits are imperative for them as well as the heart failure patients.

Due to the many reports on the importance of having culturally competent nurses to deliver care, intervention research is needed on the delivery of culturally competent, personalized discharge instructions to African American heart failure patients and their caregivers. Studies comparing and analyzing cultural sensitivity when delivering heart failure discharge instruction are needed. Analysis of the differences between nurses and patients from different racial and ethnic backgrounds is needed to see if nurses are providing culturally competent care. Care that is culturally congruent has the potential to improve the nurse-patient-caregiver relationship and thus improve patients' health outcomes.

### **Limitations**

This research resulted in a descriptive phenomenological qualitative study in which a homogeneous sample was used to describe the experience of the participants. As a result, the study findings may not be generalizable to other ethnic groups. Majority of the participants had 2 or more years of college, thus the findings may not be reflective of the general African American population or the African American caregiver population. This current study suggested that the more education a person has, the easier it is for them to communicate with health care providers. As a result, this finding may not be transferable to African Americans with low income and or with less than high school education. There is a higher probability that someone who did not complete high school or attend college will have a lower level of literacy and health literacy skills. A person with low literacy and low health literacy skills will likely have more difficulty understanding and grasping

medical concepts, (US Department of Health and Human Services, 2008) and be less likely to carry out discharge instruction accurately. Without adequate knowledge and understanding of the disease process, and because of cultural beliefs, one may not understand the depth of importance in caring for a heart failure patient appropriately. This can also translate into difficulty communicating with the health care provider.

### **Conclusion**

The themes that emerged from the interviews done for this study demonstrate that African American caregivers encounter enormous challenges as they attempt to care for heart failure patients and themselves. Heart failure is a complex disease, and this study allowed for the voices of African American caregivers to be heard. The study findings reinforce what the literature illustrates about caregivers of heart failure patients. They also add to our knowledge of African American caregivers caring for African American heart failure patient. The study also highlights the challenges that are unique to African Americans. Though they experience many of the same things as caregiver from other ethnic backgrounds, African American caregivers react to and cope differently with issues that arise, based on their cultural upbringing. These caregivers experienced depressive symptoms, but they did not seek professional mental health services. Many did not perceive their depressive symptoms to be severe or as anything that needed urgent intervention. This suggests that it is essential to increase caregivers' awareness about depression, its signs, symptoms and effects on a person's life. Finding alternative ways of treating depressive symptoms is also essential.

Most caregivers did not have a healthy diet, which made it more difficult for the heart failure patient to maintain a healthy lifestyle. What this study highlights, reinforcing

the finding in Hamilton (2013), is that there is an association between caregivers' eating habits and non-compliant, unhealthy eating habits among patients. Most heart failure patients were not eating healthy because they did not have support from their caregiver. The caregivers were not eating healthy meals, so the heart failure patients were not motivated to eat healthy foods.

In this study, the majority of participants had more than one risk factor for heart disease, and more than half had one or more comorbidities. These statistics are similar to what the literature reports about African American caregivers caring for patients with cancer, Alzheimer, stroke and dementia.

This study also highlights the huge financial issues that exist among African American caregivers. Thornton and Pratt (2011) and Durant et al. (2013) studies, which focused on caregivers for African American heart failure patients, did not discuss the financial implications associated with caring for a heart failure patient. The other studies (Molloy et al 2005; Molloy, et al, 2008; Woodend et al., 2008) on caregivers of heart failure patients did not discuss the race or ethnic background of the study participants. Nor did these studies highlight any financial issues that African American caregivers experienced. However studies (Clay et al 2008; Lahaie et al, 2012; Rozario & DeRienzi, 2008; Saunders, 2008; Saunders, 2009) on caregivers caring for African American patients with Alzheimer's disease, dementia and cancer did discuss financial implications. Knowing that African American caregivers experience financial difficulties, health care providers should be able to start a dialogue about caregiver and the heart failure patient finances.

The connections between the caregiver's emotional well-being, burdens, heart failure patient's lack of adherence to the doctor's regimen, frequent hospitalization of heart failure patient, the physical health of the caregiver, the financial status of the caregiver and communication between the caregiver, the heart failure patient and their provider all impact the caregiver and the heart failure patient's quality of life. Many caregivers are living in silence, dealing with the burden of caring for the heart failure patient, quietly living with depressive symptoms and watching the decline of their own health, feeling frustrated and less empowered. It is imperative that health care providers take these dynamics into account, which could help empower both patients and caregivers.

It is also important that nurses recognize that the caregiver and patient as a dyad and that both be included in any and all discharge planning, since the needs of both must be assessed and supported to improve the health of African Americans. A multi-disciplinary team is needed to provide effective care to caregivers and heart failure patients. Information learned from this study can be shared with doctors, nurses, social workers and other health care providers. Results obtained can be used to develop culturally congruent interventions whose implementation will be helpful to African American caregivers caring for African American heart failure patients. These interventions will also help nurses who are an integral part of the discharge planning and delivery to be more sensitive to the needs of this population. Having nurses and other health care providers who deliver culturally sensitive care is an important step in helping to improve the lives of caregivers and creating a path that can help to decrease the health disparities that exist between Whites and Blacks.



