EXAMINING HEALTH-RELATED DECISION MAKING PATTERNS OF AFRICAN AMERICANS WITH CORONARY HEART DISEASE: A HERMENEUTIC PHENOMENOLOGICAL STUDY

by

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“After 348 years racial injustice is still the Negro’s burden and America’s shame. Yet for his own inner health and outer functioning, the Negro is called upon to be as resourceful, as productive and as responsible as those who have not known such oppression and exploitation. This is the Negro’s dilemma. He who starts behind in a race must forever remain behind or run faster than the man in front. What a dilemma! It is a call to do the impossible. It is enough to cause the Negro to give up in despair.”

-Martin Luther King, Jr. “Where Do We Go From Here: Chaos or Community?” (Beacon Press, 1968, p. 127).

I would like to dedicate this book to my family. I began this journey because I wanted to accomplish something that would make a difference in their lives. I completed this journey because they gave me the strength and courage to see it through. Thank you.
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Examining Health-related Decision Making Patterns of African Americans with Coronary Heart Disease: A Hermeneutic Phenomenological Study

Abstract

by

TIFFANY ANN LOVE

The purpose of this study was to explore the themes that affected the day-to-day health-related decision making of African Americans managing coronary heart disease (CHD). Understanding the lived experience of African Americans with CHD can offer health care providers additional strategies to improve disease management. A hermeneutic phenomenological approach was utilized to explore: 1) what is the lived experience of managing CHD among older African Americans? 2) What is the essence of health-related decision making among older African Americans living with CHD? Two audio taped 30 to 60 minute open ended in-depth interviews per participant. Purposive sampling resulted in eight African Americans male = 4; female = 4 over age 45 admitted with acute coronary syndrome (ACS) to a large metropolitan hospital. Bracketing and phenomenological reduction elicited units of general meaning and allowed openness of the themes that emerged. The results of this study indicate that the lived experience of African Americans with newly diagnosed CHD respond similar to other racial/ethnic groups. In this study a new functional limitation was almost certain for older African Americans recovering from an ACS. Physical limitations led to feelings of loss of freedom, loss of control, and symptoms of depression. African Americans seem to have a different manifestation of depressive symptoms. Females were more likely to lack sources of support. Although the practice environment was not the focus of this study, it
is important to note that national guidelines for reducing health disparities related to CHD had been implemented in the clinical setting. The data support the idea that culture is influential in health-related decision making. More importantly, the African Americans in this small sample demonstrated self-management skills and viewed their provider as partners in disease management. The majority of participants had established primary care providers whom they visited regularly. Participants verbalized medical trust.
Purpose

The purpose of this study was to explore the themes that affected the day-to-day health-related decision making patterns of African Americans managing newly diagnosed coronary heart disease (CHD). There has been a dramatic increase in the number of African Americans living with CHD. With advancement in technology mortality rates of CHD have decreased but the likelihood of African Americans living with CHD and disability has increased (Office of Minority Health and Health Disparities [OMHHD], 2007). African Americans have been disproportionately affected by CHD when compared to their White counterparts (Healthy People, 2007). Understanding the lived experience of African Americans living with CHD is important for cardiovascular disease (CVD) prevention, education, and treatment. The hermeneutic phenomenological approach was used to explore the participant’s perceptions and experiences of managing CHD after an acute coronary syndrome (ACS) and its effect on their day-to-day health-related decision making patterns.

Cardiovascular disease is the number one cause of death in the United States and throughout the western world (World Health Organization [WHO], 2009). It is estimated that 17 million people die from CVD throughout the world every year (WHO, 2009). While CVD includes CHD, hypertension, heart failure, congenital CVD, and stroke, this study focused on the effects of CHD. The American Heart Association (AHA) has reported that CHD accounts for the majority of morbidity and mortality of CVD (AHA, 2009). Approximately 16 million Americans have had a heart attack, angina pectoris, or
both annually (Healthy People, 2007). In 2010 approximately 785,000 had their first heart attack and 470,000 Americans had a recurrent heart attack (CDC, 2011).

In 2007, the death rate from CVD for Black, non-Hispanic Americans was 251.9 per 1000, compared to that of 191.4 per 1000 for White, non-Hispanic Americans (United States department of Health and Human Services [USDHHS], 2010). The USDHHS (2010) reported African Americans are more likely to be diagnosed with CHD and subsequently die from CHD. African American men were 30% more likely to die from CHD than their White non-Hispanic counterparts (USDHHS, 2010). The Institute of Medicine (IOM) provided evidence that racial/ethnic minorities receive a lower quality and inequity (also known as disparity) of healthcare than their White counterparts (IOM, 2002, p. 39). In the treatment of CVD, this racial/ethnic disparity was the strongest and most consistent (IOM, 2002, p. 39). Notwithstanding the IOM report, racial/ethnic minorities continue to suffer the consequences of this inequity in poor health profiles, multiple comorbid conditions, disability, and mortality (CDC, 2007; IOM, 2002, p.5).

Considerable research has been conducted on specific aspects of living with CHD. Researchers have examined the race of the physician, patient’s decision to not receive recommended lifesaving therapy and the clinician’s awareness of disparity in treatment (Chen, Rathore, Radford, Wang, & Krumholz, 2001; Allen, Scott, Stewart, & Young, 2004; Lurie, Fremont, Jain, Taylor, McLaughlin, et al., 2005). Inductive research methods are better suited to elicit the patients’ understandings and perceptions of illness that affect health-related decision making patterns. This chapter will address the importance of focusing on the day-to-day health-related decision making patterns of
African Americans when developing an intervention to eliminate disparity in the management of CHD.

Descriptive decision making theories have identified the gap between what people should do and what they are observed doing (Lipschitz & Cohen, 2005). The patient’s decision to adhere to the recommended plan of care is paramount in the management of CHD. Consequently, the day-to-day health-related decision making patterns of African Americans with CHD required further exploration. Therefore, this study utilized a hermeneutic phenomenological approach with a series of in-depth interviews to explore the participant’s perceptions and experiences of having an ACS and managing CHD and its effect on their day-to-day health-related decision making patterns.

Background

There is racial/ethnic disparity in the long-term mortality of cardiac arrest survivors (Groeneveld, Heidenreich & Garber, 2003). Studies that report the patient’s decision as the reason for not receiving the recommended life-saving therapies do not provide a detailed account of the themes influencing the patient’s decision (Allen et al., 2004; Groeneveld, Heidenreich & Garber, 2003; Russo, Hafley, Lee, Stamato, Lehmann, et al., 2003; IOM, 2002, p.50). Mistrust of healthcare providers (medical mistrust) has been cited as a reason for racial/ethnic minority patients not receiving life-saving medical therapies (Keating, Gandhi, Orav, Bates, Ayanian, 2004; LaVeist, Nickerson, and Bowie, 2000; Lillie Blanton et al., 2000; Thom et al, 2002). It has been concluded that the mistrust could have been a result of the limited interaction that a patient has with the specialist performing the procedure (Keating et al., 2004). Nonetheless, the evidence is sparse.
Additional studies demonstrated that African Americans and other minorities reported a greater degree of participation in their care and health-related decision making when they received care from a doctor of their own race (LaVeist et al., 2000). Research has assessed the provision of culturally sensitive healthcare services (Anderson et al., 2003). The results suggested the potential to reduce racial/ethnic disparities in the treatment heart disease, but the evidence was insufficient (Anderson). The decision making process is complex and each phase of selecting the most appropriate course of action is itself a complex process (Lipschitz & Cohen, 2005). Therefore, the focus of any intervention to eliminate the disparity in the treatment of CHD should focus on empowering the patient to make the most appropriate decision to manage their disease.

Despite advances in treatment, CHD remains the leading cause of death and disability for Americans (CDC, 2011). As with many chronic conditions, the morbidity and mortality of CHD disproportionately affects African Americans (IOM, 2002, p.5). Previous research describing the observed interracial treatment differences in CHD has focused on the decision making patterns of clinicians (Barnhart, Fang, & Alderman, 2003). Research has found the clinician’s decision to order noninvasive or invasive cardiac testing was the most influential factor leading to racial/ethnic disparity in the evaluation and treatment of CHD (Bashore et al., 2001). Yet, there is limited research exploring the patient’s decision to accept the recommendation to undergo a revascularization procedure.

Coronary heart disease is a chronic disease that causes pain, loss of functional health, loss of physical independence, and disability (CDC, 2011; Boult et al., 2001). Coronary heart disease can lead to multiple encounters with the health care system,
avoidable health care expenditures and ultimately result in death (CDC, 2011; Boult et al., 2001). Racial/ethnic minorities and low-income individuals have a disproportionate burden of death and disability from CHD (OMHHD, 2007). The goal of this study was to explore the subjective meaning of managing CHD as an older African American. The goal of this study was to explore the beliefs and actions that may have led to increased rates of death and disability among older African Americans with CHD.

The estimated total cost of CVD was 448.5 billion dollars in 2008 (CDC, 2008). This total cost was the estimated direct and indirect cost of healthcare, lost productivity, disability and death due to CVD (CDC, 2008). Nearly ten billion dollars greater than its estimated cost in the past five years, the total cost of CVD continues to rise (CDC, 2008). The increased financial burden of CVD is directly related to its declining mortality and increased morbidity (CDC, 2008). This study helped the researcher gain insight into the social actions, situations, and worldview that impacted the day-to-day health-related decision making of older African Americans who experienced an acute coronary syndrome and were managing CHD. The insight gained from this study could translate into an approach to support health-related decision making among African Americans who have suffered an acute coronary syndrome and are managing newly diagnosed CHD.

