11-24-2023

The Effect of Caregiver Communication on Self-Care Outcomes for African Americans With Heart Failure

Adrienne Michelle Johnson
Walden University

Walden University

College of Nursing

This is to certify that the doctoral dissertation by

Adrienne Michelle Johnson

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee
Dr. Leslie Hussey, Committee Chairperson, Nursing Faculty
Dr. Janice Long, Committee Member, Nursing Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

Walden University
2023

Abstract

The Effect of Caregiver Communication on Self-Care Outcomes for African Americans with Heart Failure

by

Adrienne Michelle Johnson

MS, Barnes-Jewish College, 2013

BS, Barnes-Jewish College, 2010

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Nursing

Walden University
November 2023

Abstract

Heart failure (HF) is a chronic condition that is a leading cause of hospitalizations in all racial/ethnic groups in the United States. Dyadic HF self-care interventions have been used across various ethnic groups and cultures; however, the benefits for the African American (AA) dyad have not been established. The purposes of this comparative analysis, which was underpinned by the self-care of chronic illness theory and the dyadic illness management theory, were to determine whether there was a relationship (a) between AA caregiver communication of AA persons living with HF and (b) if the relationship between the AA person with HF and the caregiver role were affected by cultural factors and symptom management. Data were collected from 100 AA participants with HF and 101 caregivers of an AA person living with HF. Two one-way multivariate analyses of variance revealed a significant difference in the communication of the AA person with HF and their caregiver. Results also showed cultural differences and symptom perception of the AA HF dyad. Further research is needed on the informal caregiver role and on the AA HF dyad and culture. Understanding the HF dyadic partnership for AA patients may enable health care providers to provide more tailored treatment, which may promote positive social change through more culturally responsive treatments.

The Effect of Caregiver Communication on Self-Care Outcomes for African Americans With Heart Failure

by

Adrienne Michelle Johnson

MS, Barnes-Jewish College, 2013

BS, Barnes-Jewish College, 2010

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Nursing

Walden University
November 2023

Dedication

This project is dedicated to my brother, Brian; you are deeply missed. It is because of your struggles that I pushed through my limitations to complete this work. This dissertation is greater than me; this is for my grandparents, William and Gussie Washington and Fred and Delilah Morgan. This is for my parents, William, and Mary Washington, for pushing me to never give up on my dream. The faith you demonstrated in my ability helped me forge ahead. This is for my beloved husband, Michael; I thank you for believing in, pushing, and challenging me to be better. This is for my sons, William, and Isaiah; you are the best sons a mother could ask God for. You have shared me with the world of academia while you forged ahead in your endeavors in life. To Autumn and Mila, my granddaughters, I hope my journey inspires you to push past your limits and become the best version of yourselves. This is for my sister; you are an exceptional person and my first best friend. Thank you for cheering for me. To my sweet nieces, Shannon, Courtney and Bria, I did this so you would know we can do all things.

This is for every African American person who faces the challenges of heart failure and not feeling adequately represented in health care. I pray this study opens the doors to better understanding of our experiences as African Americans. Our experiences with heart failure are important, and we need to tell our story.

Acknowledgments

I thank the Lord God, for preparing me for this journey, blowing your wind into my sail and propelling me forward to completion. I am humbled you chose me for this journey.

To my chair, Dr. Leslie Hussey, your feedback was invaluable. Your calm disposition helped me to believe in myself, and your words of encouragement always arrived at the right time. To Dr. Htway Zin, I thank you and appreciate you for taking the time to help me understand the differences in statistical tests. To Dr. Sunny Liu, I thank you and appreciate your expertise on the methods portion. To my other committee members for your feedback and guidance, as I maneuvered through this journey, I thank you.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Study

Heart failure (HF) is a chronic condition affecting more than 6,000,000 adults in the United States and accounts for the greatest proportion of all-cause hospitalizations (Benjamin et al. 2019). Almost half of hospitalized patients with HF will die within 5 years of discharge (Go et al., 2013). African American (AA) persons are disproportionately affected by HF and are 5 times more likely to be hospitalized than their European American counterparts (Go et al. 2013). AAs living with systemic comorbid conditions, such as HF, diabetes, and hypertension, and who have a high-risk lifestyle, marked by increased use of alcohol and tobacco, become sick at an earlier age compared with their European American counterparts with the same comorbid conditions and similar lifestyles (Go et al. 2013; Albert et al. 2009).

Persons living with HF must manage and monitor their health by practicing daily self-care for improvement of cardiac health (Riegel et al., 2011). Self-care management requires having daily weight checks, monitoring sodium intake, and practicing activities of daily living, such as medication administration and grooming (Munshi et al., 2016). As the symptoms of HF progressively increase, persons living with HF will seek assistance from family members and friends, requiring a more participative approach to care (Nasstrom et al., 2017). Family members and friends often become the caregiver to persons living with HF, helping the person identify changes and manage symptoms communicated to health care providers. Persons with HF and the caregiver may understand symptoms but are often unclear about how to manage the symptoms (Sevilla-Cazas et al., 2018). When persons with HF and their caregivers communicate with a health care professional, the focus is the symptomatology and decision-making strategies of the person with HF.

Because of the more adverse impacts of HF on AAs, it is important to understand the dyadic relationship between a patient and their caregiver. AA persons with HF and their caregivers, however, are often underrepresented in research, with many AAs not participating in research studies (George et al., 2014; Hughes et al., 2017). Dyadic relationships within the AA community are often comprised of adult children assisting their family members with self-care (Buck et al., 2018; Epps et al., 2019; Mayberry et al., 2016). The purpose of this study was to explore the dyadic relationship between the AA person with HF and the caregiver and how the dyad communicates with each other and with the health care team. Social implications of this study include developing a more robust understanding of the AA dyad, which is often comprised of spouses, significant others, and adult children (Kim et al., 2019). This knowledge may inform the development of strategies to support and promote shared decision-making regarding the disease process within the AA community. This study increases the understanding of patient–caregiver communication within the AA community, which may enable policy makers, medical professionals, and advocates to develop ways to confront health care disparities.

Chapter 1 includes discussion of HF self-care management educational strategies utilized by AA persons with HF and their caregivers, relationship dynamics of caregiver communication with persons with HF and health care providers, and the effects of disease on the dyad during exacerbation. High rates of hospital readmissions indicate inadequate self-management decision-making skills by the person with HF and their caregiver and highlights the lack of communication between the dyad and the health care provider (Hobbs et al., 2016). This study aimed to explore whether the communication between caregivers of AA HF patients affected the self-care management, maintenance, and perception of the person living with the chronic condition. Furthermore, this study aimed to explore if dyadic cultural preferences were a contributing factor to the communicative process of the dyad. I used a descriptive comparative study design to investigate the research problem.

Background of the Study

AA persons with HF experience increased morbidity and mortality rates compared with other ethnicities because of the increased prevalence of risk factors, such as obesity, cigarette smoking, hypertension, and diabetes (Banks et al. 2016). Self-care decision-making skills and practice guidelines are in place to assist persons with HF to better manage their symptoms and decrease disease progression. Despite self-care education, AA persons with HF often require additional support from their family members to manage symptoms and disease processes (Banks et al. 2016; Krishnamoorthy et al., 2016). The caregiver role is complex and multifaceted, requiring the caregiver to contribute to the self-care processes of the person with HF by monitoring their signs and symptoms while attempting to balance work obligations and loss of personal time and insufficient caregiver support (Graven et al., 2020). Although studies show varying amounts of time spent by caregivers assisting a person with HF, they consistently highlight higher reported self-care knowledge among caregivers than among persons living with HF (Bidwell et al., 2018; Deek et al., 2017).

Increased demands placed on the caregiver of persons with HF lead to burden and stress resulting in less communication and not seeking help for exacerbations in a timely manner, which lead to increased hospitalizations (Graven et al. 2020; Harkness et al, 2014; Krishnamoorthy et al. 2016;). Negative influences on the relationship of persons with HF and their caregiver are psychological distress, lower well-being, and lower perceived control, as well as social determinants such as the region in which persons with HF and their caregiver live (Bidwell et al, 2017; DeSousa et al. 2017; Grigorovich et al. 2017; Lee et al. 2017). Socioeconomic status and race are associated with poorer health and a lower quality of life (Bidwell et al, 2017; DeSousa et al. 2017; Grigorovich et al. 2017; Lee et al. 2017). Dickens, Dickson, and Piano (2019) contend poorer outcomes and lower quality of life are attributed to the inability to pay for necessities such as rent and the caring for their family is more important than their own health. Moreover, physical and psychological aspects of their condition affect engagement among AA persons with HF in spiritual self-care practices to help them cope with their chronic illness (White, 2013). Underutilization of palliative care interventions and culturally sensitive information from health care providers further reduces the quality of life for these individuals (Hopp et al. 2016; Piamjariyakul et al. 2016).

Symptom monitoring and adherence to dietary regulations present challenges that can result in feelings of uncertainty for persons with HF and their caregivers (Piamjariyakul et al. 2015; Reeder et al. 2015). These issues also demonstrate poor understanding of what to do in the self-management monitoring phase of the disease. Higher prevalence of comorbid conditions, such as hypertension and diabetes, are also indicators of poor self-care, as the person is not aware of which disease process is causing the decline in health (Wu et al 2017). Environmental factors related to persons living in low-income urban areas with fewer healthy food options also pose challenges for positive self-care behaviors (Woda et al. 2015). Spirituality also added to the complexity of self-care behaviors, as this concept is an integral part of everyday life and can influence all aspects of the AA person with HF and their caregiver's lives and affect their beliefs and health outcomes (White, 2013).

Predictors of behaviors and self-care among AAs should encompass cultural values and overall life satisfaction, rather than sets of values and standards that have been tested within other ethnic groups (Woda et al., 2019). Dyadic relationships between AA persons with HF and their caregivers are multidimensional, requiring a more in-depth understanding of the complexities of the AA culture, disease progression, self-care and self-care assistance, and communication strategies. Researchers have attempted to promote culturally appropriate care for AAs, yet despite efforts to promote inclusion, minorities remain underrepresented in clinical trials, and the central concepts of AA values are often not part of the social construct needed for effective decision-making skills (Fontaine et al. 2017; Johnson & Carter, 2020). Centralized themes that have emerged in AA HF studies include the low accuracy of HF illness beliefs, lack of trust in the health care system and providers, and the lack of research specific to minority needs (Albert et al. 2009; Banks et al. 2016). The research indicates AA persons with HF have self-care issues and the lack of culturally appropriate tools has limited their ability to practice adequate self-care (Cohen, 2006; Woda et al., 2015).

Problem Statement

HF is a leading cause of mortality in AA persons (Sharma et al., 2014). AA HF caregivers are often the patient's spouse, children, and other kin; they report spending a moderate amount of time on caregiving activities (Bidwell et al., 2021). Self-care is increasingly complex for persons with HF, their caregivers' lives are also complex because they cannot make decisions about their own lives without thinking of the effects their decisions will have on the person they are caring for (Kitko et al., 2020). Caregivers juggle their own health needs with those of the individual they are caring for, adding additional feelings of frustration and isolation while increasing the burden felt by the caregiver (Hooker et al. 2018).

The AA dyad is comprised of more than the person with HF and a family member; it is communal with siblings, children, and grandchildren helping with activities of daily care and management of self-care activities. Socioeconomic and cultural roles are also important contributory factors in understanding the differences in the AA dyad (Banks et al. 2016). Some caregivers may not be able to respond to the self-care needs and demands of the person with HF because of poor recognition of symptomatology and disease processes, potentially leading to diminished self-care management skills of the dyad. Additionally, the inability to communicate within the dyad can lead to increased burden of care for the caregiver and diminished quality of life, which includes physical health, psychological, and social relationships, and, consequently, lower life expectancy

(White, 2013). Knowledge is needed of the communication process, the cultural factors that trigger exacerbations, and the needs of the person with HF and their caregivers. Cultural factors, behaviors, language, and history are highly correlated to include caregiver characteristics that include cognitive skills that pertain to the health care system processes and health care providers (Chou et al., 2015; Palos et al., 2011; Stewart & Bennett, 2011). Despite the interventions that have been developed to assist AA persons with HF and their caregiver, there is limited understanding about how communication affects dyadic education.

Purpose of the Study

The purposes of this study were to compare (a) communication of caregivers of AA persons with HF and self-care management and maintenance and symptom perception of AA persons with HF; and (b) cultural factors and symptom perceptions of AA persons with HF and their caregivers. In this descriptive comparative quantitative study, I explored the dyadic relationship between AA persons living with HF and their caregiver. I used a descriptive research design to explore the differences in communicative components of cultural factors and the self-care management and maintenance relationship among the dyad (Lyons & Lee, 2018).

Research Questions and Hypotheses

The research questions (RQs) and hypotheses for the study were as follows:

RQ1: What is the difference between communication (trust, culture, and spirituality) of caregivers of AA persons with HF and self-care management and maintenance and symptom perception of AA persons with HF**?**

$H_0$1: There is no difference between communication (trust, culture, and spirituality) of caregivers of AA persons with HF and, self-care management and maintenance, and symptom perception of AA persons with HF. AA caregiver communication and self-care management and maintenance of AA persons living with HF.

H_a1: There is a difference communication (trust, culture, and spirituality) of caregivers of AA persons with HF and, self-care management and maintenance, and symptom perception of AA persons with HF.

RQ2: What is the difference between cultural factors of AA persons with HF and their caregivers?

*H*02: There is no difference between cultural factors of AA persons with HF and their caregivers.

*H*a2: There is a difference between cultural factors of AA persons with HF and their caregivers.

The variables of interest for this descriptive study were cultural factors, self-care management and self-care maintenance, communication, and symptom perception. To measure the variables, I used two survey instruments: the Self-Care of Heart Failure Instrument (SCHFI) v7.2 developed by Riegel et al. (2018) and the Caregiver Contribution to Self-Care of Heart Failure Index (CC-SCHFI) v2 developed by Vellone et al. (2014). Using both instruments allowed me to obtain information that described characteristics of the dyadic relationship that could increase understanding of communication within the dyad.

Theoretical Framework

Underpinnings of a research study is the theoretical framework, which provides the organization and structure to inform, interpret and analyze the data (Grant & Osanloo, 2014). Theoretical underpinnings of this study were the theory of self-care of chronic illness and the theory of dyadic illness management. Self-care of chronic illness is a middle-range theory developed by Riegel et al. (2012) to address self-care behaviors and the decision-making process influenced by reflection. The integration of symptomatology with self-care offers a comprehensive approach to care incorporating symptom interpretation with symptom response to affect self-care outcomes (Riegel et al., 2019). The theory of dyadic illness management views the specific needs of both the patient and caregiver as interdependent (Lyons & Lee, 2018). Four central concepts of the theory of dyadic illness are illness management, dyadic appraisal, dyadic management behaviors, and dyadic health.

The theory of self-care of chronic illness developed further by Riegel et al. (2019) includes symptomatology and incorporates a more in-depth approach to identify bodily changes within social and cultural norms. The theory of self-care of chronic illness incorporates early detection and bodily changes that link symptom management perspectives that are often overlooked within the paradigm of symptom clusters and symptom experiences (Riegel et al., 2019). Self-care is a more in-depth approach to symptomatology and is influenced by cultural beliefs, values, habits, support from caregivers, reflection, and access to health care (Riegel et al. 2019). This study's dyadical approach to self-care of HF necessitated a theory that emphasizes that members of the dyad are important and should have their needs met.

The theory of dyadic illness emphasizes the interdependence of the person with HF and their caregiver as mutually important. The theory of dyadic illness focuses on the person with HF and their caregiver as a unit rather than as individuals; together, they engage in behaviors that are integral to management of the illness (Lyons et al. 2018). Dyadic management of HF includes moving past the individual role perspective; the patient and care partner become the focus of dyadic management and behaviors (Lyons et al. 2018). The incorporation of both theories may allow researchers to shift from patient-centric or caregiver-centric approaches to a more useful dyadic approach allowing the needs of all persons to be integral in self-care management. More details on the theory of self-care of chronic illness and the theory of dyadic illness management are presented in Chapter 2.

Nature of the Study

I used a quantitative comparative design to examine communication among AA persons with HF and their caregivers. To increase knowledge of the dyadic relationship, I examined how persons with HF and their caregivers manage disease processes through communication. I wanted to determine the difference that caregiver management, self-care management, cultural factors, and symptom perception have on the dyad. This study further focused on the relationship dyad, in particular dyadic symptom appraisal and cultural factors of communication with persons with HF and the health care provider. The variables of interest for this study were cultural factors, symptom perception, self-care management, and caregiver management.

I selected a mixed-mode survey methodology. Before doing so, I considered solely using online survey methods. An online survey approach decreases cost and increases efficiency in speed of responses; however, some demographics do not have access to online surveys, which can lead to concerns of generalizability (Babbie, 2011; Wharton et al., 2003). Moreover, in studies conducted by Zhang et al. (2017) and Volkom et al. (2014), survey methods differed according to participants' age with older adults more affected by survey methodology than younger participants. Guo et al. (2016) advised that the characteristics of survey participants should reflect the target population to decrease bias and increase accuracy of sampling. I used the mixed-mode survey methodology, which involves the use of both traditional paper and pencil surveys and the online survey method, to potentially increase the likelihood that individuals who did not have a computer or internet access could participate in the study.

Definitions

Caregiver: A person who provides care for another person.

Caregiver communication: Constructive and effective communication that is clear and concise (Communication Tips for Caregivers, n.d.).

Cultural factors: *A* set of beliefs, moral values, traditions, language, and laws (or rules of behavior) held in common by a defined group of people (Jin et al. 2016).

Dyad: A social group composed of two members who interact in most social processes (Miller, 2007).

Heart failure (HF): A serious heart condition in which the heart is unable to sufficiently pump enough oxygenated blood to meet the metabolic demands during rest or exercise (Surikova et al. 2020).

Mortality: The state of susceptibility to death (CDC, 2014b).

Quality of life: "A person's perception of their position in life as it relate to the culture and value systems in which they live; quality of life accounts for their goals, expectations, standards, and concerns" (WHO | WHOQOL, n.d.).

Self-care: The monitoring of symptoms, restrictions, and medication regimen (Surikova et al. 2020).

Self-care management: The process of learning and practicing skills that enables persons to manage their health condition on a day-to-day basis, by adopting specific behaviors (CDC, 2020).

Self-care maintenance: Behaviors that promote physiological integrity and prevent acute exacerbations through the monitoring and evaluation of symptoms and adherence to a treatment regimen (Graven et al. 2021).

Symptom perception: A term that refers to listening to one's body, monitoring signs, recognizing and interpreting the symptoms, and assigning meaning to the changes an individual may experience (Santos et al. 2019).

Assumptions

Assumptions are principles that are believed to be true without verification (Polit & Beck, 2012). Assumptions derive from how people think and act and are not under the control of a researcher (Simon, 2011). Although research suggests poor self-care has been linked to low levels of social support within the AA community and potentially contribute to diminished social interactions (Cousin et al., 2022), I had the assumption that AA persons with HF and their caregivers desired high quality social interactions which would potentially lead to better outcomes.

Scope and Delimitations

I chose a quantitative comparative method to investigate the dyadic relationship between AA persons with HF and their caregivers. I considered using a correlational research design to evaluate whether the dependent variables, self-care management and self-care maintenance, were related; however, this determination was not the aim of the study. I considered a pre and posttest research design; however, measures taken by public health officials in response to the COVID-19 pandemic prevented in-person meetings and the ability to perform education in a face-to-face environment (Coronavirus Disease 2019 (COVID-19)| CDC, n.d.). I chose the quantitative comparative research design because it would allow me to describe the dyadic relationship of AA persons with HF and their caregivers, not test the strength of the relationship between variables.

Delimitations are characteristics of a study that result from specific choices made by a researcher (Simon & Goes, 2013). The scope of this study was limited to community-dwelling AA persons living with HF; these individuals did not reside in skilled nursing facilities or assisted nursing facilities. They had caregivers who they selected who helped with daily self-care activities and were 18 years of age or older with no cognitive impairments. Community-dwelling individuals were chosen because most persons living in skilled nursing facilities or assisted nursing facilities receive care from health care workers. Theoretical underpinnings of this quantitative study design included a dyadic approach to self-care within the context of chronic illness management.

The theoretical framework for this study were the theory of self-care of chronic illness and the theory of dyadic illness management, which allowed for the incorporation of core elements of each theory for the foundation of this research study. The inclusion of two theories allowed me to capture an integrated approach which focused on influences of the self-care decision-making process from an interdependent team approach. Both theories used in this study were inclusive of a dyadic approach. I considered the self-regulation model of illness developed by Cameron et al. (1993), which incorporates the experience of physical symptoms and the nature of illness with social environments and contextual factors on persons with HF’s response to illness (see Jurgens et al., 2009). The self-regulation model of illness was not chosen because comparing monitoring behaviors of different ethnicities or even within the same context could potentially lead to diminishing self-worth (Blanton, 2013). I also considered the actor-partner interdependence model, which focuses on the interpersonal relationship and how individuals are influenced by the characteristics and qualities of the members of the dyad; however, the model was not chosen as interdependencies are unaccounted for and can lead to bias significance tests (McCabe, 2017). The findings from my study should be evaluated in other populations to determine the transferability of the dyadic approach to caregiver communication in chronic disease management.

Limitations

A limitation of this study was the inability to meet participants face-to-face due to COVID-19 restrictions that limited social contact (Coronavirus Disease 2019 (COVID-19)| CDC, n.d.). Limitations restrict accurate representation of the target population, which reduces generalizability (Baltar & Brunet, 2012). Furthermore, the use of survey instruments limits the participants to categorical responses and does not allow the participants to ask questions or seek clarification (Simon & Goes, 2013). Simon and Goes (2013) also noted that the time it takes a person to complete a survey could potentially leave participants feeling too overworked. A major limitation to the descriptive research design is the participants' willingness to answer items honestly in a survey method of data collection, as well as the reliability of the items within the survey (Siedleki, 2020).In summary, despite the limitations of study, the survey instruments were useful in capturing the intended information.

Significance

Some AA persons with HF and their caregivers are unable to effectively communicate with each other and with the health care provider. The needs of both the AA person with HF and the caregiver are fundamental to the understanding of self-care management and the decision-making processes for the dyad (Kitko et al. 2020). This study provides information to explore effective communication with persons with HF and their caregivers. AA persons with HF are at a greater risk for comorbid conditions that significantly decrease health status (Banks et al. 2016). An understanding of HF from a communication standpoint may affect positive social change by revealing how self-care is managed within the dyad. The study findings may increase dyadic understanding and support improved self-care outcomes, which, in turn, may decrease hospitalizations, morbidity, and mortality rates and lead to better quality of life (Bidwell et al., 0218).

Summary

HF affects the quality of life for individuals with the condition and their caregivers. Research into self-care from the dyadic standpoint is important to provide knowledge that stakeholders can use to potentially decrease the probability of worsening disease symptomatology and quality of life. AAs with HF and their caregivers are underrepresented in research across varying study types, and this study may improve knowledge regarding communication within this culture (Fisher & Kalbaugh, 2011; Ma et al., 2021; and Scharff et al., 2010). With greater knowledge, policy makers, advocates, and medical professionals may be able to improve health outcomes, decrease morbidity and mortality, and improve quality of life for the dyad. The findings may support the assumptions that the dyad is integral to the success of self-care for the AA person with HF and their caregiver with emphasis on communication of self-care needs as the most effective method to improve quality of life (Bidwell et al., 2019). This chapter included the purpose of the research and the problem statement, which indicated why the research was necessary. The RQs, hypotheses, assumptions, and theoretical framework were included in this chapter. Chapter 2 will include a review of the literature that substantiates the gap in research as well as more details on the two theories that constituted the study's theoretical framework. I synthesize literature on the social and cultural influences of behaviors within the AA dyad.

Chapter 2: Literature Review

Introduction

HF affects almost 6,000,000 patients and families in the United States each year and is rapidly growing, with estimates of over 8,000,000 people living with heart failure by 2030 and annual costs of more than $31 million annually (Heidenreich et al, 2013; Piamjariyakul et al., 2015). AAs have been disproportionately affected by HF compared to other ethnic groups resulting in greater mortality and complications because of social determinants and biological factors (Piamjariyarkul et al., 2016). With increased intensity of symptom management, the caregiver role is integral in the success of the person living with HF. Research has demonstrated that living with HF is a shared experience for the person living with the condition and their caregiver, who often demonstrate negative symptoms related to the caregiver role and the strain associated with worsening HF symptoms (Beach et al., 2000; Bidwell et al., 2017; Chung et al., 2016; Rohrbaugh et al., 2009). All-cause rehospitalizations are a priority of the Center for Medicare and Medicaid Services (n.d.); these have also become an increasing priority for hospital systems because of increasing readmissions related to HF, according to the agency.

For these reasons, it is imperative that caregivers of individuals with HF understand how to effectively care for their loved ones through symptom management and adherence to the prescribed regimen (Heidenreich et al. 2013). The purposes of this quantitative study were to compare (a) communication of caregivers of AA persons with HF and self-care management and maintenance, and symptom perception of AA persons with HF; and (b) cultural factors and symptom perceptions of AA persons with HF and their caregivers. This chapter includes the following sections: (a) Literature Search Strategy, (b) Theoretical Foundation, (c) Literature Review of Variables and/or Concepts, (d) Summary and Conclusions. The key variables for this study were HF, caregiver role, caregiver communication, racial/ethnic disparities, and adherence.

Literature Search Strategy

I retrieved scholarly literature by searching the following websites, journals, and computerized databases: Cochrane, CINAHL (1982 to present), EBSCOhost, PubMed, OVID MEDLINE (1966 to present), Center for Medicare and Medicaid Services, American Heart Association journals, and Science Direct journals (1991 to present). The search was limited to English-language articles. The literature review focused on caregiver role in symptom management among AA persons with HF, caregiver communication among persons living with disease, and self-care outcomes of persons with HF. A total of 35,632 research and review articles populated the search results. Four hundred fifty-six articles were retrieved, which included primary research and literature reviews on the caregiver role and communication, self-care, and HF. I reviewed over 200 research articles, and utilized 160 articles for this research study. Keywords and phrases used in the literature search included *heart failure*, *self-care*, *caregiver role*, *caregiver communication*, *caregiver stress*, *caregiver strain*, *heart failure outcomes*, *low functional social support*, *symptom management*, *medication adherence*, *symptom distress*, *health disparities*, *AA health disparities*, *AA persons with heart failure*, *caregiver role in the AA community*, *caregiver demographics*, *caregiver education*, *heart failure caregiver AA* *statistics*, *caregiver coping strategies*, *health literacy*, *AA culture*, *spirituality*, and *socioeconomic disadvantage.*

Theoretical Foundation

The theory of self-care of chronic illnesses was the theoretical underpinning for this quantitative study that addressed the process of maintaining health among AA persons with heart failure and their caregivers. Self-care is a set of behaviors performed in both the healthy and disease state; it is a process of managing the symptoms experienced among individuals with chronic illnesses that is undertaken by both the patient and caregiver (Riegel et al., 2012). The theoretical constructs of self-care of chronic illness are self-care maintenance, self-care monitoring, and self-care management (Riegel et al., 2012). Each element works singularly and in conjunction with the other to help the individual living with the disease to identify behaviors to better care for themselves. Conversely, caregivers also engage in care of the person with chronic illness, making them an active participant in the management of the disease.

Self-care maintenance is described as behaviors used to maintain physical and emotional stability, improve well-being, and preserve health, focusing on self-improvement in persons who are well, while mirroring the recommendations of providers during illness (Riegel et al. 2012). The process of self-care monitoring is a normal function, characterized as observing changes in various body functions; however, in chronic illness, the process of determining an action to respond to the change is necessary before the situation escalates and is the vital link between self-care maintenance and management (Riegel et al., 2012). Riegel and colleagues (2012) further contended that self-care management is the process of evaluation of the changes in signs and symptoms of illness and determination of the best course of action.

Riegel et al. (2012) developed the middle-range theory of self-care of chronic illness while caring for persons living with HF. The theory focuses on the challenges and decision-making skills of the person with HF and the assumptions that self-care during illness is situation-specific. The theory of chronic illness is undergirded by three assumptions: how the person with the disease is influenced by their caregivers, how the person with chronic illness processes the information given to them, and their ability to understand their comorbid conditions as a whole-body process rather than considering each illness independent of the other. The theory of self-care of chronic illness is also supported by seven testable propositions (Riegel et al., 2012):

1. Self-care of chronic illness has core similarities, regardless of the illness. Self-care monitoring is necessary for patients regardless of illness type. For instance, self-care is necessary in persons with diabetes, cancer, or heart disease.
2. Learning occurs through personal experience. Patients with previous experience of caring for themselves or others with similar illnesses increases learning.
3. Self-care is learned through critical self-reflection, which happens when patients engage in critical analysis of themselves and the care they provide for themselves or others.

4. Misconceptions and misunderstanding lead to insufficient self-care. The relationship between patients and health care providers is integral and can lead to lack of knowledge contributing to low rates of self-care.
5. A person must master self-care maintenance before self-care management can be mastered. Self-care management is more complex than self-care maintenance because self-care maintenance requires fewer decision-making skills.
6. Understanding changes in signs and symptoms is necessary for effective self-care management. Monitoring of signs and symptoms leads to effective decision-making skills.
7. Evidence based self-care leads to better outcomes than self-care that is not evidence based. Using a problem-solving approach of evidence-based care combines study findings and patient care data that improves patient outcomes (Melnyk et al., 2010).

The theory of self-care of chronic illness is primarily focused on patient-centered outcomes which are imbedded in illness stability, increased control over the illness and the anxiety associated with the illness (Riegel et al., 2012).

Vital to patient success is the involvement of the family members in effective self-care, which requires the caregiver needs to also be met (Lyons & Lee, 2018). The theory of dyadic illness management also lends to the theoretical underpinning for this quantitative research because it is an important aspect of the research regarding the relationship between the caregiver and the person living with heart failure. Illness management theories are often patient-centric and focus primarily on the person caring for themselves; conversely, the primary focus of caregiver theories is on patient provisions and patient strain, while the dyadic theory focuses on the dyadic phenomenon of an interdependent team (Lyons & Lee, 2018). The theory of dyadic illness management moves beyond addressing patient-centricity or evaluation of the proxy method, to the dyad analyzing and interpreting symptoms and the response to the illness. The dyadic perspective fosters collaboration and builds on existing familial relationships which could lead to better outcomes for both patient and caregiver (Lyons & Lee, 2018). The care value system is also important to the dyadic model because it focuses on the plan and goals for the team, ensuring they are effectively balanced. Dyadic health focuses on illuminating the needs of the patient and caregiver because the mental and physical needs of all members of the dyad are equally important and must be effectively balanced.