Table 3  
New York Heart Association Functional Classification

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

---

Note adapted from the American Heart Association, Classes of heart failure (2011), p.1  
[http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/Classes-of-Heart-Failure\\_UCM\\_306328\\_Article.jsp](http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/Classes-of-Heart-Failure_UCM_306328_Article.jsp) (p.1)

## References

- Albert, N.M., Trochelman, K., Meyer, K.H., Nutter, B. (2009). Characteristics Associated with Racial Disparities in Illness Beliefs of Patients with Heart Failure. *Behavioral Medicine*, 35(4), 112-125.
- American Heart Association. Classes of Heart Failure (2011). Retrieved from [http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/Classes-of-Heart-Failure\\_UCM\\_306328\\_Article.jsp](http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/Classes-of-Heart-Failure_UCM_306328_Article.jsp)
- American Heart Association. *Heart and Stroke Statistics- 2014 Updates*. Retrieved from [http://www.heart.org/HEARTORG/General/Heart-and-Stroke-Association-Statistics\\_UCM\\_319064\\_SubHomePage.jsp](http://www.heart.org/HEARTORG/General/Heart-and-Stroke-Association-Statistics_UCM_319064_SubHomePage.jsp)
- American Heart Association. *Heart and Stroke Statistics- 2012 Updates*. Association. Retrieved, from <http://circ.ahajournals.org/content/125/1/e2.extract>
- American Nurses Association (2010) Nursing: Scope and Standards of Practice (2<sup>nd</sup> ed). Retrieved from <http://www.nursingworld.org>
- Bibbins-Domingo, K., Pletcher, M. J., Lin, F., Vittinghoff, E., Gardin, J. M., Arynchyn, A., & Hulley, S. B. (2009). Racial differences in incident heart failure among young adults. *New England Journal of Medicine*, 360(12), 1179-1190.  
doi:10.1056/NEJMoa0807265
- Brownstein, J.N., Chowdhury, F.M., Norris, S.L., Horsley, T., Jack, L., Jr, Zhang, X., and Satterfield, D. (2007). Effectiveness of community health workers in the care of people with hypertension. *American Journal of Preventative Medicine*. 32:435–47.
- Brummett, B.H., Siegler, I. C. Dilworth-Anderson, P. (2012). Associations of social support and 8-year follow-up depressive symptoms: Differences in African

- American and White caregivers. *Clinical Gerontologist: The Journal of Aging and Mental Health*, 35(4): 289–302.
- Calderon, V. & Tennstedt, S. (1998). Ethnic differences in the expression of caregiver burden: Results of a qualitative study. *Journal of Gerontological Social Work*, 30, 159–178.
- Centers for Disease Control and Prevention (2014). Black or African American Populations. Retrieved from [www.cdc.gov/minorityhealth/populations/REMP/black.html](http://www.cdc.gov/minorityhealth/populations/REMP/black.html)
- Chen, J., Normand, S.L., Wang, Y., & Krumholz, H.M. (2011). National and regional trends in heart failure hospitalization and mortality rates for Medicare beneficiaries, 1998-2008. *Journal of the American Medical Association*, 306, 1669–1678. doi:10.1016/j.jpainsymman.2011.09.018
- Chung, M.L., Moser, D.K., Lennie, T.A., Rayens, M.K. (2009). The effects of depressive symptoms and anxiety on HRQOL in patients with heart failure and their spouses: testing dyadic dynamics using Actor-Partner Interdependence Model. *Journal of Psychosomator Research*, 67, 29–35.
- Clark, A.L. (2012). Instrumental activities of daily living: more than just piano-playing? *European Journal of Heart Failure*, 14(6), 565-566
- Clay, O. J., Roth, D. L., Wadley, V. G., & Haley, W. E. (2008). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and White dementia caregivers. *International Journal of Geriatric Psychiatry*, 23(8), 857-862. doi:10.1002/gps.1996
- Colaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R.

- Valle & M. King (Eds), *Existential-phenomenological alternatives for psychology* (pp 48-71). New York: Oxford University Press.
- Coogle, C. L. (2002). The Families Who Care project: Meeting the educational needs of African American and rural family caregivers dealing with dementia. *Educational Gerontology*, 28(1), 59-71.
- Covinsky, K. E., Newcomber, R, Fox, P., Wood, J., Sands, L., Dane, K., & Yaffe, K. (2003). Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *Journal of General Internal Medicine*, 18, 1006-1014.
- Dilworth-Anderson, P., Williams, I. C., & Gibson, B.E. (2002). Issues of race, ethnicity, and culture in caregiving research: A twenty-year review (1980-2000). *The Gerontologist*, 42, 272-327.
- Dilworth-Anderson P, Goodwin, P.Y. & Williams, S.W. (2004). Can culture help explain the physical health effects of caregiving over time among African American caregivers? *Journal of Gerontology: Social Sciences*, 59(3), S138–S145.
- Durant, R. W., Brown, Q. L., Cherrington, A. L., Andreae, L. J., Hardy, C. M., & Scarinci, I. C. (2013). Social support among African Americans with heart failure: Is there a role for community health advisors? *Heart & Lung*, 42(1), 19-25.  
doi:10.1016/j.hrtlng.2012.06.007
- Family Caregiver Alliance, National Center on Caregiving (2013). Retrieved from <http://www.caregiver.org/caregiver/jsp/home.jsp>
- Gamble, V. N. (1997). Under the shadow of Tuskegee: African Americans and health care. *American Journal of Public Health*, 87(11), 1773–1778.