Disparities are associated with age, gender, education, healthcare access, difference in socioeconomic status and treatment regimen. Studies have shown that lower level income and education contribute to the higher rate of CHD in racial/ethnic minority populations (National Heart, Lung and Blood Institute, 1995). A substantial number of deaths from CHD are attributed to preventable risk factors (WHO, 2009). For individuals throughout the world, primary and secondary prevention strategies rely on the patient’s
personal decision to modify behavior (WHO, 2009). While the sources of racial/ethnic disparity are multifactorial, this further emphasizes the importance of focusing on the patient’s role in the day-to-day decision making process when designing interventions to eliminate racial/ethnic disparity in the treatment and management of CHD.

Significance

Disparity in the treatment of CHD is a global problem that has important ramifications for multiple disciplines. Disparity is a priority for nursing research because better management of CHD is possible and necessary. Many of the risk factors for CHD are modifiable and nurses can educate, motivate, and support patients through nursing interventions. Nurses have the opportunity to work with patients, families, medical and ancillary professionals to improve the environment and health status of all persons with CHD. Nurses work within agencies and institutions within diverse community health programs and are the best candidates to investigate the multi-factorial causes of disparity in the treatment and management of ACS and CHD.

The information gained from this study will inform nursing practice. Knowing more about the experience of African Americans experiencing ACS and managing CHD as it is lived can help improve disease management strategies of nurses, patient educators, and physicians. Hence, the solution to the problem will require interdisciplinary dissemination of knowledge. This study provides insight into what older African Americans with ACS and CHD are advised to do, choose to do, choose not to do, and why.

Managing CHD and its effect on a day-to-day basis requires self-management skills. Self-management is a concept that was introduced to the chronic disease literature
in the 1960’s by Thomas Creer and others (Lorig, & Holman, 2009). Self-management requires that an individual be an active participant and responsible for the day-to-day management of their disease (Lorig, & Holman, 2009). The individual’s perceived problem is the basis of the self-management interventions. These interventions are aimed at activation of the patient and improving self-efficacy with regard to managing symptoms, medical treatments, physical and psychological consequences, and lifestyle modification (Lorig, & Holman, 2009; Powell, Calvin, Mendes de Leon, Richardson, Grady, Flynn et al., 2008). Self-efficacy theory posits that the strength of belief in one’s capability is a good predictor of future motivation and health behaviors (Lorig, & Holman, 2009). Additionally, it is enhanced through improved performance and modeling of desired behavior (Lorig, & Holman, 2009). Reinterpretation of physiological symptoms and social persuasion leads to further improvement in behavior, motivation, cognitive appraisal, and emotional wellbeing (Lorig, & Holman, 2009). Powell et al. (2008) focused on enhancing the five self-management skills of: environmental restructuring, self-monitoring, cognitive restructuring, relaxation, and problem solving.

Education in self-management focuses on the concerns and problems identified in a detailed needs assessment (Lorig, & Holman, 2009). A key message is constructed by the healthcare professional to convey an educational message in a simple and concise format (Lorig, & Holman, 2009). The key message is combined with the five core self-management skills: problem solving, decision making, resource utilization, forming a patient/health care provider partnership, and taking action (Lorig, & Holman, 2009). Basic problem solving skills include problem definition, generation of possible solutions,
including the solicitation of suggestions from peers and providers, solution
implementation and evaluation (Lorig, & Holman, 2009).

This study focused on the second self-management skill of decision making.
Health-related decision making must be made on a day-to-day basis (Lorig, & Holman, 2009). Day-to-day health-related decision making is made regarding physical activity, symptom management, medication regimens, dietary intake, and information seeking behavior (Lorig, & Holman, 2009; Torke, Giselle, Corbie-Smith, & Branch, 2004; Woodard, Hernandez, Lees, & Peterson, 2005).


Day-to-day decision making constitutes reality that persons categorize according to types of thought (Omery, & Mack, 1995, p.139). Therefore, the thoughts regarding day-to-day health-related decision making of older African Americans experiencing an ACS and managing CHD constitute their reality. These thoughts can be viewed as opinions, beliefs and knowledge (Omery et al., 1995, p.139). Hence, past experiences,
health beliefs, and educational level will impact a person’s day-to-day health-related decision making patterns.

Examining the nature and structure of the lived experience is important because an individual’s knowledge is grounded in their lived experience (Omery et al., 1995, p.140). Thoughts constitute realities that correspond to a phenomenon (Omery et al., 1995, p.139). The phenomenon of interest in this study is the experience of ACS and management of CHD. Hence, a key characteristic of knowledge is the mutual agreement of a specific reality among a group of individuals (Omery et al., 1995, p.140). The reality has greater acceptance as knowledge when the group is large (Omery et al., 1995, p.140). This study proposed finding the mutually accepted reality of the lived experience of ACS and managing CHD among eight older African Americans.

Understanding the thoughts and feelings of African Americans experiencing ACS and managing CHD and the impact it has on their day-to-day health-related decision making allows healthcare providers to implement appropriate evidence-based interventions. This study used a research method that focused on the participant’s subjective interpretation of their environment and how it affected their ability to maintain and promote health in congruence with the nursing metaparadigm. The nursing metaparadigm supports the nurse’s ability and societal mandate to diagnose and treat the human response to actual or potential health problems (Donaldson & Crowley, 1978; Hardy, 1978). The nursing profession promotes the health of the public through scientific investigations and interventions that promote health, prevent disease and disability at all levels of care (American Nurses Association, 2009).
The conceptual framework in this study viewed the participant holistically. The phenomena of African Americans experiencing ACS and managing CHD can only be understood when the individual is observed in their environment, utilizing their resources to maintain and promote their health. This research sought to offer scientific data that would contribute to the elimination of preventable loss of life and disability in accordance with societal expectations and needs. Obtaining knowledge regarding the patient’s lived experience of ACS and managing CHD is important because it will help the advanced practice nurse plan patient focused strategies to modify risk factors. Modification of risk factors reduces mortality and morbidity in all persons at risk for ACS and CHD (WHO, 2009).

There is evidence and guidelines to support the benefit of lifestyle modification and prophylactic drug therapy in individuals with diagnosed and undiagnosed CHD (WHO, 2009). Yet, individuals with recent cardiac events continue to have difficulty maintaining necessary behavior modifications (Moore et al., 2006). Persons with CHD can be educated on the benefit of lifestyle modification and continue to forgo the opportunity to select the most desirable course of action (Moore). Hence, patient education and counseling on the best course of action to prevent a reoccurrence of a cardiac event is successful (Moore). Unfortunately, there are large numbers of informed individuals who do not commit to long-term lifestyle modification (Moore). Knowing an individual’s knowledge is grounded in lived experience, this study sought to expand on the opportunities to improve the day-to-day health-related decision making of African Americans who have experienced ACS and are managing CHD.
There is research that focuses on patient decision making. Little has been reported in the nursing literature focusing on the day-to-day health-related decision making patterns of older African Americans who have had an ACS and are managing CHD. Amplifying the themes that affect the day-to-day health-related decision making patterns of older African Americans managing CHD supports the holistic approach to patient care in accordance with the philosophical foundation of the nursing profession. Advanced Practice Nurses are trained to consider every interaction with the patient as an opportunity to gain rapport and have a critical impact on the patient’s understanding of their diagnosis and treatment. It is imperative that nurses understand the subjective experience of older African Americans experiencing ACS and managing CHD and the potential to facilitate better disease management and patient outcomes. The descriptive data obtained in this study has helped identify targets for prescriptive intervention.

*Conceptual Framework*

There were several theoretical frameworks that were considered for this study. The first was the Lipschitz *decision making in three modes*, which proposes the human decision process, is comprised of at least three modes (Lipschitz, 1994). Lipschitz’s *decision making in three modes* is a naturalistic decision making theory (Lipschitz, 1994). These three modes are mutually exclusive (Lipschitz, 2007). The three fundamental modes of Lipschitz’s decision making theory are: *consequential choice, matching and reassessment* (Lipschitz, 1994). This conceptual framework has been primarily utilized in organizational learning (Lipschitz, Popper, & Friedman, 2002). Naturalistic decision making has the five essential characteristics of: recognition-primed decisions, coping with uncertainty, team decision making, decision errors, and methodology (Lipschitz,
Klein, Orasanu, & Salas, 2001). Lipschitz also defines ten basic attributes of the decision making process: action argument, decision framing, decision strategy, deliberateness, commitment, uncertainty, temporal orientation, logic, handicaps, and therapies.

*Consequential choice* is a term that refers to comparing alternatives in terms of expected consequences (Lipschitz, 1994). Consequential choice allows the decision maker to commit to an alternative because it is superior to the others (Lipschitz, 2007). The consequential choice decision framing leads the individual to compare choice alternatives based on the risk and uncertainty of potential outcomes (Lipschitz, 2007). Consequential choice decision strategies prescribe how the choice will be made (Lipschitz, 2007). The handicaps of consequential choice are the result of bias constructed by the evaluation of risk in trial and error (Lipschitz, 2007). Temporal orientation of consequential choice is future oriented (Lipschitz, 2007). Utilitarian logic predicts consequential choice (Lipschitz, 2007).