Lyons and Lee (2018) purported there are four contextual risk-protective factors that influence appraisal and management of behaviors and operate within the realm of how persons with disease and their caregivers communicate in the social context. These risk protective factors which are individual, dyadic, social, and cultural, influence the management of behaviors within the dyad over time leading to fluctuations in dyadic management and collaborative behaviors. Individual risk factors which influence dyadic management are age, gender, comorbid conditions affecting the patient or caregiver, and severity of illness. The quality of the relationship and effective communication are examples of dyadic factor that influence appraisal. Social support is the most protective conceptual factor because it encompasses the support from family and friends and often includes multiple caregivers helping to manage the illness together. Cultural risk protective factors include each member of the dyad's beliefs, values, and traditions, and includes the health care culture of patient centricity. The authors further suggested patient and caregiver demographics such as age, gender and comorbid conditions influence the individual management of the dyadic behavior. Dyadic confidence is influenced by the status of the relationship and communication of the members within the dyad to understand and manage the illness. The theory also posits that social support is important to the protective factor because the influence of family and friends are often overlooked in theories relating to the caregiver role. Culture is also an important influence in the management and appraisal of the dyad focusing on moving to a higher level of influence, which focuses on the family-centered care.

The theory of dyadic illness management focuses on the health of the patient and caregivers as interdependent and specific to the needs of everyone within the dyad (Lyons & Lee, 2018). However, incongruency, which is evidenced by the differences in the patient and caregiver's feelings and thoughts about the effects of the disease are noted if the dyad is non-spousal, causing the level of concealment to be greater than in the spousal dyad (Revenson et al., 2016). Similarly, incongruence was also noted regarding relationship strain and protective factors, such as the caregivers age and family support (Bidwell et al., 2015). The level of protective factors varies within each dyad, according to each person's level of understanding of cultural and individual factors and the collaboration within each dyad (Lyons & Lee, 2018).

The theories of self-care of chronic illness and dyadic illness management informed my quantitative study, which focuses on maintaining health with health promoting practices for both members of the dyad (Lyons & Lee, 2018; Riegel et al., 2012). Factors such as age, gender, social support, and socioeconomic status influence self-care of the person with heart failure and overlap with factors that influence the dyad, such as health of both members of the dyad and cultural beliefs, which influences the outcomes of both members of the dyad. The use of a dyad centric theory departs from patient or caregiver -centric theories and entails the appraisal and management of symptoms and overall health of both members and lends to the heterogeneity of the dyad. The integration of both theories to inform this quantitative study focuses on using important aspects of each theory which explain the dynamics of the communicative process between both the person with the disease process and the caregiver. The theory of self-care of chronic illness focuses on the person with the disease maintaining their health through health promoting activities, while the theory of dyadic illness focuses on each member of the dyad equally, ensuring each person's needs are acknowledged. The core concepts of both theories were the basis for the study, with self-care maintenance, self-care monitoring, and self-care management as the foundation and the dyadic concepts of symptom appraisal, dyad health, and behavior management as the pillars supporting the foundation.

The appraisal of symptoms is a concept which includes factors of self-care such as experience, skill, cognition, and confidence (Riegel et al., 2012). The health of the dyad is a concept that involves attributes of self-care which include access to health and support from other members of the larger dyad, such as adult children and friends. Furthermore, behavioral management is an important concept comprised of dyadic culture, habits, confidence, motivation, and functional ability to engage in self-care. Integral to both theories are the communicative process of the members of the dyad, how each member understands and exchanges information and can achieve optimal outcomes that are mutually beneficial for both members. Figures 1 and 2 are a map and table of the key concepts of how the theory of self-care of chronic illness and the dyadic illness management theory integrate to inform this research study.

Theory of self-care of chronic illness was used to capture a holistic view of how a person with HF self-cares (Jaarsma et al., 2013; Riegel et al. 2018; Vellone et al., 2016). The focus of the theory of self-care of chronic illness is identifying challenges that persons with HF have when caring for themselves and their ability to make decisions regarding their lifestyles and their chronic conditions. Additionally, the core concepts of the TSCCI are self-care monitoring, self-care management, and self-care maintenance, with each concept being an integral part of the holistic view of self-care. Change in disease may not always render symptoms or a change in objective data, thus, symptoms can influence various parts of the self-care process. Studies with the theoretical underpinning of the TSCCI are focused on the dynamics of self-care of the person with the disease process with limited consideration of the dyad as an important concept (Jaarsma et al., 2013; Riegel et al., 2018).

Jaarsma et al. (2013) performed a secondary analysis using studies from 22 different countries, which identified persons with HF, not the dyad. The secondary analysis included data from studies conducted in countries such as Spain, the Netherlands, Brazil, and the United States identified. Findings of the study suggested culture is an important consideration in HF self-care, but also most self-care behaviors can be improved through patient education. Jaarsma et al. (2013) considered culture an important aspect of patient education, the researchers did not focus on the family dyad as an important piece of the culture or subculture within this study.

Riegel et al. (2018), conducted a cross-sectional survey design using a 20-item self-report instrument with three separate scales measuring each aspect of the TSCCI, self-care maintenance, self-care monitoring, and self-care management. The research was performed to evaluate the validity and reliability of the instrument, but also revealed two dimensions of behavior by people with chronic illness, autonomous behaviors, and consulting behaviors. Autonomous behaviors were defined as those which the person with chronic illness innately performed, while consulting behaviors were suggested while talking with others. The research identified the consulting behaviors as those of health care providers, with no identification of the contribution of the dyad. Additionally, the researchers noted many of the participants were middle-aged European American men, which limits the generalizability to AA persons with HF. AA persons with HF were underrepresented in the identified research studies; therefore, the studies lacked the generalizability to appreciate the cultural differences and socioeconomic indicators of the AA population.

The theories that underpinned this quantitative research study lack the generalizability needed to include the AA culture. To better understand how AA persons with HF self-care within the dyad using effective communication skills, it is necessary to use existing theories that support effective self-care and relationship and cultural dynamics. the theory of self-care of chronic illness and the theory of dyadic illness management have a shared focus on patient and caregiver (see Figure 1). Incorporation of health promoting activities encourages the communicative process to ensure the exchange of information continues between the patient and caregiver. The needs of the dyad are being met through the exchange of information during the communicative process. Dyad health is the central theme to successful incorporation of symptom appraisal and behavior management.

Figure 1

Comparisons of the Theories of Self-Care of Chronic Illness and Dyadic Illness Management

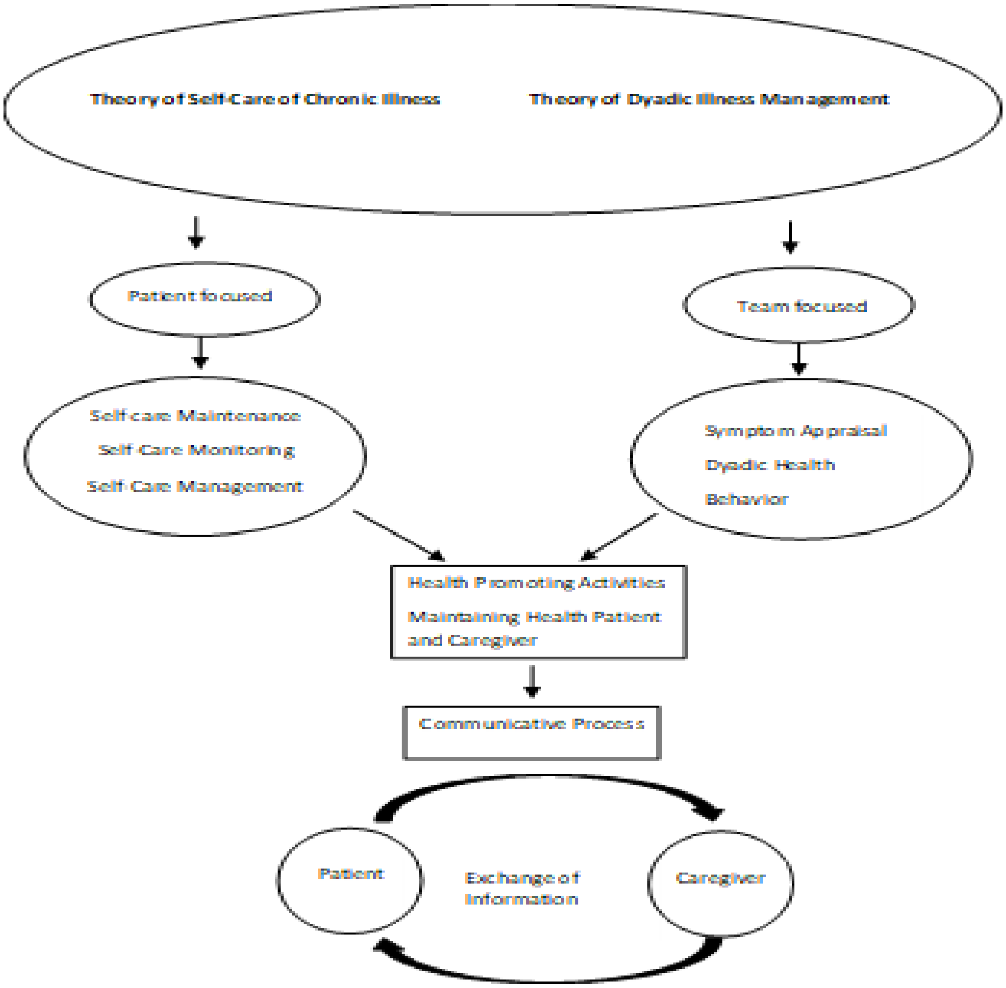
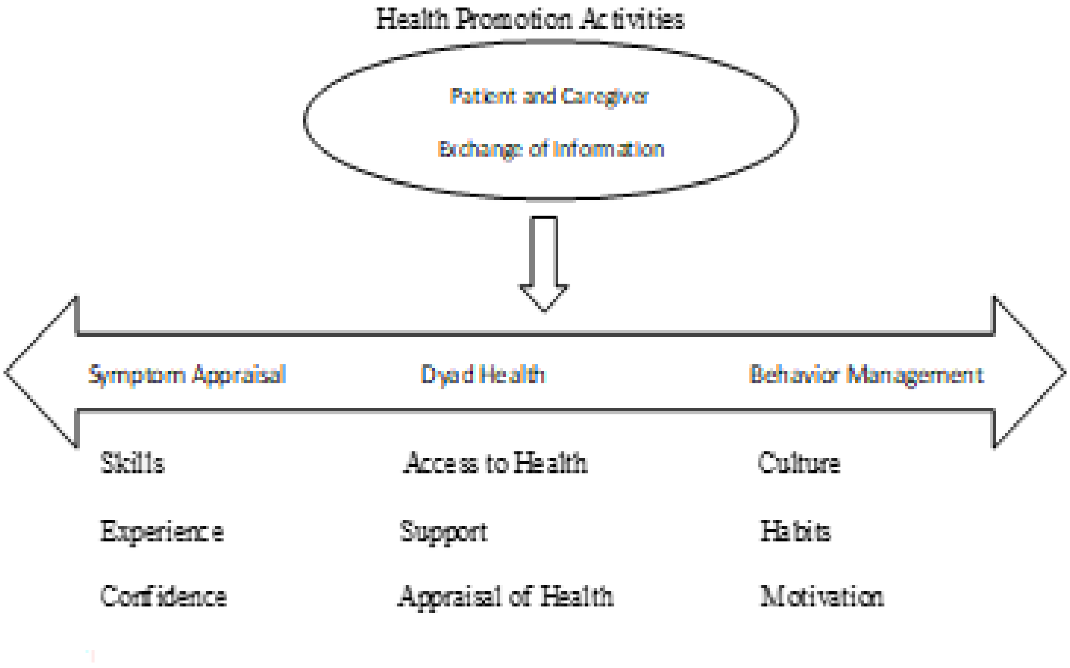


Figure 2

Integration of Theory of Self-Care of Chronic Illness and Theory of Dyadic Illness Management



Literature Review Related to Key Concepts and/or Variables

Self-Care Management and Maintenance

Self-care maintenance is complex process of maintaining physiological stability through routine symptom monitoring and adherence to treatments (Chuang et al., 2019). Behaviors of self-care maintenance include following health care providers advice, making healthy lifestyle choices and monitoring symptoms (Sethares et al., 2017). Findings by Chuang et al. (2019) note self-care maintenance is positively affected by self-care management and positively affects self-care confidence, which is consistent with the findings by Massouh et al. (2020) of increased self-care maintenance is significantly associated with self-care confidence. Heart failure specific knowledge was also associated with increased self-care maintenance and decreased depressive symptoms (Chang et al. 2019; Massouh et al. 2020;).

Self-care management is defined as a set of specific behaviors that an individual practices daily which can reduce the emotional and physical impact of illness and prevent exacerbations, and promote health (Mammen et al. 2018). The requisites of self-care management entail symptom recognition, symptom perception and management of symptoms (Baah et al., 2021). Symptom recognition is challenging and consists of awareness of bodily changes, symptom perception is the ability to interpret and label the symptoms, while symptom management is treating symptoms based on symptomatology and evaluation of the treatment (Hedemalm et al., 2008; Lee et al. 2015; Santos & Schafer-Keller, 2021; Sousa et al. 2021).

Treatment of disease specific symptoms requires identifying and understanding the symptoms at the onset and prompt treatment of the symptoms (Sousa et al. 2021). Important to the overall well-being of the person living with chronic disease is the need to evaluate whether the treatment was effective and performing additional care if the treatment was ineffective (Anekwe et al. 2018).

Symptom recognition is an important function of self-care management requiring a set of behaviors which are specific to the decision-making process and vital components of successful self-care and can lead to better health outcomes (Al-Hammouri et al. 2020; Biddle et al. 2020). Sho and Chen (2019) found that persons who receive self-management interventions showed significantly lower HF-related symptoms than persons that did not receive an intervention, which agrees with a study performed by Lee et al. (2017) suggested persons who practice self-care behaviors are less likely to be hospitalized or need emergency care than those who have poor self-management. A limitation of the study conducted by Shao and Chen (2019) was an increased rate of attrition and the use of a caregiver group without record of the caregiver demographics, excluding their results from the study; however, a limitation of both studies was recall bias. Lee et al. (2017) had limited access to the patient medical record and had to rely on the caregiver as the historian, whereas, Shao and Chen (2019) noted the advanced age of the participants a limitation to the study. Strengths of the studies were large sample sizes, allowing the identification of standards deemed as best practice within the field of HF.

Symptom perception refers to whether a person notices a change in how they usually feel or behave when they are not having an exacerbation (Okada et al. 2019). Findings suggest perceived changes are difficult for persons with HF because the symptoms are not severe enough to seek treatment and the person has difficulty understanding and attributing symptoms to HF if the symptoms are not clustered, for instance, fatigue and weight gain (Okada et al. 2019; Riegel et al. 2018). Furthermore, additional findings demonstrate when a person struggles with interpretation of symptoms, they have reduced decision-making skills which are attributed to longer delays in seeking care. Lastly, comorbid conditions and increased age were also indicative of poor symptom perception and led to longer delays in seeking care, which is consistent with the findings noted (Okada et al. 2019; Riegel et al. 2018).

The large sample size was a notable strength of the study by Okada et al. (2019) and a small sample in the study by Riegel et al. (2018) allowed more depth, which both studies suggest are useful in clearly recognizing the relationship between symptom perception and delays in seeking medical treatment. A notable limitation of both studies was the lack of diversity, with both studies enrolling more men with HF than women, reducing homogeneity of the findings. Additional limitations of the findings were the advanced age, which could potentially lead to recall bias. Moreover, comorbid conditions were noted in participants with advanced age, leading to attributing symptom characteristics being similar in varying chronic illnesses, which also led to delay in seeking care.

Identification and management of heart failure symptoms requires early recognition and interventions to decrease delays in treatment (Vuckovic et al. 2020). Symptom management in HF includes reducing symptom experience and improving symptom severity by minimizing the common symptoms experienced by persons with heart failure (Thida et al. 2021; Heo et al. 2020). Symptom management in persons living with HF is complex because of the diverse cluster of symptoms experienced and the subjective nature of symptomatology, which can vary daily (Koshy et al. 2020; Thida, et al. 2021; Vuckovic et al. 2020). If persons living with HF understood the pathology of the illness and had the ability to identify early signs and symptoms of the disease, it would result in better symptom status and fewer hospital readmissions (Chin et al., 2020; Sousa & Santos, 2019). However, heart failure symptoms are not disease specific and persons with HF often have comorbid conditions which inhibit the ability to recognize HF symptoms versus symptoms of other chronic conditions (Thida et al. 2021; Vuckovic et al. 2020). People with chronic conditions must take responsibility for managing their symptoms while incorporating strategies to better manage their symptoms instead of taking the "wait and see" approach to symptom management (Thida et al. 2021).

Worsening heart failure and increased hospitalizations were attributed to poor symptom assessment (Heo et al., 2020; Thida et al. 2021). The underlying theme of the studies were the recognition of signs and symptoms of worsening HF did not always lead to persons with HF seeking attention of medical providers (Sethares et al., 2021; Thida et al. 2021; Wang et al., 2020). Common reasons for delay in seeking medical treatment were the inability to attribute symptoms to a specific chronic condition. The delay in recognition of changes in persons with HF are due to changes in cognitive status such as advanced age, leading to some forgetfulness, and psychological factors, such as symptoms of depression (Heo et al., 2020; Sethares et al. 2021; Wang et al., 2020).

Limitations varied in each study according to the study design; for instance, one notable limitation of the cross-sectional study performed by Heo et al. (2020) was the inability to examine the causal relationships among the variables of symptom management, which coincides with limitations noted in the studies by Sethares et al. (2021) and Wang et al. (2020) which also identifies the need to analyze causality among the physical and psychological variables of symptom management. Limitations noted in the studies were the person with HFs ability to identify and recognize symptoms specific to heart failure if there were comorbid or multimorbid conditions (Heo et al. 2020; Thida et al. 2021). The use of a self-reported questionnaire was also a limitation because of the advanced age and inability to recall symptoms specific to HF (Heo et al. 2020; Sethares et al. 2021). Of the studies noted, dyadic influence was limitation with little to no information given regarding how the dyad affected self-care maintenance or management.

Self-care behaviors of persons with heart failure are actions taken by a person to improve their health, which include diet, exercise, lifestyle modifications, visiting their health care provider regularly and getting the proper amount of rest. Three core concepts of self-care identified by Riegel et al. (2016), self-care maintenance, symptom perception, and self-care management. Self-care maintenance includes treatment adherence and healthy behaviors, while symptom perception includes detection of symptoms and interpretation of symptom meaning. Lastly, self-care management is how the person with heart failure responds to their symptoms.

Heart failure symptoms and self-care behaviors affect patient outcomes, with symptoms an important driver in limiting the amount of self-care performed (Auld et al., 2018). Auld et al. (2018), conducted a longitudinal study to determine whether patterns of physical symptom are associated with self-care behaviors in persons living with heart failure; conversely, Liljeroos et al. (2020) conducted a study clarifying the relationship between self-care and clinical outcomes and to identify factors related to self-care changes. The educational intervention by Auld et al. (2018) showed improvement in self-care outcomes and suggested the more severe the symptoms, the more engaged in self-care behaviors the person with HF becomes. This contrasts the findings by Leljeroos et al, (2020) which showed the participants had poor self-care despite the education and follow-up at a HF clinic. Both studies suggested an increase in depression were associated with low levels of self-care leading to decreased self-care behavior.

Lee et al. (2017) performed a study involving community-dwelling HF patients which measured the self-care behaviors of maintenance, management, confidence, and consulting behaviors. In a related study, Schumacher et al. (2018) explored the self-care decision-making processes of community-dwelling individuals with heart failure. The aim of the study by Lee and colleagues identified three patterns of self-care, good self-care, poor self-care, and maintenance focused behavior, whereas Schumacher et al. (2018) identified patterns of self-care behaviors in HF patients and their association with clinical events, identified as good symptom response, hospitalization, or emergency care during follow-up. Interestingly, findings by Lee et al. (2017) revealed a correlation between poor symptom response and worse HF metrics, such as functional class, and burden of HF symptoms, which aligns with the findings by Schumacher et al. (2018), which showed participants aligned their life with their disease and monitor symptoms for changes; however, the change in symptoms did not always warrant effective action, such as contacting their provider. The implementation of behaviors to minimize and eliminate symptoms of HF resulted in progression towards a sedentary lifestyle (Schumacher et al. 2018), which consequently aligned with the findings by Lee et al. (2017) which indicates an important predictor of clinical outcomes is how the patient with HF’s ability to recognize and response to symptoms.

A noticeable weakness in both studies is they lacked diversity, with no AA participants noted in the study by Schumacher et al. (2018) and the lack of demographic information regarding the ethnic characteristics in the study by Lee et al. (2017), which took place in Italy. The lack of AA participants noted in both studies decreases generalizability. Furthermore, both studies took place in various regions of the world and lacked sufficient data to generalize to other regions, as noted by both Lee et al. (2017) and Schumacher et al. (2018). Additionally, age and educational background were noticeable weaknesses in both studies with most HF patients over 70 years of age and the lack of diversity within the educational realm, with few college graduates noted in both studies. The large sample size of the study by Lee et al. (2017) was a noticeable strength which allowed the emergence of the distinct patterns of self-care; while the sample size of the study by Schumacher et al. (2018) was small, the researchers used the triangulation methodology which increased the credibility and validity (Polit & Beck, 2012).

Self-care of the person with heart failure encompasses the three core concepts of self-care, self-care maintenance, self-care perception, and self-care management. Auld et al. (2018) and Yang and Kang (2018) suggested the more engaged the person with heart failure is with their symptoms, the more likely they are to engage in self-care and address the unpleasant symptoms associated with the disease. Through self-care education, the person with heart failure increases their self-efficacy and confidence by addressing the symptoms of heart failure. The findings are also congruent with the findings by Al-Sutari and Ahmad (2017), which indicated educational programs improved self-care behaviors among patients with heart failure. Conversely, the findings by Schumacher et al. (2018) do not support the notion that community-dwelling persons with heart failure are experts at self-management even after education. Instead, the findings by Schumacher et al.

(2018) suggested persons with heart failure implement behaviors to minimize, eliminate, and avoid symptoms by reducing participation in exertional activities, which leads to a more sedentary lifestyle. Monitoring of symptoms was reported as an easy task; however, monitoring did not affect how the person responded to the reported changes in condition. These results are consistent with findings by Lee et al. (2018), which suggested low levels of symptom response behaviors were partly due to poor symptom perception.

Heart Failure Self-Care

Self-care by people with heart failure (HF) is vital for successful management and essential for optimal disease management (Gallagher et al., 2011). Successful self-care can be challenging with few patients developing enough knowledge to avoid repeated hospitalization (Riegel et al., 2007). The key components of self-care for persons with HF include behaviors that engage patients in the maintenance and monitoring of symptoms and increases their ability to manage their disease process through implementation of lifestyle changes, which can decrease heart failure symptoms and delay disease progression (Fivecoat et al., 2018; Liou et al., 2015). Self-care includes monitoring and recognizing symptoms, adhering to a treatment plan, taking appropriate action to manage symptoms, and evaluating the effectiveness of actions (Chamberlain, 2017). Integral in effective self-care is the management of unpleasant symptoms, which include chest pain, difficulty sleeping, palpitations, lack of energy, shortness of breath, lack of appetite and swelling of arms and legs (Yang & Kang, 2018). Additionally, obstacles affecting the person with heart failure's ability to practice self-care are the lack of knowledge regarding recurrent signs and symptoms of HF and challenges that prevent effective care including language barriers and patent participation (Bui & Fanarow, 2012; Heidenreich et al., 2013).

Self-care of patients with HF is often complicated by comorbidities, which may lessen the patients' ability to effectively monitor the syndrome processes well (Buck, 2012). Dickson, Buck, and Riegel (2013) argued each condition comes with a unique set of symptoms, self-care practices and clinical management requirements. The ability to monitor and recognize symptoms of HF exacerbation through reflection can lead to increased knowledge and improvement in self-care management (Sethares & Asselin, 2017). For instance, symptoms of heart failure may mimic symptoms of other disease processes, such as dementia. A person living with dementia and heart failure may attribute their increase in confusion to their dementia, without recognizing increased confusion is also a complication of HF.

Individuals of lower socioeconomic status (SES) and those who were uninsured tended to have more difficulty performing self-care because they were more likely to have less than a high school education, they were often unemployed and lived below the poverty line with an annual income of less than $10,000 per year (Macabasco-O'Connell et al., 2008). In studies conducted by Macabasco-O'Connell et al. (2008) and Schnell-Hoehn et al. (2009) persons with heart failure demonstrated difficulty adhering to dietary guidelines because they often purchased prepackaged foods, which are high in sodium, because of the inability to afford fresh fruits and vegetables. Similarly, low health literacy was also correlated with less knowledge regarding prescription medication labels and inadequate engagement in self-care behaviors, while also overutilizing health resources (Wu et al., 2017).

Self-care of the person living with HF is influenced by family values and cultural and religious beliefs and caregiver roles that are not consistent with the medical model of how self-care should be performed (Riegel & Dickson, 2015). Studies by Riegel et al. (2015) and Deek et al. (2015) suggested the role of caregiver is an integral part of self-care, which is often demanding and can lead to caregiver burden and reduced quality of life. In similar studies conducted by Herber et al. (2017) and Rong et al. (2016) self-care behaviors were both positively and negatively supported through cultural preferences and habits that were part of the broader life experience.

Self-Care and Comorbid Conditions

Persons with HF often live with other comorbid conditions, such as diabetes, chronic kidney disease, high blood pressure, obesity, and various forms of cancer, requiring treatment from multiple health care providers (von Haeling et al., 2016). HF affects multiple body systems, such as heart and renal systems, causing abnormal hemodynamic processes and the activation of inflammatory processes (Rushton et al., 2011). There is strong correlation in persons with HF having a higher prevalence of noncardiac comorbidities leading to adverse clinical outcomes (von Haeling et al., 2016). Confounding conditions can lead to a delay in disease diagnosis and increases the potential to lack of specificity regarding the diagnosis or treatment of heart failure (NICE, 2010). Comorbid conditions come with varying symptoms and symptom management, requiring the person to integrate self-care instructions for multiple conditions into a coherent whole (Dickson et al., 2012).

Comorbid conditions are associated with a decrease in a person’s ability to perform self-care and lead to increases in hospitalization and inadequate quality of life (Buck et al. 2015). Chronic diseases affect each aspect of an individual’s life, psychologically, socially, and physically, resulting in difficulties fulfilling expected family roles, limitations in social activities, and increasing social isolation. Dogu and Aydemir (2018) conducted a cross-sectional study designed to evaluate and compare the emotional status of persons receiving inpatient treatment for chronic diseases, such as heart failure, kidney disease, and chronic obstructive pulmonary disease (COPD) and identify factors associated with anxiety and depression. Similarly, Aggelopoulou et al. (2017) conducted an observational study which assessed the level of anxiety, depression, and quality of life in persons with HF. The research findings of both studies identified increased loneliness and the inability of an individual to meet their own needs caused by disease progression, which diminished and degraded the person with HF’s quality of life, leading to a more sedentary lifestyle (Aggelopoulou et al. 2017; Dogu & Ayedemir, 2018). Additionally, depression scores were higher in persons with HF over the age of fifty in one study, while anxiety rates within the same study were lower in persons with HF than in in those patients with other chronic diseases, such as renal disease and COPD (Dogu & Ayedemir, 2018). However, Aggelopoulou et al. (2017) noted the severity of disease progression, utilizing the New York Heart Association (NYHA) Class scale, increased symptoms of both anxiety and depression. Moreover, anxiety and depression negatively impact the treatment of persons living with chronic diseases (Dogu & Ayedemir, 2018; Aggelopoulou et al., 2017).

The lack of community-dwelling participants in both studies hindered the generalizability of the findings. Yeh and Shao (2018) conducted a cross-sectional study to determine the ratio of community-dwelling older adults living with HF who also had depression. Findings of the study aligned with the previous findings noted by Dogu and Ayedemir (2018) and Aggelopoulou et al. (2017) which purported the higher the classification of NYHA of HF, the more depressive symptoms the individual experienced. Interestingly, married participants accounted for more of the study sample across all three studies than unmarried persons. Mean average age was closely related in all three studies, with the average age over the age of 55 years old. Finally, the findings indicated health care practitioners must consider disease conditions and other factors, such as marital status, when providing effective nonmedication interventions for depression and HF.

Buck et al. (2015), conducted a secondary analysis of persons living with heart failure and other comorbid conditions. Results revealed that self-efficacy was important to the person's self-care maintenance behaviors at each level of comorbidity. Participants had at least one comorbid condition, were primarily married, male, and had lived with HF more than 4 years. The findings supported prior studies which suggested self-efficacy is associated with a better quality of life and the inability to differentiate between symptoms is extremely difficult for persons with HF and other comorbid conditions (Riegel & Dickson, 2008; Dickson et al., 2011; Dickson et al., 2013).

Obesity is a common comorbid condition of heart failure and significantly increases the risk of new-onset HF (Horwich et al., 2018). However, mild to moderate obesity is associated with improved survival compared to normal-weight patients. This paradox is important to understand and the how the effects of obesity are different in varying age groups. According to the Framingham study, an increase of 1kg/m^2 increases the risk of HF by 7% in women and 5% in men, yet despite the increase in risk of HF with increase in weight; overweight and obese persons have a better short and intermediate-term prognosis than persons with a leaner BMI (Kenchaiah et al., 2002; Lavie et al. 2016).

Halldin et al. (2016), conducted a prospective analysis to examine the obesity and overweight impact on the risk of developing HF in women of different ages. The reported findings included persons between the ages of 25 and 65. Women, who were obese, had an increased risk of hospitalization and mortality with HF than those over women 65 years of age, who became obese later in their life. Obesity proved more harmful in the development of HF in younger ages than in older women and significantly increased in obese middle-aged women (Clark et al., 2018).

Approximately 30% of HF patients have diabetes (von Haelhing et al., 2016). Lee et al. (2017), explored whether the relationship between body mass index (BMI) and survival differs in persons with HF and persons with HF and diabetes mellitus (DM). The research participants with HF and diabetes had a greater BMI and more comorbid conditions than the persons without diabetes. Findings suggest obesity was associated with longer survival in heart failure patients without diabetes than in persons with diabetes; therefore, negating the positive impact obesity had in persons with heart failure (Lee et al. 2017). Conversely, in a prospective study in Asia, the relationship between HF outcomes and obesity were investigated using a more combined approach to obesity, BMI, and weight-to-height ratio (Chandramouli et al, 2019). Findings suggested higher BMI is associated with better outcomes and worse outcomes were observed in persons with low BMI and higher weight-to-height ratios, such as, more trunk fat and lower skeletal mass.

Lind et al. (2012) explored the relationship between glycemic control and hospitalization in persons with HF. Results of this study indicated an increased risk of hospitalization if the person has poor glycemic control in Type I or type II DM, with Hemoglobin A1C (HgbA1C) greater than 7%, compared to persons with a HgbA1C less than 7%. Persons with DM type I had a 30% increased incidence of HF compared with persons with DM Type II, who had a 12% increase in HF, due to longer periods of exposure in Type I DM. Persons with HF who were also obese and had DM had poor survival rates when compared with persons with HF who were only obese (Lee et al., 2017). HF is the most frequent cardiovascular event in persons with diabetes, compared with other comorbid conditions, such as myocardial infarction and stroke (McMurray et al., 2016).