Grady, K.L., Dracup, K., Kennedy, G., Moser, D.K., Piano, M., Stevenson, L.W., Young,

J.B. (2000) AHA Scientific Statement. Team management of patients with heart failure: A statement for healthcare professionals from the Cardiovascular Nursing Council of the American Heart Association. *Circulation*, 102, 2443–2456.

Haley, W. E., Gitlin, L. N., Wisniewski, S. R., Feeney Mahoney, D., Coon, D. W., Winter, L., Corcoran, M., Schinfeld, S. & Ory, M. (2004). Well-being, appraisal, and coping in African-American and Caucasian dementia caregivers: Findings from the REACH Study. *Aging and Mental Health*, 8, 316-329.

Hamilton, H. (2013). The lived experience of African Americans with heart failure: Phenomenology study. Unpublished Manuscript. University of Connecticut.

Heart Failure Society of America. (2010). *Comprehensive Heart Failure Practice Guideline*. Retrieved from [www.heartfailureguideline.org](http://www.heartfailureguideline.org)

Hellesø, R., Eines, J., & Fagermoen, M. S. (2012). The significance of informal caregivers in information management from the perspective of heart failure patients. *Journal of Clinical Nursing*, 21(3), 495-503. doi:10.1111/j.1365-2702.2011.03927.x

Heidegger, M. (1962). *Being and time*. J. Macquarrie & E. Robinson (Trans.), New York: Harper & Row.

Hinojosa, M. S., Zsembik, B., & Rittman, M. (2009). Patterns of informal care among Puerto Rican, African American, and White stroke survivors. *Ethnicity and Health*, 14(6), 591-606. doi:10.1080/13557850903165403

Humphrey, L. Kulich, K., Deschaseaux, C. Blackburn, S. Stromberg, A. (2013). The caregiver burden questionnaire for heart failure (CBQ-HF): face and content validity. *Health and Quality of Life Outcomes*, 11, 84.

- Husserl, E. (1931). IDEAS General Introduction to Pure Phenomenology. Collier books:  
Collier-Macmillan LTD., London
- Husserl, E. (1970a). *The Crisis of European Sciences and Transcendental Phenomenology: An Introduction to Phenomenological Philosophy*. D. Carr (Trans.). Evanston, IL: Northwestern University Press.
- Husserl, E. (1970b). *Logical investigations*. (J. N. Findlay, Trans.). New York: Humanities Press.
- Husserl, E. (1999). The train of thoughts in lectures. In E. Polifroni and M. Welch (Eds). *Perspectives on philosophy of science in nursing* (pp. 247-262). Philadelphia, PA: Lippincott, Williams, & Wilkins
- Hwang, B., Fleischmann, K. E., Howie-Esquivel, J., Stotts, N. A. & Dracup, K. (2011). Caregiving for patients with heart failure: Impact on patients' families. *American Journal of Critical Care*, 20(6), 431-442. doi:10.4037/ajcc2011472
- Jaarsma, T., Brons, M., Kraai, I., Luttik, M. L., & Stromberg, A. (2013). Components of heart failure management in home care: A literature review. *European Journal of Cardiovascular Nursing*, 12(3), 230-241. doi:10.1177/1474515112449539
- Jacobs, E.A., Rolle, I., Ferrans, C.S., Whitaker, E. E. & Warnecke, R. B. (2006). Understanding African Americans' views of the trustworthiness of physicians. *Journal of General Internal Medicine*, 21(6), 642–647.
- Kang, X., Li, Z., & Nolan, M., T. (2011). Informal caregivers' experiences of caring for patients with chronic heart failure: Systematic review and metasynthesis of qualitative studies. *Journal of Cardiovascular Nursing*, 26(5), 386-394.
- Kaufman, A.V., Kosberg, J.I., Leeper, J.D., Tang, M. (2010) Social support, caregiver

- burden and life satisfaction in a sample of rural African American and White caregivers of older persons with dementia. *Journal of Gerontological Social Work*, 53 (3), 251-269.
- Knight, B. G., Longmire, C. V. F., Dave, J., Kim, J. H., & David, S. (2007). Mental health and physical health of family caregivers for persons with dementia: A comparison of African American and White caregivers. *Aging and Mental Health*, 11(5), 538-546. doi:10.1080/13607860601086561
- Kramer, B. (1997). Differential predictors of strain and gain among husbands caring for wives with dementia. *The Gerontologist*, 37(2), 239-249.
- Lahaie, C., Earle, A., & Heymann, J. (2012). An uneven burden: social disparities in adult caregiving responsibilities, working conditions, and caregiver outcomes. *Research on Aging*, 35(3), 243-274. doi:10.1177/0164027512446028
- Lewis-Beck, M. S., Bryman, A., & Liao, T. F. (Eds.). (2004). *Encyclopedia of social science research methods*. (Vols. 1-3). Thousand Oaks, CA: SAGE Publications, Inc. doi: <http://dx.doi.org/10.4135/9781412950589>
- Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Luttik, M. L., Jaarsma, T., Lesman, I., Sanderman, R., & Hagedoorn, M. (2009). Quality of life in partners of people with congestive heart failure: Gender and involvement in care. *Journal of Advanced Nursing*, 65(7), 1442-1451. doi:10.1111/j.1365-2648.2009.05004.x
- Luttik, M.L. Blaauwbroek, A. Dijkster A. Jaarsma, T. (2007a). Living with heart failure: Partner perspectives. *Journal of Cardiovascular Nursing* 22, 131-137.
- Luttik, M. L., Jaarsma, T., Veeger, N., Tijssen, J., Sanderman, R., & van Veldhuisen, D. J.