*Matching* is evaluating single options in terms of a certain criterion (Lipschitz, 1994). Matching guides the decision maker to make a choice because it is the best choice in the context of the situation (Lipschitz, 2007). The matching decision framework would lead the individual to match potential actions based on their past experiences (Lipschitz, 2007). The matching decision framework involves the individual using their intuition, habits and personal values to commit to a choice (Lipschitz, 2007).

Matching decision strategies involves assessing how the current strategy compares to previous strategies (Lipschitz, 2007). Temporal orientation matching connects the current situation with the appropriate actions (Lipschitz, 2007). Matching preschools a deontological logic (Lipschitz, 2007). Matching *handicaps* interfere with
development of useful situation awareness (Lipschitz, 2007). Matching *therapies* are evidence-based training programs and decision aids that assist individuals at improving the decision making process (Lipschitz, 2007).

*Reassessment* is re-evaluating an action to which one is already committed (Lipschitz, 1994). The reassessment action argument guides the decision maker to make a choice based on the fact that it survived the decision maker’s critical analysis (Lipschitz, 2007). Decisional framing reassessment takes into account all of the risk, uncertainty, individual level attributes, and the attributes of the individual’s environment (Lipschitz, 2007). Decision strategy reassessment offers the opportunity to contemplate failures of critical reassessment and reflection (Lipschitz, 2007).

Commitment Reassessment causes the decision maker to feel restricted (Lipschitz, 2007). Temporal orientation reassessment is concerned with retrospective reflection (Lipschitz, 2007). Reassessment relies on non-foundational logic (Lipschitz, 2007). Reassessment *handicaps* are obstacles to commitment to action (Lipschitz, 2007). Reassessment *therapies* are training programs and decision aids that assist individuals with improving critical thinking skills (Lipschitz, 2007).

Arguments drive the decision making process. These arguments are *action arguments* (Lipschitz, 2007). The decision maker may conduct this argument with themselves or with the people who provide social support (Lipschitz, 2007). Each of the three modes of decision making has its own action argument (Lipschitz, 2007).

*Decision framing* is a parameter that specifies the way problems present themselves (Lipschitz, 2007). The decision framing is constructed by the individual or social support persons (Lipschitz, 2007). The standard operating procedures of societal
structures and social norms contribute to decision framing (Lipschitz, 2007). The way in which the option to be implemented is selected is the decision strategy (Lipschitz, 2007). The degree of intuitiveness of strategy execution is deliberateness (Lipschitz, 2007). Commitment refers to the obligation in the decision making process (Lipschitz, 2007).

Uncertainty is a common barrier in decision making. Uncertainty is the sense of doubt that hinders action (Lipschitz & Strauss, 1997). There can be positive and negative responses to uncertainty. It can inspire vigilance and the gathering and processing of information or it can lead the individual to procrastinate and become fearful of the commitment to the decision (Lipschitz, 2007).

Different problems offer different rationale and require different prescription; this parameter is logic (Lipschitz, 2007). Handicaps are barriers that hinder decision making quality (Lipschitz, 2007). Therapies are interventions to help the decision maker estimate the probability of outcomes and reduce bias in decision making (Lipschitz, 2007).

Lipschitz’s decision making theory in three modes has several assumptions. The first assumption is that the decision makers critically contemplate their actions prior to committing to a choice (Lipschitz, 2007). Second is the assumption that commitment to a decision is a goal (Lipschitz, 2007). Last, is the assumption that the processing of information takes place after there is a commitment to a decision (Lipschitz, 2007).

The individual’s life experiences are the basis on which decisions are made. Decisions are bound by societal constraints. Posturing and rationalization often follow the commitment to a decision (Lipschitz, 2007). Uncertainty is unavoidable in “real world” decision making (Lipschitz, 2007).
Conceptualization of risk in decision making with regard to one’s work is likely different than the conceptualization of risk while managing one’s health. Additionally, disparity in the treatment of CHD is not solely based on the patient’s ability to decide to proceed with the best-recommended treatment regimen. The older African American (decision maker) may not be aware of all possible alternatives in day-to-day health-related decision making. The decision maker may feel unable to act due to lack of information and lack of comprehension regarding the recommended treatment options and possible health outcomes. Feeling overwhelmed with the abundance of information being presented can compromise the coping skills of the older African American patient, as well as, hinder the decision making process.

Organizational learning is a complex process of interpersonal communication that is occurring in the larger context of the corporate social setting (Lipschitz, Popper, & Friedman, 2002). While organizational learning may be similar to individual learning, the organization’s cultural, psychological, and contextual expectations will have a significant impact on the manner in which an individual proceeds to make day-to-day decisions. Furthermore, the perceived barriers and consequences of overcoming human reasoning and behavioral patterns that limit learning and hinder productive learning would be handled differently. Finally, the literature regarding this theories assumptions and propositions of this theory are not well defined. Therefore, Lipschitz’s decision making in three modes was not chosen as the conceptual framework for this study.

The second conceptual framework considered for this study was the health belief model (HBM). The HBM was developed by researchers at the United States public health service in the 1950’s and is the most commonly used theory in health education and
health promotion (Glanz, Rimer, & Lewis, 2002; Rosenstock, Strecher, Becker, 1988). The HBM posits health behavior is determined by personal beliefs about disease and the treatments available (Jones & Bartlett, 2009). These beliefs affect health seeking behavior (Jones & Bartlett, 2009). The original constructs of perceived seriousness, perceived susceptibility, and perceived benefit have been expanded to include: cues to action, motivating factors, and self-efficacy (Jones & Bartlett, 2009).

Perceived seriousness is a theoretical construct that refers to the individual’s perception of the seriousness or severity of their illness (Jones & Bartlett, 2009). This construct is influenced by the individual’s personal experience and perceptions of the illness in addition to what is told to them by health care providers (Jones & Bartlett, 2009). The construct that prompts people to modify behavior is perceived susceptibility (Jones & Bartlett, 2009). If there is a perception of serious personal risk or perception of susceptibility, then there is a greater chance of behavior change (Jones & Bartlett, 2009).

Perceived susceptibility is one of the more influential constructs (Jones & Bartlett, 2009).

Perceived benefit plays a key role in promoting secondary prevention behaviors (Jones & Bartlett, 2009). An individual’s opinion of the utility of a new behavior affects their ability to adhere to the change (Jones & Bartlett, 2009). The individual’s perception of obstacles to behavior change is a perceived barrier that is most limiting and must be overcome to promote healthy behavior (Jones & Bartlett, 2009). The individual’s perception of risk to benefit ratio will have a great impact on their commitment to consistently perform new health behaviors (Jones & Bartlett, 2009).

There are modifying variables that alter the four major theoretical constructs of the HBM (Jones & Bartlett, 2009). A modifying variable is a personal characteristic that
influences an individual’s perception (Jones & Bartlett, 2009). Life experiences, learning experiences, and culture are examples of modifying variables (Jones & Bartlett, 2009). Events that give incentive to modify behavior are known as cues to action (Jones & Bartlett, 2009). The event can be the dissemination of health information through the media, interaction with healthcare providers, or the illness of a loved one (Jones & Bartlett, 2009).

The belief that an individual is capable of performing in a certain manner to attain a specified goal is self-efficacy (Jones & Bartlett, 2009). Self-efficacy was added to the four major theoretical constructs in 1988 (Jones & Bartlett, 2009). One of the strongest predictors of behavior modification is self-efficacy (Jones & Bartlett, 2009). The HBM has been widely utilized in healthcare to explain health behavior and patterns of adherence (Jones & Bartlett, 2009). Public health promotion and disease prevention programs have greatly benefited from the insight of the HBM (Jones & Bartlett, 2009).

The HBM may be effective when an individual is in agreement with the recommended plan of care. However, this may not always be the case. In the healthcare setting, there are often times when individuals are fully aware of the risk of serious health conditions and chose not to follow the recommended plan of care. The individual has the right to decline the recommended therapy (against medical advice). In this scenario, the HBM is not as useful. The medical therapy that is recommended may be the best treatment that is available but may not offer the benefits the individual desires. Hence, the patient declines. This would be a case in which the health beliefs of the individual are mismatched with the health beliefs of the provider. The individual should be encouraged
to actively participate in health-related decision making, even when it is contrary to the desired decision of the provider.

Since the HBM is one of the most commonly used conceptual models in health education and health promotion, there is a vast amount of literature regarding its application. The HBM theory is not always predictive of health behavior (Wulfert, Edelgard, Wan, & Choi, 1993). The researcher of this proposed study felt disparity in the treatment of acute coronary syndrome and coronary heart disease required a fresh perspective with a second look at its determining themes and possible interventions. Hence, the HBM was not chosen.