As the United States population ages continues to age, heart failure and cancer will become increasingly more prevalent. According to the National Cancer Institute (NCI), cancer treatments such as chemotherapy, chest radiation, and immunotherapy can increase the likelihood a person will develop heart failure. Harrison et al. (2018)

conducted a retrospective cohort study to examine the association between heart failure and long-term survival among older women with breast cancer. The findings indicated lower survival rates among women with HF and early-stage cancer than HF alone, and even less if they have a more advanced form of breast cancer. Women with HF had a greater comorbidity burden that may contribute to mortality than if they had breast cancer alone. Additionally, cancer survival rates exceeded 70% in women with stage I and II breast cancer and decreased to 48% in women with stage III and IV breast cancer. Cancer treatment should be multimodal and individualized as effects of cancer treatment can lead to cardiovascular complications and reduced quality of life (Harrison et al. 2018).

An increased risk of cancer was noted in a large study conducted by Bankes et al. (2016) in the Danish population living with HF. The findings are consistent with research findings by Hassin et al. (2013), who reported a 60% increased risk of cancer in American HF patients. Tuzovic et al. (2019) argue comorbid HF and cancer have a higher risk of inpatient mortality because often the patients are older and have other comorbid conditions, including hypertension, COPD, chronic kidney disease and DM. A recent study argues malignancy is fostered by HF-induced pathways through and a causal relationship between tumor growth and HF (Meijers et al., 2018).

Persons with HF often have other chronic health conditions which cause them to have persistent symptoms and inadequate quality of life (Lawson et al., 2018). Numerous chronic disease conditions have symptoms which mimic heart failure, causing a delay in diagnosis and treatment. When treatment occurs, it often focuses on the cardiovascular status rather than individualized treatment of each person with HF and other comorbid conditions. Lawson et al. (2018) found that comorbid conditions were associated with more several overall symptom burden than cardiovascular comorbidities, with shortness of breath attributed to non-cardiovascular comorbidities, such as renal failure and diabetes. The findings suggested individualized treatment is the best option to align symptoms for each person with different chronic conditions, increasing overall quality of life.

The rate of cardiovascular disease is higher among Aas than European Americans, with significantly higher HF hospitalizations among AAs compared to other ethnicities (Ziaeian et al. 2017). The burden of HF hospitalization among AA men and women reflects the higher morbidity and mortality from cardiovascular disease (Ziaeian et al. 2017). Moreover, Discrimination and chronic stress contribute to adverse cardiovascular health among minority groups (Ziaeian et al. (2017). Health care and nursing have been purposeful in working on disease-targeted roles and single disease trajectories, which does not include the view of the integrated approach to care of the person with HF and other comorbid conditions (Rushton et al. 2011). The review of the literature substantiates that limited research has been conducted on comorbidities in AAs (see also Banks et al., 2016).

Caregiver Role

The role of caregiver is an integral function for persons living with HF as the complexity of the illness increases the burden placed on the caregiver increases (Burke et al., 2019; Gusdal et al.,2016). As persons with heart failure continue to age and become less active, they often depend more on others for self-care, which negatively affects quality of life of family caregivers (Puuerveen et al., 2018). The caregiver role is multifaceted, involving the daily demands of heart failure, such as self-care activities which include preparing meals, medication preparation and monitoring food intake (Grant & Graham, 2019).

Heart Failure Patient and Caregiver Communication

The relationship between the person with HF and the caregiver is significant to effective communication when navigating the health care system (Dionne-Odom et al. 2017). Research revealed the lack of communication about the prognosis of the person with HF as a major obstacle (Fitzsimmons, 2019). Effective communication between patient and caregiver is an important concept measured in families by their ability to communicate with each other and health care providers (Im et al. 2019). The quality of the relationship between the person with HF and the caregiver depends on how well they communicate and the impact of living with a chronic condition (Bouldin et al. 2019).

Studies aimed at understanding the dyadic relationship, focused on how patient outcomes impacted the caregiver and caregiver burden; however, the studies noted did not assess the dyadic communication level or the marital or relationship quality (Agren et al. 2012; Bidwell et al. 2018; Bouldin et al. 2019; Deek et al. 2017). Assessment of dyadic relationships used the latent class analysis model, which used patient reported relationship quality (Bouldin et al. 2019). The four reported relationship classifications were collaborative, avoidant, distant or antagonistic. The patient described collaborative dyadic relationships as close in nature, with frequent communication, which included face-to-face visits. The antagonistic dyad, while initially providing more in-home care;

90% (n=30) of the participants in the antagonistic group reported feelings of at least one negative emotion when talking to their caregiver. The avoidant dyadic relationship was described as close, with frequent communication but many patients avoided the conversation about HF. In distant dyadic relationships, 60% (n=35) of the patients described the relationship as close in nature, with HF discussion important; however, in less than 15% (n=35) of the participants, they saw their caregiver face-to-face less than two times per week and talked on the phone to them less than two times per week (n=35, 0%). Each dyad demonstrated depressive symptoms created communication barriers, however, relationships improved so did the quality of the interactions, allowing the caregiver to better recognize the signs of depression in the person living with HF (Bouldin, 2019).

Dyads were excluded if the caregiver did not rate the person living with HF's depressive symptoms. Generalizability was limited because the study took place in a single source setting, making it difficult for the distinct group to represent similar groups. Additional limitations of the study were the lack of female participants in the patient group, only 1% were female, while 69% of caregivers were female. AA participation was also low, with 22% of the patients and 23% of the caregivers of AA origin, which also limits generalizability. Strengths of the research were the sample size and emergence of dyadic relationships which will inform practice on how to manage depressive symptoms in patients.

Patients and their caregivers were often knowledgeable about their illness but are deficient in social support and how inadequate communication impacts shared decision-making skills, increasing the physical burden on the caregiver (Lyons et al. 2020; Bouldin et al. 2019; Fitzsimons et al. 2019; Chi et al., 2018; and DeSanto-Medeya & Safizadeh, 2017). The caregivers' ability to monitor the patient's self-care relies heavily on the quality of the relationship and how well the dyad communicates (Bouldin et al. 2019). Communication barriers reported by the caregiver where the patient was critical of the care they received and avoidant of discussing the disease. Moreover, ineffective communication led to inadequate understanding of the disease, psychological distress, such as anxiety, and resulted in the caregiver's feelings of loneliness and lack of social support (Bidwell et al. 2018; Chi et al. 2018; Fitzsimmons et al. 2019). Lyons et al. (2020) suggests poor communication within the dyad lessens collaboration and stifles the relationship. Support for the caregiver through open communication with the patient with HF and the health care provider, can help lessen caregiver dissatisfaction (DeSanto-Madeya & Safizadeh, 2017).

Notable limitations across the studies noted were the low response by AAs participants and small sample size (Chi et al. 2018; Im et al. 2019; and DeSanto-Medeya & Safizadeh, 2017). However, in similar studies conducted by Bidwell et al. (2018), or Lyons et al. (2020) sample size was not a limitation. The use of a single study site also limited generalizability across the studies.

The dyadic relationship between the AA person and their caregiver is a limited research topic because response rate is low. My research study may provide insight and inform initiatives toward increased self-care outcomes for AA persons with HF and their caregiver in the community-dwelling setting.

Summary and Conclusions

There are multiple studies regarding the self-care of heart failure; however, little is known about the communicative process between the AA person with HF and their caregiver. Caregiver involvement in daily self-care activities has led to positive effects in clinical outcomes in HF; however, research does not address the well-being of the caregiver of the person with the chronic condition in the AA community. AA caregivers accounted for less than half of participants and those included in the studies were significantly less than other ethnic backgrounds. The dyadic relationship is complex, and the phenomena there is limited research in the context of simultaneous integration of care. Education to mutually support the person with HF and their caregiver to promote increased communication is necessary to understand the complexities of the AA person with HF and their caregiver. Conducting a descriptive comparative study to discover and understand the dyadic relationship between AA persons with HF and caregiver's communication with health care providers will provide insight and inform initiatives aimed at the improvement of self-care outcomes for both patient and caregiver in the community setting.

Chapter 3: Research Method

Introduction

The purposes of this descriptive comparative analysis research study were to examine (a) communication of caregivers of AA persons with HF and self-care management and maintenance, and symptom perception of AA persons with HF; and (b) cultural factors and symptom perceptions of AA persons with HF and their caregivers. I examined the differences in self-care management, self-care maintenance, and cultural factors of the dyad. In this chapter, I outline the methodological approach I used to identify and describe dyadic communication between AA persons with HF and their caregivers involving self-care decision-making processes.

Chapter 3 includes a description of the research design and rationale; methodology, including criteria for participant selection, sampling and sampling procedures, instrumentation and operationalization of constructs, ethical considerations, and threats to validity.

Research Design and Rationale

I used a descriptive comparative analysis research design. Data were collected via a descriptive survey, which was administered to participants identified during the recruitment process. I placed the domain address on the flyer for persons who met inclusion criteria to complete the survey. Some persons completing the survey may have had limited internet access or computer capability. The use of a mixed-mode survey approach allowed participants to respond via online or mail methods. The use of such an approach addresses major concerns and inadequacies of limited internet access and computer availability by improving coverage, increasing response rates, reducing nonresponse error, and reducing cost (de Bernardo & Curtis, 2013; de Leeuw 2018). Furthermore, the mixed-mode methodology of online and mail questionnaire is similar in mode measurement effects and can be utilized in the same questionnaire (de Leeuw 2018).

I collected data to describe the communication relationship between the AA person with HF and their caregiver. I chose the survey method because it aligned with the RQs and purpose. The use of survey instrumentation was the most beneficial method to gather data describing how the AA person with HF and their caregiver communicate their self-care needs. Researchers use the survey method to describe attitudes and behaviors and explain and explore constructs and characteristics of given populations (Burkholder et al. 2016). For RQ1, the independent variables were AA persons with HF and the caregiver of the AA person with HF. The dependent variables were communication (culture, mistrust, and spirituality); self-care management, self-care maintenance, and symptom perception of the AA person with HF; and the self-care management and maintenance of the caregiver of the AA person with HF. I used a descriptive research design to align the RQs to demonstrate whether there was a difference between variables and how each variable influences communication within the dyad.

An advantage of using a quantitative descriptive survey design is that it allows data to be collected in a purposeful way from groups of respondents whose characteristics reflect those of the larger population (Babbie, 2014). Additionally, Burkholder et al. (2016) reported that self-administered surveys are less costly than other types of surveys and afford the participants a greater sense of privacy; because they are confidential, participants are more willing to answer sensitive questions. Thus, the comparative analysis design aligned with the RQs and methodology as a useful tool to gather information about how each person within the dyad engages in self-care activities. I used this design to describe how the members of the dyad communicate with each other.

Methodology

In describing their methodological approach, a researcher describes how they will undertake, or undertook, their research (Howell, 2013). As part of my methodological approach, I used a descriptive comparative analysis research design. Key aspects included the sample, setting, data collection procedures, and instrumentation.

Population

The target population consists of individuals within a well-defined group being studied whose members have a certain set of characteristics (Fain, 2009). According to the U.S. Census Bureau (2020), there were 308,700,000 people living in the United States, approximately 6,200,000 of them living with HF and AA are the second largest minority population in the US at 13.4%. The prevalence of HF in AA persons was 9.1 per 1,000 years and they are 2.5 times more likely to suffer and die from complications of HF (*Heart Failure Facts & Information*, n.d.; Nayak, 2020; Wu et al. 2016). The target population for this research study were (a) AA persons aged 18 and over who have HF and (b) caregivers aged 18 and over who assisted with self-care activities for AA persons with HF.

Sampling and Sampling Procedures

A sample is a subset of the population that is selected as representative of the population because its key characteristics are viewed as similar (Polit & Beck, 2012). Sampling is the process of selecting observations for analysis and is classified as either probability or nonprobability sampling (Babbie, 2014). For this research study, I chose the nonprobability sampling method of snowball sampling to reach the target population of AA persons with HF and persons identified as their caregiver. To reach potential participants, I used the approved social media platforms Facebook, Instagram, LinkedIn, and Twitter. Additionally, email invitations were sent to colleagues, coworkers, family, and associates to share with members of their communities and organizations. In addition, I emailed pastors of local churches and requested that they include my recruitment flyer in their Sunday bulletins. The snowball sampling approach is the most appropriate method to utilize when recruiting participants from a specific population who are difficult to locate and when using online methods, such as Facebook, Instagram, LinkedIn, and TikTok to reach the target population (Babbie, 2017; Valerio et al., 2016).

To establish the sample size needed for this study, I utilized the G* Power program to ascertain the number of participants needed for the study design (Faul et al. 2009). A power analysis was performed to determine the sample size needed for this study, with the confidence interval set at 0.05 and a confidence level of 95%. The chance of making a Type I error is 5% when the confidence level is set at 95%. I ran a power analysis with a power test of 0.80, an effect size of 0.25 f(V) and an alpha of .05 which yielded a sample size of 200 participants, 100 participants from each category, AA person with HF and their caregiver, to capture the dyad.

Criteria for inclusion were characteristics, which included demographic information and clinical characteristics specific to the target population being investigated, which would help answer RQs. Criteria for exclusion within a research study are those characteristics which disqualify a participant from taking part in a research study (Patino et al. 2018; Salkind, 2010). The inclusion criteria for the sample frame included AA men and women, 18 years of age or older with a diagnosis of HF. Additional criteria included those persons listed above who have listed a caregiver that is 18 years of age or older. All members of the study had to speak English. Exclusion criteria included AA persons younger than 18 years of age with HF and members of the caregiver group younger than 18 years of age, and members of the targeted population who were unable to answer the survey questions.

Exclusion criteria also included persons of non-AA descent with HF regardless of age. The following sampling frame lists inclusion and exclusion criteria. The inclusion criteria were

- Adults $\geq$18 years of age or older
- AA, non-Hispanic Black person living with HF
- caregiver of an AA, non-Hispanic Black person living with HF
- primary diagnosis of HF (AA, non-Hispanic)
- English speaking

Exclusion criteria were

- persons, regardless of ethnicity, younger than 18 years of age
- non-AA persons with HF
- one member of the dyad unwilling to participate
- a member of the dyad unable to answer the survey questions.

Procedures for Recruitment, Participation, and Data Collection

To reach varying generations, such as baby boomers and millennials, regardless of geographical locations, different methodological approaches to data collection were important to incorporate in research design, steps for recruitment are noted below (Stephens & Gunther, 2016). I recruited potential participants using social media platforms such as Facebook, and flyers given to pastors to share in their weekly bulletin, within the targeted community. Additionally, I solicited the assistance of coworkers, colleagues, family, sorority members, and friends to outreach to individuals within their social framework by sharing my research flyer for participation in the research study. Social media platforms, such as Facebook, impact collaboration and provide resources to encourage users to exchange ideas, find answers to questions, and provide a platform for networking (Shellenbarger & Robb, 2013).

Data were collected via the survey method, without influence from me to assist with answers to survey questions. The mixed-mode survey was available online and were mailed to individual recipients who did not have internet access with a self-addressed stamped return envelope with a post office box to return the survey tool. If participants did not have access to the online website, the participant could request a survey be sent to them via mail by contacting me using the phone number provided on the flyer.

Information returned via mail were scanned into the computer to prevent manipulation of information by me and to ensure the validity of the returned survey instrument.

Prior to survey access, each potential participant was asked to read the informed consent form. I used SurveyMonkey to collect demographic information (see Appendix A) and responses to the SCHFI v 7.2 and CC-SCHFI v2. I obtained permission from the developers of each instrument to include the items in the survey (see Appendix B). To reduce coercion, acknowledgement of informed consent was needed prior to survey entry. Monetary inducements were not considered for this research study. If a member of the dyad chose not to take part in the research study, the members of the dyad will be excluded from participation.

I collected demographic information via SurveyMonkey, as it directly affects health outcomes, age, race and ethnicity, employment status and income, marital status, and if persons with HF live alone (see Appendix A). I used my social media platforms to list my study on my Facebook, LinkedIn, and Instagram and asked those followers within my social media platforms to forward the information to potential participants. I also emailed local church pastors and clergy to place my study in their weekly announcements for potential participants.

Instrumentation and Operationalization of Constructs

The instruments used for this descriptive quantitative research study were the SCHFI v7.2 developed by Riegel et al. (2018) and the caregiver communication to heart failure self-care instrument v2 developed by Vellone et al. (2020). I received permission to use both instruments from the authors (see Appendix B). The SCHFI v7.2 and the CC-

SCHFI v2 are scales that can be used in dyadic studies to measure self-care and caregiver contributions to self-care, respectively, of persons with HF (Lyons et al., 2015). The SCHFI v7.2 and the CC-SCHFI v2 both demonstrated good psychometric properties of validity and reliability in measuring self-care and caregiver contributions to HF patient self-care, respectively and can be used in dyadical studies to facilitate analyses (Self-Care Measures, n.d.).

Utilizing a dyadical approach, the RQs will be addressed by everyone taking part in the research study; AA persons with HF will be given the SCHFI v7.2 instrument and the caregiver will be given the CC-SCHFI v2. Participants were asked to answer each question, which uses a 5-point Likert scale., I computed the scores separately for each participant, then transform the raw score to a standardized score using the transformation of scales scores named by the authors of each instrument to correlate the responses for analyses (Self-Care Measures, n.d.).

The instruments, SCHFI v7.2 and the CC-SCHFI, v2, are widely used instruments in heart failure studies for analyses of the three dimensions of self-care: self-care maintenance, self-care management and symptom perception. Participants with HF were asked to answer questions relating to self-care management using an ordinal scale, with the range from never to always to determine which behaviors were used to help them with daily tasks of self-care, such as washing hands to avoid sickness, and eating a low salt diet. Similarly, the caregivers were asked the same questions in the caregiver version, CC-SCHFI v2 instrument, which also uses an ordinal scale to determine how often the caregiver recommends to the person with HF to perform self-care activities, such as taking medications as prescribed, or eating a low salt diet. Each question on the SCHFI v7.2 has a correlating question within the CC-SCHFI v2. For RQ1, Table 1 shows the corresponding questions from both instruments.

Table 1

Comparison of Instrument Questions for the Dyadic Analysis for Research Question 1

Category	Instrument	
	SCHFI v7.2	CC-SCHFI v2
Self-care maintenance (treatment adherence and healthy behaviors)	Section A: How often do you routinely perform the following activities?	Section A: How often do you recommend self-care activities to the person you care for or perform the activities for the person when they are unable to complete them for themselves?
	Take a walk Eat less salt Take medications as prescribed Regularly see a health care provider	Take a walk Eat less salt Take medications as prescribed Regularly see a health care provider
Self-care perception (detection of physical symptoms and interpretation of the meaning	Section B: Monitoring Symptoms – How often do you:	Section B: Monitoring Symptoms – How often do you recommend the person you care for do the following or do you do the following if the person is unable to do for themselves:
	Monitor daily weight Pay attention to changes in how you feel Look for medication side effects Tired more than usual doing normal activities	Monitor daily weight Pay attention to changes in how they feel Look for medication side effects Notice whether tire more than usual doing normal activities

Self-care management (assessment of the response to symptoms	Section C: How likely are you to use one of the following if you have symptoms:	Section C: When the person you care for has symptoms, how likely are you to recommend they do the following, or perform the care for them:
	Limit salt you eat Reduce fluid intake Take medicine Call the health care provider Try to figure out why you have symptoms	Limit salt intake Reduce fluid intake Take medicine Call the health care provider Try to figure out why the person has symptoms

Note. SCHFI v7.2 = Self-Care of Heart Failure Instrument v7.2; CC-SCHFI = Caregiver Contribution to Self-Care of Heart Failure Index.

RQ2 was, what is the difference between cultural factors of AA persons with HF and their caregivers, will be addressed using the SCHFI v7.2 and CC-SCHFI v2 (see Table 2). Health discussions in the AA family structure are influenced in how they share health information across generations for fear of familial conflict and gossip (Thompson et al., 2015).

Table 2

Comparison of Instrument Questions for the Dyadic Analysis for Research 2

Category	Instrument	
	SCHFI v7.2	CC-SCHFI v2
Self-care maintenance (treatment adherence and healthy behaviors)	Section A: How often do you routinely perform the following activities?	Section A: How often do you recommend self-care activities to the person you care for or perform the activities for the person when they are unable to complete them for themselves?
	Make sure to get a flu shot annually	Make sure to get a flu shot annually
	Ask for low salt foods when visits family and friends	Ask for low salt foods when visits family and friends
	Order low salt items when eating out	Order low salt items when eating out
	Ask the health care provider about medication	Ask the health care provider about medication
Self-care perception (detection of physical symptoms and interpretation of the meaning	Section B: Monitoring Symptoms – How often do you:	Section B: Monitoring Symptoms – How often do you recommend the person you care for do the following or do you do the following if the person is unable to do for themselves:
	Pay attention to how you feel	Pay attention to changes in how they feel
	Monitor closely for symptoms	Monitor closely for symptoms
	Check for ankle swelling	Check for ankle swelling
	Check for shortness of breath with activity such as bathing and dressing	Check for shortness of breath with activity such as bathing and dressing

Self-care management (assessment of the response to symptoms	Section C: How likely are you to use one of the following if you have symptoms:	Section C: When the person you care for has symptoms, how likely are you to recommend they do the following, or perform the care for them:
	Limit salt you eat	Limit salt you eat
	Reduce fluid intake	Reduce fluid intake
	Take medicine	Take medicine
	Call the health care provider	Call the health care provider
	Try to figure out why you have symptoms	Try to figure out why you have symptoms
	Limit activity untilfeeling better	Limit activity until feeling better

Note. SCHFI v7.2 = Self-Care of Heart Failure Instrument v7.2; CC-SCHFI = Caregiver Contribution to Self-Care of Heart Failure Index.

The SCHFI is a widely used theory-based tool which measures self-care maintenance, symptom perception, and self-care management, which has been evaluated in various populations, such as the United States, Brazil, and Italy and cited in more than 5000 articles. The SCHFI was updated to the most current version, 7.2, in 2018 to match the updated theoretical framework, the situation specific theory of HF self-care which was revised in 2016. The original version of the SCHFI scale, v4, was a 15-item scale divided into three scales which measured self-care maintenance, self-care management, and self-care confidence, with a four-point response scale, had an overall reliability tested by Cronbach's alpha and found to be adequate with an overall score of 0.76 (Riegel et al. 2019). The original version of the SCHFI scale rendered Cronbach's alpha of 0.56, 0.70, and 0.82, respectively (Riegel et al. 2019).

The updated SCHFI v7.2 has undergone psychometric analysis and has been testing using the global reliability index for multidimensional scales, which is considered by the researchers to be more appropriate when determining reliability in multidimensional scales (Riegel et al. 2019). The revised version of the SCHFI scale, v7.2, is divided into three scales, measuring self-care maintenance, symptom perception, and self-care management, and consists of 29 items, and each scale is scored separately and has been tested in the United States and more recently in an Italian population. The instrument was tested using the confirmatory factor analysis (CFA) method, test-retest reliability, and coefficient alpha for reliability testing. I used the CFA to test instrument validity, with the goodness-of-fit indices comparing the comparative fit index (CFI) and the Tucker Lewis index (TLI) with the null model, rendering values between 0.90 to 0.95 which demonstrate acceptable fit and values greater than 0.95 indicate a good model, CFA for the model had excellent fit indices noted as CFI ranging from 0.94 to 0.97 and TLI = 0.96 in one study. The root mean square error for approximation is used to estimate the lack of model fit, results from both studies were noted between 0.7 to 0.4, indicating a moderate to good fit (Riegel, et al. 2019). Test-retest methodology measured in two studies ranged between 0.70 to 0.88 with participants response noted on two separate dates within 2 weeks (Riegel et al. 2019; Vellone et al. 2020;). The Cronbach's alpha noted in both studies ranged from 0.71 to 0.88.

The CC-SCHFI is a theory-based instrument that measures caregiver contributions in self-care maintenance and self-care management of persons with HF. The CC-SCHFI is based on the SCHFI v6.2 and was designed to measure the caregiver contributions in an instrument which measured independent contributions of the caregiver rather than instrumentation that was developed as a proxy measure of the person with

HF's self-care (Vellone et al. 2013). The original version of the CC-SCHFI was comprised of three scales measuring 22 items. The revised version of the CC-SCHFI v2 was updated to reflect the most current version of the SCHFI v7.2 and is comprised of three scales with 29 measures and uses a five-point Likert scale.

The original CC-SCHFI v1 instrument was examined for validity using the nonparametric Mann-Whitney U test to compare caregivers who received education with the caregivers who had not. Internal consistency was measured using the CFAs for each scale of self-care maintenance, self-care management and self-care confidence, and the interclass correlation coefficient. Results of the CFAs for caregiver contribution to self-care maintenance fit the data well with CFI noted at 0.97 and 0.98; additionally, CFA for caregiver contribution to self-care management rendered results which fit the model good, with CFI noted at 0.96; lastly, the CFA for caregiver confidence in contributing to self-care resulted in a poor fit with a CFI of 0.77. However, given the dimensionality of the three separate CFAs, the goodness-of-fit indices supported the hypothesized models by demonstrating a hierarchal structure were valid and reliable factors which support the conventional use of total scores for global assessment (Vellone et al. 2013).

The most current version of the CC-SCHFI v2 was found to be valid and reliable using the CFA to test factorial structure in an Italian population of caregivers of persons with HF. The indices used were like those used in the SCHFI v7.2, the CFI and the TLI with values between 0.90 to 0.95, indicating a good fit and values greater than 0.95 indicating a supportive fit. The results for this psychometric analysis of caregiver contribution to self-care maintenance rendered an adequate fit with CFI, 0.95 and TLI, 0.93. The Cronbach alpha was noted at 0.83 and global reliability index scale which consider the multidimensionality of the instrument, was 0.79. Caregiver contributions to symptom perception was noted to have a good fit, CFI, 0.94 and TLI, 0.93. Internal consistency tested using Cronbach alpha for the entire scale was noted at 0.81 and global reliability was 0.85.

The SCHFI v7.2 and the CC-SCHFI v2 were both found to be psychometrically sound and valid and reliable instruments for measuring the self-care outcomes of persons with HF. The SCHFI v7.2 is a reliable instrument to measure self-care maintenance, management, and confidence in a multidimensional method, and the CC-SCHFI v2 is also a reliable instrument for measuring the caregiver contributions to self-care maintenance, management and confidence demonstrated by using a multidimensional methodology which considers all dimensions rather than using a unidimensional validity scale such as Cronbach's alpha. Both instruments utilized the test-retest reliability and were noted as between 0.77 and as high as 0.90 in both instruments (Clark et al. 2015; Riegel et al. 2020; Vellone et al., 2020).

When both instruments are used in collaboration with each other, it lends to a more comprehensive study to analyze dyadic processes on the self-care processes of AA persons living with HF and their caregiver (Vellone et al., 2020). The instruments, SCHFI v7.2 and the CC-SCHFI v2, are scored using a standardized score computed individually for each participant (Riegel & Vellone, n.d). The SCHFI v6.2 and the CC-SCHFI have been used to examine the relationship quality associated with self-care in dyads by Buck et al. (2018).

Data Analysis Plan

The survey consisted of 38 items for AA participants with HF, and 30 items for caregiver participants using SurveyMonkey to collect the data and exported to SPSS for analysis. Using a dyadical methodology, the variables were correlated to examine how the AA person with HF and the caregiver of the person with HF communicate. The dependent variable is communication which incorporates the following factors: trust, culture, and spirituality. Current levels of self-care management, self-care maintenance, and symptom perception serve as dependent variables.

The demographic data form (see Appendix A) was used to determine if the participants were a representative sample of the target population (Salkind, 2010). The independent variable for RQ2 is cultural factors, which encompasses spirituality, gender roles, occupation, and dietary habits of the AA person with HF and their caregiver. The dependent variable was symptom perception of the AA person with HF and their caregiver.

I uploaded the data into the SPSS v27 system based on inclusion criteria and de-identified to ensure anonymity of participants. Each respondents survey was scored using the scoring methodology identified by the instrument's developers. Incorporation of codebooks to keep data organized during research was implemented prior to data collection. I used the codebook to organize the variable labels and names, and value labels.

Research Questions and Hypotheses

RQ1: What is the difference between AA caregiver communication (trust, culture, and spirituality) and self-care management, maintenance, and symptom perception of caregivers of AA persons living with heart failure?

$H_0$1: There is no difference between AA caregiver communication and self-care management and maintenance of AA persons living with HF.

H_a1: There is a difference between the AA caregiver communication and self-care management and maintenance of AA persons living with HF.

RQ2: What is the difference between cultural factors and symptom perception among the AA person with HF and their caregiver?

$H_0$2: There is no difference between cultural factors and symptom perception among the AA person with HF and their caregiver.

H_a2: There is a difference between cultural factors and symptom perception among the AA person with HF and their caregiver.

The data were cleaned of missing data values, which is important in data analyses using SPSS because the computer program cannot interpret missing values. After data cleansing, I conducted two one-way multivariate analyses of variance (MANOVAs). The one-way MANOVA statistical test is used in research to determine differences between independent groups on more than three continuous dependent variables (Laerd, n.d.). Possible differences in communication as it relates to self-care management and self-care maintenance between the person living with HF and their caregiver will be analyzed using the one-way MANOVA test for RQ1. This type of analysis is used to test linear relationships between the dependent and independent variables. That is, whether there is a two-way interaction between the independent variables, communication factors: trust, culture, and spirituality. Current levels of self-care management, self-care maintenance, and symptom perception serve as the dependent variables for RQ1.

For RQ2, after data cleansing, I conducted a one-way MANOVA to determine if cultural differences affect symptom perception among the AA person with HF and their caregiver. The dependent variables for RQ2 are cultural factors, which included dietary considerations and trust. The one-way MANOVA is most useful when the research is focused on understanding if there is an interaction between two independent variables on a set of dependent variables (Laerd, n.d.). The dependent variable was symptom perception of the person with HF and their caregiver. The aim of the analysis was to determine if cultural factors affect symptom perception of the caregiver or the person living with HF.

I ran a Cronbach's alpha to measure the internal consistency between the items in both instruments' subscales, Self-Care of Heart Failure v7.2 and the Caregiver Communication – Self-Care of Heart failure v2 instrument. The Cronbach's alpha is used to determine the reliability in the responses of the questionnaire which indicate the stability of the instruments (Bujang et al., 2018). Performing Cronbach's alpha will determine if the subscales in both instruments can be compared to each other statistically (Emerson, 2019).

Threats to Validity

Validity is a concept which describes whether the findings of the research are well-grounded and unbiased and disclosure of potential threats to the research study are vital to disclose (Polit & Beck, 2015). In descriptive nonexperimental research designs, the researcher intends to describe the meaning of existing phenomena without manipulation of the independent or dependent variables; however, extraneous variables can potentially cause a threat to internal validity (Fain, 2009). In nonexperimental research, research is used to explain, predict, or describe relationships and measure the variables association. Threats to internal validity do not apply to nonexperimental research (Edmonds & Kennedy, 2017). Potential threats to internal validity disclosed in this research study will include the comorbid conditions of the person with HF, the length of time the person with HF has been in this state and the reliance on the caregiver. An additional threat to internal validity is the caregiver's health conditions. External threats to validity are the marital status of the person with HF, the caregiver marital status and the caregiver's support system. Additional threats to validity may emerge post hoc.