- (2007b). Caregiver burden in partners of heart failure patient: limited influence of disease severity. *European Journal of Heart Failure*, 9(6), 695-701.  
doi:10.1016/j.ejheart.2007.01.006
- Martensson J., Dracup K., Fridlund B. (2001). Decisive situations influencing spouses' support of patients with heart failure: a critical incident technique analysis. *Heart Lung*, 30:341-350.
- McCallum, T.J., Longmire, C.F., Knight, B.G. (2007). African American and White female caregivers and the sociocultural stress and coping model. *Clinical Gerontologist*. 30(4), 25–37. doi:10.1300/J018v30n04\_02
- Merleau-Ponty, M. (1956). What is phenomenology? *Cross Currents*, 6, 59-70.
- Merleau-Ponty, M. (1962). *Phenomenology of perception*. New York: Routledge.
- Meyer, P.A., Yoon, P.W. & Kaufmann, R.B. (2013). *Introduction: CDC Health Disparities and Inequalities Report — United States*. Retrieved on May 30, 2014 from <http://www.cdc.gov/mmwr/pdf/other/su6203.pdf>
- Molloy, G. J., Johnston, D. W., Johnston, M., Gao, C., Witham, M. D., Struthers, A. D., & McMurdo, M. E. T. (2008). Using the demand-control model of job strain to predict caregiver burden and caregiver satisfaction in the informal caregivers of heart failure patients. *British Journal of Health Psychology*, 13(3), 401-417.  
doi:10.1348/135910707X203363
- Molloy, G. J., Johnston, D. W., & Witham, M. D. (2005). Family caregiving and congestive heart failure. Review and analysis. *European Journal of Heart Failure*, 7(4), 592-603. doi:10.1016/j.ejheart.2004.07.008



- Nauser, J.A., Bakas, T. & Welch, J.L. (2011). A new instrument to measure quality of life of heart failure family caregivers. *Journal of Cardiovascular Nursing*, 26(1), 53-64.
- Pattenden, J.F., Roberts, H., & Lewin, R.J.P. (2007). Living with heart failure; patient and carer perspectives. *European Journal of Cardiovascular Nursing*, 6(4), 273-279. doi:10.1016/j.ejcnurse.2007.01.097.
- Patterson, J. & Zderad, L. (1976) Humanistic nursing. New York: Wiley
- Phillips, J.M. & Malone, B. (2014) Increasing racial/ethnic diversity in nursing to reduce health disparities and achieve health equity. *Public Health Reports*, 2014 Supplement 2, 129, pp. 45-50.
- Picot, S. (1995). Choice and social exchange theory and the rewards of African American caregivers. *Journal of National Black Nurses Association*, 7(2), 29-40.
- Plant, E. & Sachs-Ericsson, N. (2004). Racial and ethnic differences in depression: The role of social support and meeting basic needs. *Journal of Consulting and Clinical Psychology*, 72(1), 41-52.
- Polit, D.F. & Beck, C.T. (2012). Nursing Research Principle and Methods, (9<sup>th</sup> ed) Philadelphia:Lippincott Williams and Wilkins.
- Pressler, S.J., Gradus-Pizlo, I., Chubinski, S.D., Smith, G., Wheeler, S., Wu, J. & Sloan, R. (2009) Family caregiver outcomes in heart failure. *American Journal of Critical Care*, 18(2), 149-59. doi: 10.4037/ajcc2009300
- Riegel, B., Moser, D.K., & Anker, S.D., (2009). State of the science: Promoting self-care in persons with heart failure: A scientific statement from the American Heart Association. *Circulation*, 120:1141–1163.

- Roth, D.L., Haley, W.E., Owen, J.E., Clay, O.J. & Goode, K.T. (2001). Latent growth models and the longitudinal effects of dementia caregiving: A comparison of African American and White family caregivers. *Psychology and Aging*, 2001, 16:427–436.
- Rotter, J. B. (1945). *Social learning and clinical psychology*. New York, NY: Prentice-Hall.
- Rozario, P.A. & DeRienzi, D. (2008). Familism beliefs and psychological distress among African American women caregivers. *Gerontologist*, 48, 772–780. doi: 10.1093/geront/48.6.772
- Sadler, G.R., Lee H-C., Lim, R. S-H, & Fullerton J (2010) Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. *Nursing Health Science*, 12, 369–374.
- Samuel-Hodge, C., Headen, S., Skelly, A., Ingram, A., Keyserling, T., Jackson, E. & Elasy, T. (2000). Influences on day-to-day self-management of type 2 diabetes among African-American women: Spirituality, the multi-caregiver role, and other social context factors. *Diabetes Care*, 23(7), 928-933.
- Saunders, M. M. (2008). Factors associated with caregiver burden in heart failure family caregivers. *Western Journal of Nursing Research*, 30(8), 943-959.
- Saunders, M. M. (2009). Indicators of health-related quality of life in heart failure family caregivers. *Journal of Community Health Nursing*, 26(4), 173-182.  
doi:10.1080/07370010903259196
- Saunders, M. M. (2012). Perspectives from family caregivers receiving home nursing support: Findings from a qualitative study of home care patients with heart failure.