The conceptual framework that guided the methodology of this study was complexity science theory (CST). This theory began as a nonlinear mathematical theory (Capra, 2005). Complexity science theory has been used as the conceptual framework in the research of artificial life, chemistry, computer information science, economics, evolutionary computation, molecular biology, neuroscience, physics and sociology (Capra, 2005). Nobel Laureate Ilya Prigogine was one of the first scientists to study dissipative systems and living systems utilizing a nonlinear dynamic theory/CTS (Prigogine & Glandsdorff, 1971; Capra, 2005). Prigogine described living systems as open systems that require a state far from equilibrium to sustain life, maintain structure, and emerge (Prigogine & Glandsdorff, 1971; Capra, 2005). Stuart Kauffman refined the concept of emergence and studied attractor models in various cell types (1991; 1993; 1995). Goodwin studied genetic structures and cellular biochemistry (1994). Complexity science theory has many pioneers and its development has not been attributed to any

*Complexity science theory* is a post-positivist theory that emerged in the late twentieth century as an integration of quantum mechanics, chaos theory, cybernetics, and general systems theory (Heylighen, Cilliers, & Gershen, 2007). The seminal literature of CST developed in the technical fields (Kauffman, 1995; Mainzer 1995). This theory has been utilized by many social scientists (Brodnick & Kraft, 1997; Davis & Sumara, 1997; McAndrew, 1997; Rosenhead, 1998). Nurses have also utilized CST to examine the concept of participation in decision making among nurses (Liu, 2008). *Complexity science theory* has been utilized to explain physics of Complex adaptive systems (CAS), emergence in evolutionary systems, information processing and computation in CAS, emergence of living systems, and the dynamic/quantitative studies of human behavior (SFI, 2009). The researchers and educators at the Santa Fe Institute (SFI) have refined CST (SFI, 2009).

*Complexity science* was been chosen because it posits that a system is best understood as an integrated whole (Anderson, 2005; Cilliers, 1998, p. 119). Complexity science provides an explanation of humans as CAS that are not merely constituted by the sum of their parts (Plsek & Greenhalgh, 2001; Cilliers, 1998, p. 119). Thus, it guided the questions asked of the participant and interpretation of data in this study. *Complexity science* states that the parts of a system have intricate relationships that are destroyed by reductionistic methods (Anderson, 2005; Plsek & Greenhalgh, 2001; Cilliers, 1998, p. 120; Capra, 2005). In order to ensure survival, CAS operate under conditions that are far from equilibrium (Capra, 2005).
Complexity science theory posits that CAS consist of multiple components that are understood by observing their rich non-linear interaction holistically (Sweeney & Griffiths, 2002, p.2; Anderson, 2005; Cilliers, 1998, p.4). The intricate relationships between these components constitute the CAS, and are integral in understanding its function and evolution (Anderson, 2005). The interaction between components is not reliably predictable but informative (Sweeney & Griffiths, 2002, p.2). Not only do CAS have a history that is continuously transforming, but also this history is sensitive to initial conditions and determines future interactions (Plsek & Greenhalgh, 2001; Sweeney & Griffiths, 2002, p.2; Cilliers, 1998, p.108; Merry, 1995, p.28).

Major Concepts

Human beings are CAS (Merry, 1995, p.183). The focal system in this study is the bio-psychosocial system of the participant. The participant was considered a CAS living in a larger CAS that consists of their local community and society at large (Sweeney & Griffiths, 2002, p.60). The day-to-day health-related decision making of the participants were the observed outcome of the rich nonlinear interaction between the participant and their environment. While the day-to-day health-related decision making patterns of the participant could not be reliably predicted, they were informative.

Complex adaptive systems interact with and are influenced by their environment (Sweeney & Griffiths, 2002, p.2; Cilliers, 1998, p.4). The participant’s mental and physical health at the time of the acute coronary syndrome was considered their initial conditions. The participant’s previous life experiences were considered their history. Interactions can be physical or the transference of information (Cilliers, 1998, p.3).
Nonlinear interaction of the CAS is usually short range between neighboring elements (Cilliers, 1998, p.4).

Negative and positive feedback loops were essential to the recurrence of the CAS (Cilliers, 1998, p.4). Negative feedback loops are detracting and inhibiting (Cilliers, 1998, p.4). Anginal symptoms were considered negative feedback loops in this study. Positive feedback loops are enhancing and stimulating to the CAS (Cilliers, 1998, p.4). Examples of positive feedback loops in this study were the absence of angina symptoms.

There is a history that evolves through time and influences the behavior of the CAS (Cilliers, 1998, p.4). The effect of inputs into the system cannot be determined by the size of the input (Sweeney & Griffiths, 2002, p.2; Cilliers, 1998, p.4). Understanding of the interactions within the focal system cannot be explained through deductive methods (Sweeney & Griffiths, 2002, p.2). The evolution of new properties arises as the result of the CAS interacting with its environment and other CAS; this essential feature is known as emergence (Sweeney & Griffiths, 2002, p.42; Merry, 1995, p.172).

While observing the focal system, the researcher looked for interactions of the focal system at the macrosystem level and the microsystem level (IOM, 2001, p.309). A macrosystem is composed of microsystems (IOM, 2001, p.310). The healthcare system in the participant’s community was the macrosystem (IOM, 2001, p.310). The healthcare system was composed of hospitals, clinics, doctor’s offices, long-term care facilities, pharmacies, internet websites, and other resources that provided comprehensive continuity of care (IOM, 2001, p.310). The microsystems are the smaller self-contained systems within the macrosystem (IOM, 2001, p.309). Therefore, when the participant was
hospitalized, the researcher considered it an interaction with a *microsystem* of the *macosystem* (IOM, 2001, p.310).

The number and strength of *interconnections* between the elements of a system are determined at the system level (IOM, 2001, p.309). The *interconnections* in the healthcare system were the flow of patients and information within the system for the purpose of maintaining and improving participant health outcomes (IOM, 2001, p.309). Examples of interconnections in this study were the communications between the primary care provider, the cardiologist, and any other specialists who consulted on the participant’s plan of care. These interconnections included but were not limited to the hospital pharmacy, dietary, the laboratory department, and all of the departments that contributed to the flow of care provided to the participant during the hospitalization.

Emergent behavior was observed at the macrosystem level and the microsystem level (IOM, 2001, p.310). *Emergence* is the spontaneous order that resulted at a critical point of instability and is an integral feature of *CAS* (Capra, 2005). Regaining myocardial perfusion and hemodynamic stability during the acute coronary syndrome was considered an example of emergence at the micro system level. The evolving patient-physician relationship of trust was considered an example of *emergence* at the microsystem level.

The population of African Americans surviving an ACS and living with newly diagnosed CHD is an example of *emergence* that affected the macrosystem. As the African American population ages, the healthcare system has displayed innovation and blunder as it strives to *evolve* to improve the health of older adults. Disparity in the treatment of heart disease is an example of that blunder. The development of new
protocols to decrease the lag time from diagnosis of ACS to coronary angiography and intervention is an example of emergence of the macrosystem.

The patient’s diagnosis, treatment, and self-management are the outcome of the interactions of participants with their doctors, nurses, and ancillary staff in the microsystem. The increased desire for shared health-related decision making among older African Americans is an example of emergence that affected the microsystem level. Trust in healthcare providers is a key factor in facilitating that emergence. African American’s reporting participation in health-related decision making, and a trusting relationship with their healthcare providers would be considered as experiencing emergence.

The literature regarding CAS utilizes the terms components and agents interchangeably (Cilliers, 1998, p.3). Agents have not been explicitly defined in the literature. However, Anderson et al. (2005) state that agents can be: people, human processes, nursing processes, medical processes, administrative processes and computer systems. An agent can simultaneously have membership in multiple systems and the membership can change unpredictably (Plsek & Greenhalgh, 2001). Each agent is nested within a system of other multilevel systems and the evolution of one system influences the co-evolution of them all (Plsek & Greenhalgh, 2001). Co-evolution of a CAS is dependent upon the fitness of that system and the systems with which it interacts because the co-evolution of the systems is simultaneous (Stein, 1989, p. 529). The rate of adaption and co-evolution of the systems are dependent upon the size of the system, and number of components or agents (Stein, 1989, p. 530).

In the bio-psychosocial system of African Americans in this study, agents will be all of the internal and external elements that affect the system (i.e. medications, nutrients,
environmental components). The actions of an *agent* are sometimes unpredictable and a change in one can cause change in others (Plsek & Greenhalgh, 2001). These actions are driven by the *agent’s* response to its environment and internalized rules (Plsek & Greenhalgh, 2001). The rich nonlinear patterns of local interaction of the *agents* produce the complexity that *emerges* in the *CAS* (Anderson, et al., 2005; (Plsek & Greenhalgh, 2001). The elements only respond to limited, local information and do not respond or interact with the system as a whole (Cilliers, 1998, p.5).

A living system is an *open system*; therefore, the participants were considered *open systems* that were constantly changing (Capra, 2005). An *open system* is a system that interacts with its environment, exchanging matter and energy to ensure survival (Capra, 2005; Heylighen, Cilliers, & Gershen, 2007). As the researcher interviewed the participants, the researcher became part of the system.

Another key feature of *CAS* is their large number of *elements*, which have rich interaction that can be physical or simply transfer information (Cilliers, 1998, p. 3). Human systems are constantly collecting data from their environment, choosing what is relevant, and utilizing that information to guide its reactive and proactive behavior (Merry, 1995, p.183). The literature describes *elements* as being sparsely or richly connected in the system (Cilliers, 1998, p. 4). The *elements* within the *CAS* are ignorant of the behavior of the other elements but influence and are influenced by other *elements* in the system (Cilliers, 1998, p. 4).

The *interaction* between the *elements* in this study effected the management of risk factors. In this study, the consumption of medication, dietary intake, physical activity/ inactivity, and psychosocial interactions affected the participant’s ability to
manage CHD. For instance, when a participant had an adverse reaction to a medication the participant was less likely to take the medication as prescribed. The participants reported physical and psychological responses to the medications that could not be measured or reliably predicted; yet it could be observed.