Ethical Procedures

I followed ethical procedures to ensure the anonymity and confidentiality of participants, and, before I collected data, I obtained Walden University Institutional Review Board approval (no. 09-06-22-0534518). To ensure confidentiality, individual names of patients and caregivers will be de-identified, along with their addresses and any information that could potentially breach patient confidentiality within any part of this research study. I locked the data in a secure computer, which could not be accessed by anyone except me. Written consent will be obtained for each participant via SurveyMonkey, which will enable each participant to enter the survey upon completion of the consent form. Participants were not coerced into participation by me or anyone that may share the research study with potential participants via social media or flyer.

Summary

In Chapter 3, I introduced the research design and methodology, which entailed gathering data from participants who voluntarily chose to participate in this research study. I ensured patient information is data cleansed and de-identified following ethical procedures. I conducted statistical analyses utilizing two one-way MANOVAs to examine the difference in communication and how communication affects self-care management and self-care maintenance, and how self-care management relates to symptom perception using a dyadical methodology. In Chapter 4, I present the analysis and results.

Chapter 4: Results

Introduction

The purposes of this descriptive comparative analysis research study were to examine (a) communication of caregivers of AA persons with HF and self-care management and maintenance, and symptom perception of AA persons with HF; and (b) cultural factors and symptom perceptions of AA persons with HF and their caregivers.. The RQs and hypotheses were

RQ1: What is the difference between the communication (trust, culture, and spirituality) of caregivers of AA persons with HF and self-care management and maintenance and symptom perception of AA persons with HF?

> $H_0$1: There is no difference between communication (trust, culture, and spirituality) of caregivers of AA persons with HF and, self-care management and maintenance, and symptom perception of AA persons with HF. AA caregiver communication and self-care management and maintenance of AA persons living with HF.
>
> H_a1: There is a difference communication (trust, culture, and spirituality) of caregivers of AA persons with HF and, self-care management and maintenance, and symptom perception of AA persons with HF.

RQ2: What is the difference between cultural factors of AA persons with HF and their caregivers?

> $H_0$2: There is no difference between cultural factors of AA persons with HF and their caregivers.

*H*a2: There is a difference between cultural factors of AA persons with HF and their caregivers.

In Chapter 4, I discuss the data collection procedures, including procedural changes, time restraints, and response rates, in detail. Descriptive statistics, including basic demographic data of the sample, are presented along with an evaluation of statistical assumptions and the results of the one-way MANOVAs and other statistical analyses. I will also discuss the validity and reliability of the data, present the results of the survey, address how the findings relate to the RQs, the hypotheses, and evaluate the research findings.

Data Collection

I collected the data using two instruments, which were the SCHFI v7.2 and the CC-SCHFI v2 (see Appendix B) for documentation of permission to use both instruments). The instruments contain Likert-type survey questions that allowed participants to answer questions on a scale from *never* to *always* (La Salle et al., 2017). I collected data from AA persons living with HF and caregivers of AA persons living with HF. One hundred individuals met the inclusion criteria for AA persons living with HF whereas 101 individuals met the criteria for caregiver of AA persons living with HF. The study began on September 4, 2022, and lasted 14 weeks, ending on December 12, 2022. I recruited participants from the Walden University participant pool, social media platforms (Facebook, Instagram, LinkedIn, and Snapchat), flyers posted in grocery stores, and emails sent to local church leadership in parts of the southwestern and southeastern United States. I also used snowball sampling to identify potential participants.

There were 205 surveys completed in total. One hundred two surveys were returned for AA persons with HF and 103 surveys for caregiver of AA persons with HF. I inspected data for missing information and removed the survey if 50% of the survey was incomplete. Due to missing data, I removed surveys for two participants from the AA person living with HF sample. I removed one survey from the caregiver survey because less than 50% of the survey was completed.

I used the triangulation method to understand the dyadic relationship between the AA person living with HF and the caregiver of the AA person with HF. I recruited participants to complete a survey either via mail with a self-addressed stamped envelope to return the survey or through the online survey site, SurveyMonkey. If participants used the online survey site, they could access the site by clicking a link or scanning the code on the flyer. Participants were invited to participate in the survey by reviewing the eligibility requirements, and consent was given by selecting “Next” if they agreed to take the survey. Additionally, if the participant mailed the survey, they provided consent by returning the survey. Participants could close the survey at any time if they chose not to participate in the study or consent. I deactivated the survey link once I reached the required sample size. The data collection process consisted of a mixed-mode survey approach featuring an online survey and a mail-in survey. The average length of time for persons with HF to complete the survey was 14 min, and for caregivers of persons with HF, the average length of time was noted at 9 min. All participants completed the demographic information.

I did not link the surveys for the two groups, which was a notable change from the data collection procedure outlined in Chapter 3. The original research approach was not appropriate to ensure confidentiality for each member of the dyad. Additionally, I would need both the person with HF and their caregiver to participate to link the survey instruments to each other. Chi Eta Phi Sorority, Inc., was considered a partner organization, which was not in the initial study design; therefore, the ability to share the study with Chi Eta Phi was removed. Additionally, I did not distribute flyers to church parishioners as the sidewalk and parking lots adjacent were considered part of church property. Via email, I sent the study flier to church leadership and asked them to share with their parishioners. Last, to further reduce coercion, I did not ask my family and friends to share my flyer as noted in Chapter 3. My Facebook social media posts were shared over 20 times, and my Instagram posts were shared via Instagram friends to their personal pages.

I asked individuals to confirm they met the eligibility criteria for participation in the respective survey by identifying if they were an AA person with HF or the caregiver of an AA person with HF. If criteria were not met, participants were directed to exit the study. I collected demographic data at the beginning of the survey. The SCHFI v7.2, developed by Regiel et al. (2018) is comprised of forty-eight questions. The CC-SCHFI v2, developed by Vellone, et al. (2018) included 37 questions.

Results

The AA person with HF sample was representative of the target population and was comprised of ninety-nine participants, slightly more female (n=52, 51%) than male (n= 47, 47.1%) males. Table 3 shows participants' ages ranged from 30 to 80 +, median age range was between 50 - 69 years of age (median = 4.57, SD = 1.18). The median relationship status were most individuals identified as married or divorced (mean = 2.75, SD = 1.57). Socioeconomic indicators were widely dispersed, which is consistent with the target population. The median income was 3.00 (between \$56 – 75K per year, SD = 1.07) and the median educational status was 3.1 (Ranging between some college and trade school, SD = 1.23. HF severity data were collected using the NYHA class scale. Most respondents ranged from NYHA Class Scale I, asymptomatic to NYHA Class Scale III, symptoms with minimal exertion. Table 3 is a complete list of demographic information and clinical variables for AA persons with HF.

The caregiver of AA persons with HF sample consisted of 101 participants, with markedly more women caregivers than men, 81% of the sample were comprised of females (n = 81), 19% were males (n = 20), and one participant identified as non-binary (n = 1). The average age range of individuals within the caregiver sample were between 40 to 59 years of age (mean = 3.57, SD = 1.28), and 35% of the participants were married (mean = 2.09, SD = 1.00). The average income of caregiver participants earned an average salary between \$50,000 and \$75,000 (mean 3.70, SD = 1.11). Table 3 is comprised of demographic information associated with the caregiver sample and the AA person with HF sample.

Table 3

Demographic and Clinical Variables of Participants

	N	**%**

	AA HF Participant		
Gender			
	Male	46	45.5%
	Female	52	51.5%
Age			
	30-39	2	2%
	40-49	19	18.8%
	50-59	26	25.2%
	60-69	29	28.7%
	70-79	19	18.8%
	80+	4	4%
Relationship			
	Prefer not to say	5	5%
	Single, never married	15	14.9%
	Married	35	34.7%
	Divorced	13	12.9%
	Domestic Partnership	10	9.9%
	Widowed	18	17.8%
	Separated	3	3%
Education			
	Some Highschool	9	8.9%
	Highschool Graduate	26	25.7%
	Some College	28	27.7%
	Technical or Trade School	19	18.8%
	College Graduate	17	16.8%
Employment			
	Employed	55	54.5%
	Retired	29	28.7%
	Unable to Work	15	14.9%
Income			
	$0 – 30,999	6	5.9%
	$31 – 55,999	25	24.8%
	$56 – 75,999	37	36.6%
	$76 – 99,999	20	19.8%
	$100,000 +	11	10.9%
NYHA Class Scale			
	Unknown	20	19.8%
	NYHA Class I	18	17.8%
	NYHA Class II	21	20.8%
	NYHA Class III	24	23.8%

	NYHA Class IV	15	14.9%
	Caregiver		
Gender			
	Male	20	19.4%
	Female	81	78.6%
	Non-Binary	1	1%
Age			
	18-29	3	3.0%
	30-39	19	18.8%
	40-49	27	26.7%
	50-59	30	29.7%
	60-69	15	14.9%
	70-79	5	5.0%
	80+	2	2.0%
Ethnicity			
	AA or Black	90	89.1%
	European American or White	7	6.9%
	Other	4	4.0%
Relationship			
	Single, never married	26	25.7%
	Married	57	56.4%
	Divorced	4	4.0%
	Domestic Partnership	11	10.9%
	Widowed	3	3.0%
Education			
	Did not answer	2	2.0%
	Some Highschool	3	3.0%
	Highschool Graduate	23	22.8%
	Some College	29	28.7%
	College Graduate	44	43.6%
Employment			
	Did not answer	1	1.0%
	Employed	81	80.2%
	Retired	14	13.9%
	Unable to Work	2	2.0%
Income			
	Did not answer	1	1.0%
	$0 – $30,999	2	2.0%
	$31 – $55,999	14	13.9%

$56 – $75,999	26	25.7%
$76 – $99,999	28	27.7%
$100,000 +	30	29.7%

To appropriately analyze the results for both RQs, I ran two one-way MANOVA tests, which requires independent samples from the population, and normal distribution of the data across both groups of independent variables (Laerd, 2023). The first three assumptions relate to the study design, and the last seven assumptions relate to how well the data fits the model (Statology, 2023).

The first three assumptions of the one-way MANOVA were met in this study for RQs 1 and 2. Dependent variables must be measured at the continuous level; for this study, the dependent variables were interval using a 5-point Likert scale for each question. Interval scales involve ranking, such as strongly disagree to strongly agree, and are often used in questionnaires and surveys to measure attitudes, which places categories in a reasonable order, the numbers indicate ranking from lowest to highest rather than precise measurements (Measurement in Nursing Research, n.d.).

The second assumption, the independent variable must consist of two or more independent groups. I had two groups which were the AA person living with HF, and the caregiver of the AA person living with HF. The third assumption was independence of observations. I had two distinct groups of participants, and the sample size is adequate with more respondents than dependent variables. The sample was robust, with a total of 201 participants, 99 for the AA person living with HF and 101 for the caregiver of the AA person living with HF.

The final seven assumptions of the one-way MANOVA are related to data. Prior to conducting a one-way MANOVA test for both RQs, I ran a series of parametric tests. First, I tested the fourth assumption of univariate and multivariate normality for outliers, which are scores that are extremely large or small compared to the other scores and can negatively affect the results of the tests (Laerd, 2023). The boxplot did not identify outliers in the data, for RQs 1 or 2, as assessed by inspection of a boxplot the boxplots (see Figure 3 and Figure 4).

Figure 3

RQ1: Detection of Outliers for Self-Care Maintenance, Self-Care Management and Self-Care Perception

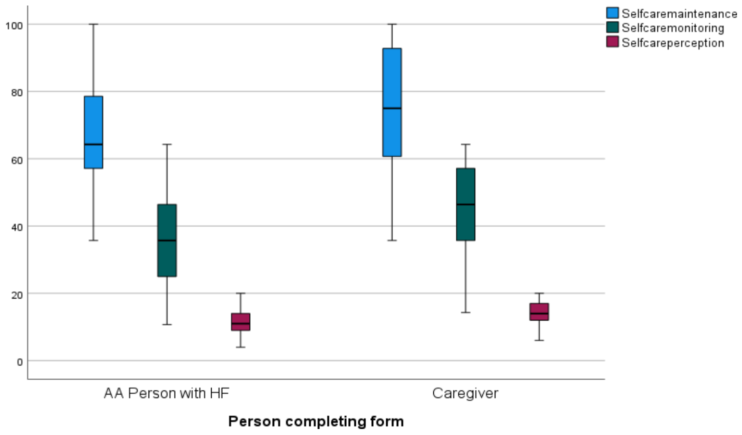
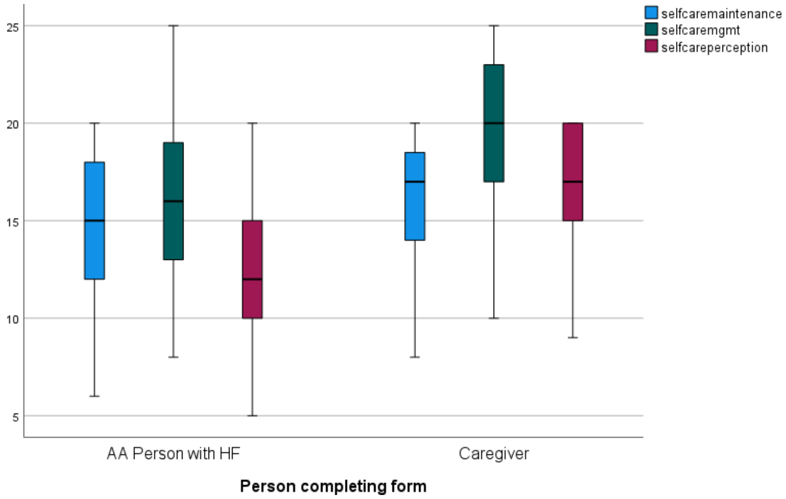


Figure 4

RQ 2: Detection of Outliers for Self-Care Maintenance, Self-Care Management and Self-Care Perception



I then performed the Mahalanobis *d* to identify if there were outliers in statistical analysis for RQs 1 and 2 for each dependent variable, self-care maintenance, self-care management, and self-care perception. There were no multivariate outliers noted by visual inspection; however, I ran a q-q plot (see Figure 5 and Figure 6) for RQs 1 and 2. The observed data did not indicate multivariate abnormality for RQ1 or RQ2, the assumption of multivariate normality was met.

For RQ1, the Mahalanobis distance test were normally distributed for the dependent variables, self-care maintenance, self-care management, and self-care perception for each group of participants, AA persons with HF, and caregivers of AA persons with HF. Next, I ran the Mahalanobis distance test for RQ2, to test whether self-care maintenance, self-care management, and self-care perception were normally distributed across both groups of participants. The results of the Mahalanobis distance test are presented in Figure 5 and Figure 6 using the q-q plot.

Figure 5

Q-Q plot for Mahalanobis distance for RQ 1

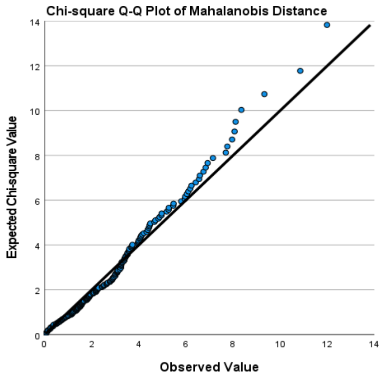
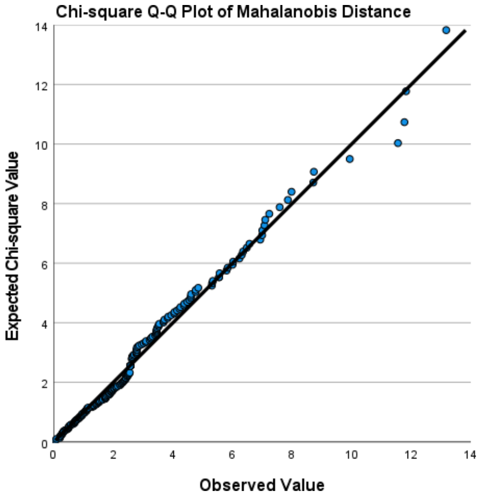


Figure 6

Q-Q plot for Mahalanobis distance for RQ 2



The fifth assumption of the one-way MANOVA was to determine whether the data were normally distributed. For both independent variables, the AA person with HF, and the caregiver of the AA person with HF, there were more than 50 observations for each combination of response variables. I did not run the Shapiro-Wilk test for normality because the sample size was larger than 50 and would flag deviations as statistically significant; instead, I used the Normal Quantile-Quantile (Q-Q) Plot because of the large sample size (Laerd, 2023) (See Figure 5). Distributions were noted using the Q-Q plot for each dependent variable to assess whether the data were normally distributed.

The data tended to follow the 45-degree, which means the data were likely normally distributed (Statology, 2023). The Q-Q plots for each dependent variable are shown in Figure 5 for RQ1 one and in Figure 6 for RQ2, with the actual data displayed on the y-axis and is a visual check to determine if the data set is normally distributed. The parameters of the population are unknown and the sample data from my study infers how the population would be normally distributed. The normal distribution location parameters for RQ1 dependent variables, self-care maintenance, self-care monitoring, and self-care perception were 71.2224, 41.80110, and 12.9596, respectively. The normal distribution location parameters for RQ2 dependent variables, self-care maintenance, self-care monitoring, and self-care perception were 15.6717, 18.1111, and 14.8889, respectively. The data for self-care maintenance, self-care monitoring, and self-care perception were normally distributed along the Q-Q plot for both RQs, which met the fifth statistical assumption.

Figure 7

Normal Quantile-Quantile Plots for RQ1: Self-Care Maintenance

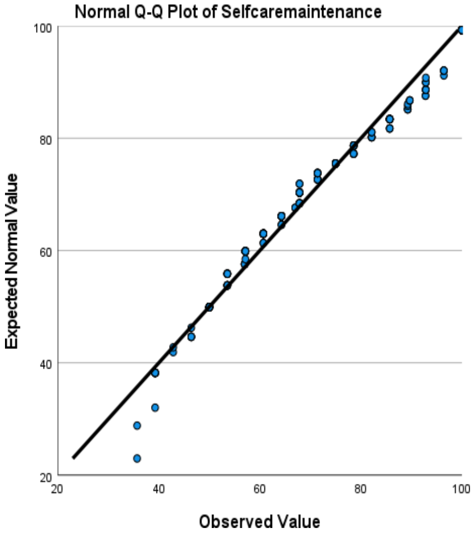


Figure 8

Normal Quantile-Quantile Plots for RQ1: Self-Care Management

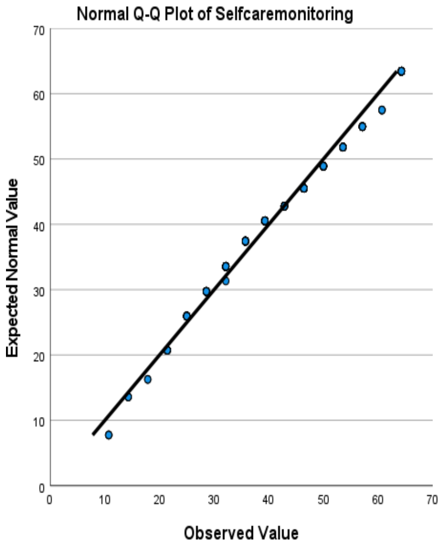


Figure 9

Normal Quantile-Quantile Plots for RQ1: Self-Care Perception

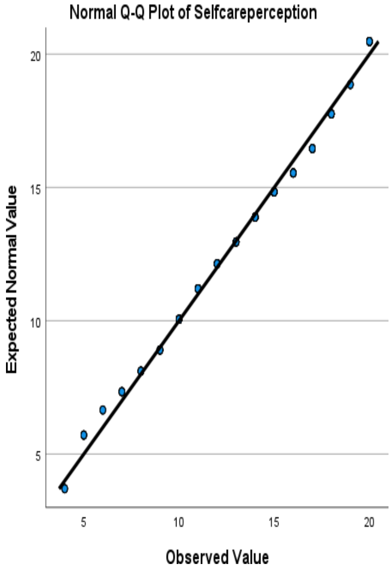


Figure 10

Normal Quartile-Quartile Plots for RQ 2: Self-Care Maintenance

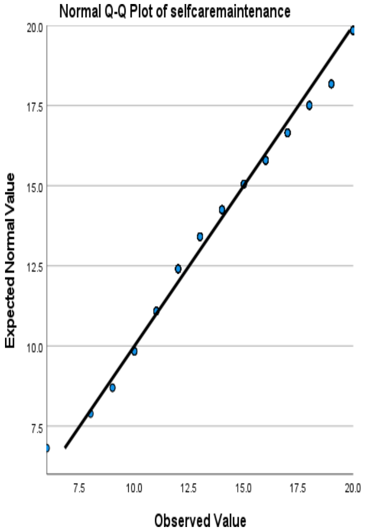


Figure 11

Normal Quartile-Quartile Plots for RQ 2: Self-Care Monitoring

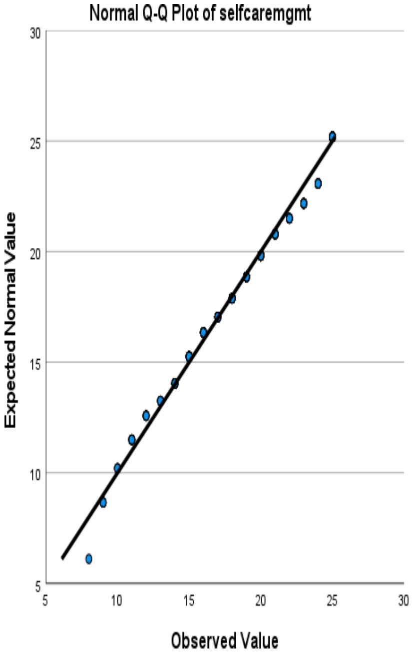
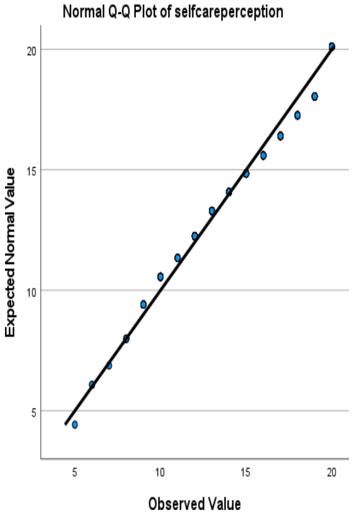


Figure 12

Normal Quartile-Quartile Plots for RQ 2: Self-Care Perception



The sixth assumption of the one-way MANOVA tests whether the dependent variables were correlated. I ran a Pearson correlation test for both RQ1 and RQ2 to determine whether multicollinearity existed between the dependent variables. The Pearson correlation measurements range from -1, which indicates a perfect negative correlation, to 1, which indicates a positive correlation; and if the results are close to 0, this indicates a weak correlation of the variables (Laerd, 2023).

There was no multicollinearity, for RQ1, as assessed by Pearson correlation between self-care management and self-care maintenance ($r = .790$, $p < .001$), self-care management and self-care perception ($r = .266$, $p < .001$) and self-care perception and self-care maintenance ($r = .231$, $p < .001$) (see Table 4). For RQ2, the variables were moderately correlated; however, the variables did not violate the assumption of multicollinearity. Self-care maintenance and self-care management were moderately correlated, as assessed by Pearson correlation (r = .706, *p* < .001), self-care maintenance and self-care perception were also moderately correlated (r = .620, *p* < .001, and self-care management and self-care perception were also moderately correlated (r = .809, *p* < .001). RQs 1 and 2 met the assumption of multicollinearity.

Table 4

RQ 1: Pearson Correlations between Dependent Variables (with 2 groups)

	Self-Care Maintenance	Self-Care Management	Self-Care Perception
Mean	71.22	41.81	12.96
SD	17.67	14.19	4.03
Correlations	.790	.266	.231

Note. **. Correlation is significant at the 0.01 level (2-tailed).

Table 5

RQ 2: Pearson Correlation between Dependent Variables

Variables	1	2	3
1. Mean	15.67	18.11	14.89
2. SD	3.24	4.39	3.83
3. Correlations	.706**	.620**	.809**

Note. **. Correlation is significant at the 0.01 level (2-tailed).

To test statistical assumption seven whether the variables are linearly related, I utilized a scatterplot matrix for the independent variables, AA persons with HF and caregiver of AA persons with HF. There were overlapping data points when I performed a scatterplot; therefore, I incorporated the use of jitter, which spreads out the data points but does not change the underlying data (Laerd, 2023). Jitter is a technique used when multiple data points are located at the same place, making it difficult to see the actual data points on the scatterplot. I tested each dependent variable for both participant groups for both RQs. The data point distributions demonstrated a linear relationship between the dependent variables within each group of independent variables, AA persons with HF and caregivers, satisfying the assumption (see Figure 10, 11, 12, and 13), respectively. There was a linear relationship between self-care maintenance, self-care management, and self-care perception, as assessed by scatterplot, satisfying the seventh assumption.

Figure 13

Scatterdot Matrix RQ1- AA Person with HF Dependent Variables

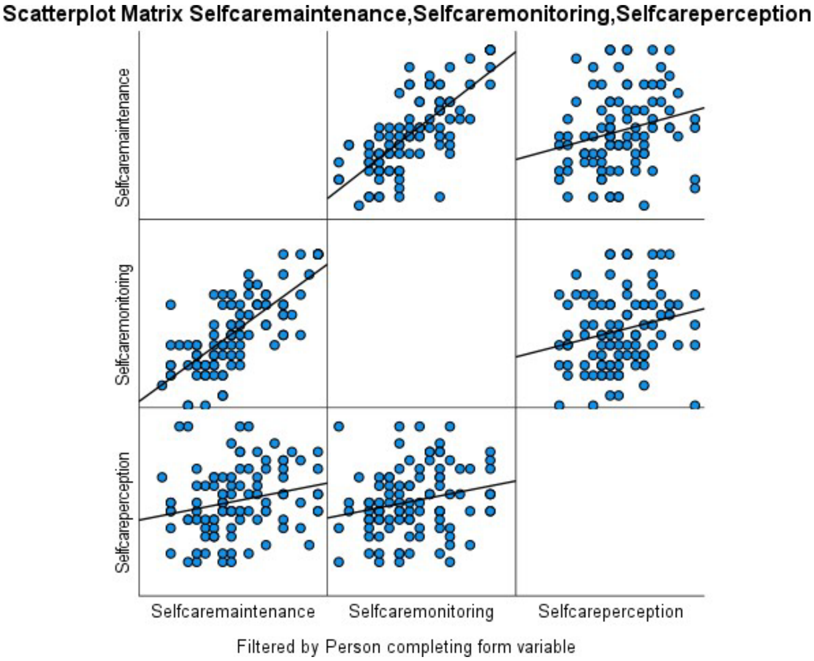


Figure 14

Scatterdot Matrix RQ1- Caregiver of AA Person with HF Dependent Variables

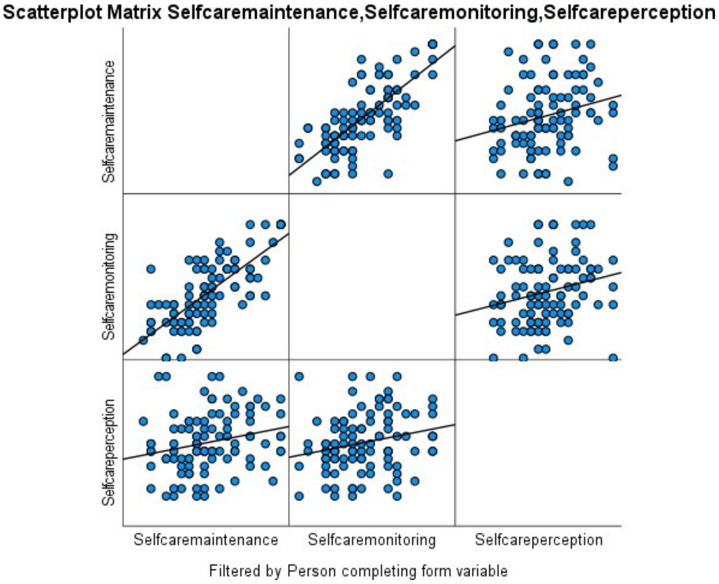


Figure 15

Scatterdot Matrix RQ2- AA Person with HF Dependent Variables

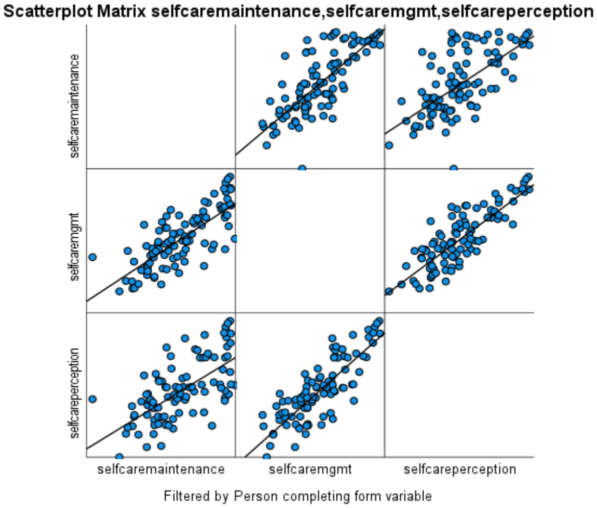
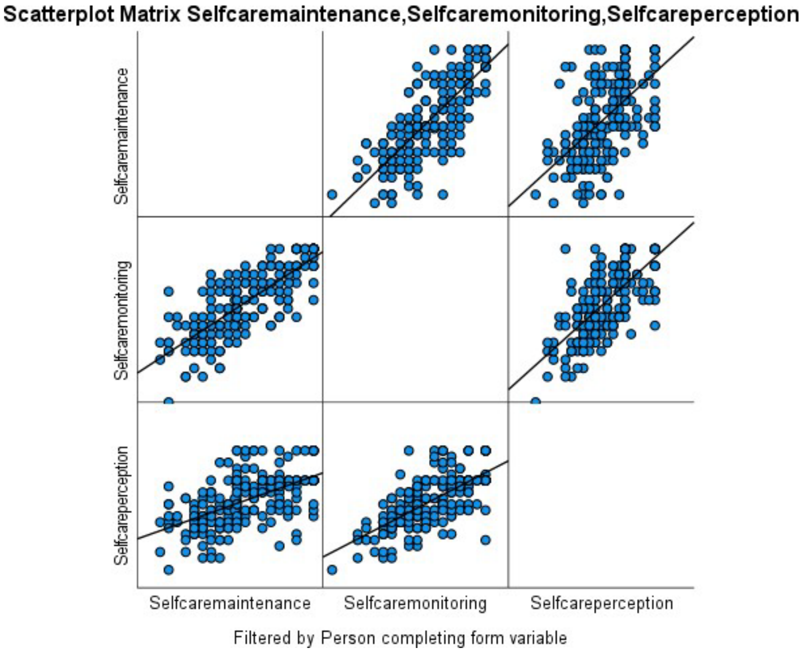


Figure 16

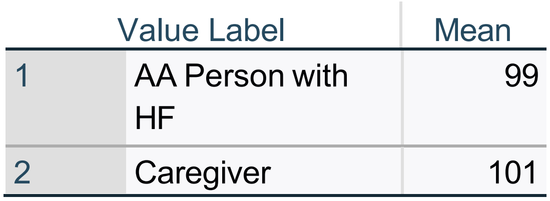
Scatterdot Matrix RQ2- Caregiver of AA Person with HF Dependent Variables



Assumption eight of adequate sample size of the one-way MANOVA was met as there are as many participants in each group of independent variables as there are dependent variables (see Figure 11).