- Home Healthcare Nurse*, 30(2), 82-90. doi:10.1097/NHH.0b013e3182429337
- Sebern, M. D., & Woda, A. (2012). Shared care dyadic intervention: Outcome patterns for heart failure care partners. *Western Journal of Nursing Research*, 34(3), 289-316. doi:10.1177/0193945911399088
- Siabani, S., Leeder, S., & Davidson, P. (2013). Barriers and facilitators to self-care in chronic heart failure: A meta-synthesis of qualitative studies. *Springerplus*, 2, 320.
- Smedley, B.D., Stith, A.Y. & Nelson, A.R. (2003) *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, D.C.: Institute of Medicine of the National Academies Press.
- Stanley, J.M., Capers, C.F. & Berlin, L.E. (2007). Changing the face of nursing faculty: Minority faculty recruitment and retention. *Journal of Professional Nursing*, 23(5), 253-61.
- Sullivan, L. (2004). Missing persons: Minorities in the health professions: A report of the Sullivan Commission on Diversity in the Healthcare Workforce. Retrieved from <http://www.aacn.nche.edu/media-relations/SullivanReport.pdf>
- Thornton, N., & Hopp, F. P. (2011). "So I just took over": African American daughters caregiving for parents with heart failure. *Families in Society*, 92(2), 211-217. doi:10.1606/1044-3894.4103
- U.S.Census.gov. (2012). Facts for Features: Black (African-American) History Month: February 2014, Retrieved from [http://www.census.gov/newsroom/releases/archives/facts\\_for\\_features\\_special\\_editions/cb14-ff03.html](http://www.census.gov/newsroom/releases/archives/facts_for_features_special_editions/cb14-ff03.html)
- U.S. Department of Health and Human Services. (2008) America's Health Literacy: Why

- We Need Accessible Health Information (2008). An Issue Brief From. Retrieved from <http://www.health.gov/communication/literacy/issuebrief/>
- U.S. Department of Health and Human Services. Health Resources and Services Administration. (2011) Community Health Workers Evidence-Based Models Toolbox. HRSA Office of Rural Health. Retrieved from <http://www.hrsa.gov/ruralhealth/pdf/chwtoolkit.pdf>
- U.S. Department of Health and Human Services, National Institute of Health and National Heart Blood and Lung Institute (2008). Heart Healthy Home Cooking African American Style With Every Heartbeat is Life. Retrieved from <https://www.nhlbi.nih.gov/health/public/heart/other/chdblack/cooking.pdf>
- Van Manen, M. (2014) Phenomenology of Practice: Meaning-Giving Methods in Phenomenological Research and Writing. Left Coast Press: Walnut Creek, CA
- Van Manen, M. (1990). Researching lived experience: Human Science for an Action Sensitive Pedagogy. NY: SUNY Press
- Walden J.A., Walden, K., Dracup, C., Westlake, V, Erickson, M. A., Hamilton, & Fonarow, G.C.. (2001). Educational needs of patients with advanced heart failure and their caregivers. *Journal of Heart Lung Transplant*, 20,766-769.

- Washington, K. T., Meadows, S. E., Elliott, S. G., & Koopman, R. J. (2011). Information needs of informal caregivers of older adults with chronic health conditions. *Patient Education and Counseling*, 83(1), 37-44. doi:10.1016/j.pec.2010.04.017
- Whittingham, K., Barnes, S., & Gardiner, C. (2013). Tools to measure quality of life and carer burden in informal carers of heart failure patients: A narrative review. *Palliative Medicine*, 27(7), 596-607. doi:10.1177/0269216313477179
- Woodend, A.K., Sherrad, H., Fraser, M., Stuewe, L., Chueng, T. & Struthers, C. (2008). Telehome monitoring reduced readmissions and improved quality of life in heart failure or angina. *Evidence Based Nursing*, 11(3), 86-86.
- Zauszniewski, J. A., Picot, S. J., Roberts, B. L., Debanne, S. M., & Wykle, M. L. (2005). Predictors of resourcefulness in African American women. *Journal of Aging and Health*, 17(5), 609-633. doi:10.1177/0898264305279871
- Zaya, M., Phan, A. & Schwarz, E.R. (2012). Predictors of re-hospitalization in patients with chronic heart failure. *World Journal of Cardiology*, 4(2): 23-30.

## Appendix A: University of Connecticut IRB approval letter



**DATE:** March 21, 2014

**TO:** Anne Bavier, Ph.D., RN, FAAN  
Heather Hamilton, MSN, RN, Student Investigator  
Nursing, Unit 2026

**FROM:** Blair T. Johnson, Ph.D.  
Institutional Review Board Member  
FWA# 00007125

**RE:** Protocol #H14-060: "The Lived Experience of African American Caregivers  
Caring for Adult African American Patients with Heart Failure: A  
Phenomenological Study"  
*Please refer to the Protocol# in all future correspondence with the IRB.*  
Funding Source: Investigator Out-of-Pocket  
**Approval Period: From: March 21, 2014 Valid Through: March 21, 2015**  
"Expiration Date"

On March 20, 2014, the Institutional Review Board (IRB) reviewed the above-referenced research study by expedited review and determined that modifications were required to secure approval. Those requirements have been met, and the IRB granted approval of the study on March 21, 2014. The research presents no more than minimal risk to human subjects and qualifies for expedited approval under category # 7 - Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Enclosed is the validated consent form, which is valid through March 21, 2014. **A copy of the approved, validated consent form (with the IRB's stamp) must be used to consent each subject.**

All investigators at the University of Connecticut are responsible for complying with the attached IRB "Responsibilities of Research Investigators."