The future of the CAS is determined by its past or initial conditions, making its behavior predictable in the short term but not in the long term (Merry, 1995, p.26). The focal system is sensitive to initial conditions (Merry, 1995, p.28). The researcher considered the age, physical health, psychological health, and socioeconomic status at the time the participant had their first cardiac event or diagnosis. The participant was also sensitive to the initial conditions of the nurse staffing, insurance status, and treatment guideline recommendations of the American College of Cardiology (ACC)/ American Heart Association (AHA) at the time of diagnosis and treatment (Anderson et al., 2007). The system has moved in a variety of ways in the post myocardial infarction phase, depending on the initial conditions (Capra, 2005). Ultimately, it will settle down to a characteristic long-term behavior (Capra, 2005). The participant’s social support system at the time of diagnosis and beyond, also affected their emergence. The history that the participant had with the key support persons also affected their ability to adhere to recommended therapy. The client’s reliance on other individuals to transport them to the grocery store, pharmacy, or doctor’s appointments chiefly determined their ability to do so.

Inputs into the system had minor as well as profound effects without regard to the size of the input (Sweeney& Griffiths, 2002, p.2). In the bio-psychosocial system, an input could be social interactions at cardiac rehabilitation, interactions with healthcare
facility office staff, and the influence of the internet. Emails from unknown senders and written publications of an individual’s experience with illness had negative or positive effects on the participant’s desire to adhere to recommended therapies. The physician’s open expression of religious beliefs, and family members having the same primary care provider and comparing symptom presentation with others who suffered from the same condition, were all considered input.

In order to survive a changing environment, CAS must be able to retain information, and have the enhanced automaticity to adapt its structure a priori (Cilliers, 1998, p.10). Self-organization is the order that arises within the biological system to maintain hemodynamic stability of the participant (Plsek & Greenhalgh, 2001; Sweeney & Griffiths, 2002, p.64; Cilliers, 1998, p.12). Self-organization in this study referred to the process in which many actions of the participant, members of the healthcare system, family members & friends taken to meet the needs of the participant (Plsek & Greenhalgh, 2001; Cilliers, 1998, p.12). The mutual adjustment in behavior and adaptation of structure to cope with the internal and external environmental demands was self-organization (Anderson, et al., 2005; Cilliers, 1998, p. 10).

The ability to self-organize allowed the focal system to spontaneously reinvent itself through evolution, changes of internal structure, and adaptability that creates a structure at a higher level (Gaddis, 2002, p.84; Cilliers, 1998, p.90; Merry, 1995,p. 172). This feature allows the CAS to manipulate and survive in a changing environment (Cilliers, 1998, p.90). The focal system often appears to be unpredictable and disorderly at times, however order arises from within the system. Self-organization is a never-ending iterative process (Merry, 1995, pp. 33). The new system properties and
characteristics that emerged were nonexistent in the previous system and could not have been predicted through the analysis of the lower-level components (Merry, 1995, pp. 173).

Adaption is the change in a CAS that result from the change in its agents over time (Plsek & Greenhalgh, 2001). Human beings have countless variables that help them adapt to turbulent circumstances (Merry, 1995, p.183). An example of biochemical level adaption is the development of antibiotic resistance (Plsek & Greenhalgh, 2001). As the bio-psychosocial system changes (development of diabetes mellitus, worsening symptoms of lung disease), the surrounding systems change to meet the new needs of the focal system (physiological change, prescription of oxygen or new medications); this is adaptation. When there were changes in the bio-psychosocial system, alterations in medication regimens, dietary requirements, and physical activity were required to ensure survival of the participant.

The behavior of the CAS may be governed by a set of simple rules (Cilliers, 1998, p.15). The rules demonstrate logical relationships between concepts in the model of the CAS (Cilliers, 1998, p.15). Biological organization rules can vary from specifying individual molecular processes to the laws of physics and chemistry (Stein, 1989, p.255). Therefore, in this study, the simple rules of the bio-psychosocial system are the rules that allow the bio-psychosocial system to maintain blood pressure, heart rate and cardiac output.

Plsek and Greenhalgh, describe human level rules as being chemical reactions that are expressed by instincts, constructs, and mental models (2001). These human level
rules can also be the patient’s ideas, concerns, and expectations (Plsek & Greenhalgh, 2001). The rules are not explicit and may appear irrational (Plsek & Greenhalgh, 2001).

There are various initial conditions that the CAS is driven toward; this region/ set of conditions is referred to as the attractor (Stein, 1989, p.27). Attractors are specific types of patterns that are fundamentally unpredictable but observable and informative (Plsek & Greenhalgh, 2001). An attractor is a point or area of the CAS that the system will continuously move toward (Sweeney & Griffiths, 2002, p.6). The set points that comprise the attractor are the basin of attraction (Stein, 1989, p.27). Dynamical CAS are systems that evolve in time according to a set of well-defined rules and the future of the CAS is determined by the present (Stein, 1989, p.27). Dynamical CAS can have more than one attractor and each has its own basin of attraction (Stein, 1989, p.27).

Attractors can be simple or complex and overt or concealed (Sweeney & Griffiths, 2002, p.6). In this study, the attractor was the “usual” state of health as defined by the participant and the healthcare team. The participant and the healthcare team were not always in agreement as to what the attractor state was. In some instances the biologic system had aged, the attractor state changed and there was a new attractor state. The biologic system continued to move toward that state, however that state was no longer attainable. Hence, there was a new attractor state for most of the participants in this study.

The following research questions will be explored:

1.) What is the lived experience of managing CHD among older African Americans?

2.) What is the essence of health-related decision making among older African Americans living with CHD?
These questions were explored using a hermeneutic phenomenological approach. This study focused on the human level *simple rules* that govern the *CAS*. These were ideas, concerns, and expectations of older African Americans who had experienced an acute coronary syndrome and recently diagnosed with CHD. The researcher attempted to construct a full interpretive description of the participant’s thoughts and feelings regarding their lifeworld and how it had changed since they were diagnosed with an ACS and CHD.
Chapter 2
Literature Review

The purpose of this study was to explore the themes that affected the day-to-day health-related decision making patterns of older African Americans managing coronary heart disease (CHD). The purpose of this review was to determine what characteristics most described the phenomena of being an African American with newly diagnosed CHD. The researcher looked for research studies that provided a perspective on health-related decision making, self-management strategies, and self-care interventions. This review summarized the benefits and disadvantages of these strategies in reducing racial/ethnic disparity in the treatment of CHD and their success in the treatment of other chronic illness. The chapter will conclude with the significance of this study.

First, to assess the evidence of current racial/ethnic disparity in the treatment of CHD literature was reviewed by searching Pubmed (750 articles) and Medline (88 articles) databases to identify studies that examine racial and ethnic differences in the evaluation and treatment of heart disease. This search using the key terms heart disease and ethnic differences yielded over 800 citations. The second search utilized the key terms patient-centered decision making to find research utilizing health-related decision making (Pubmed 763 & Medline 12). Finally, using the key terms self-management and Lorig, the literature utilizing self-management and self-care strategies was reviewed (Pubmed 67 & Medline 54). The search was limited to studies that controlled or adjusted for racial/ethnic differences in insurance status and were conducted in the United States. There is significant literature that extends beyond the usual five year cut off, therefore this review included studies published since the year 2000. Hence, there are 41 articles in this literature review.
Many themes contribute to disparity in the treatment of CHD. The Institute of Medicine (IOM) analysis (2001, p. 180) identify patients, healthcare providers, healthcare systems, and utilization managers as the major sources contributing to racial/ethnic disparity in healthcare. The studies in this literature review support these findings. This review also focused on the limitation of previous studies and recommended interventions that could potentially eliminated disparity in the treatment of African Americans with CHD.

**Decision making**

To decide is to select a course of action (Merriam-Webster, 2009). A decision can also be viewed as committing oneself to a certain opinion or course of action (Lipschitz, 2007). The decision making process is complex and fraught with uncertainty, risk, and ambiguity (Lipschitz, 1994). Additionally, the decision maker may not have knowledge of all possible alternatives. Therefore, decision making is not the result of making a selective intellectual judgment when presented with several complex alternatives defining a course of action. Naturalistic decision making has the five essential characteristics of: recognition-primed decisions, coping with uncertainty, team decision making, decision errors, and methodology (Lipschitz, Klein, Orasanu, & Salas, 2001). According to Lipschitz, there are three modes of decision making: *consequential choice*, *matching* and *reassessment* (Lipschitz, 1994). *Consequential choice* is a term that refers to comparing alternatives in terms of expected consequences (Lipschitz, 1994). *Matching* is evaluating single options in terms of a certain criterion. *Reassessment* is re-evaluating an action to which one is already committed (Lipschitz, 1994).

*Health-related Decision Making*
Health-related decision making involves but is not limited to individuals making decisions about medication regimens, treatment decisions, and encounters with the healthcare system (Kremer, Ironson, Schneiderman, & Hautzinger, 2007). These decisions involve the individual making decisions that affect and are affected by their personal health, family relationships, career, finances, and life events (Kremer et al., 2007). These choices often involve risk, loss, regret, and challenge the individual’s wellbeing (Kremer). When health care providers do not provide adequate education regarding health-related decisions, it often leaves patients feeling frustrated and confused (Goldman, Parker, Eaton, Borkman, Grambling & Cover et al., 2006; Woodard, et al., 2005).