Figure 17

Sample Size



	Value Label	Mean
1	AA Person with HF	99
2	Caregiver	101

To test assumption nine for a one-way MANOVA, I ran a parametric test, Box's M test for equivalence of covariance matrices, which tests the null hypothesis: There was no difference between communication (trust, culture, and spirituality) of caregivers of AA persons with HF and, self-care management and maintenance, and symptom perception of AA persons with HF.

I ran Box's M tests of equality for RQ1, testing the attributes of each dependent variable. For self-care monitoring, I tested the attributes: get some exercise, eat a low salt diet, take prescribed medications without missing a dose, and routinely seeing the health provider. For self-care management, the attributes of the variable: further limit salt intake, reduce fluid intake, taking a medication for symptoms, and calling the health care provider. Lastly, for the dependent variable self-care perception, I tested the attributes: monitor weight daily, pay attention to changes, look for medication side-effects and notice when you tire more than usual performing normal activities. There are disadvantages to performing a Box’s M test for homogeneity of covariance, such as sensitivity to normal distribution and sensitivity to a large sample size; I chose to continue with the Box’s M because this is an important assumption of the one-way MANOVA, because it tests if there are similar patterns across the two groups of independent variables (Hahs-Vaughn, 2016). The result of the Box’s M test for RQ1 was not statistically significant, $p < .353$, the assumption was met.

Table 6

Box’s Test of Equality of Covariance Matrices for Self-Care Maintenance, Self-Care Monitoring, and Self-Care Perception RQ 1

Box’s M	6.775
F	1.350
df1	6
df2	278024.495
Sig.	.353

For RQ2, I also ran the one-way MANOVA to test the attributes of the three dependent variables, self-care maintenance, self-care management, and self-care perception. For RQ2, the attributes of self-care maintenance were: make sure to get an annual influenza shot, ask for low salt foods when visiting family and friend, order low salt foods when eating out, and ask your health care provider about your medications. For self-care monitoring, the survey questions were: further limit the salt you eat, take an additional medication, call the health care provider for guidance, try to figure out why you have symptoms, and limit activity until feeling better. Lastly, the survey questions for self-care perception were: pay attention to how you feel, monitor symptoms closely, check for ankle swelling and check for shortness of breath with activity. The result for Box’s M for RQ2 were not statistically significant, $p = .006$, the assumption of homogeneity of variance-covariance matrices met. RQ2 met the statistical assumption of equality of covariance matrices.

Table 7

Box’s Test of Equality of Covariance Matrices for Self-Care Maintenance, Self-Care Monitoring, and Self-Care Perception RQ 2

Box’s M	18.213
F	2.985
df1	6
df2	278024.495
Sig.	.006

Lastly, to test the assumption of homogeneity of variances, which assumes there are equal variances between the two groups of independent variables, AA person with HF and the caregiver, for each dependent variable, self-care management, self-care maintenance, and self-care perception for RQ1 and RQ2. There was homogeneity of variances, as assessed by Levene’s test of homogeneity of variance for RQ1, self-care maintenance (*p* =.157), self-care management (*p* = .920) (see Table 8). The Levene’s Test shows the variances were significantly different for self-care perception between the AA person with HF and the caregiver of the groups, F (1, 198) = 23.56, *p* < .001for self-care perception. For RQ2, there was assumption of homogeneity of variance, as assessed by Levene’s test of homogeneity of variance, self-care maintenance (*p* = .058), self-care management (*p* = .206), and self-care perception (*p* = .038) (see Table 9).

Table 8

RQ1: Levene’s Test of Equality for Dependent Variables

Levene's Test of Equality of Error Variances^a

		Levene Statistic	df1	df2	Sig.
Selfcaremaintenance	Mean	2.165	1	196	.143
Selfcaremonitoring	Mean	.094	1	196	.760
Selfcareperception	Mean	2.391	1	196	.124

Table 9

RQ2: Levene’s Test of Equality for Dependent Variables

Levene's Test of Equality of Error Variances[a]

		Levene Statistic	df1	df2	Sig.
Selfcare maintenance	Mean	3.644	1	196	.058
Selfcare management	Mean	1.612	1	196	.206
Selfcare perception	Mean	4.359	1	196	.038

Both instruments were scored using a standardized formula which is an algebraic equation to reach the responses for each scale, respectively (Reigel, et al. 2022). The minimum number of points for each scale was seven, the maximum point for Self-Care Maintenance was 35, and for Self-Care Monitoring, and Self-Care Management was 25. After computing each raw score, I entered the scores into the self-care scoring algorithm, the transformation of scale formula, to achieve the sum responses.

The average score for each scale of the SCHFI v7.2 were self-care maintenance 65.8, self-care management 36.5, and self-care perception was 51.44. The average score for each scale for caregiver contribution – self-care of heart failure instrument (CC-SCHFI v2) (a) self-care maintenance scale score was 74.77, (b) the self-care management scale score was 45.52, and (c) the self-care perception scale score was 51.55. The self-care maintenance scores for AA persons with HF was markedly lower than scores for the caregiver of AA persons with HF; suggesting a general overall understanding of adherence; conversely, the average score for caregivers were 75%, suggesting a better overall understanding of adherence by the caregiver as compared to the person living with the chronic condition.

Self-care monitoring scales also suggest caregivers of AA persons living with HF pay more attention to changes in health conditions than the person living with HF. The AA person living with HF and the caregiver scored similarly in self-care perception, which suggests both understand the importance of changing the treatment regimen based on clinical symptoms of worsening symptomatology.

I developed two RQs to support this study. The RQs were designed to explore the differences in communicative components of cultural factors and the self-care management and -maintenance relationship among the dyad. I used the one-way MANOVA to determine if there was a statistical significance between AA persons with HF and caregivers of AA persons with HF. To appropriately analyze the data, I ran a one-way MANOVA after I tested the assumption.

Research Question 1 and Corresponding Hypotheses

The first RQ was, What is the difference between AA caregiver communication (trust, culture, and spirituality) and self-care management, maintenance, and symptom perception of caregivers of AA persons living with heart failure?

$H_0 1$: There is no difference between AA caregiver communication and self-care management and maintenance of AA persons living with HF.

*H*a1: There is a difference between the AA caregiver communication and self-care management and maintenance of AA persons living with HF.

Communication incorporated the following factors: trust, culture, and spirituality which were measured using the SCHFI v7.2 and the CC-SCHFI v2 and correlating the attributes identified and tests were performed using the one-way MANOVA.

After all assumptions were tested, I analyzed the data by using a one-way MANOVA to examine the differences of cultural factors of the dyad on the dependent variables self-care maintenance, self-care monitoring, and self-care perception. Table 11 displays the mean, standard deviation, and the number of cases for the dependent variables, self-care maintenance, self-care monitoring, and self-care perception, separately for the AA person with HF and the caregiver role, and the overall score for each group. AA persons with HF scored lower in self-care maintenance and self-care management than the caregiver participant (M = 66.5816, SD = 16.46; M = 75.77, SD = 17.70 and M = 37.43, SD = 13.64, and M = 46.11; SD = 13.44 respectively) and scores for self-care perception were lower for AA persons with HF than the caregiver (M = 11.21, SD = 3.98, and 14.67, SD = 3.28, respectively).

Table 10

Group Descriptive Statistics for Research Question 1

	Person Completing Form	N	Mean	SD	Stand Error	95% Confidence Interval Lower Bound	Upper Bound
Self-care maintenance	AA Person with HF	98	66.5816	16.46048	1.727	63.175	69.988
	Caregiver	100	75.7703	17.70061	1.710	72.398	79.142
Self-care management	AA Person with HF	98	37.4271	13.63803	1.368	34.730	40.124
	Caregiver	100	46.1071	13.44088	1.354	43.437	48.777
Self-care perception	AA Person with HF	98	11.2143	3.97998	.368	10.489	11.940
	Caregiver	100	14.6700	3.27850	.364	13.952	15.388

To determine which dependent variables contributed to the statistical significance of the one-way MANOVA, I inspected the test of between-subject effects. There was a statistically significant difference between the two groups on the three dependent variables, self-care maintenance, self-care monitoring, and self-care perception, F (3, 194) = 18.807, *p* < .001; Wilks' λ = .755; partial n^2 = .225. The sample size for the dyad was slightly unequal at 99 persons in AA person with HF group and 101 persons in the caregiver group; however, both Wilks' Lambda and Pillai's trace were both statistically significant, therefore I chose to report Wilks' Lambda instead of Pillai's trace.

Table 11

RQ 1: Multivariate Tests

Multivariate Tests

Effect	Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared

Person completing this form	Pillai's Trace	.225	18.807[b]	3.000	194.000	<.001	.225
	Wilks' Lambda	.775	18.807[b]	3.000	194.000	<.001	.225

Note: b is exact statistic

Based on the statistically significant results, the test of between-subjects was analyzed to determine which variable contributed to the statistically significant MANOVA. The statistical significance level was set at $p < .05$ for the three dependent variables. Follow-up univariate analysis of variance tests showed significant difference in self-care maintenance scores between the dyad F (1, 196) = 14.295, $p < .001$; and medium effect size, $\eta^2 = .068$. There was also statistical significance in self-care management scores between the dyad F (1,196) = 20.344, $p < .001$; the effect size of the same was medium, $\eta^2 = .094$. Lastly, there was statistical significance in self-care perception scores between the dyad F (1, 196) = 44.547, $p = .001$; and effect size was medium, $\eta^2 = .185$ (see Table 13). Post hoc tests were not run by SPSS because there were fewer than three subject groups and it has been determined there is difference between the two groups of independent variables (Laerd, 2023). Based on the analysis presented, I rejected the null hypothesis.

Table 12

RQ1: Tests of Between-Subjects

Tests of Between-Subjects Effects

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared

Person completing this form	Selfcaremaintenance	4178.964	1	4178.964	14.295	<.001	.068
	Selfcaremonitoring	3729.118	1	3729.118	20.344	<.001	.094
	Selfcareperception	591.067	1	591.067	44.547	<.001	.185
Error	Selfcaremaintenance	57299.746	196	292.346			
	Selfcaremonitoring	35926.678	196	183.299			
	Selfcareperception	2600.610	196	13.268			

Research Question 2 and Corresponding Hypotheses

The second RQ was, What is the difference between cultural factors of AA persons with HF and their caregivers?

$H_0$2: There is no difference between cultural factors of AA persons with HF and their caregivers.

H_a2: There is a difference between cultural factors of AA persons with HF and their caregivers.

Cultural factors included dietary considerations, customs and traditions of AA person and trust, measured using the Self-Care of Heart Failure Index v7.2 (SCHFI v7.2) and the CC-SCHFI v2 and correlating the attributes identified and tests were performed using the one-way multivariate analysis of variance (MANOVA).

Table 13 for RQ2 displays the mean, standard deviation, and the number of cases for the dependent variables, self-care maintenance, self-care monitoring, and self-care perception for the AA person with HF and the caregiver role, and the overall score for each group. AA persons with HF scored lower in self-care maintenance (M = 15.15, SD = 3.43, M = 16.18, SD = 2.98, respectively), self-care management (M = 37.43, SD =

13.64, and M = 46.11; SD = 13.44, respectively) and self-care perception (M = 12.69, SD = 3.55, and 17.05, SD = 2.71, respectively) than the caregiver of the AA person with HF.

Table 13

Group Statistics for RQ2

						95% Confidence Interval	
	Person completing form	N	Mean	SD	Stand Error	Lower Bound	Upper Bound
Self-care maintenance	AA Person with HF	98	15.153	3.43227	.324	14.514	15.793
	Caregiver	100	16.180	2.97593	.321	15.547	16.813
Self-care management	AA Person with HF	98	16.429	3.24285	.412	15.617	17.240
	Caregiver	100	19.760	4.32685	.407	18.956	20.564
Self-care perception	AA Person with HF	98	12.684	3.81152	.318	12.056	13.312
	Caregiver	100	17.050	4.39402	.315	16.428	17.672

There was a statistically significant difference between the caregivers on the combined dependent variables, self-care maintenance, self-care management, and self-care perception, F (3, 194) = 41.225, $p < .001$; Wilks' $\Lambda = .611$, partial $\eta^2 = .389$ (Table 14). To determine which dependent variables contributed to the statistical significance of the one-way MANOVA, I inspected the test of between-subject effects (Table 15). Follow-up univariate analysis of variance tests did not show a statistically significant difference in self-care maintenance between groups, F (1, 196) = 5.066, $p = .026$, the effect size was medium, partial $\eta^2 = .025$.

Table 14

RQ 2: One-Way MANOVA Results.

Multivariate Tests[a]

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Person completing this form	Pillai's Trace	.389	41.225[b]	3.000	194.000	<.001	.389
	Wilks' Lambda	.611	41.225[b]	3.000	194.000	<.001	.389

Table 15

Between Subjects Test RQ 2

Tests of Between-Subjects Effects

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Person completing form	selfcaremaintenance	52.198	1	52.198	5.066	.026	.025
	Selfcaremgmt	549.316	1	549.316	33.085	<.001	.144
	selfcareperception	943.612	1	943.612	94.945	<.001	.326
Error	selfcaremaintenance	2019.464	196	10.303			
	Selfcaremgmt	3254.240	196	16.603			
	selfcareperception	1947.944	196	9.938			

There was a statistically significant difference in self-care management between groups, F (1, 196) = 33.085, $p < .001$, with a medium effect size noted, partial $\eta^2 = .144$, and self-care perception between groups, F (1, 194) = 94.95, $p < .001$, with a medium effect size, partial $\eta^2 = .326$ (see Table 16). Post hoc tests were not run by SPSS because there were fewer than three subject groups and it has been determined there is difference between the two groups of independent variables (Laerd, 2023). Based on the analysis presented, the null hypothesis for RQ2 was rejected; there is not a significant difference between the AA person with HF and the caregiver.

Reliability Analysis

The SCHFI v7.2 and the CC-SCHFI v2 are separated into three scales within each survey instrument, Self-Care Maintenance, Self-Care Monitoring, and Self-Care Management. To address the reliability of the data, Cronbach's analyses were conducted. The alpha levels for the SCHFI v7.2 instrument was greater than 0.713, which indicates each variable had a sufficient level of reliability and internal consistency in measuring the constructs of the study (see Table 17). The alpha levels for the CC-SCHFI v2 also rendered a composite score greater than 0.761, indicating each variable had a sufficient level of reliability and internal consistency for each variable (see Table 16). The Cronbach's alpha coefficients demonstrates the instrument is valid and reliable for measuring self-care maintenance, self-care monitoring, and self-care management for each survey instrument.

Table 16

Reliability Analysis

Composite Score	**Cronbach's alpha**
	SCHFI v7.2
Self-Care Maintenance	.724
Self-Care Monitoring	.713
Self-Care Management	.837
	CC-SCHFI v2
Self-Care Maintenance	.802
Self-Care Monitoring	.755
Self-Care Management	.809

Heart failure self-care was measured dyadically, using the SCHFI v7.2 congruently with the CC-SCHFI v2. The established cut point for both instruments was 70, which is adequate self-care (Riegel, et al., 2009). Overall total scores were computed and transformed using the transformation of scale scores (Self-Care Measures, n.d.). AA persons with HF scored less than adequate on the self-care maintenance scale as compared to the caregiver, with an average score of 74.88. Additionally, the self-care monitoring scores were higher in the caregiver group than the AA person with HF. The self-care perception scores were similar with no differences noted between the scores.

The mean self-care maintenance scores were higher in persons with HF than in the caregiver (See Table 17).

Table 17

SCHFI v7.2 and CC-SCHFI v2 Scale Ranges and Averages

Scale		**Lowest and Highest Possible Raw Scores**	**Lowest to Highest – Possible Scores**	**Average Score**	**Range of Actual Scores**
	SCHFI v7.2				
Self-Care Maintenance		7, 35	0 – 100	65.8	35.7 – 96.4
Self-Care Monitoring		7, 25	0 – 64.29	36.5	0 – 64.29
Self-Care Perception		7, 25	0 – 64.29	51.44	10.17 – 82.14
	CC-SCHFI v2				
Self-Care Maintenance		7, 35	0 – 100	74.88	39.28 – 100
Self-Care Monitoring		7, 25	0 – 64.29	45.52	14.29 – 64.29
Self-Care Perception		7, 25	0 – 64.29	51.55	14.29 – 64.29

Summary

AA persons are disproportionately impacted by HF as compared with other racial or ethnic groups (Sharma, et al., 2014). Persons with HF require daily assistance with treatment regimens related to increased disease burden and rely on their informal caregivers to assist with symptom relief (Bernard et al, 2023). Informal caregivers are often seen as a gender specific role or a cultural expectation in specific subgroups of the population, such as AA (Carr & Utz, 2020; Unson et al., 2020). Unfortunately, AA persons are persistently underrepresented in HF clinical studies despite a higher prevalence of disease and adverse outcomes (Azam & Colvin, 2021).

The purpose of this study was to investigate whether there is a difference in caregiver communication between the AA person with HF and the caregiver. A one-way MANOVA was conducted to examine the communicative process of the dyad, the AA person with HF and the caregiver. Utilizing a dyadic approach, the groups were slightly unequal in size, the caregiver group had two additional respondents than did the person with HF group. There were no post hoc tests run by SPSS, as there were only two independent variable groups. Results of the analysis indicated statistical significance between the AA caregiver communication (trust, culture, and spirituality) and self-care management, maintenance, and symptom perception of caregivers of AA persons living with heart failure. Results also showed there was not a statistical difference between cultural factors of AA persons with HF and their caregivers.

This chapter included the reliability analysis of both survey instruments, the statistical results of both RQs, and the evaluation of the findings. In Chapter 5, I present the interpretation of the research findings, implications, recommendation for future research, and study conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this quantitative, descriptive study was to investigate the communicative relationship between AA persons with HF and caregivers of AA person with HF. The quantitative research design was appropriate for this research study because I wanted to test the differences between groups on a set of interrelated dependent variables (see Laerd, 2023). The theories supporting this research study were the self-care of chronic illness developed by Riegel et al. (2012) and the theory of dyadic illness management developed by Lyons and Lee (2018). The integration of two theories allowed me to incorporate concepts of self-care behaviors with the decision-making processes influenced by reflection. I ran one-way multivariance of analysis (MANOVA) tests for each RQ. The results for RQ1 showed that communication concepts between the AA person with HF and the caregiver were significantly different. The results for RQ2 showed statistically significant differences between self-care management and self-care perception. However, there were no differences between AA persons with HF and caregiver on self-care maintenance. AA persons with HF differed in cultural factors, which are described as behaviors, language, and history, as compared to the caregiver. I discuss interpretation of the findings, limitations of the study, future recommendations, and implications for the AA dyad, professional practice, and social change.

Interpretation of the Findings

The purpose of this study was to examine the differences in communication between AA persons with HF and caregivers and to increase the understanding of the impact of self-care on the dyad. The results may increase health care professionals' understanding of the AA dyad and the communication between the dyad. My results showed significance in AA persons with HF and caregiver with respect to self-care maintenance, self-care management, and self-care perception. This finding is similar to previous studies, which indicated that ineffective communication leads to inadequate understanding of the disease and lack of social support (Bidwell et al., 2018; Chi et al., 2018; Fitzsimmons et al., 2019; Lyons et al., 2020). Furthermore, patients and caregivers display inadequate communication, which affects shared decision-making and increases the burden on the caregiver and the ability of the caregiver to monitor the patient's self-care (Bouldin et al., 2019; Chi et al., 2018; DeSanto-Medeya & Safizadeh, 2017; Fitzsimmons et al., 2019; Lyons et al., 2020). Inadequate communication lessens collaboration and stifles the relationship and results in the caregiver feeling less supported (DeSanto-Madeya & Safizadeh, 2017; Lyons et al., 2020).

Results from the study indicated statistically significant differences in self-care management, self-care maintenance and self-care perception between persons with HF and caregivers, with higher scores noted in the caregiver population. This supports the findings by De Maria et al. (2022), which suggested that self-care maintenance activities can be individual or collaborative activities. Although De Maria et al. used a different study design, they used the same dyadic instrumentation as I did, the SCHFI 7.2 developed by Riegel et al. (2018) and CC-SCHFI v2 developed by Vellone et al. (2018). De Maria et al. collected a sample of 493 patient-caregiver dyads but did not report on race or ethnic background. Consistent with the findings of my research, the dyadic population were mostly female and employed. The annual income was similar, with the current reported income higher in the caregiver group than the person with HF. De Maria et al. (2022) included agreement between the dyad prior to participation in their study.

Self-care perception relates to the value placed on activities, which is forgotten by the person with HF and needs to be reinforced. Bidwell et al. (2019) found significant amounts of incongruence between the patient and caregiver-dyad, which were different than the findings in my study. Cothran et al. (2022) suggested that the low overall self-care perception scores indicate cultural undertones of gender role expectations, financial and environmental safety concerns of the caregiver, as well as assistance in navigating the needed resources and benefits. My findings support the concept that self-care perception needs to be reinforced in the dyad to improve self-care outcomes. Although the scores were similar in my study, caregivers scored higher overall than AA persons with HF. Wu et al. (2019) found that although persons with HF had high knowledge, their self-care scores were low. The low overall self-care perception scores in my findings suggest that there are obstacles within the patient-caregiver dyad that prevent them from engaging in adequate self-care.

Self-care maintenance is influenced by dyadic social norms, and social support influences health behaviors, according to Massouh et al. (2020). Dickson et al. (2013) found that self-care maintenance varied according to specific behaviors. Both sets of researchers noted that although persons with HF understood the rationale behind weighing themselves and heeding fluid restrictions, they did not adhere to the prescribed treatment and had insignificant social support. Symptoms of HF were described as ambiguous, and food also influenced decisions made by the dyad; poor self-care maintenance scores demonstrated that persons living with HF did not titrate medications when having symptoms, nor did they seek low-salt alternatives (Dickson et al., 2019). The self-care maintenance scores in my findings were lower in the AA person with HF compared to the caregiver scores, which aligns with the findings by Dickson et al., 2019 and Massouh et al., 2020. Additionally, Dickson et al., 2019 found that decision-making was influenced by the limited resources available and the physical environment, which I did not account for within my study.

Effective self-care requires dyadic needs to be met. Lyons and Lee (2018) asserted that there are four contextual factors that influence the behaviors of how persons with disease and their caregivers communicate socially. This social support includes multiple caregivers assisting the patient manage their disease process, which was not accounted for within my research study and did not lend additional knowledge. Self-care management includes behaviors that are practiced daily and that reduce the impact of illness, such as limiting salt intake, taking medication, and reducing fluid intake (Riegel et al., 2018). However, self-care management differed significantly between patient and caregiver in this study, which concurs with findings from the literature that symptom management is complex because of the diverse cluster of symptoms and the subjective nature of symptomatology (Koshy et al., 2020; Thida et al., 2021; Vuckovic et al., 2020). Demonstrated difficulties related to symptom management are the ability to afford healthy foods and adherence to dietary guidelines, such as salt restrictions (Macabasco-O’Connell et al., 2008; Schnell-Hoehn et al., 2009). In my study, the caregiver scored higher in the self-care management scale than the person with HF, which is consistent with the findings noted by Martins et al. (2023). Moreover, Heo et al. (2022) performed a qualitative research study that revealed that patients with HF do not fully follow the recommended low sodium diet because of barriers such as insufficient knowledge and distaste of low sodium foods.

HF self-care findings were statistically significant between the person with HF and the caregiver which confirms cultural preferences and perceived social support influence self-care in AAs (Cousin et al., 2022). Dyads demonstrated difficulty adhering to dietary guidelines because of the inability to afford fresh fruits and vegetables, inadequate engagement in self-care behaviors, and overutilization of health resources (Wu et al., 2017). Cultural preferences, family values and religious beliefs were part of the life experience and not consistent with the medical model of how self-care should be performed (Herber et al., 2017; Rong et al., 2016; Riegel & Dickson, 2015). My results further extend the knowledge that culturally congruent care is weak, health care providers prioritize best practices in disease management, which are not culturally appropriate and contribute to non-compliance and less successful outcomes (Banks et al., 2016).

Mammen et al. (2018) and Lee et al. (2017) posited that individuals who practice optimal self-care management reduce the physical impact of the illness and prevent exacerbations and promote health. Okada et al. (2019) and Riegel et al. (2018) postulated that perceived changes in HF are difficult for the person to understand because symptoms are not severe enough or clustered together to attribute them to HF. Furthermore, inability to interpret symptoms leads to delays in decision-making and is indicative of poor symptom perception (Okada et al., 2019). Communication barriers, or the quality of the interaction does not allow the caregiver to recognize signs and symptoms of HF, which further extends the literature (Bouldin, 2019). Competing life challenges include the disparity of social support between the AA person with HF and the caregiver (Cousin et al., 2022). My results further extend the findings of Wali et al. (2019) that communication differences can be attributed to limited understanding of symptoms of HF, as education is not always customized to the person with HF.

AAs attach great value on interdependence and collectivism in studies that examine coping strategies of racial populations and rely heavily on problem focused coping strategies (Kuo, 2013; Sharpe & Boyas, 2011). The low self-care perception scores of the dyad within my study further extend the findings of Dickson et al. (2014) that food is a major part of the cultural make-up with food-related social norms which negatively affect persons with HF as they did not want to draw attention to their special dietary needs (Dickson et al., 2013). Additionally, the low self-care perception scores of the dyad further extend the literature findings of Lee and Riegel (2018), which noted edema-related symptoms, lower extremity edema and weight gain, were poorly detected before hospitalization.

Dyadic incongruence was found between persons with HF and their caregivers with substantial knowledge variability, which reported higher caregiver participation and contribution to self-care, than the patient (Bidwell et al., 2018). In my study, the self-care maintenance scores were higher in the caregiver than the person with HF, which is consistent with the findings by Wilson et al. (2022), which identified HF self-care scores as higher in the caregiver than in the person with HF and consisted of a large AA dyadic makeup. Wilson et al. (2022) postulated caregiver contribution to the self-care of the person with HF is fundamental. The findings of my research showed the caregiver scored adequate in self-care maintenance, whereas the person with HF scored below adequate, which agrees with the findings by Bidwell et al. (2018) that dyadic self-care maintained two domains of self-care, allocating responsibility for each domain independently and collaboratively. The caregiver demonstrated higher self-care management scores in a study by Vellone et al. (2020) when the person with HF had worsening conditions, and that caregivers contribute more effectively with improved preparedness.

Self-care findings in the cross-sectional study conducted by Buck et al. (2018), demonstrated dyadic self-care adequacy is nuanced and takes place individually and relationally. Caregivers scored higher than the person with HF in self-care management, but not in self-care maintenance, and demonstrates the dyadic shift when patients with HF have symptoms, such as swelling (Buck et al., 2018). Complex interpersonal relationships were shown in my study to not improve during self-care but suggest adequate self-care is better than inadequate self-care, which emerged as the more adequate the dyad feels, the less likely they are to change and find it difficult to switch course as the patient deteriorates (Buck et al., 2018).

Limitations of the Study

There were several limitations that were considered during interpretation of the study results. There were several threats to internal validity. Response bias is an internal threat, which happens when respondents answer questions in a socially desirable manner

(Randall & Fernandes, 1991). I hypothesized AA persons with HF and the caregiver did not have differences in communication regarding self-care management, self-care maintenance, or self-care perception. However, in the study, the differences in self-care maintenance and self-care management were measured concurrently and did not provide a basis for knowing which was the antecedent. Additionally, homogenous sampling was also a threat to validity as respondents were recruited based on a specific population. To reduce the threat, the participants were recruited via social media sites, the Walden Participant pool, and snowball sampling. Additionally, because this was an anonymous survey, results could cause bias since there is no method of knowing if the participants were truly AAs with HF or the caregiver (Grant & Graven, 2018).

Another threat to internal validity was the extraneous variables which could not be separated and measured, such as environmental factors, time of day surveys were taken, or natural intelligence (Statology, 2023). This survey was a mixed method survey; mail or online methodology, the mood of the respondent was unknown and could potentially influence responses. Inconsistent data were removed, if greater than 50% of the survey was incomplete, and completion was limited to the one sitting and one attempt, which attempted to resolve the issue of extraneous variables. Collection of self-reported measures relied on truthfulness of the respondent in answering questions regarding sociodemographic variables and self-reported measures, as well as disadvantages in research, such as age restriction, with reported ages upwards of 80. This could negatively impact the results with limited recall or social desirability. However, I attempted to reduce recall bias and social desirability bias, through exclusionary criteria of dementia or memory loss and removing the dyadic partnership. This could not be controlled since the survey was an anonymous online survey.

Recommendations

The dyadic relationship is complex, the phenomena of simultaneous integrative care for HF has limited research (Buck et al., 2018; MacInnes & Williams, 2018). Mutually supportive education for the AA person with HF and their caregiver to promote increased communication is necessary to understand the complexities of the disease in the AA population. The integration of qualitative and quantitative data in dyadic engagement in HF self-care communication could reveal and inform initiatives aimed at the improvement of self-care outcomes for both patient and caregiver within the community setting (Buck et al., 2018).

The dyadic experience of the caregiver of the AA person with HF scored higher on the CC-SCHFI v2 than the AA person with HF. This study did not account for other racial/ethnic populations and how they care for the AA person with HF, as the study did not expand the understanding of cross-cultural dyads. Cross cultural understanding of the dyad needs to be explored within a qualitative setting to account for the various cultural differences of the dyad.

Further research is needed to explore the social and comorbid conditions of either member of the dyad, as well as the understanding of the generational gaps in patient-caregiver dynamics. Analyses of AA dyads during the early stages of disease could be conducted to produce “clinically actionable results” and provide emotional support to diminish the total burden through focused interventions on the dyad and not just the person with HF (Piamjariyakul et al., 2015). My findings reiterate the need for continued research into the importance of the informal caregiver role and enhancing the dyadic understanding with respect to the AA dyad and culture (Nelson et al., 2022).

Implications

Implications for Dyads

The findings of this quantitative analysis are important to the AA community and how HF impacts and influences the outcomes of the dyad. I identified self-care differences that are influenced by communication differences in caregivers and patients across cultural, educational, and generational factors (Abrams et al., 2016; Wali et al., 2020). Emotional and physical support should be addressed for both members of the dyad to reduce isolation (Hodson, et al., 2019). HF self-care is associated with the dyadic differences in self-care maintenance and self-care monitoring and are influenced by culture and a combination of socioeconomic factors (Agren et al., 2012; Buck et al., 2019; Lee et al., 2017).

Implications for Professional Practice

Self-care management and maintenance behaviors are important to both members of the HF dyad (Uchmanowicz et al., 2022). It is important for health care providers to treat each dyad according to their dyadic type (Bidwell et al., 2018; Cameron et al., 2017). The theory of dyadic illness management helps explain the results, which suggests the quality of, and effective communication are examples of dyadic factors which influence appraisal and encompasses the support from caregivers in managing the illness together (Lyons & Lee, 2018). Social support is the most protective conceptual factor because it encompasses the support from family and friends and often includes multiple caregivers helping to manage the illness together (Feeney & Collins, 2015). Cultural risk protective factors include each member of the dyad's beliefs, values, and traditions, and includes the health care culture of patient centricity (Lyons & Lee, 2018). Understanding the theory of dyadic illness also explains that dyadic confidence is influenced by the status of the relationship and communication of the members within the dyad to understand and manage the illness which is an important because influence of the caregiver is necessary to the caregiver role.