**Re-approval:** It is the investigator's responsibility to apply for re-approval of ongoing research at **least once yearly**, or more often if specified by the IRB. The Re-approval/Completion Form (IRB-2) and other applicable re-approval materials must be submitted **one month** prior to the expiration date noted above.

**Modifications:** If you wish to change any aspect of this study, such as the procedures, the consent forms, the investigators, or funding source, please submit the changes in writing to the IRB using the Amendment Review Form (IRB-3). All modifications must be reviewed and

approved by the IRB prior to initiation.

Audit: All protocols approved by the IRB may be audited by the Post Approval Monitor.

*Please keep this letter with your copy of the approved protocol.*

Attachments:

1. Validated Consent Forms
2. Validated Recruitment Flyer
3. Validated Appendix A
4. Validated IRB-1
5. "Responsibilities of Research Investigators"

## Appendix B: Rev.com Privacy Policy

**CLIENT NON-DISCLOSURE AGREEMENT**

This CLIENT NON-DISCLOSURE AGREEMENT, effective as of the date last set forth below (this "Agreement"), between the undersigned actual or potential client ("Client") and **Rev.com, Inc.** ("Rev.com") is made to confirm the understanding and agreement of the parties hereto with respect to certain proprietary information being provided to Rev.com for the purpose of performing translation, transcription and other document related services (the "Rev.com Services"). In consideration for the mutual agreements contained herein and the other provisions of this Agreement, the parties hereto agree as follows:

**1. Scope of Confidential Information**

**1.1.** "Confidential Information" means, subject to the exceptions set forth in Section 1.2 hereof, any documents or other text supplied by Client to Rev.com for the purpose of performing the Rev.com Services.

**1.2.** Confidential Information does not include information that: (i) was available to Rev.com prior to disclosure of such information by Client and free of any confidentiality obligation in favor of Client known to Rev.com at the time of disclosure; (ii) is made available to Rev.com from a third party not known by Rev.com at the time of such availability to be subject to a confidentiality obligation in favor of Client; (iii) is made available to third parties by Client without restriction on the disclosure of such information; (iv) is or becomes available to the public other than as a result of disclosure by Rev.com prohibited by this Agreement; or (v) is developed independently by Rev.com or Rev.com's directors, officers, members, partners, employees, consultants, contractors, agents, representatives or affiliated entities (collectively, "Associated Persons").

**2. Use and Disclosure of Confidential Information**

**2.1.** Rev.com will keep secret and will not disclose to anyone any of the Confidential Information, other than furnishing the Confidential Information to Associated Persons; provided that such Associated Persons are bound by agreements respecting confidential information. Rev.com will not use any of the Confidential Information for any purpose other than performing the Rev.com Services on Client's behalf. Rev.com will use reasonable care and adequate measures to protect the security of the Confidential Information and to attempt to prevent any Confidential Information from being disclosed or otherwise made available to unauthorized persons or used in violation of the foregoing.

**2.2.** Notwithstanding anything to the contrary herein, Rev.com is free to make, and this Agreement does not restrict, disclosure of any Confidential Information in a judicial, legislative or administrative investigation or proceeding or to a government or other regulatory agency; provided that, if permitted by law, Rev.com provides to Client prior notice of the intended disclosure and permits Client to intervene

therein to protect its interests in the Confidential Information, and cooperate and assist Client in seeking to obtain such protection.

**3. Certain Rights and Limitations**

**3.1.** All Confidential Information will remain the property of Client.

**3.2.** This Agreement imposes no obligations on either party to purchase, sell, license, transfer or otherwise transact in any products, services or technology.

**4. Termination**

**4.1.** Upon Client's written request, Rev.com agrees to use good faith efforts to return promptly to Client any Confidential Information that is in writing and in the possession of Rev.com and to certify the return or destruction of all Confidential Information; provided that Rev.com may retain a summary description of Confidential Information for archival purposes.

**4.2.** The rights and obligations of the parties hereto contained in Sections 2 (Use and Disclosure of Confidential Information) (subject to Section 2.1), 3 (Certain Rights and Limitations), 4 (Termination), and 5 (Miscellaneous) will survive the return of any tangible embodiments of Confidential Information and any termination of this Agreement.