Preferences in the level of participation in health-related decision making vary among and within racial/ethnic groups. Patients may have an active, passive, or collaborative role in health-related decision making (Kremer et al., 2007). The provider’s attitudes and behaviors were seen as facilitators or barriers to the participant’s level of participation (Belcher, Fried, Agostini, & Tinetti, 2006; Woodard et al., 2005). Regardless of the level of participation health-related decision making is complex and making decisions regarding treatment strategies is more so. Unfortunately, the patient’s desired role may not match their actual role in health-related decision making (Kremer). Nevertheless, the themes that influence health-related decision making are important. In this literature review the common themes that affected health-related decision making were uncertainty, self-efficacy, and trust in health care providers.

Trust in health care providers begins with establishing a relationship, the exchange of desired health information and good communication skills. A recent study
showed no major difference in knowledge of risk factors for CHD between Whites and African Americans (Woodard et al., 2005). Both valued effective communication of information regarding their illness and recommended therapies (Belcher et al., 2006; Woodard et al., 2005). However, several participants gave accounts of racism experienced in daily life and interactions in the healthcare system (Woodard). Some African Americans perceived the physician’s refusal to address their issues of concern as racism (Woodard). The participant’s stated their decision making was directly affected by the physician-patient relationship (Woodard). Several White participants were concerned that they received a lower quality of care due to socioeconomic status (Woodard). African Americans expressed concern regarding the efficacy of generic medications (Woodard).

Themes/Predictors of Health-related Decision Making

Few research studies since 2000 have investigated minority patient perspectives on health-related decision making. Two studies found African Americans desire information regarding medical procedures to provide reassurance, alleviation of fear, and to gain knowledge of additional testing required (Torke, Giselle, Corbie-Smith, & Branch, 2004; Woodard et al., 2005). The most important themes affecting health-related decision making in the Torke et al. (2004) study were: concern about disease diagnosis, risk of adverse effects of the procedure, benefits of the procedure, provider information, comprehension of the purpose of testing, and concern regarding their health.

Fear and anxiety regarding illness were associated with patients not wanting to participate in health-related decision making in several studies (Belcher, et al., 2006; Torke et al., 2004). These participants preferred to rely on the health care provider’s
expertise in choosing the best course of action. There were also participants who thought
they could not and should not participate in health-related decision making (Belcher et
al., 2006). Concern regarding adverse side effects of medications was mentioned more
than the beneficial effects (Belcher et al., 2006).

With health-related decision making comes the concept of decisional control.
Decisional control involves the individual’s power to choose their level of involvement in
health-related decision making (Ervin & Pierangeli, 2005). There is a positive
relationship between increased decisional control and health (Ervin & Pierangeli, 2005).
Most often, individuals do not have their desired level of decisional control in health-
related decision making (Ervin & Pierangeli, 2005). Achieving the individual’s desired
level of decisional control leads to higher patient satisfaction with decisional outcomes
(Ervin & Pierangeli, 2005). However, it is important to note that the patient may not be in
agreement with the provider regarding the desired course of action (Ervin & Pierangeli,
2005).

Health-related Decision Making: African Americans

Trust of the care provider was an important factor affecting African American’s
decision making (Belcher et al., 2006; Torke et al., 2004; Woodard et al., 2005). The
patience, kindness, provider showing interest in patient, and continuity of care build trust
in the provider to make recommendations regarding patient care (Torke; Woodard). Trust
was broken when the patient perceived the provider to be in a rush, dishonest or
withholding information (Belcher; Torke).

The perceptions of the healthcare provider being in a rush and not addressing
patient issues probably reinforce the fear that the healthcare provider does not see the
patient as an individual. Some patients report waiting all day, just to spend ten minutes with the health care provider (Woodard et al., 2005). The patient is likely seeking reassurance to calm fears related to their diagnosis and prognosis. Only to be disappointed by the health care provider’s apparent rushed behavior. This perception leads to lower levels of satisfaction with the care provided.

Coronary Heart Disease (CHD)

The National heart lung and blood institute (NHLBI) defines CHD as a condition in which plaque forms in the lining of the coronary arteries (2009). The coronary arteries supply your heart with the oxygen and blood needed to perform properly (NHLBI, 2009). Plaque is composed of fat, cholesterol, calcium and other atherogenic substances found in the blood (NHLBI, 2009). Narrowing of the coronary arteries from plaque buildup causes a reduction in the amount of blood and oxygen to nourish the heart muscle (NHLBI, 2009). Deprivation of oxygen and blood flow to the heart muscle can cause chest pain also known as angina (NHLBI, 2009). Prolonged lack of oxygen and blood flow to the heart muscle can lead to heart (myocardial) cell injury and cell death/myocardial infarction (MI) (NHLBI, 2009).

The major risk factors for CHD are high low-density cholesterol (LDL), high blood pressure (HTN), diabetes, tobacco use, lack of physical activity, metabolic syndromes, family history of CHD, and advanced age (NHLBI, 2009). The more risk factors that individuals have increase their risk of developing CHD (NHLBI, 2009). The majority of the risk factors are modifiable. A family history of CHD is a predisposition, not a pre-destiny. Primary prevention efforts are beneficial for all persons with risk factors of CHD (Healthy People, 2007).
Disease Management

Screening for risk factors is the first step in primary prevention (Healthy People, 2007). Early detection primary prevention strategies are aimed at individuals who have risk factors for CHD but have not been diagnosed with CHD (Healthy People, 2007). In this case, strategies focus on lowering cholesterol and blood pressure. Smoking cessation is of paramount importance. Increasing physical activity and dietary modification will assist in weight loss and controlling glucose levels in diabetic patients (Healthy People, 2007). There are recommended medication regimens for each comorbid condition that is not well controlled (Healthy People, 2007).

Once CHD is detected, treatment should not be delayed. Early treatment of a heart attack reduces the amount of muscle damaged and leads to better patient outcomes (Healthy People, 2007). Delay in treatment leads to increased morbidity and mortality (Healthy People, 2007). Secondary prevention strategies are essentially the same as primary prevention with the addition of routine monitoring of myocardial perfusion with stress testing, coronary angiography, and revascularization when appropriate (Healthy people, 2007; NHLBI, 2009).

Self-Management/ Self-Care and Themes Affecting Disease Management

Self-management is an educational strategy utilized in individuals with chronic illness to engage them into a more active role in the day-to-day management of their disease (Lorig, & Holman, 2009). Even when disseminated through the mail, self-management tools are effective in improving health status, health behavior, and self-efficacy in chronically ill individuals (Goeppinger, Lorig, Ritter, Mutatkar, Villa, & Gizlice, 2009). The success of self-management is largely dependent upon an individual’s

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The theory of self-efficacy posits that the strength of belief in one’s capability is a good predictor of future motivation and behaviors (Lorig & Holman, 2009).

Myerson and Kline’s study (2009) demonstrated how the theme of self-efficacy relating to self-management was crucial to the emergence of beneficial health outcomes in heart failure patients. Many participants cited a lack of confidence in their self-management skills (Meyerson, & Kline, 2009). However, many also cited competing priorities (Meyerson, & Kline, 2009). Competing priorities were barriers to self-management and often related to the management of other co-morbid conditions, coping with pain, anxiety, and grief (Meyerson, & Kline, 2009). Examples were: grieving the loss of a family member, being newly diagnosed with a terminal illness, and dealing with hypoglycemic episodes.

There were self-management studies that reported improved self-efficacy and a reduction in emergency room visits (Lorig, et al., 2001). However, it is unclear whether the self-management strategy improved self-efficacy or whether the self-efficacy of the individual made the self-management intervention successful. Participants in the Lorig et al. (2001) study also reported reduction in health distress and marginal improvement in energy levels. A more recent study showed long-term improvement in depression, communication with providers, healthy eating habits and patient activation in addition to improved self-efficacy (Lorig, Ritter, Villa, & Armas, 2009).

Several studies in this review used self-care and self-management strategies simultaneously. Self-care and self-management are similar in that both rely on self-efficacy and an individual’s self-confidence in their ability to make day-to-day health-
related decisions for success. While the combination of these strategies was effective in decreasing the number of hospitalizations, there was a high attrition rate due to mortality (Lin, Cavendish, Boren, Ofstad, & Seidensticker, 2008). Lin et al. (2008) reported significant improvement in the increased use of appropriate medications, completion of cardiac rehabilitation, symptoms, and less physical limitation. Maintaining physical independence is an important goal in this patient population (Meyerson, & Kline, 2009). Lin et al. (2008) also documented improvement in dietary compliance and exercise.

The success of self-care is contingent upon the individual’s willingness to undertake therapeutic self-care behavior (Schnell-Hoehn, Naimark, & Tate, 2009). The premise of the self-care conceptual framework is that behaviors are consistent with the individual’s beliefs, values, and motives (Connelly, 1987). The Schnell-Hoehn et al. (2009) study describes how self-care education has to be congruent with cultural beliefs of the individual, otherwise the intervention is ineffective. Higher self-efficacy was a predictor of fewer hospitalizations (Schnell-Hoehn et al., 2009). This is likely due to the finding that individuals with higher self-efficacy practice self-care behaviors more frequently (Schnell-Hoehn et al., 2009). Once again, the success of the intervention relies on the individual’s self-efficacy. Participants with fewer comorbid conditions had higher self-efficacy. Additionally, individuals with more than five comorbidities reported the least self-care (Schnell-Hoehn et al., 2009).