Implications for Social Change

My results showed that AAs feel undervalued in health care and adequate access to health care. The need to be heard as well as understanding by the health care provider is important to the AA dyad. This is attributed to the theory of dyadic illness management and the theory of self-care of chronic illness which is a holistic view of self-care for both the patient and the caregiver and identifies challenges the dyad have with decision-making about chronic conditions. Furthermore, my findings also suggest health care providers need to address the underlying issues of the AA person with HF by understanding the cultural identity of the person. Addressing the types of foods that are customary to the person will assist in increasing trust and lifestyle changes as they relate to chronic conditions. Social change is required to create an awareness that dyadic partnership is important and incorporating ways to increase dyadic relationships can help to reduce the HF self-care effects through trust.

Conclusion

HF is a serious condition, and the increased burden of self-care is placed on the caregiver. The aging population and the prevalence of HF is likely to increase, with higher morbidity and mortality rates. The findings of this study can be utilized to identify areas that need improvement. The cultural and generational differences within the dyad in the AA population and how they access health care can improve with the understanding of the norms. The family dyad is integral to the self-care outcomes of the person living with HF. The gaps in health care may be decreased when the caregiver needs are met as well as the person living with HF.

References

Abrams, J. A., Javier, S. J., Maxell, M. L., Belgrave, F. Z., & Nguyen, A. B. (2016). Distant but relative: similarities and differences in gender role beliefs among African American and Vietnamese American women. *Cultural Diversity and Ethnic Minority Psychology*, *22*(2), 256–267. https://doi.org/10.1037.cdp0000038

Abshire Saylor, M., Clair, C. A., Curriero, S., DeGroot, L., Nelson, K., Pavlovic, N., Taylor, J., Gallo, J. J., & Szanton, S. (2023). Analysis of action planning, achievement and life purpose statements in an intervention to support caregivers of persons with heart failure. *Heart & Lung*, *61*, 8–15. https://doi.org/10.1016/j.hrtlng.2023.04.002

Acharya, A., Prakash, A., Saxena, P., & Nigam, A. (2013). Sampling: why and how of it? *Indian Journal of Medical Specialties, 4*(2), 330-333. https://dx.doi.org/10.7713/ijms.2013.0032

Adler, N. E., Cutler, D. M., Fielding, J. E., Galea, S., Glymour, M. M., Koh, H, K., Satcher, D. (2016, September 19). Addressing social determinants of health and health disparities: A vital direction for health and health care [Discussion paper]. *National Academy of Medicine*. https://doi.org/10.31478/201609t

Ågren, S., Evangelista, L. S., Hjelm, C., & Strömberg, A. (2012). Dyads affected by chronic heart failure: A randomized study evaluating effects of education and psychosocial support to patients with heart failure and their partners. *Journal of Cardiac Failure*, *18*(5), 359–366. https://doi.org/10.1016/j.cardfail.2012.01.014

Albert, N. M., Trochelman, K., Meyer, K. H., & Nutter, B. (2009). Characteristics associated with racial disparities in illness beliefs of patients with heart failure. *Journal of Behavioral Medicine*, *35*(4), 112–125. https://doi.org/10.1080/08964280903334519

Allen, M. (2017). *The SAGE encyclopedia of communication research methods*. SAGE Publications. https://doi.org/10.4135/9781483381411

Alpert, M. A., Lavie, C. J., Agrawal, H., Aggarwal, K. B., & Kumar, S. A. (2014). Obesity and heart failure: Epidemiology, pathophysiology, clinical manifestations, and management. *Translational Research*, *164*(4), 345–356. https://doi.org/10.1016/j.trsl.2014.04.010

Al-Hammouri, M. M., Rababah, J. A., Hall, L. A., Moser, D. K., Dawood, Z., Jawhar, W., & Alawawdeh, A. (2020). Self-care behavior: A new insight of the role of impulsivity into decision making process in persons with heart failure. *BMC Cardiovascular Disorders*, *20*, Article 349. https://doi.org/10.1186/s12872-020-01617-8

AMSTAT Consulting. (2023, January 20). *One-way MANOVA*. https://www.amstatisticalconsulting.com/one-way-manova/

Al-Sutari, M. M., & Ahmad, M. M. (2017). Effect of educational program on self-care behaviors and health outcome among patients with heart failure: An experimental study. *JBI Evidence Implementation*, *15*(4), 178–185. https://doi.org/10.1097/XEB.0000000000000108

Anekwe, T. D., & Rahkovsky, I. (2018). Self-management: A comprehensive approach to management of chronic conditions. *American Journal of Public Health*, *108*(Suppl. 6), S430–S436. https://doi.org/10.2105/AJPH.2014.302041r

Artinian, N. T., Magnan, M., Sloan, M., & Lange, M. P. (2002). Self-care behaviors among patients with heart failure. *Heart & Lung*, *31*(3), 161–172. https://doi.org/10.1067/mhl.2002.123672

Auld, J. P, Mudd, J. O., Gelow, J. M., Lyons, K. S., Hiatt, S. O., Lee, C. S. (2018). Patterns of heart failure symptoms are associated with self-care behaviors over 6 months. *European Journal of Cardiovascular Nursing, 17*(6), 543–551. https://doi.org/10.1177/1474515118759074

Ausili, D., Rebora, P., Di Mauro, S., Riegel, B., Valsecchi, R. A., Paturzo, M., Alvaro, R., & Vellone, E. (2016). Clinical and socio-demographic determinants of self-care behaviours in patients with heart failure and diabetes mellitus: A multicenter cross-sectional study. *International Journal of Nursing Studies*, *63*, 18–27. https://doi.org/10.1016/j.ijnurstu.2016.08.006

Ávila, C. W., De Maria, M., Vellone, E., Riegel, B., Bernardes, D., Silveira, L. J., Rabelo-Silva, E. R. (2020). Psychometric Characteristics of the Caregiver Contribution to Self-care of Heart Failure Index in a South American Population. *Journal of Cardiovascular Nursing*, *35*(5), 435–444. https://doi.org/10.1097/JCN.0000000000000704

Azam, T. U., & Colvin, M. M. (2021). Representation of Black patients in heart failure clinical trials. *Current Opinion in Cardiology*, *36*(3), 329–334. https://doi.org/10.1097/HCO.0000000000000849

Bader, F., Atallah, B., Sadik, Z. G., Tbishat, L., Gabra, G., Soliman, M., Bakr, K., Ferrer, R., Stapleton, J., Khalil, M. (2018). Nurse-led education for heart failure patients in developing countries. *British Journal of Nursing*, *27*(12), 690–696. https://doi.org/10.12968/bjon.2018.27.12.690

Banke, A., Schou, M., Videbæk, L., Møller, J. E., Torp-Pedersen, C., Gustafsson, F., … Gislason, G. H. (2016). Incidence of cancer in patients with chronic heart failure: a long-term follow-up study. *European Journal of Heart Failure*, *18*(3), 260–266. https://doi.org/10.1002/ejhf.472

Banks, A. D., Ong-Flaherty, C., Sharifi, C. (2016). Culture of oppression in African Americans with heart failure. *Journal of Cultural Diversity*, 23(4), 139-143.

Beach, S. R., Schulz, R., Yee, J. L., Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the caregiver health effects study. *Psychology of Aging*, 15(2), 259-271. https://doi.org/10.1037/0882-7974.15.2.259

Becker, G., Gates, R. J., Newsom, E. (2004). Self-care among chronically ill African Americans: Culture health disparities, and health insurance status. *American Journal of Public Health*, 94(12), 2066-2073. https://doi.org/10.2105/ajph.94.12.2066

Benjamin, E. J., Muntner, P., Alonso, A., Bittencourt, M. S., Callaway, C. W., Carson, A. P., Chamberlain, A. M., Chang, A. R., Cheng, S., Das, S. R., Delling, F. N., Djousse, L., Elkind, M. S. V., Ferguson, J. F., Fornage, M., Jordan, L. C., Khan, S. S., Kissela, B. M., Knutson, K. L., Kwan, T. W., Lackland, D. T., …Virani, S. S.… On behalf of the American Heart Association Council on Epidemiology and

Prevention Statistics Committee and Stroke Statistics Subcommittee. (2019). Heart Disease and Stroke Statistics—2019 Update: A Report from the American Heart Association. *Circulation*, *139*(10). https://doi.org/10.1161/CIR.0000000000000659

Bernard, T. L., Hetland, B., Schmaderer, M., Zolty, R., Pozehl, B. (2023). Nurse-led heart failure educational interventions for patient and informal caregiver dyads: An integrative review. *Heart & Lung*, *59*, 44–51. https://doi.org/10.1016/j.hrtlng.2023.01.014

Bevans, M. F., & Sternberg, E. M. (2012). Caregiving Burden, Stress, and Health Effects Among Family Caregivers of Adult Cancer Patients. *Jama*, *307*(4), 398-403https://doi.org/10.1001/jama.2012.29

Biddle, M. J., Moser, D. K., Pelter, M. M., Robinson, S., Dracup, K. (2020). Predictors of adherence to self-care in rural patients with heart failure. *Journal of Rural Health*, *36*(1), 120–129. https://doi.org/10.1111/jrh.12405

Bidwell, J., Lyons, K. S., Lee, C. S. (2017). Caregiver well-being and patient outcomes in heart failure: A meta-analysis. *Journal of Cardiovascular Nursing*, *32*(4), 372-38https://doi.org/10.1097/JCN.0000000000000350

Bidwell, J. T., Vellone, E., Lyons, K. S., D’Agostino, F., Riegel, B., Paturzo, M., Hiatt, S. O., Alvaro, R., Lee, C. S. (2017). Caregiver determinants of patient clinical event risk in heart failure. *European Journal of Cardiovascular Nursing*, *16*(8), 707–714. https://doi.org/10.1177/1474515117711305

Bidwell, J. T., Vellone, E., Lyons, K. S., D’Agostino, F., Riegel, B., Juárez-Vela, R., Hiatt, S. O., Alvaro, R., Lee, C. S. (2015). Determinants of heart failure self-care maintenance and management in patients and caregivers: A dyadic analysis. *Research in Nursing & Health*, *38*(5), 392–402. https://doi.org/10.1002/nur.21675

Bidwell, J. T., Vellone, E., Lyons, K. S., D'Agostino, F., Riegel, B., Juárez-Vela, R., Hiatt, S. O., Alvaro, R., Lee, C. S. (2015). Determinants of Heart Failure Self-Care Maintenance and Management in Patients and Caregivers: A Dyadic Analysis: DETERMINANTS OF HEART FAILURE SELF-CARE IN DYADS. *Research in Nursing & Health*, *38*(5), 392–402. https://doi.org/10.1002/nur.21675

Bouthoorn, S., Gohar, A., Valstar, G., den Ruijter, H. M., Reitsma, J. B., Hoes, A. W., & Rutten, F. H. (2018). Prevalence of left ventricular systolic dysfunction and heart failure with reduced ejection fraction in men and women with type 2 diabetes mellitus: a systematic review and meta-analysis. *Cardiovascular Diabetology*, *17*(1), 58–58. https://doi/10.1186/s12933-018-0690-3

Braunstein, J. B., Anderson, G. F., Gerstenblith, G., Weller, W., Niefeld, M., Herbert, R., Wu, A. W. (2003). Noncardiac comorbidity increases preventable hospitalizations and mortality among Medicare beneficiaries with chronic heart failure. *Journal of the American College of Cardiology; New York*, *42*(7), 1226–1233. https://Doi.org/10.1016/S0735-1097(03)00947-1

Braverman, P. A., Cubbin, C., Egerter, S., Williams, D. R., Pamuk, E. (2010). Socioeconomic disparities in health in the United States: What the patterns tell us. *American Journal of Public Health*, *100*(1), S186-S196. https://doi.org/10.2105/AJPH.2009.166082

Brown, G. S., White, K. G. (2009). Measuring discriminability when there are multiple sources of bias.*Behavior Research Methods, 41*(1), 75-84. https://www.proquest.com/scholarly-journals/measuring-discriminability-when-there-are/docview/204303203/se-2

Buck, H. G., Dickson, V. V., Fida, R., Riegel, B., D'Agostino, F., Alvaro, R., Vellone, E. (2015). Predictors of hospitalization and quality of life in heart failure: A model of comorbidity, self-efficacy and self-care. *International Journal of Nursing Studies*, *52*(11), 1714–1722. https://doi.org10.1016/j.ijnurstu.2015.06.018

Buck, H.G., Hupcey, J., Juarez-Vela, R., Vellone, E., Riegel, B. (2019). Heart failure care dyadic typology: initial conceptualization, advances in thinking, and future direction of a clinically relevant classification system. *Journal of Cardiovascular Nursing*, 34 (2), 159-165. https://10.1097/JCN0000000000000548.

Buck, H. G., Hupcey, J., Wang, H.-L., Fradley, M., Donovan, K. A., Watach, A. (2018). Heart failure self-care within the context of patient and informal caregiver dyadic engagement: A Mixed Methods Study. *Journal of Cardiovascular Nursing*, *33*(4), 384–391. https://doi.org/10.1097/JCN.0000000000000465

Buck, H. G., Stromberg, A., Chung, M. L., Donovan, K. A., Harkness, K., Howard, A. M., Kato, N., Polo, R., Evangelista, L. S. (2017). A systematic review of heart failure dyadic self-care interventions focusing on intervention components, contexts, and outcomes. *International Journal of Nursing Studies*, *77,* 232-242. https://doi.org/10.1016/j.ijnurstu.2017.10.007

Burke, R. E., Jones, J., Ho, P. M., & Bekelman, D. B. (2014). Caregivers' Perceived Roles in Caring for Patients with Heart Failure: What Do Clinicians Need to Know? *Journal of Cardiac Failure*, *20*(10), 731–738. https://doi.org/10.1016/j.cardfail.2014.07.011

Byrd, G. S., Edwards, C. L., Kelkar, V. A., Phillips, R. G., Byrd, J. R., Pim-Pong, D. S., Pericak-Vance, M. (2011). Recruiting intergenerational African American males for biomedical research studies: A major research challenge. *Journal of the National Medical Association*, 103(6), 480-487. https://doi.org/10.1016/S0027-9684(15)30361-8

Bujang, M. A., Omar, E. D., & Baharum, N. A. (2018). A Review on Sample Size Determination for Cronbach's Alpha Test: A Simple Guide for Researchers. *Malaysian Journal of Medical Sciences, 25*(6), 85–99. https://doi:10.21315/mjms2018.25.6.9

Callahan, C. M., Unverzagt, F. W., Hui, S. L., Perkins, A. J., Hendrie, H. C. (2002). Six-Item Screener to Identify Cognitive Impairment Among Potential Subjects for Clinical Research: *Medical Care*, *40*(9), 771–781. https://doi.org/10.1097/00005650-200209000-00007

Carr, D., Utz, R. L. (2020). Families in Later Life: A Decade in Review. *Journal of Marriage and Family*, *82*(1), 346–363. https://doi.org/10.1111/jomf.12609

Centers for Disease Control and Prevention. (2014a). Heart failure fact sheet. Retrieved from http://www.cdc.gov/dhdsp/data_statistics/fact_sheets/fs_heart_failure.htm

Centers for Disease Control and Prevention. (2014b). Mortality from congestive heart failure United States. Retrieved from http://www.cdc.gov/nchs/fastats/map_page.htm https://doi.org/ezp.waldenulibrary.org/10.21315/mjms2018.25.6.9

Chandramouli C., Tay W. T., Bamadhaj, N. S., Tromp, J., Teng, T-H. K., Yap, J. J. L., MacDOnald, M. R., Hung, C-H., Streng, K., Naik, A., Wander, G. S., Sawhney, J., Ling, H. L., Richards, A. M., Anand, I., Voors, A. A., Lam, C. S. P. (2019) Association of obesity with heart failure outcomes in 11 Asian regions: A cohort study. PLoS Med 16 (9): e1002916. https://doi.org/10.1371/journal.pmed.1002916

Chevret, S., Seaman, S., Resche-Rigon, M. (2015). Multiple imputation: A mature approach to dealing with missing data. *Intensive Care Medicine*, *41*(2), 348–350. https://doi.org/10.1007/s00134-014-3624-x

Chin, B., Cohen, S. (2020). Review of the association between number of social roles and cardiovascular disease: graded or threshold effect? *Psychosomatic Medicine, 8*(5), 471-486. https://doi.org/ 10.1097/PSY.0000000000000809

Chronic heart failure in adults: management | Guidance and guidelines | NICE. (n.d.). Retrieved January 5, 2019, from https://www.nice.org.uk/guidance/cg108

Chuang, H.-W., Kao, C.-W., Lin, W.-S., Chang, Y.-C. (2019). Factors affecting self-care maintenance and management in patients with heart failure: testing a path model. *Journal of Cardiovascular Nursing*, *34*(4), 297–305. https://doi.org/10.1097/JCN.0000000000000575

Chung, M. L., Lennie, T. A., Mudd-Martin, G., Dunbar, S. B., Pressler, S. J., Moser, D.

K., (2016). Depressive symptoms in patients with heart failure negatively affect family caregiver outcomes and quality of life. *European Journal of Cardiovascular Nursing,* 15(1), 30-38. https://doi.org/10.1177/1474515114535329

Clark, A. L., Fonarow, G. C., Horwich, T. B. (2015). Impact of cardiorespiratory fitness on the obesity paradox in patients with systolic heart failure. *The American Journal of Cardiology*, 115(2), 209-213. https://doi.org/10.1016/j.amjcard.2014.10.023

Clark, A. L., Fonarow, G. C., Horwich, T. B. (2014). Obesity and the obesity paradox in heart failure. *Progress in Cardiovascular Disease*, 56, 409-414. https://doi.org/10.1016/j.pcad.2013.10.004

Cohn, J. N. (2006). The use of race and ethnicity in medicine: lessons from the African American heart failure trial. *Journal of Law, Medicine, & Ethics, 24*(3), 552-554. https://doi.org/10.1111/j.1748-720x.2006.00068.x

Cothran, D. A., Paun, O., Strayhorn, S., Barnes, L. L. (2022). "Walk a mile in my shoes." African American caregiver perceptions of caregiving and self-care. *Ethnicity & Health*. 2022; *27*(2):435-452. https://doi.10.1080/13557858.2020.1734777

Cousin, L., Bugajski, A., Buck, H., Lennie, T., Chung, M. L., Moser, D. K. (2022). Race Moderates the Relationship Between Perceived Social Support and Self-care Confidence in Patients With Heart Failure. *Journal of Cardiovascular Nursing*, *37*(4), E73–E80. https://doi.org/10.1097/JCN.0000000000000822

Cuevas, A. G., O'Brien, K. (2019). Racial centrality may be linked to mistrust in healthcare institutions for AAs. *Journal of Health Psychology*, *24*(14), 2022–2030. https://doii.org/10.1177/1359105317715092

"Cultural Factors." Encyclopedia of Public Health. Retrieved April 15, 2021, from Encyclopedia.com: https://www.encyclopedia.com/education/encyclopedias-almanacs-transcripts-and-maps.cultural factors

Cunningham, T. J., Croft, J. B., Liu, Y., Lu, H., Eke, P. I., & Giles, W. H. (2017). Vital signs: Racial disparities in age-specific mortality among Blacks or African Americans – United States, 1999-2015. *Morbidity and Mortality Weekly Report*, *66*(17), 444-456. https://doi.org/10.15585/mmwr.mm6617e1

Current status of inclusion of black participants in neuropsychological studies: A scoping review and call to action. (n.d.). Retrieved October 2, 2023, from https://www.tandfonline.com/doi/epdf/10.1080/13854046.2021.2019314?needAccess=true

Curtin, S. C. (2019). *Mortality Trends by Race and Ethnicity Among Adults Aged 25 and over: United States, 2000–2017*. *342*, 8.

Cutilli, C. C., Simko, L. C., Colbert, A. M., Bennett, I. M. (2018). Health literacy, health disparities, and sources of health information in U.S. older adults. *Orthopaedic Nursing*, *37*(1), 54-59. https://doi.org/10.1097/NOR.0000000000000418

Cuyjet, A. B., & Akinboboye, O. (2014). Acute heart failure in the AA patient. *Journal of Cardiac Failure*, *20*(7), 533–540. https://doi.org/10.1016/j.cardfail.2014.04.018

de Bernardo, D. H., Curtis, A. (2013). Using online and paper surveys: The effectiveness of mixed-mode methodology for populations over 50. *Research on Aging*, *35*(2), 220–240. https://doi.org/10.1177/0164027512441611

de Leeuw, E. D. (2018). *Mixed-Mode: Past, Present, and Future*. Survey Research Methods; European Survey Research Association. https://doi.org/10.18148/srm/2018.v12i2.7402

De Maria, M., Ausili, D., Lorini, S., Vellone, E., Riegel, B., Matarese, M. (2022). Patient Self-Care and Caregiver Contribution to Patient Self-Care of Chronic Conditions: What Is Dyadic and What It Is Not. *Value in Health*, *25*(7), 1165–1173. https://doi.org/10.1016/j.jval.2022.01.007

Dickson, V. V., McCarthy, M., Howe, A. (2013). Sociocultural influences on heart failure self-care among an ethnic minority black population. *Journal of Cardiovascular Nursing*, *28*, 111-118.https://doi.org/10.1097/JCN.)b)13e31823db328

Dickson, V. V., Buck, H., Riegel, B. (2013). Multiple Comorbid Conditions Challenge Heart Failure Self-Care by Decreasing Self-Efficacy. *Nursing Research*, *62*(1), 2–9. https://doi.org/10.1097/NNR.0b013e31827337b3

Dickson, V., Buck, H., Riegel, B. (2011). A qualitative meta-analysis of heart failure self-practices among individuals with multiple comorbid conditions. *Journal of Cardiac Health*, *17*(5). https://doi.org/10.1016/j/cardfail.2010.11.011

Dogu, O., Ayedemir, Y. (2018). Anxiety and depression as emotional problems in patients with chronic heart, kidney, and respiratory disorders. *International Journal of Caring Sciences*, 543-549.

Dolce, M. C. (2011). The internet as a source of health information: Experiences of cancer survivors and caregivers with healthcare providers. *Oncology Nursing Forum, 38*(3), 353-359. https://doi.org/10.1188/11.ONF.353-359

Doshi, R. P., Yan, J., Aseltine, R. H. (2020). Age differences in racial/ethnic disparities in preventable hospitalizations for heart failure in Connecticut, 2009-2015: A population-based longitudinal study. *Public Health Reports*, *135*(1), 56–65.

Doyle, D. M., Factor-Litvak, P., Link, B. G. (2018). Modeling racial disparities in physical health via close relationship functioning: A life course approach. *Social Science & Medicine*, *204*, 31-38. https://doi.org/10.1016/j.socscimed.2018.02.002

Dunbar, S. B., Tan, X., Lautsch, D., Maculaitis, M. C., Ricker, B., Nagle, T., Clark, L. T., Hilkert, R., Brady, J. E., Black, H. L., & Spertus, J. A. (2023). The association between social determinants of health and patient-centered outcomes in adults with heart failure with reduced ejection fraction. *Journal of Advanced Nursing*, *79*(9), 3535–3548. https://doi.org/10.1111/jan.15682

Durant, R. W., Legedza, A. T., Marcantonio, E. R., Freeman, M. B., & Landon, B. E. (2011). Different types of distrust in clinical research among Whites and AAs. *Journal of the National Medical Association*, *103*(2), 123-130. https://doi.org10.1016/S0027-9684(15)30261-3

Edmonds, W. A., Kennedy, T. D. (2017). *An Applied Guide to Research Designs: Quantitative, Qualitative, and Mixed Methods*. SAGE Publications, Inc. https://doi.org/10.4135/9781071802779

Emerson, R. W. (2019). Cronbach's Alpha Explained. *Journal of Visual Impairment & Blindness*, *113*(3), 327–327. https://doi.org/10.1177/0145482X19858866

Epps, F., Rose, K. M., Lopez, R. P. (2019). Who's your family?: AA caregivers of older adults with dementia. *Research in Gerontological Nursing*, *12*(1), 20-26. https://doi.org/10.3928/19404921-20181212-04

Etemadifar, S. Bahrami, M., Shahriari, M., & Farsani, A.K. (2014). The effectiveness of a supportive educative group intervention on family caregiver burden of patients with heart failure. *Iranian Journal of Nursing and Midwifery Research,* 19(3), 217-223. PMID: 24949057.

Experiences of and factors associated with dietary sodium adherence in heart failure from patients' and their caregivers' perspectives: A qualitative study—ScienceDirect. (n.d.). Retrieved October 2, 2023, from https://www.sciencedirect.com/science/article/pii/S0197457221002597

Extraneous Variable: Definition & Examples—Statology. (n.d.). October 4, 2023, from https://www.statology.org/extraneous-variable/

Fain, J. A. (2015). Reading, understanding, and applying nursing research. F.A. Davis Company.

Faul, F., Erdfelder, E., Buchner, A., Lang, A.-G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods*, *41*, 1149-1160.

Feagin, J., Bennefield, Z. (2014). Systemic racism and U.S. health care. *Social Science & Medicine*, *103*, 7-14. https://doi.org/10.1016/j.socscimed.2013.09.006

Feeney, B. C., Collins, N. L. (2015). New look at social support: a theoretical perspective on thriving through relationship. *Pers Soc Psychol*, *19* (2), https://doi.org/10.1177/1088868314544222

Fisher, K., Markle-Reid, M., Ploeg, J., Bartholomew, A., Griffith, L. E., Gafni, A., Thabane, L., Yous, M.-L. (2020). Self-management program versus usual care for community-dwelling older adults with multimorbidity: A pragmatic randomized controlled trial in Ontario, Canada. *Journal of Comorbidity*, *10*, 2235042X20963390. https://doi.org/10.1177/2235042X20963390

Fitzsimons, D., Doherty, L. C., Murphy, M., Dixon, L., Donnelly, P., McDonald, K., McIlfatrick, S. (2019). Inadequate communication exacerbates the support needs of current and bereaved caregivers in advanced heart failure and impeded shared decision-making. *Journal of Cardiovascular Nursing, 34*(1), 11-19. https://doi.org/10.1097/JCN.0000000000000516

Fivecoat, H., C., Sayers, S. L., Riegel, B. (2018). Social Support predicts self-care confidence in patients with heart failure. *European Journal of Cardiovascular Nursing*, *17*(7), 598-604. https://doi.org/10.1177/1474515118762800

Fried, T. R., Bradley, E. H., O'Leary, J. R., Byers, A. L. (2005). Unmet desire for caregiver-patient communication and increased caregiver burden. *Journal of the American Geriatrics Society*, *53*(1), 59-65. https://doi.org/10.1111/j/1532-5415.2005.53011.x

Gallagher, R., Luttic, M., Jaarsma, T. (2011). Social support and self-care in heart failure. *Journal of Cardiovascular Nursing, 26*(6), 439-445. https://doi.org/10.1097/JCN.0b013e31820984e1

Gamble, V. N. (1997). Under the shadow of Tuskegee: AAs and health care. *American*

Journal of Public Health, *87*(11). 1773-1778. https://doi.org/10.2105/AJPH.87.11.1773

George, S., Duran, N., Norris, K. (2014). A Systematic Review of Barriers and Facilitators to Minority Research Participation Among AAs, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health*, *104*(2), e16–e31. https://doi.org/10.2105/AJPH.2013.301706

Go, A. S., Mozaffarian, D., Roger, V. L., Benjamin, E. J., Berry, J. D., Borden, W. B., Bravata, D. M., Dai, S., Ford, E. S., Fox, C. S., Franco, S., Fullerton, H. J., Gillespie, C., Hailpern, S. M., Heit, J. A., Howard, V. J., Huffman, M. D., Kissela, B. M., Kittner, S. J., Lackland, D. T., Lichtman, J., H., …Turner, M. B. (2013). Heart Disease and Stroke Statistics—2013 Update: A Report from the American Heart Association. *Circulation*, *127*(1). https://doi.org/10.1161/CIR.0b013e31828124ad

Goeres, L. M., Gille, A., Furono, J. P., Erten-Lyons, D., Hartung, D.M., Clavert, J. F., Ahmed, S. M., Lee, D. S. H. (2015). Rural-urban differences in chronic disease and drug utilization in older Oregonians. *The Journal of Rural Health*, *32*, 269-279. https://doi.org/10.1111/jrh.12153

Gordon, P. A. Perron, K. M. (2004). When spouses become caregivers: Counseling implications for younger couples. *Journal of Rehabilitation*, *70*(2), 27-32. https://doi.org/10.2105/AJPH/87.11.1773

Granger, B. B., Moser, D., Harrell, J., Sandelowski, M., Ekman, I. (2007). A practice use of theory to study adherence. *Progress in Cardiovascular Nursing, 22*, 152-

158.https://doi.org/10.1111/j.0889-7204.2007.888144.x

Grant, M. (2015). Resolving communication challenges in the intensive care unit. *AACN Advanced Critical Care*, *26*(2), 123-130. https://doi.org/10.1097/NCI.0000000000000076

Grant, J. S., Graven, L. J. (2019). High priority problems experienced by informal caregivers of individuals with heart failure. *Home Health Care Management & Practice*. https://doi.org/10.1177/1084822318800296

Graven, L. J., Azuero, A., Abbott, L., Grant, J. S. (2020). Psychosocial factors related to adverse outcomes in heart failure caregivers: A structural equation modeling analysis. *The Journal of Cardiovascular Nursing*, *35*(2), 137–148. https://doi.org/10.1097/JCN.0000000000000634

Gujral, D. M., Cleator, S. J., Bhattacharyya, S. (2018). Cardiac safety evaluation in cancer clinical trials. *European Journal of Cancer*, *103*, 143–146. https://doi.org/10.1016/j.ejca.2018.07.141

Hagedoorn, E. I., Paans, W., Jaarsma T., Keers, J. C. van der Schans, C., Luttil, M. L. (2017). Aspects of family caregiving as addressed in planned discussions between nurses, patients with chronic diseases and family caregivers: A qualitative content analysis. *BioMed Central*, *16*(37). https://doi.org/10.1186/s12912-017-0231-5

Hall, W. J., Chapman, M. V., Lee, K. M., Merino, Y. M., Thomas, T. W., Payne, B. K.,Coyne-Beasley, T. (2015). Implicit racial/ethnic bias among health care professionals and its influence on healthcare outcomes: A systematic review. *American Journal of Public Health*, *105*(12), e60-e76.

https://doi.org/10.2105/APJH.2015.302903

Halldin, A.-K., Schaufelberger, M., Lernfelt, B., Björck, L., Rosengren, A., Lissner, L., Björkelund, C. (2017). Obesity in middle age increases risk of later heart failure in women—Results from the prospective population study of women and H70 studies in Gothenburg, Sweden. *Journal of Cardiac Failure*, *23*(5), 363–369. https://doi.org/10.1016/j.cardfail.2016.12.003

Harrison, J. M., Friese, C. R., Barton, D. L., Janz, N. K., Pressler, S. J., Davis, M. A. (2018). Heart failure and long-term survival among older women with breast cancer. *Oncology Nursing Forum*, *45*(1), 77–87. https://doi.org/10.1188/18.ONF.77-87

Hasin, T., Gerber, Y., McNallan, S. M., Weston, S. A., Kushwaha, S. S., Nelson, T. J., Cerhas, J. R., Roger, V. L. (2013). Patients with heart failure have an increased risk of incident cancer. *Journal of American College of Cardiology*, *62*, 881-886. https://doi.org/10.1016.j.jacc.2013.04.088

Haviland, M. G., Morales, L. S., Dial, T. H., Pincus, H. A. (2005). Race/ethnicity, socioeconomic status, and satisfaction with health care. *American Journal of Medical Quality*, *20*(4), 195-203. https://doi.org/10.1177/1062860605275754

Healthy People 2020. (2014). Health disparities. Retrieved from www.healthypeople.gov

Hobbs, J. K., Escutia, D., Harrison, H., Moore, A., Sarpong, E. (2016). Reducing hospital readmission rates in patients with heart failure. *MedSurg Nursing, 25*(3), 145-152.