**5. Miscellaneous**

**5.1.** Client and Rev.com are independent contractors and will so represent themselves in all regards. Nothing in this Agreement will be construed to make either party the agent or legal representative of the other or to make the parties partners or joint venturers, and neither party may bind the other in any way. This Agreement will be governed by and construed in accordance with the laws of the State of California governing such agreements, without regard to conflicts-of-law principles. The sole and exclusive jurisdiction and venue for any litigation arising out of this Agreement shall be an appropriate federal or state court located in the State of California, and the parties agree not to raise, and waive, any objections or defenses based upon venue or forum non conveniens. This Agreement (together with any





## Appendix B: Rev.com Privacy Policy

agreement for the Rev.com Services) contains the complete and exclusive agreement of the parties with respect to the subject matter hereof and supersedes all prior agreements and understandings with respect thereto, whether written or oral, express or implied. If any provision of this Agreement is held invalid, illegal or unenforceable by a court of competent jurisdiction, such will not affect any other provision of this Agreement, which will remain in full force and effect. No amendment or alteration of the terms of this Agreement will be effective unless made in writing and

executed by both parties hereto. A failure or delay in exercising any right in respect to this Agreement will not be presumed to operate as a waiver, and a single or partial exercise of any right will not be presumed to preclude any subsequent or further exercise of that right or the exercise of any other right. Any modification or waiver of any provision of this Agreement will not be effective unless made in writing. Any such waiver will be effective only in the specific instance and for the purpose given.

**IN WITNESS WHEREOF**, the parties have caused this Agreement to be executed below by their duly authorized signatories.

**CLIENT****REV.COM, INC.**

Print Name: \_\_\_\_\_

By: \_\_\_\_\_

Name:

Title:

Date:

Address for notices to Client:

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

By: \_\_\_\_\_

Name: DAVID ABRAMETO

Title: CFO

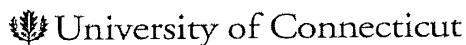
Date: 12/6/13

Address for notices to Rev.com, Inc.:

461 Bush St., 4th floor  
San Francisco, CA 94108

## Appendix C: Consent Form

### Consent Form for Participation in a Research Study



**Principal Investigator:** Anne Bavier PhD, RN, FAAN

**Student Researcher:** Heather Hamilton MSN, RN.

**Study Title:** Lived experience of African American caregivers caring for African American Heart Failure patients

#### Introduction

You are invited to participate in this study. This study concerns African American caregivers and their experiences caring for African American heart failure (HF) patients.

#### Why is this study being done?

More research is needed concerning how African American caregivers assist African American heart failure patients. Given the limited information on African American caregivers and African American heart failure patients, clinicians have limited knowledge to engage in the most culturally sensitive techniques to support African American caregivers, and the health of heart failure patients. Findings from this research could be instrumental in decreasing the number of heart failure-related hospitalizations, and in improving quality of life for heart failure patients and their caregivers.

#### What are the study procedures? What will I be asked to do?

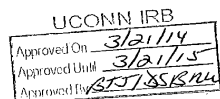
The interviews will be electronically recorded and will take place in a quiet place, such as a library or in your home. Your participation on this study may take one hour. You will be asked to speak about your experience as a caregiver caring for a African American patient living with heart failure. You will be asked to share all your thoughts and feelings regarding your experience

#### What other options are there?

You can decide not to participate in this study. During the interview, if you decide not to continue with the study you can stop at anytime.

#### What are the risks or inconveniences of the study?

There are no risks to the participants, however the time spent doing the interview may be an inconvenience for the participants.



Page 1 of 3

## Appendix C: Consent Form

### What are the benefits of the study?

There are no benefits to the participants. However the information obtained will be used to improve the lives of African American caregivers and the lives of patients living with heart failure. Information learned regarding the experience of African American caregivers of heart failure patients obtained through this research will enhance the resources for health care professionals in delivering culturally sensitive care and support to African American caregivers, and to enhance the health of heart failure patient. Findings from this research could be helpful to decreasing the number of heart failure-related hospitalizations and in improving quality of life for HF patients and their caregivers.

### Will I receive payment for participation? Are there costs to participate?

Participants will receive a \$20 gift card for completing the study. It will not cost any money to participate in the study.

### How will my personal information be protected?

Research records from this study will be labeled with codes derived from a sequence of five letters followed by three numbers. The letters will consist of the abbreviation for caregivers and heart failure patients (CGHFP) and the sequential three-digit numbers will reflect the number of people enrolled in the study. Only the researcher and her advisor will have access to passwords. Shared data will be encoded as described above to protect participant identity. All information will be stored in a lock cabinet.

You should also know that the UConn Institutional Review Board (IRB) and the Office of Research Compliance may inspect study records as part of its auditing program, but these reviews will only focus on the researchers' efforts and not on your responses or involvement. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

### Can I stop being in the study and what are my rights?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

### Whom do I contact if I have questions about the study?

Take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this research, you may contact the Student researcher Heather Morrison, PhD (c) at: at 908-327-1265 or email:

UConn IRB	
Approved On	3/21/14
Approved Until	3/21/15
Approved By	BJS/XS&M

Page 2 of 3

## Appendix C: Consent Form

[heather.morrison@uconn.edu](mailto:heather.morrison@uconn.edu), and or the principal Investigator, Anne Bavier PhD, RN at 860-617-9940 or email: [anne.bavier@uconn.edu](mailto:anne.bavier@uconn.edu)  
If you have any questions concerning your rights as a research subject, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.

### Documentation of Consent:

I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement and possible hazards and inconveniences have been explained to my satisfaction. I understand that I can withdraw at any time. My signature also indicates that I have received a copy of this consent form.