**African Americans with CHD**

Numerous themes are thought to contribute to racial/ethnic disparity in the treatment of CHD. Of the literature that focused on CHD, ninety-two percent of the studies in this review found race/ethnicity to have a significant impact on whether the
patient received the appropriate interventions for their diagnosis. The doctor’s decision to order noninvasive/invasive cardiac testing remains the most influential factor causing disparity in the treatment of heart disease. Eighty-one percent of these studies identified the doctor’s decision to order testing and procedures as a factor that prevented non-White patients from receiving the recommended treatments for their type of heart disease.

Seventy-three percent of the studies focusing on CHD showed African American patients were less likely to undergo potentially life-saving procedures such as cardiac catheterizations, coronary artery bypass grafting, implantable-cardioverter defibrillators (ICD), and insertion of an intra-aortic balloon pump (IABP) during cardiogenic shock. There was only one study that analyzed the relationship between the race/ethnicity of the doctor and the race/ethnicity of the patient (Chen, Rathore, Radford, Wang, & Krumholz, 2001). No differences in treatment regarding this relationship were observed. African American patients were less likely to undergo cardiac catheterization regardless of the race of the doctor. Three studies demonstrated that African American patients are less likely to be treated by a board-certified cardiologist in addition to being less likely to undergo cardiac catheterization (Auerbach, et al., 2000; Chen et al., 2001; Cromwell, J., McCall, Burton, & Urato, 2005).

Education, socioeconomic status, geographic location, age, gender, ethnicity and race are the social determinants of disparity that are factors in this literature review. Three studies identified lack of education as a predictor of poor health outcomes (Allen, Scott, Stewart, & Young 2004; Chen et al., 2001; Ibrahim, et al., 2003). Lack of education has been closely linked to low socioeconomic status. In addition to low socioeconomic status, the lack of private insurance was identified as a factor in the
disparity of medical treatment in five of the studies that focused on CHD (Allen et al., 2004; Barnhart, Fang & Alderman, 2003; Auerbach, et al., 2000; Venkat, et al., 2003; Werner, Asch, & Polsky, 2005). While only one study evaluated geographic location, living in a disadvantaged neighborhood was a factor associated with an increased incidence of disparity in receiving life-saving therapy (Groeneveld, Heidenreich, & Garber, 2005).

When assessing age as a factor effecting disparity in CHD, literature showed that older clients were less likely to receive referrals to cardiac rehabilitation (Allen et al., 2004). Additionally, older adults were less likely to receive care from a board certified cardiologist (Auerbach et al., 2000). Older adults were also less likely to receive an implantable cardiac defibrillator (Groeneveld, Heidenreich & Garber, 2003). Even when presenting with a ST-elevation MI, they were less likely to receive same day percutaneous coronary intervention (Pathak, & Strom, 2008). Consequently, the combination of race/ethnicity and age dramatically decrease the chances of receiving life-saving therapy.

The compounding effects of having more than one factor contributing to the disparity in heart disease was also seen with women. Coronary heart disease is a major cause of disability and death for women (CDC, 2005). While improvements in the treatment of heart disease have been made, the treatment of women with risk factors for heart disease remains inadequate (Allen et al., 2004; Vaccarino, et al., 2005). In fact, several studies show that women have lower rates of revascularization (Pathak, & Strom, 2008; Shaw, et al., 2008; Vaccarino et al., 2005). One study that showed White non-Hispanic women to have the highest in-hospital mortality, however the population was
ninety percent White individuals (Shaw, et al., 2008). This study was contrary to the majority of studies in this review.

Moreover, there was a study that showed how having two factors contributing to disparity in CHD resulted in the lowest rate of intervention use and higher mortality rates (Vaccarino et al., 2005). When presenting with an acute MI, African American women were shown to have the lowest rate of revascularization and highest mortality (Vaccarino et al., 2005). African American women were least likely to receive an implantable cardiac defibrillator, when indicated (Thomas, et al., 2007). Notably, one study showed the rate of revascularization improved for African American women between 2001 and 2005 (Pathak, & Strom, 2008). Only one study demonstrated women received angiography more frequently than men, however the setting was in an institution with a predominantly population was male (Ibrahim et al., 2003).

Coronary Heart Disease management

Early coronary revascularization and aggressive medical management strategies are important regardless of race. Research has shown that patients undergoing primary angioplasty have a lower mortality rate in a high-volume hospital (Bradley, et al, 2004). African American patients are more likely to receive angiography at low-volume hospitals and have higher post-procedure mortality rates (Bradley; Trivedi, Sequist, & Ayanian, 2006). This is likely the result being emergently transported to the hospital closest to their residence.

Healthy People 2010 have objectives for reducing mortality from CHD through increasing early coronary revascularization in racial/ethnic minority patients (Healthy People, 2007). Two of the objectives are: to have racial/ethnic minority patients receive
artery-opening therapy within an hour of symptom onset, and receive percutaneous coronary intervention (PCI) within 90 minutes of symptom onset (Healthy People, 2007). One large database study showed that African American patients had the longest door-to-drug time (fibrinolytic therapy to dissolve a clot in the coronary artery) and longest door-to-balloon time (angiography with PCI) of patients presenting with an acute ST-elevation MI, resulting in worse clinical outcomes (Bradley et al., 2004). Non-Whites were also least likely to undergo any diagnostic procedure (Barnhart et al., 2003). In addition to not being referred for coronary angiography, if African American patients were referred, they were less likely to receive a stent (Sabatine, et al., 2005).

Using Administrative Databases to Monitor CHD Management

Almost sixty percent of the studies in this review used nationwide administrative databases (Barnhart, et al., 2003; Bradley et al., 2004; Chen et al, 2001; Cromwell, et al., 2005; Groeneveld, et al., 2003; Groeneveld, et al., 2005; McGruder, Malarcher, Antoine, Greenlund, & Croft, 2004; Okelo, et al., 2001; Palmeri, et al., 2005; Pathak, & Strom, 2008; Shaw, et al., 2008; Thomas, et al., 2007; Vaccarino et al., 2005; Trivedi et al., 2006; Venkat, et al., 2003; Werner et al, 2005; Wong, Shapiro, Boscardin, & Ettner, 2002; Young, Maynard, & Boyko, 2003). Using nationwide databases is an excellent strategy to design a study with a large sample size. Unfortunately, most nationwide databases do not yield the detail-rich data that could be obtained from personal interviews with doctors and patients regarding decisions made in the treatment of CHD. Since trained research assistants are not collecting the data that is entered into these databases, there is a higher chance of inaccuracy in the documentation (Groeneveld et al., 2003; Wong et al., 2002; Young et al., 2003).
There has been speculation that the severity of CHD is different among racial/ethnic groups. Three studies found that African American patients were less likely to have obstructive CHD, implying that revascularization was not appropriate (Okelo et al., 2001; Shaw et al., 2008; Whittle, et al., 2006). This study did find that not all of the patients with positive nuclear imaging studies were referred for coronary angiography (Whittle). Yet, Whittle (2006) does identify the racial composition of the patients who were not referred for coronary angiography.

The nuclear testing portion of the Whittle et al. (2006) study was the portion that was not blinded, and this was a limitation of this study. Whittle et al. (2006) do not deny the fact that African American patients are more likely to suffer mortality from CHD (CDC, 2005). The results of this review show that African American patients were less likely to receive referrals to undergo coronary angiography (Auerbach, et al., 2000; Barnhart et al., 2003; Chen et al., 2001; Cromwell et al., 2005; Gaglia, et al., 2009; Goldstein, et al., 2003; Ibrahim et L., 2003; Sabatine et al., 2005; Vaccarino et al., 2005; Venkat et al, 2003). Unfortunately, once referred for coronary angiography, they were less likely to receive percutaneous intervention (Kaul et al., 2005; Sabatine et al., 2005; Venkat et al., 2003) and coronary artery bypass grafting (Conigliaro, et al., 2000; Cromwell et al., 2005; Okelo et al., 2001; Werner et al., 2005) than Whites.

Financial and Institutional Factors

Disparities are associated with socioeconomic differences lessen when the factors of insurance and income level are controlled (IOM, 2002p.5). Nevertheless, even after these factors are controlled, disparities persist (IOM, 2002p.5). Thirty-eight percent of the studies in this review included income in their evaluation of disparity. Income appeared
to be a factor in the lack of cardiac rehabilitation referrals (Allen et al., 2004). Wealthier patients with were also more likely to be treated by a board certified cardiologist (Auerbach et al., 2000). Ultimately, low socioeconomic status was an independent predictor of worse cardiovascular outcomes (Gaglia et al., 2009).

Sixty-five percent of the studies in this review considered insurance in their assessment of the mechanism of disparity. One study found that patients with higher levels of education were more likely to have health insurance (Auerbach et al., 2000; Mensah, Mokdad, Ford, Greenlund, & Croft, 2005). Lack of insurance was found to increase the racial disparity of not having cardiac markers tested and a propensity toward receiving medical management versus revascularization (Venkat et al., 2003). One study found education and insurance was not a factor (Thomas et al., 2007). Several studies found African American patients were more likely to be on Medicaid or uninsured (Barnhart et al., 2003; Werner et al., 2005). While, Hispanic patients were least likely to have insurance (Mensah et al., 2005).