Hooker, S. A., Schmiege, S. J., Trivedi, R. B., Amoyal, N. R., Bekelman, D. B. (2018). Mutuality and heart failure sef-care in patients and their informal caregivers.

European Journal of Cardiovascular Nursing, 17(2), 102-113 https://doi.org/10.1177/1474515117730184

Jin, X., Liu, G. G., Luo, N., Li, H., Guan, H., Xie, F. (2016). Is bad living better than good death? Impact of demographic and cultural factors on health state preference. *Quality of Life Research*, *25*(4), 979–986. https://doi.org/10.1007/s11136-015-1129-x

Heart Disease and Stroke Statistics—2019 Update: A Report from the American Heart *Association* | *Circulation*. (n.d.). https://www.ahajournals.org/doi/10.1161/CIR.0000000000000659

Hedemalm, A., Schaifelberg, M., Ekmanm I. (2008). Symptom recognition and health care seeking among immigrants and native Swedish patients with heart failure. *BMC Nurs*e, 7, 9 (2008). https://doi.org/10.1186/1472-6955-7-9

Heo, S., Moser, D. K., Lennie, T. A., Fischer, M., Kim, J., Walsh, M. N., Thurston, M. M., Webster, J. H. (2021). Varied Factors were Associated with Different Types of Self-Care in Heart Failure. *Western Journal of Nursing Research*, *43*(4), 298–306. https://doi.org/10.1177/0193945920950334

Heo, S., Kim, J., Shim, J. L., Barbe, T., Black, V., Lee, M. O. (2021). Experiences of and factors associated with dietary sodium adherence in heart failure from patients' and their caregivers' perspectives: A qualitative study. *Geriatric Nursing*, *42*(5), 1190–1197. https://doi.org/10.1016/j.gerinurse.2021.07.001

Heidenreich, P. A., Albert, N. M., Allen, L. A., Bluemke, D. A., Butler, J., Fonarow, G. C., Ikonomidis, J. S., Khavjou, O., Konstam, M. A., Maddoz, T. M., Nichol, G., Pha., M, Pina, I., Trogdon, J. G. (2013). Forecasting the impact of heart failure in the United States: A policy statement from the American Heart Association. *Circulation: Heart Failure*, *6*, 606-619. https://doi.org/10.1161/HHF.0b013e318291329a

Higher Risk of Heart Failure Seen in Some Cancers. (2018, March 26). [cgvBlogPost]. Retrieved January 2, 2019, from https://www.cancer.gov/news-events/cancer-currents-blog/2018/increased-heart-failure-risk

Hodson, A. R., Peacock, S., Holtslander, L. (2019). Family caregiving for persons with advanced heart failure: an integrative review. *Palliative & Supportive Care*, *17* (6), 720-734. https://doi.org/10.1017/S1478951519000245

Holt, C. L., Clark, E. M., Debnam, K. J., Roth, D. L. (2014). Religion and Health in African Americans: The Role of Religious Coping. *American Journal of Health Behavior*, *38*(2), 190–199. https://doi.org/10.5993/AJHB.38.2.4

Hopp, F. P., Marsack, C., Camp, J. K., Thomas, S. (2014). Go to the Hospital or Stay at Home? A Qualitative Study of Expected Hospital Decision Making Among Older African Americans With Advanced Heart Failure. *Journal of Gerontological Social Work*, *57*(1), 4–23. https://doi.org/10.1080/01634372.2013.848966

Hopp, L. (2015). Risk of bias reporting in Cochrane systematic reviews. *International Journal of Nursing Practice*, *21*(5), 683–686. https://doi.org/10.1111/ijn.12252

Irani, E., Mogle, J., Durante, Á., Juárez-Vela, R., Vellone, E., Buck, H. G. (2022). Understanding and Optimizing Family Caregiver Participation in Dyadic Research. *Nursing Research*, *71*(6), 477–482.

https://doi.org/10.1097/NNR.0000000000000609

Irani, E., Niyomyart, A., Hickman, R. L. (2020). Systematic Review of Technology-Based Interventions Targeting Chronically Ill Adults and Their Caregivers. *Western Journal of Nursing Research*, *42*(11), 974–992. https://doi.org/10.1177/0193945919897011

Horwich, T. B., Fonarow, G. C., Clark, A. L. (2018). Obesity and the obesity paradox in heart failure. *Progress in Cardiovascular Diseases*, *61*(2), 151–156. https://doi.org/10.1016/j.pcad.2018.05.005

Hughes, T. B., Varma, V. R., Pettigrew, C., Albert, M. S. (2017). African Americans and clinical research: evidence concerning barriers and facilitators to participation and recruitment recommendations. *The Gerontologist*, *57*(2), 348-358. https://doi.org/10.1093/geront/gnv118

Jaarsma, T., Stromberg, A., Ben Gal, T., Cameron, J., Driscoll, A., Duengen, H. D., Simon, I., Huang, T-Y., Huyen, N. N., Kato, N., Koberich, S., Lupon, J., Moser, D. K., Pulignano, G., Rabelo, E. R., Suwanno, J., Thompson, D. R., Vellone, E., Alvaro., R., Yu, D., Riegel, B. (2013). Comparison of self-care behaviors of heart failure patients in 15 countries worldwide. *Patient Education and Counseling*, *92*, 114-120. https://doi.org/10.1016/j.pec.2013.02.017

James, C. V., Moonesinghe, R., Wilson-Frederick, S. M., Hall, J. E., Penman-Aguilar, A., Bouye, K. (2017). Racial/ethnic health disparities among rural adults – United States, 2012-2015. *Journal of Health Care for the Poor and Underserved*, *29*, 19-34. https://doi.org/10.15585/mmwr. ss6623a1

Johnson, V. E., Carter, R. T. (2020). Black cultural strengths and psychosocial well-being: an empirical analysis with Black American adults. *Journal of Black Psychology*, *46*(1), 55–89. https://doi.org/10.1177/0095798419889752

Kandola, D., Banner, D., O'Keefe-McCarthy, S., Jassal, D. (2014). Sampling Methods in Cardiovascular Nursing Research: An Overview. *Canadian Journal of Cardiovascular Nursing*, *24*(3), 15–18. PMID: 27356461.

Kenchaiah, S., Evans, J., Levy, D., Wilson, P. W. F., Benjamin, E. J., Larson, S. D., Kannel, W. B., Vasan, R. S. (2002). Obesity and the risk of heart failure. *New England Journal of Medicine*, *347*, 305-313. https://doi.org/10.1056/NEJMoa020245

Kessing, D., Denollet, J., Widdershoven, J., Kupper, N. (2019). Self-Care and Pathophysiological Function in Patients with Chronic Heart Failure. *International Journal of Behavioral Medicine*, *26*(6), 629–644. https://doi.org/10.1007/s12529-019-09822-2

Kheirbek, R. E., Alemi, F., Fletcher, R. (2015). Heart failure prognosis: comorbidities matter. *Journal of Palliative Medicine*, *18*(5), 447–452. https://doi.org/10.1089/jpm.2014.0365

Kilbourne, A. M., Switzer, G., Hyman, K., Crowley-Matoka, M., Fine, M. J. (2006). Advancing health disparities research within the health care system: A conceptual framework. *American Journal of Public Health*, *96*(12), 2113-2121. https://doi.org/10.2105/AJPH.2005.077628

Kim, J. S. R., Risbud, R., Gray, C., Banerjee, D., Trivedi, R. (2020). The Dyadic

Experience of Managing Heart Failure: A Qualitative Investigation. *The Journal of Cardiovascular Nursing*, *35*(1), 12–18. https://doi.org/10.1097/JCN.0000000000000605

Kimberlin CL Winterstein AG. (2008). Validity and reliability of measurement instruments used in research. *American Journal of Health-System Pharmacy*, *65*(23), 2276–2284. https://doi.org/10.2146/ajhp070364

Kitko, L., McIlvennan, C. K., Bidwell, J. T., Dionne-Odom, J. N., Dunlay, S. M., Lewis, L. M., Meadows, G., Sattler, E. L. P., Schulz, R., Strömberg, A., On behalf of the American Heart Association Council on Cardiovascular and Stroke Nursing; Council on Quality of Care and Outcomes Research; Council on Clinical Cardiology; and Council on Lifestyle and Cardiometabolic Health. (2020). Family Caregiving for Individuals With Heart Failure: A Scientific Statement From the American Heart Association. *Circulation*, *141*(22). https://doi.org/10.1161/CIR.0000000000000768

Koirala, B., Himmelfarb, C. D., Budhathoki, C., Tankumpuan, T., Asano, R., Davidson, P. M. (2018). Factors affecting heart failure self-care: An integrative review. *Heart & Lung*, *47*(6), 539–545. https://doi.org/10.1016/j.hrtlng.2018.09.004

Korsgaard, M. A., Brower, H. H., Lester, S. W. (2015). It isn't always mutual: A critical review of dyadic trust. *Journal of Management*, *41*(1), 47–70. https://doi.org/10.1177/0149206314547521

Koshy, A. O., Gallivan, E. R., McGinlay, M., Straw, S., Drozd, M., Toms, A. G., Gierula, J., Cubbon, R. M., Kearney, M. T., Witte, K. K. (2020). Prioritizing symptom management in the treatment of chronic heart failure. *ESC Heart Failure, 7*(5), 2193 – 2207. https://doi.org/10.1002/ehf2.12875

Kyoung, S. L. (2017). Obesity paradox: Comparison of heart failure patients with and without comorbid diabetes. *American Journal of Critical Care*, *26*(2), 140–148. https://doi.org/10.4037/ajcc2017634

Lang, R., Kelkar, V. A., Byrd, J. R., Edwards, C. L., Pericak-Vance, M., Byrd, G. S.(2013). African American participation in health-related research studies: Indicators for effective recruitment. *Journal of Public Health Management and Practice: JPHMP*, *19*(2), 110–118. https://doi.org/10.1097/PHH.0b013e31825717ef

Lani, J. (2009, June 26). *Multicollinearity*. Statistics Solutions. https://www.statisticssolutions.com/multicollinearity/

Lavie, C., Arena, R., Alpert, M., Milani, R., Ventura, H. (2018). Management of cardiovascular diseases in patients with obesity. *Nature Reviews Cardiology, 15*, 45-56. https://doi.org/10.1038/nrcardio.2017.108

Ledermann, T., Kenny, D. A. (2017). Analyzing dyadic data with multilevel modeling versus structural equation modeling: A tale of two methods. *Journal of Family Psychology*, *31*(4), 442–452. https://doi.org/10.1037/fam0000290

Lee, C. S., Bidwell, J. T., Paturzo, M., Alvaro, R., Cocchieri, A., Jaarsma, T., …Vellone, E. (2017). Patterns of self-care and clinical events in a cohort of adults with heart failure: 1 year follow-up. *Heart & Lung*, *47*(1), 40-46. https://doi.org/10.1016/jhrtlng.2017.09.004

Lee, C. S., Mudd, J. O., Auld, J., Gelow, J. M., Hiatt, S. O., Chien, C. V., Bidwell, J. T., Lyons, K. S. (2017). Patterns, relevance and predictors of heart failure dyadic symptom appraisal. *European Journal of Cardiovascular Nursing*, *16*(7), 595–604. https://doi.org/ 10.1177/1474515117700760

Lee, C. S., Vellone, E., Lyons, K. S., Cocchieri, A., Bidwell, J. T., D'Agostino, F., Hiatt, S. O., Alvaro, R., Buck, H. G., Riegel, B. (2015). Patterns and predictors of patient and caregiver engagement in heart failure care: A multi-level dyadic study. *International Journal of Nursing Studies*, *52*(2), 588–597. https://doi.org/10.1016/j.ijnurstu.2014.11.005

Lee, K. S., Moser, D. K., Dracup, K. (2018). Relationship between self-care and comprehensive understanding of heart failure and its signs and symptoms. *European Journal of Cardiovascular Nursing*, 17(6), 496-504. https://doi.org/10.1177/1474515117745056

Lee, S. M., Riegel, B. (2018). State of the science in heart failure symptom perception research: An integrative review. *Journal of Cardiovascular Nursing*, *33*(3), 204–210. https://doi.org./10.1097/JCN.0000000000000445

Levine, J. A. (2011). Poverty and obesity in the U.S. *Diabetes*, *60*(11), 2667-2668. https://doi.org/10.2337/db11-1118

Lewis, M. E., Myhra, L. L. (2018). Integrated care with indigenous populations: Considering the role of health care systems in health disparities. *Journal of Health Care for the Poor and Underserved*, *29*(3), 1083-1107. https://doi.org/10.1353/hpu.2018.0081

Lewis, S. (2014). Medical-surgical nursing: Assessment and management of clinical problems (9th ed.). Maryland Heights, MO: Elsevier/Mosby

Liljeroos, M., Kato, N. P., van der Wal, M. H., Brons, M., Luttik, M. L., van Veldhuisen, D. J., Strömberg, A., Jaarsma, T. (2020). Trajectory of self-care behaviour in patients with heart failure: The impact on clinical outcomes and influencing factors. *European Journal of Cardiovascular Nursing*, *19*(5), 421–432. https://doi.org/10.1177/1474515120902317

Lin, C., Miller, J. L., Lennie, T. A., Biddle, M. J., Mudd-Martin, G., Hammash, M. & Moser, D. K. (2020). Perceived control predicts symptom status in patients with heart failure. *The Journal of Cardiovascular Nursing, 35*(6),530-537. https://doi.org/10.1097/JCN.0000000000000684

Lind, M., Olsson, M., Rosengren, A., Svensson, A.-M., Bounias, I., Gudbjörnsdottir, S. (2012). The relationship between glycemic control and heart failure in 83,021 patients with type 2 diabetes. *Diabetologia*, *55*(11), 2946–2953. https://doi.org/10.1007/s00125-012-2681-3

Little, T. D. (2013). *Oxford Handbook of Quantitative Methods, Volume 1: Foundations*. Oxford University Press, Incorporated. http://ebookcentral.proquest.com/lib/waldenu/detail.action?docID=1591022

Lyons, K. (2020). The Roles of Communication, Collaboration, and Social Support on Dyadic Mental Health in the Context of Chronic Pain. *Innovation in Aging*, *4*(Supplement_1), 648–648. https://doi.org/10.1093/geroni/igaa057.2233

Lyons, K. S., Sadowski, T., Lee, C. S. (2020). The role of concealment and relationship quality on patient hospitalizations, care strain and depressive symptoms in heart failure dyads. *European Journal of Cardiovascular Nursing*, *19*(2), 118–124. https://doi.org/10.1177/1474515119863791

Lyons, K. S., Hiatt, S. O., Gelow, J. M., Auld, J., Mudd, J. O., Chien, C. V., Lee, C. S. (2018). Depressive symptoms in couples living with heart failure: The role of congruent engagement in heart failure management. *Aging & Mental Health*, *22*(12), 1585–1591. https://doi.org/10.1080/13607863.2017.1381945

Lyons, K. S., Lee, C. S. (2018). The theory of dyadic illness management. *Journal of Family Nursing*, *24*(1), 8-28. https://doi.org/10.1177/1074840717745669

Ma, M. A., Gutierrez, D. E., Frausto, J. M., Al-Delaimy, W. K. (2021). Minority representation in clinical trials in the United States: trends over the past 25 years. *Mayo Clinic Proceeding, 96*(1), 264-266. https://doi.org/10.1016/j.mayocp.2020.10.027

Macabasco-O'Connell, A., Crawford, M. H., Stotts, N., Stewart, A., Froelicher, E. S. (2008). Self-care behaviors in indigent patients with heart failure. *The Journal of Cardiovascular Nursing*, *23*(3), 223-230. https://doi.org/10.1097/01.JCN.0000317427.21716.5f

Macabasco-O'Connell, A., Dewalt, D. A., Broucksou, K. A., Hawk, V., Baker, D. W., Schillinger, D., Ruo, B., Bibbins-Domingo, K., Holmes, G. M., Erman, B., Weinberger, M., Pignone, M. (2011). Relationship between literacy, knowledge, self-care behaviors, and heart failure-related quality of life among patients with heart failure. *Journal of General Internal Medicine*, *26*(9), 979–986.

https://doi.org/10.1007/s11606-011-1668-y

MacInnes, J., Williams, L. (2018). A review of integrated heart failure care. *Primary Health Care Research & Development*, *20*, e57. https://doi.org/10.1017/S1463423618000312

Mammen, J., Rhee, H., Norton, S. A., Butz, A. M., Halterman, J. S., Arcoleo, K. (2018). An integrated operation definition and conceptual model of asthma self-management in teens. *Journal of Asthma*, *55*(12), 1315-1327. https://doi.org/10.1080/0277903.2017.1418888

Mayberry, L. S., Berg, C. A., Harper, K. J., Osborn, C. Y. (2016). The design, usability, and feasibility of a family-focused diabetes self-care support health intervention for diverse, low-income adults with type 2 diabetes. *Journal of Diabetes Research*, *2016*. https://doi.org/10.1155/2016/7586385

Mayberry, L. S., Rothman, R. L., Osborn, C. Y. (2014). Family members' obstructive behaviors appear to be more harmful among adults with type 2 diabetes and limited health literacy. *Journal of Health Communication – International Perspectives*, *19*(2), 132-143. https://doi.org/10.1080/10810730.2014.938840

McCabe, G. (2017). *Actor-Partner Interdependence Model* (pp. 1–2). https://doi.org/10.1007/978-3-319-28099-8_1197-1

McMurray, J. J. V., Gerstein, H. C., Holman, R. R., Pfeffer, M. A. (2014). Heart failure: a cardiovascular outcome in diabetes that can no longer be ignored. *The Lancet Diabetes & Endocrinology*, *2*(10), 843–851. https://doi.org/10.1016/S2213-8587(14)70031-2

Measurement in Nursing Research. (n.d.). Retrieved August 19, 2023, from https://oce.ovid.com/article/00000446-202106000-00027?relatedarticle=y

Melnyk, B. M., Fineout-Overholt, E., Stillwell, S. B., Williamson, K. M. (2010). Evidence-Based Practice: Step by Step: The Seven Steps of Evidence-Based Practice. *AJN The American Journal of Nursing*, *110*(1), 51–53. https://doi.org/10.1097/01.NAJ.0000366056.06605.d2

Meltzoff, J., Cooper, H. (2018). Research designs and threats to internal validity. In *Critical thinking about research: Psychology and related fields., 2nd ed.* (2017-38006-007; pp. 97–116). American Psychological Association. https://doi.org/10.1037/0000052-007

Miller, D. E. (2007). Dyad/Triad. In *The Blackwell Encyclopedia of Sociology*. American Cancer Society. https://doi.org/10.1002/9781405165518.wbeosd100

Moser, D., Watkins, J. (2008). Conceptualizing self-care in the heart failure patient: A life course model of characteristics. *Journal of Cardiovascular Nursing*, *23*(3), 205-218. https://doi.org/10.1097/01.JCN.0000305097.09710.a5

Mouzon, D. M., Link to external site, this link will open in a new tab, Watkins, D. C., Perry, R., Simpson, T. M., Mitchell, J. A. (2019). Intergenerational Mobility and Goal-Striving Stress Among Black Americans: The Roles of Ethnicity and Nativity Status. *Journal of Immigrant and Minority Health*, *21*(2), 393–400. https://doi.org/10.1007/s10903-018-0735-4

Mozaffarian D., Benjamin, E.J., Go, A.S., Arnett, D. K., Blaha, M. J., Cushman, M., Das, S. R., de Ferranti, S., Despres, J.-P., Fullerto, H. J., Howard, V. J., Huffman, M.

D., Isasi, C. R., Jimenez, M. C., Judd, S. E., Kissela, B. M., Lichtman, J. H., Lisbeth, L. D., Liu, S., Mackey, R. H., …, Turner, M. B. (2016). Heart disease and stroke statistics V2016 update: a report from the American Heart Association. *Circulation*;*133*: e38-e360. https://doi.org/10.1161/CIR.0000000000000350

Munshi, M. N., Florez, H., Huang, E. S., Kalyani, R. R., Mupanomunda, M., Pandya, N., Swift, C. S., Taveira, T. H., Haas, L. B. (2016). Management of diabetes in long-term care and skilled nursing facilities: a position statement of the American Diabetes Association. *Diabetes Care*, *39*(2), 308-318. https://doi.org/10.2337/dc15-2512

Nadeem, R. (2022, April 7). 3. Black Americans' views about health disparities, experiences with health care. *Pew Research Center Science & Society*. https://www.pewresearch.org/science/2022/04/07/black-americans-views-about-health-disparities-experiences-with-health-care/

Nadrian, H., Shojafard, J., Mahmoodi, H., Rouhi, Z., Rezeipsndari, H. (2018). Cognitive determinants of self-care behaviors among patients with heart failure: A path analysis. *Health Promotion Perspectives*, *8*(4), 275-282. https://doi.org/10.15171/hpp.2018.39

Nasstrom, L., Luttik, M. L., Idvall, E., Stromgberg, A. (2016). Exploring partners' perspectives on participation in heart failure home care: a mixed-method design. *Journal of Advanced Nursing, 73*(5), 1208-1219. https://doi.org/10.1111/jan.13216

Nayak, A., Hicks, A., Morris, A. (2020). Understanding the complexity of heart failure risk and treatment in Black patients. *Circulation: Heart Failure*, *13*(8) https://doi.org/10.1161/CIRCHEARTFAILURE.120.007264

NHS England » Partnerships and relationships. (n.d.). Retrieved October 4, 2023, from https://www.england.nhs.uk/ourwork/part-rel/

Oh, H., Noh, H., Sims, O. T., Guo, Y., Sawyer, P. (2018). A comparison of urban and non-urban African American older adults on health related characteristics. *Journal of Social Work in Health Care*, *57*(9), 762-773. https://doi.org/10.1080/00981389.2018.1497748

One-way MANOVA in Stata | Step-by-step procedure including discussion of assumptions. (n.d.). https://statistics.laerd.com/stata-tutorials/one-way-manova-using-stata.php

Okada, A., Tsuchihashi-Makaya, M., Kang, J., Aoki, Y., Fukawa, M. Matsuoka, S. (2019). Symptom perception, evaluation, response to symptom, and delayed care seeking in patients with acute heart failure. *The Journal of Cardiovascular Nursing, 34*(1), 36-43. https://doi.org/10.1097/JCN.0000000000000526

Patino, C. M., Ferreira, J. C., Patino, C. M., Ferreira, J. C. (2018). Inclusion and exclusion criteria in research studies: Definitions and why they matter. *Jornal Brasileiro de Pneumologia*, *44*(2), 84–84. https://doi.org/10.1590/s1806-37562018000000088

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. https://doi.org/10.1016/j.ejcnurse.2007.01.097

Piamjariyakul, U., Smith, C. E., Werkowitch, M., Elyachar, A. (2012). Part 2: Enhancing heart failure home management: integrated evidence for a new family caregiver educational plan. *Applied Nursing Research*, *25*(4), 246–250. https://doi.org/10.1016/j.apnr.2011.07.003

Piamjariyakul, U., Smith, C. E., Werkowitch, M., Thompson, N., Fox, M., Porter Williamson, K., Olson, L. (2016). Designing and testing an end-of-life discussion intervention for African American patients with heart failure and their families. *Journal of Hospice and Palliative Care Nursing*, *18*(6), 528-535. https://doi.org/10.1097/NJH.0000000000000290

Piamjariyakul, U., Werkowitch, M., Wick, J., Russell, C., Vacek, J. L., Smith, C. E. (2015). Caregiver coaching program effect: Reducing heart failure patient rehospitalizations and improving caregiver outcomes among African Americans. *Heart & Lung*, *44*(6), 466–473. https://doi.org/10.1016/j.hrtlng.2015.07.007

Pereira Sousa, J., Neves, H., Pais-Vieira, M. (2021). Does Symptom Recognition Improve Self-Care in Patients with Heart Failure? A Pilot Study Randomised Controlled Trial. *Nursing Reports*, *11*(2), 418–429. https://doi.org/10.3390/nursrep11020040

Pharn, K., Thornton, D. J., Engelherg, R. A., Jackson, J. C., Curtis, J. R. (2008) Alterations during medical interpretation of ICU family conference that interfere with or enhance communication. *Chest*, *134*(1), 109-116. https://doi.org/10.11378/chest.07-2852

Polit, D. F., Kelvin, E. A., Beck, C. T., Plichta, S. B. (2012). Nursing Research, 9th Ed.

Statistical Methods for Health Care Research, 6th Ed.: Assessing Evidence for Nursing Practice. (n.p.): Lippincott Williams & Wilkins.

Ponikowski, P., Voors, A. A., Anker, S. D., Bueno, H., Cleland, J. G. F., Coats, A. J. S., Falk, V., González-Juanatey, J. R., Harjola, V.-P., Jankowska, E. A., Jessup, M., Linde, C., Nihoyannopoulos, P., Parissis, J. T., Pieske, B., Riley, J. P., Rosano, G. M. C., Ruilope, L. M., Ruschitzka, F., Rutten, F., H., Van Der Meer, P. (2016). 2016 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure: the task force for the diagnosis and treatment of acute and chronic heart failure of the European society of cardiology (ESC) developed with the special contribution of the heart failure association (HFA) of the ESC. *European Heart Journal*, *37*(27), 2129–2200. https://doi.org/10.1093/eurheartj/ehw128

Powe, B. D., Cooper, D. L., Kaw, C., Ross, L. (2013). Caregiver strain, quality of life, and symptom distress among dyads of African American cancer survivors and caregivers: *Journal of Hospice & Palliative Nursing*, *15*(5), 257–264. https://doi.org/10.1097/NJH.0b013e3182953eb3

Quinn, C., Dunbar, S. B., Clark, P. C., Strickland, O. L. (2010). Challenges and strategies of dyad research: Cardiovascular examples. *Applied Nursing Research*, *23*(2), e15–e20. https://doi.org/10.1016/j.apnr.2008.10.001

Ray, C. G. L., Hudson Mariouw, K., Anderson, K. M., George, E., Bisignano, N., Hernandez, S., Montgomery, V. L. (2022). Current status of inclusion of black participants in neuropsychological studies: A scoping review and call to action. *The Clinical Neuropsychologist*, *36*(2), 227–244.

https://doi.org/10.1080/13854046.2021.2019314

Reeder, K. M., Ercole, P. M., Peek, G. M., Smith, C. E. (2015). Symptom perception and self-care behaviors in patients who self-manager heart failure. *Journal of Cardiovascular Nursing, 30* (1), E1-E7. https://doi.org/10.1097/jcn.0000000000000117

Revenson, T., Griva, K., Luszczynska, A., Morrison, V., Panagopoulou, E., Vilchinsky, N., Hagedoorn, M. (2016). *Caregiving in the illness context*. Springer.