Participant Signature: \_\_\_\_\_

Print Name: \_\_\_\_\_

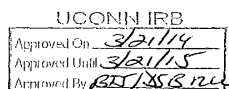
Date: \_\_\_\_\_

Relationship (only if not participant): \_\_\_\_\_

Signature of Person  
Obtaining Consent \_\_\_\_\_

Print Name: \_\_\_\_\_

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



Page 3 of 3

## Appendix D: Approval Letter from site

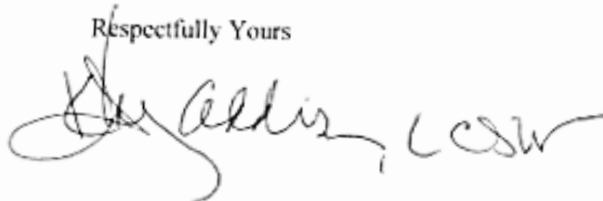
Karen Bailey- Addison  
North End Senior Center  
80 Coventry Street, Hartford, CT 06112  
July 17, 2013

Dear Ms. Morrison,

I have received your study protocol, "Lived experience of African American caregivers: Advocating for and assessing the needs of Heart Failure patients." You have permission to collect data at our facility.

I am requesting a final report of your study

Respectfully Yours

A handwritten signature in black ink, appearing to read "Karen Addison, LCSW". The signature is fluid and cursive, with a large loop at the beginning and a long horizontal stroke at the end.

## Appendix D: Approval letter from site

Pastor Audley Largie  
Bethel Church of Jesus Christ  
1409 Asbury Avenue  
Asbury Park, New Jersey 07712  
July 17, 2013

Dear Ms. Morrison,

I have received your study protocol, "Lived experience of African American caregivers: Advocating for and assessing the needs of Heart Failure patients." You have permission to collect data at our facility.

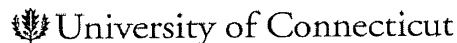
I am requesting a final report of your study

Respectfully Yours

A handwritten signature in black ink, appearing to be 'AL' followed by a long horizontal stroke.

## Appendix E: Recruitment Flyer

Participation in a Research Study



### Volunteers Wanted for a Research Study

**Study Title:** The Lived Experience of African Americans Caregivers caring for Adult

African American Patients with Heart Failure: A Phenomenology Study

You are invited to participate in this study. This study concerns African American caregivers and their experiences caring for adult African American Heart Failure patients.

“You are invited to participate in a study regarding African-American caregivers’ experiences in caring for adult African American heart failure patients. The purpose of this study is to explore and describe African-American caregivers’ experiences caring for adult African Americans with heart failure. Your participation in this study will last approximately one hour. Study participants must be English-speaking African-American adults (aged 21 years or older) caring for someone with a primary diagnosis of heart failure. The caregiver must reside with the heart failure patient and or assist the heart failure patient with activities of daily living (ADL’s) and instrumental activities of daily living (IADL’s.)”

ADL’s are daily activities necessary to meet one’s basic needs, such as bathing, dressing, grooming, feeding and physically moving the patient.

IADL’s complements basic physical needs, examples of IADL’s includes taking patients to doctors’ appointments, picking up medications at the pharmacy, sorting and arranging medications and ensuring that the patient takes them at the proper time, grocery shopping, cooking and watching the patient’s sodium intake.

Participants will receive \$20 gift card for completing the study.

This research is conducted under the direction of Dr. Anne Bavier, at University of Connecticut, School of Nursing.

To learn more about this research, contact Heather Morrison at: at 908-327-1265 or email: [heather.morrison@uconn.edu](mailto:heather.morrison@uconn.edu) and or Anne Bavier PhD, RN at 860-617-9940 or email: [anne.bavier@uconn.edu](mailto:anne.bavier@uconn.edu)

UConn IRB	
Approved On	3/21/14
Approved Until	3/21/15
Approved By	BT/AS/BN

Page 1 of 1



## Appendix F: Demographic Table

[illegible]

Table 4: Heart Healthy Diet for African Americans

<b>Table of Contents</b>	
<b>Introduction</b>	
<b>Salads, Vegetables, and Side Dishes</b>	
Good-for-You Cornbread	4
Homestyle Biscuits	5
Savory Potato Salad	6
Candied Yams	7
Smothered Greens	8
Limas and Spinach	9
Vegetable Stew	10
Classic Macaroni and Cheese	11
Autumn Salad	12
Flavorful Green Beans	13
Caribbean Casserole	

.....	14
Spicy Okra	
.....	
15	
<b>Main Dishes</b>	
Crispy Oven-Fried Chicken	
.....	18
Mouth-Watering Oven-Fried Fish	
.....	19
Finger-Licking Curried Chicken	20
Poached Salmon	
.....	21
Jamaican Jerk Chicken	22
Baked Pork Chops	
.....	23
Jumpin' Jambalaya	
.....	24
Scrumptious Meat Loaf	
.....	25
Spicy Southern Barbecued Chicken	26
<b>Desserts</b>	
1-2-3 Peach Cobbler	
.....	28
Mock-Southern Sweet Potato Pie	
.....	29
Southern Banana Pudding	

.....	30
Summer Breeze Smoothie	
.....	31
Tangy Fruit Salad	
.....	32
<b>Recipe Substitutions for HeartHealthy</b>	
<b>Cooking</b> .....	34
<b>Is It Done Yet? Temperature Rulesfor Safe</b>	
<b>Cooking</b> .....	36

Adapted from NHLBI (2008)(p.1-3) Visit

<https://www.nhlbi.nih.gov/health/public/heart/other/chdblack/cooking.pdf> for all these recipes