Rich, M. W. (2005). Heart failure in the oldest patients: the impact of comorbid conditions. *The American Journal of Geriatric Cardiology*, *14*(3), 134–141. https://doi.org/10.1111/j.1076-7460.2005.03890.x

Riegel, B., Barbaranelli, C., Sethares, K. A., Daus, M., Moser, D. K., Miller, J. L., Haedtke, C. A., Feinberg, J. L., Lee, S., Stromberg, A., Jaarsma, T. (2018). Development and initial testing of the self-care of chronic illness inventory. *Journal of Advanced Nursing, 74*, 2465-2476. https://doi.org/10.1111/jan13775

Riegel, B., Dickson, V. V., Lee, C. S., Daus, M., Hill, J., Irani, E., Lee, S., Wald, J. W., Moelter, S. T., Rathman, L., Streur, M., Baah, F. O., Ruppert, L., Schwartz, D. R., Bove, A. (2018). A mixed methods study of symptom perception in patients with chronic heart failure. *Heart & Lung*, *47*(2), 107–114. https://doi.org/10.1016/j.hrtlng.2017.11.002

Riegel, B., Dickson, V., Goldberg, L., Deatrick, J. (2007). Factors associated with the development of expertise in heart failure self-care. *Nursing Research*, *56*(4), 235-243. https://doi.org/10.1097/01.NNR.0000280615.75447f7

Riegel, B., Jaarsma, T., Stromberg, A. (2012). A middle-range theory of self-care of chronic illness. *Advances in Nursing Science*, *35*(3), 194-204. https://doi.org/10.1097/ANS.0b012e318261ba

Riegel, B. Dns., Lee, C. S., Dickson, V. V., Carlson, B. M. (2009). An Update on the Self-care of Heart Failure Index. *Journal of Cardiovascular Nursing*, *24*(6), 485–497. https://doi.org/10.1097/JCN.0b013e3181b4baa0

Riegel, B., Lee, C. S., Dickson, V. V. (2011). Self-care in patients with chronic heart failure. *Nature Reviews. Cardiology; London*, *8*(11), 644–654. https://doi.org/10.1038/nrcardio.2011.95

Riegel, B., Jaarsma, T., Lee, C. S., Strömberg, A. (2019). Integrating Symptoms Into the Middle-Range Theory of Self-Care of Chronic Illness: *Advances in Nursing Science*, *42*(3), 206–215. https://doi.org/10.1097/ANS.0000000000000237

Riegel, B., Westland, H., Iovino, P., Barelds, I., Bruins Slot, J., Stawnychy, M. A., Osokpo, O., Tarbi, E., Trappenburg, J. C. A., Vellone, E., Strömberg, A., Jaarsma, T. (2020). Characteristics of self-care interventions for patients with a chronic condition: A scoping review. *International Journal of Nursing Studies*, 103713. https://doi.org/10.1016/j.ijnurstu.2020.103713

Robles, T. F., Slatcher, R. B., Trombello, J. M., McGinn, M. M. (2014). Marital quality and health: A meta-analytic review. *Psychological Bulletin, 140*(1), 140-187. https://doi.org/10.1037/a0031859

Rohrbaugh, M. J., Shoham, V., Cleary, A. A., Berman, J. S., Ewy, G. A. (2009). Health consequences of partner distress in couples coping with heart failure. *Heart &*

Lung: The Journal of Acute & Critical Care, *38*(4), 298-305. https://doi.org/10.1016/j.hrtlng.2008.10.008

Rong, X., Peng, Y., Yu, H. P. (2016). Cultural factors influencing dietary and fluid restriction behavior: perceptions of older Chinese patient with heart failure. *Journal of Clinical Nursing: The International Voice of Nursing Research, Theory and Practice*, *26*(5-6), 717-726. https://doi.org/10.1111/jocn.13515

Rosland, A. M., Piette, J. D., Choi, H. J., Heisler, M. (2011). Family and friend participation in primary care visits of patients with diabetes or heart failure: patient and physician determinants and experiences. *Medical Care*, *49*(1), 37-45. https://doi.org/10.1097/MLR.0b013e3181f37d28

Rushton, C. A., Satchithananda, D. K., Kadam, U. T. (2011). Comorbidity in modern nursing: a closer look at heart failure. *British Journal of Nursing*, *20*(5), 280–285. https://doi.org/10.12968/bjon.2011.20.5.280

Salkind, N.J. (2010). *Encyclopedia of research design* (Vols. 1-0). Thousand Oaks, CA: Sage Publications, Inc. https://doi.org/10.4135/9781412961288

Sanford, J., Townsend-Rocchicciolli, J., Horigan, A., Hall, P. (2011). A Process of Decision Making by Caregivers of Family Members With Heart Failure. *Research and Theory for Nursing Practice*, *25*(1), 55–70. https://doi.org/10.1891/0889-7182.25.1.55

Santos, G. C., Lilkeroos, M., Dwyer, A. A., Jaques, C., Girard, J., Stromberg, A., Hullin, R., Schafer-Keller, P. (2019). Symptom perception in heart failure: a scoping review on definition, factors and instruments. *European Journal of*

Cardiovascular Nursing, *19*(2), 100-117. https://doi.org/10.1177/1474515119892797

Schafer, J. L. (1999). Multiple imputation: A primer. *Statistical Methods in Medical Research*, *8*(1), 3–15. https://doi.org/10.1177/096228029900800102

Schnell-Hoehn, K., Naimark, B., Tate, R. (2009). Determinates of self-care behaviors in community-dwelling patients with heart failure. *Journal of Cardiovascular Nursing*, *24*(1) 40-47. https://doi.org/10.1097/01.JCN.0000317470.58048.7b

Schulz, A. J., Mentz, G., Lachance, L., Johnson, J., Gaines, C., Israel, B. A. (2012). Associations between socioeconomic status and allostatic load: Effects of neighborhood poverty and tests of mediating pathways. *American Journal of Public Health*, *102*(9), 1706-1714. https://doi.org/10.2105/AJPH.2011.300412

Schumacher, C., Hussey, L., Hall, V. H. (2018). Heart failure self-management and normalizing symptoms: an exploration of decision making in the community. *Heart & Lung*, *47*, 297-303. https://doi.org/10.1016/j.hrtlng.2018.03.013

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. https://doi.org/10.1177/0193945911399088

Self-Care Measures. (n.d.). *Self-Care Scoring Algorithm*. https://self-care-measures.com/self-care-scoring-algorithm/

Sethares, K. A., Asselin, M. E. (2017). The effect of guided reflection on heart failure self-care maintenance and management: A mixed methods study. *Heart & Lung*, *46*(3), 192–198. https://doi.org/10.1016/j.hrtlng.2017.03.002

Sethares, K. A., Viveiros, J. D., Ayotte, B. (2021). Uncertainty levels differ by physical heart failure symptom cluster. *Applied Nursing Research*, *60*, N.PAG. https://doi.org/10.1016/j.apnr.2021.151435

Sevilla-Cazes, J., Ahmad, F. S., Bowles, K. H., Jaskowiak, A., Gallagher, T., Goldberg, L. R., Kangovi, S., Alexander, M., Riegel, B., Barg, F. K., Kimmel, S. E. (2018). Heart failure home management challenges and reasons for readmission: a qualitative study to understand the patient's perspective. *Journal of General Internal Medicine*, *33*(10), 1700-1707. https://doi.org/10.1007/s11606-018-4542-3

Sharma, A., Colvin-Adams, M., Yancy, C. W. (2014). Heart failure in African Americans: Disparities can be overcome. *Cleveland Clinic Journal of Medicine*, *81*(5), 301–311. https://doi.org/10.3949/ccjm.81a.13045

Shao, J. H., Chen, S. H. (2019). Randomized control trial of a self-management intervention for heart failure older adults in Norther Taiwan. *Collegian*, *26*(2), 288-294. https://doi.org/10.1016/j.colegn.2018.08.006

Siedlecki, S. (2020). Understanding descriptive research designs and methods. *Clinical Nurse Specialist*, *34*(1), 8-12. https://doi.org/10.1097/NUR.0000000000000493

Simon, M.K., Goes, J. (2013) Dissertation and Scholarly Research: Recipes for Success. Dissertation Success, LLC, Seattle, WA.

Simons, R. L., Lei, M.-K., Klopack, E., Beach, S. R. H., Gibbons, F. X., Philibert, R. A. (2021). The effects of social adversity, discrimination, and health risk behaviors on the accelerated aging of African Americans: Further support for the weathering hypothesis. *Social Science & Medicine*, *282*, 113169. https://doi.org/10.1016/j.socscimed.2020.113169

Socioeconomic Status Office: Publications. (n.d.). Https://Www.Apa.Org. Retrieved October 20, 2020, from https://www.apa.org/pi/ses/resources/publications

Song, M., Bonds, K. (2020). Challenges and Strategies for Conducting Research With Grandparent–Grandchild Dyads. *Nursing Research*, *69*(1), E1–E8. https://doi.org/10.1097/NNR.0000000000000386

Sousa, J. P., Santos, M. (2019). Symptom management and hospital readmission in heart failure patients: A qualitative study from Portugal. *Critical Care Nursing Quarterly*, *42*(1), 81–88. https://doi.org/10.1097/CNQ.0000000000000241

Spencer, K. L., Grace, M. (2018). Social foundations of health care inequality and treatment bias. *Annual Review of Sociology,42*, 101-120. https://doi.org/10.1146/annurev-soc-081715-074226

Srisuk, N., Cameron, J., Ski, C. F., Thompson, D. R. (2017). Randomized controlled trial of family-based education for patients with heart failure and their carers. *Journal of Advanced Nursing*, *73*(4), 857–870. https://doi.org/10.1111/jan.13192

Stephens, T. M., Gunther, M. E. (2016). Twitter, Millennials, and Nursing Education Research. *Nursing Education Perspectives (National League for Nursing)*, *37*(1), 23–27. https://doi.org/10.5480/14-1462

Stewart, E. C., Bennett, M. J (2011). *American cultural patterns: A cross-cultural perspective*. Hachette UK.

Summary: The handbook of multidisciplinary and integrated heart failure care. (n.d.).

Sullivan, L. T., Randolph, T., Merrill, P., Jackson, L. R., Egwim, C., Starks, M. A., Thomas, K. L. (2018). Representation of black patients in randomized clinical trials of heart failure with reduced ejection fraction. *American Heart Journal*, *197*, 43–52. https://doi.org/10.1016/j.ahj.2017.10.025

Surikova, J., Payne, A., Miller, K.-L., Ravaei, A., Nolan, R. P. (2020). A cultural and gender-based approach to understanding patient adjustment to chronic heart failure. *Health & Quality of Life Outcomes*, *18*(1), 1–8. https://doi.org/10.1186/s12955-020-01482-1

Statler, M. C., Wall, B. M., Richardson, J. W., Jones, R. A., Kools, S. (2023). African American Perceptions of Participating in Health Research Despite Historical Mistrust. *Advances in Nursing Science*, *46*(1), 41–58. https://doi.org/10.1097/ANS.0000000000000435

Thida, M., Asdornwised, U., Thosingha, O., Dumavibhat, C., Chansatitporn, N. (2021). Symptom Experience, Symptom Management Strategies, and Health Related Quality of Life among People with Heart Failure. *Pacific Rim International Journal of Nursing Research*, *25*(3), 359-374. https://he02.tci-thaijo.org/index.php/PRIJNR/article/view/243557

Thompson, T., Seo, J., Griffith, J., Baxter, M., James, A., Kaphingst, K. A. (2015). The context of collecting family health history: examining definitions of family and family communication about health among African American women. *Journal of Health Communication*, *20*(4), 416–423. https://doi.org/10.1080/10810730.2014.977466

Thurman, W. A., Johnson, K. E. Sumpter, D. F. (2019). Words Matter. Advances in Nursing Science, *42*(2), 89–108. https://doi.org/10.1097/ANS.0000000000000265

Uchmanowicz, I., Faulkner, K.. M., Vellone, E., Siennicka, A., Szczepanowski, R., Olchowska-Kotala, A. (2022). Heart failure care: testing dyadic dynamics using the actor-partner interdependence model (APIM) – a scoping review. *International Journal of Environmental Research and Public Health*, *19*(4), 1919. https://doi.org/10.3390/ijerph19041919

Umberson, D., Williams, K., Thomas, P. A., Liu, H., Thomeer, M. K. (2014). Race, gender, and chains of disadvantage. *Journal of Health and Social Behavior*, *55*(1), 20-38. https://doi.org/10.1177/0022146514521426

Unson, C., Flynn, D., Chukwurah, Q., Glendon, M. A., Testut, T. (2020). Uncertainty in Transition of African American Caregivers. *Issues in Mental Health Nursing*, *41*(5), 445–454. https://doi.org/10.1080/01612840.2019.1678080

Vellone, E., Barbaranelli, C., Pucciarelli, G., Zeffiro, V., Alvaro, R., Riegel, B. (2020). Validity and Reliability of the Caregiver Contribution to Self-Care of Heart Failure Index Version 2. *The Journal of Cardiovascular Nursing*, *35*(3), 280–290. https://doi.org/10.1097/JCN.0000000000000655

Vellone, E., Biagioli, V., Durante, A., Buck, H. G., Iovino, P., Tomietto, M., Colaceci, S., Alvaro, R., Petruzzo, A. (2020). The Influence of Caregiver Preparedness on Caregiver Contributions to Self-care in Heart Failure and the Mediating Role of Caregiver Confidence: *The Journal of Cardiovascular Nursing*, *35*(3), 243–252. https://doi.org/10.1097/JCN.0000000000000632

Vellone, E., Chung, M. L., Cocchieri, A., Rocco, G., Alvaro, R., Riegel, B. (2014). Effects of Self-Care on Quality of Life in Adults With Heart Failure and Their Spousal Caregivers: Testing Dyadic Dynamics Using the Actor–Partner Interdependence Model. *Journal of Family Nursing*, *20*(1), 120–141. https://doi.org/10.1177/1074840713510205

Vellone, E., De Maria, M., Iovino, P., Barbaranelli, C., Zeffiro, V., Pucciarelli, G., Durante, A., Alvaro, R., Riegel, B. (2020). The Self-Care of Heart Failure Index version 7.2: Further psychometric testing. *Research in Nursing & Health*, *43*(6), 640–650. https://doi.org/10.1002/nur.22083

Vellone, E., Pancani, L., Greco, A., Steca, P., Riegel, B. (2016). Self-care confidence may be more important than cognition to influence self-care behaviors in adults with heart failure: Testing a mediation model. *International Journal of Nursing Studies*, *60*, 191-199. https://doi.org/10.1016/j.ijnurstu.2016.04.016

Vellone, E., Rebora, P., Ausili, D., Zeffiro, V., Pucciarelli, G., Caggianelli, G., Masci, S., Alvaro, R., Riegel, B. (2020). Motivational interviewing to improve self-care in heart failure patients (MOTIVATE-HF): A randomized controlled trial. *ESC Heart Failure*, *7*(3), 1309–1318. https://doi.org/10.1002/ehf2.12733

Vellone, E., Riegel, B., Alvaro, R. (2019). A Situation-Specific Theory of Caregiver Contributions to Heart Failure Self-care. *Journal of Cardiovascular Nursing*, *34*(2), 166–173. https://doi.org/10.1097/JCN.0000000000000549

Vellone, E., Riegel, B., Cocchieri, A., Barbaranelli, C., D'Agostino, F., Antonetti, G., Glaser, D., Alvaro, R. (2013). Psychometric Testing of the Self-Care of Heart

Failure Index Version 6.2. *Research in Nursing & Health*, *36*(5), 500–511. https://doi.org/10.1002/nur.21554

Venetis, M. K., Magsamen-Conrad, K., Checton, M. G., Greene, K. (2014). Cancer communication and partner burden: An exploratory study. *Journal of Communication*, *64*(1), 82-102. https://doi.org/10.111/jcom.12069

von Haehling, S. (2017). Co-morbidities in heart failure beginning to sprout—and no end in sight? *European Journal of Heart Failure. Supplements*, *19*(12), 1566–1568. https://doi.org/10.1002/ejhf.1098

Von Haehling, S., Hasenfub, G., Anker, S. D. (2016). Diabetes and heart failure: Sugared words prove bitter. *Journal of the American College of Cardiology*, *68*(13), 1417-1419. https://doi.org/10.1016/j.jacc.2016.07.728

Vuckovic, K. M., Bierle, R. (Schuetz), Ryan, C. J. (2020). Navigating Symptom Management in Heart Failure: The Crucial Role of the Critical Care Nurse. *Critical Care Nurse*, *40*(2), 55–63. https://doi.org/10.4037/ccn2020685

Wali, S., Keshavjee, K., Nguyen, L., Mbuagbaw, L., Demers, C. (2020). Using an electronic app to promote home-based self-care in older patients with heart failure.: Qualitative study on patient and informal caregiver challenges. *JMIR Cardio, 4* (1). https://doi.org/10.2196/25624

Wendling, S., & Beadle, V. (2015). The relationship between self-efficacy and diabetic foot self-care. *Journal of Clinical & Translational Endocrinology*, *2*(1), 37–41. https://doi.org/10.1016/j.jcte.2015.01.001

White, M. L. (2013). Spirituality Self-care Effects on Quality of Life for Patients

Diagnosed with Chronic Illness. *Self-Care, Dependent-Care & Nursing*, *20*(1), 23–32.

Whitlatch, C. J., Orsulic-Jeras, S., Johnson, J. (2021). Challenges to and strategies for recruiting chronic care dyads into intervention research. *Chronic Illness*, *17*(3), 232–241. https://doi.org/10.1177/1742395319869434

Williams, R. L., Romney, C., Kano, M., Wright, R., Skiper, B., Getrich, C. M., Sussman, A. L., Zyzanski, S. J. (2015). Racial, gender, and socioeconomic status bias in senior medical student clinical decision-making: A national survey. *Journal of Internal Medicine*, *30*(6), 758-767. https://doi.org/10.1007/s11606-014-3168-3

Wilson, A. M. M. M., Almeida, G. S. M. de, Santos, B. de C. F. dos, Nakahara-Melo, M., Conceição, A. P. da, Cruz, D. de A. L. M. da. (2022). Factors associated with caregivers' contribution to self-care in heart failure. *Revista Latino-Americana de Enfermagem*, *30*. https://doi.org/10.1590/1518-8345.5838.3633

Wingham, J., Frost, J., Britten, N., Greaves, C., Abraham, C., Warren, F. C., Jolly, K., Miles, J., Paul, K., Doherty, P. J., Singh, S., Davies, R., Noonan, M., Dalal, H., Taylor, R. S. (2019). Caregiver outcomes of the REACH-HF multicentre randomized controlled trial of home-based rehabilitation for heart failure with reduced ejection fraction. *European Journal of Cardiovascular Nursing*, *18*(7), 611–620. https://doi.org/10.1177/1474515119850011

Wittenberg, E., Goldsmith, J Ferrell, B., Ragan, S. L. (2017) Promoting improved family caregiver health literacy: evaluation of caregiver communication resources, *26*, 935-942. https://doi.org/10.1002/pon417

Woda, A., Belknap, R. A., Haglund, K., Sebern, M., Lawrence, A. (2015). Factors influencing self-care behaviors of African Americans with heart failure: A photovoice project. *Heart & Lung*, *44*(1), 33–38. https://doi.org/10.1016/j.hrtlng.2014.09.001

Woda, A., Haglund, K., Belknap, R., Cleek, E. (2018). Photovoice: A research method and intervention to engage older adults. *Journal of Gerontological Nursing, 44*(7), 43-49. https://doi.org/10.3928/00989134-20180614-07

Wu, J.-R., Lin, C. -Y., Hammash, M, et al. (2023). Heart failure knowledge, symptom perception, and symptom management in patients with heart failure. *Journal of Cardivascular Nursing*, *38*, 312-318. https://doi.org/10.1097/JCN.0000000000000961

Wu, J.-R., Lennie, T. A., Moser, D. K. (2017). A prospective, observational study to explore health disparities in patients with heart failure—Ethnicity and financial status. *European Journal of Cardiovascular Nursing*, *16*(1), 70–78. https://doi.org/10.1177/1474515116641296

Xu, J., Arruda, S., Gallo, J. J., Wenzel, J., Nolan, M. T., Flowers, D., Szanton, S. L., Himmelfarb, C. D., Han, H.-R. (2018). Using vignettes to understand heart failure self-care. *Journal of Clinical Nursing*, *27*(19–20), 3554–3560. https://doi.org/10.1111/jocn.14581

Yeh, H.-F., Shao, J.-H. (2018). Depression in community-dwelling elderly patients with heart failure. *Archives of Psychiatric Nursing*, *32*(2), 248–255. https://doi.org/10.1016/j.apnu.2017.11.010

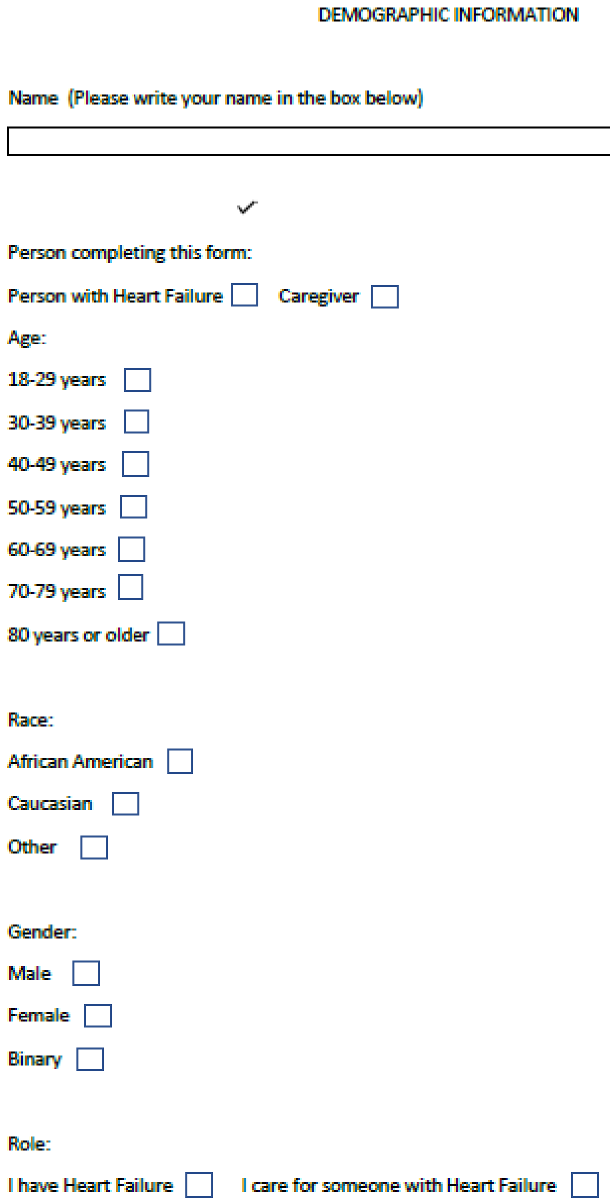
Young, A. J., Stephens, E., Goldsmith, J. V. (2016). Family caregiver communication in the ICU: Toward a relational view of health literacy. *Journal of Family Communication*, *17*(2), 137-152. https://doi.org/10.1080/15267431.2016.1247845

Yuen, E. Y. A., Knight, T., Ricciardelli, L. A., Burney, S. (2018). Health literacy of caregivers of adult care recipients: A systematic scoping review. *Health and Social Care in the Community*, *26*(92), e191-e206. https://doi.org/10.1111hsc.12368

Zhang, X.-E., Cheng, B., Wang, Q. (2016). Relationship between high blood pressure and cardiovascular outcomes in elderly frail patients: A systematic review and meta-analysis. *Geriatric Nursing*, *37*(5), 385–392. https://doi.org/10.1016/j.gerinurse.2016.05.006

Ziaeian Boback, Kominski Gerald F., Ong Michael K., Mays Vickie M., Brook Robert H., Fonarow Gregg C. (2017). National Differences in Trends for Heart Failure Hospitalizations by Sex and Race/Ethnicity. *Circulation: Cardiovascular Quality and Outcomes*, *10*(7), e003552. https://doi.org/10.1161/CIRCOUTCOMES.116.003552

Appendix A: Demographic Information



DEMOGRAPHIC INFORMATION

Name (Please write your name in the box below)

☐

✓

Person completing this form:

Person with Heart Failure ☐ Caregiver ☐

Age:

18-29 years ☐

30-39 years ☐

40-49 years ☐

50-59 years ☐

60-69 years ☐

70-79 years ☐

80 years or older ☐

Race:

African American ☐

Caucasian ☐

Other ☐

Gender:

Male ☐

Female ☐

Binary ☐

Role:

I have Heart Failure ☐ I care for someone with Heart Failure ☐

Marital Status:

Single ☐ Married ☐ Divorced ☐ Widowed ☐

Health Insurance Status:

Yes I have health insurance ☐ No, I do not have health insurance ☐

How many years have you had heart failure or caring for someone with heart failure:

Less than 1 year ☐ 1-3 years ☐ 4-7 years ☐ 8 or more years ☐

New York Heart Association Class Scale – What is your current stage of heart failure:

NYHA Class I ☐ NYHA Class II ☐ NYHA Class III ☐ NYHA Class IV ☐

I do not know my NYHA Class ☐

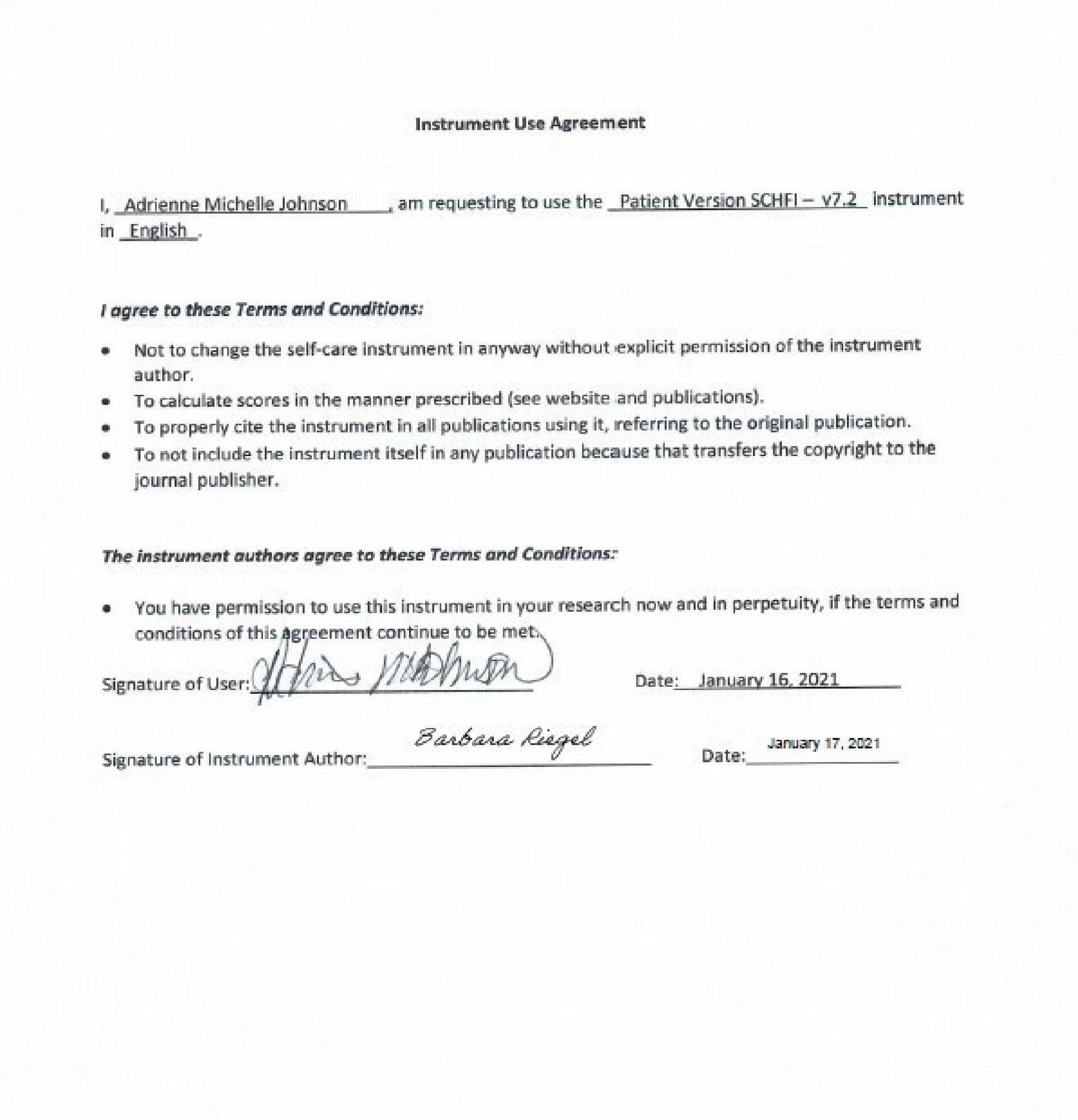
Income Status:

$0 - $30,999 / year ☐ $31 – $55,999 ☐

$56 – 75,999 / year ☐ $76 – $99,999 ☐

$100,000 or more / year ☐

Appendix B: Instrument Permission Forms



Instrument Use Agreement

I, Adrienne Michelle Johnson, am requesting to use the Patient Version SCHFI – v7.2 instrument in English.

I agree to these Terms and Conditions:

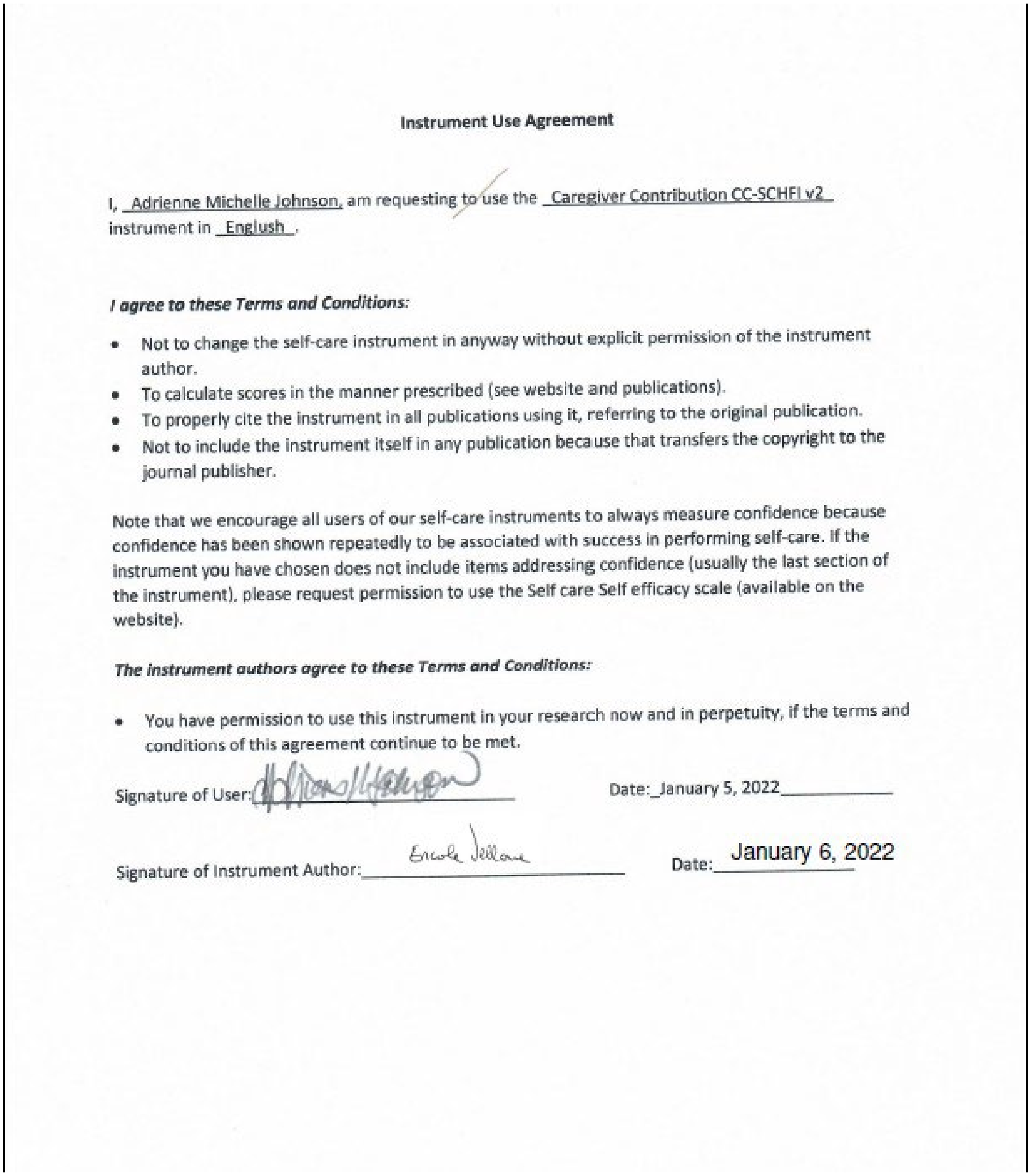
- Not to change the self-care instrument in anyway without explicit permission of the instrument author.
- To calculate scores in the manner prescribed (see website and publications).
- To properly cite the instrument in all publications using it, referring to the original publication.
- To not include the instrument itself in any publication because that transfers the copyright to the journal publisher.

The instrument authors agree to these Terms and Conditions:

- You have permission to use this instrument in your research now and in perpetuity, if the terms and conditions of this agreement continue to be met.

Signature of User: Date: January 16, 2021

Signature of Instrument Author: Barbara Riegel Date: January 17, 2021



Instrument Use Agreement

I, _Adrienne Michelle Johnson,_ am requesting to use the _Caregiver Contribution CC-SCHFI v2_ instrument in _Englush_.

I agree to these Terms and Conditions:

- Not to change the self-care instrument in anyway without explicit permission of the instrument author.
- To calculate scores in the manner prescribed (see website and publications).
- To properly cite the instrument in all publications using it, referring to the original publication.
- Not to include the instrument itself in any publication because that transfers the copyright to the journal publisher.

Note that we encourage all users of our self-care instruments to always measure confidence because confidence has been shown repeatedly to be associated with success in performing self-care. If the instrument you have chosen does not include items addressing confidence (usually the last section of the instrument), please request permission to use the Self care Self efficacy scale (available on the website).

The instrument authors agree to these Terms and Conditions:

- You have permission to use this instrument in your research now and in perpetuity, if the terms and conditions of this agreement continue to be met.

Signature of User:______________ Date:_January 5, 2022___________

Signature of Instrument Author: Ercole Vellone Date: January 6, 2022