_African Americans in Veteran Administration (VA) Hospitals_

Four studies evaluating the treatment of CHD racial/ethnic minorities were performed in the VA medical system. These studies should theoretically control for financial barriers such as insurance, and access to care. Two of these studies showed that veterans were more likely to get better quality of care at private hospitals (Conigliaro et al., 2000; Ibrahim et al., 2003). Two studies found White patients to have a higher prevalence of CHD and a higher risk of death (Whittle et al., 2006; Young et al., 2003). Aside from ordering cerebral angiography and electrocardiograms, Goldstein et al., show no difference in the treatment of heart disease in minority patients (2003). However, it is
imperative to note that these are key diagnostic tests for the treatment of CHD and stroke, and both tests are recommended in national guidelines (Healthy People, 2007).

Medical Management of African Americans

There were few studies that evaluated optimal medical management in persons with known CHD. Optimal medical management is essential in primary and secondary prevention strategies in the treatment of CHD. Sabatine et al. demonstrated that racial/ethnic minorities were less likely to be on all of the recommended cardiac medications thirty days after a cardiac event (2005).

This study was not designed to evaluate medical management beyond the list of medications that the patients were taking and did not collect subjective data, socioeconomic or insurance information that might have explained the disparity in long-term management (Sabatine et al., 2005). One study demonstrated the use of medical management as opposed to revascularization; the results were poor compliance and worsening morbidity and mortality (Venkat et al., 2003).

Appropriateness of Services

Retrospective cohort studies are usually not considered to be as rigorous in the assessment of disparity (IOM, 2002, p. 42). However, there was one study that was able to assess the potential overuse or underuse of services and the appropriateness of care (Conigliaro et al., 2000). This study was able to determine whether racial differences in the use of procedures existed by stratifying the clinical cases by the clinical appropriateness of the procedure and measured the appropriateness by a scale developed by the RAND Corporation (Conigliaro). This study determined White patients received cardiac catheterization more frequently (Conigliaro). Also, African Americans were less likely to receive percutaneous intervention when CHD was rated equivocal and less likely
to undergo CABG when indicated as appropriate or necessary (Conigliaro). Contrarily, Okelo et al. (2001) showed that Whites had increased referral for CABG due to more CHD.

Two studies found that African Americans were less likely to receive ICD when indicated (Farmer, et al., 2009; Thomas et al., 2007). One study showed this disparity had lessened over time (Groeneveld et al., 2005). Finally, when being treated for cardiogenic shock, African Americans were less likely to receive IABP and revascularization (Palmeri et al., 2005). However, Hispanic individuals were the least likely to receive either, and the most likely to die (Palmeri).

**Quality of Healthcare Facility**

There were studies that considered the type of healthcare facility as a factor causing disparity in the treatment of heart disease (Bradley et al., 2004; Chen et al., 2001; Groeneveld et al., 2003; Jacobi, et al., 2007; Sabatine et al., 2005; Trivedi et al., 2006; Vaccarino et al., 2005). University and teaching hospitals are considered to provide a higher quality of care when compared to community hospitals (Sabatine; Trivedi). The quality of the healthcare facility was seen as a factor in whether patients receive cardiac procedures (Chen; Groeneveld; Sabatine; Vaccarino). Racial/ethnic minorities are at nearly twice the amount of excess risk for adverse outcomes when treated in a community hospital versus a university hospital (Sabatine). An increased length of time to receive life-saving therapy in an emergency resulted in death and disability (Bradley; Trivedi). There was one study which demonstrated how the simple use of a critical pathway completely eliminated disparity in revascularization (Jacobi et al., 2007).
While the minimum number of cardiac catheterizations needed to confirm adequate skills have never been validated, low-volume cardiologists should only practice in high-volume facilities (Bashore et al., 2001). There is a direct correlation between laboratory, cardiologist volume, and outcomes (Bashore). Low-volume cardiologists in low-volume facilities should not perform percutaneous coronary interventions (Bashore). There is a direct effect on quality of care and patient outcomes when these guidelines are not adhered to (Trivedi et al., 2006).

While not included in this literature review, trust of healthcare providers has also been cited as a reason for minority patients not to receive life-saving medical therapies (Keating et al., 2004; LaVeist et al., 2000; Lillie-Blanton et al., 2000; Thom, Kravitz, Bell, Krupat, & Azari, 2002). There were two studies that identified that the patient’s decision or beliefs affected the outcome of the patient not receiving the recommended therapies (Allen et al., 2004; Russo et al., 2003). This may indicate mistrust of the healthcare system. The patient’s refusal of certain therapies may also indicate a need for patient education or even a lack of cultural awareness in the treatment of diverse populations.

Self-Management/ Self-Care Factors Related to Racial/Ethnic Minorities

One study demonstrated how Hispanic and African American patients had significantly lower confidence in their ability to self-manage CHD, when compared to Whites (Blustein, Valentine, Mead, & Regenstein, 2008). Therefore, there was racial disparity in confidence to self-manage. This disparity was associated with poorer health profiles, disproportionately lower income and education levels, and higher levels of physical disability (Blustein et al., 2008). One study demonstrated favorable outcomes
with *self-management* interventions in a Spanish speaking Hispanic cohort with heart
disease and other chronic illness (Lorig, Ritter, & Gonzalez, 2003). The long-term
positive benefits of fewer emergency room visits, increased healthful behaviors, and
improved health status at one year (Lorig et al., 2003). Thus, the benefits of *self-
management* transcend race and ethnicity in certain studies (Lorig). The findings of this
study may be related to the unobserved effects (taking pride in being the focus of a study)
or the group being aware that the study focused on an intervention specially designed for
this population (Hawthorne effect).

While *self-management* is effective, it would appear to be less effective among
African Americans than Whites and other racial/ethnic minorities (Lin et al., 2008; Lorig,
Ritter, & Gonzalez, 2003). This difference would appear to be more pronounced among
older Blacks (Gitlin, et al., 2008). In a phenomenological study exploring perceptions of
*self-care* and reflections after an acute myocardial infarction, African Americans
expressed fear of dying and not having their needs met in the hospital (Coye, 2009). The
*self-management* study with older African Americans showed small improvements in
time spent in physical activities, use of cognitive symptom management, social role
function, health distress, and *self-efficacy* (Gitlin).

Unfortunately, there was no significant improvement in communicating with
providers. Nor was there improvement in self-rated health, disability status, or health
utilization indicators (Gitlin et al., 2008). It is unclear whether the age of the participants
was a factor contributing to the lack of improvement in self-rated health. The most
critical barrier to maintaining a *self-management* program in a community setting was
sustaining funding (Gitlin).
Summary Analyses of Literature, Gaps, Strengths and Limitations

Undoubtedly, disparity in the treatment of CHD of African Americans persists. There is strong evidence to support the need for more critical pathways that eliminate the opportunity for bias and treat individuals according to diagnosis and clinical presentation. Health-related decision making is a task that is important for all individuals managing CHD. Decision aides have shown some benefit, but they are not as effective for the most vulnerable patients. Unfortunately, most studies of self-management and self-care strategies have found them to be more successful with Whites than racial/ethnic minorities (specifically older African Americans).

The limitations of the studies in this review is that most were not designed to dissect the majority of the social determinants that result in the inequity of the provision of healthcare. Only twelve percent of the studies in this review attempted to explore the patient’s decision to receive recommended therapies. The six studies in this review that utilized qualitative methods yielded rich subjective data regarding the challenges of the lived experience after a cardiovascular event. The qualitative studies in this review were very informative regarding African American’s perceptions regarding the task of health-related decision making. The majority of the studies in this literature review were prospective analysis (24%) or retrospective cohort studies (37%).

General Summary of Key Points

This literature review showed the importance of self-efficacy in self-management, self-care, and health-related decision making. Unfortunately, it is unclear why some African Americans do not achieve an increased level of self-efficacy with interventions designed to enhance an individual’s ability to become more active in managing their
health. Data from this review does not adequately address the lived experience of older African Americans managing CHD. This study addressed the knowledge gap of daily life of individuals who have experienced discrimination and disenfranchisement as they try to navigate the healthcare system and manage the day-to-day challenges of living with CHD.

It is important to note the American Heart Association has developed recommended protocols to eliminate disparity in the treatment of heart disease resulting from the clinician’s decision. Mission: Lifeline is a national initiative initiated by the American Heart Association (AHA) which is designed to minimize the time lag between symptom identification to coronary intervention (AHA, 2011). Theoretically, this should eliminate racial/ethnic discrimination in the evaluation and treatment of CHD among African Americans.
Chapter 3  
Methods  

The purpose of this study was to explore the experience of older African Americans managing coronary heart disease (CHD). A hermeneutic phenomenological research method was chosen to examine the themes that affect the day-to-day health-related decision making of older African Americans who suffered an acute coronary syndrome as they managed CHD. This chapter will address the research design, sampling method, data collection procedures, data analysis, ethical issues and the rationale for these choices. The chapter will conclude with a discussion of ensuring rigor of the study.

The aim of this study was to understand the perceptions and experiences of older African Americans and how they accommodate to being-in-the-world making health-related decisions regarding the day-to-day challenges of managing CHD. Complexity science theory, which views humans as whole systems of interactions with others and objects in their environment, provided the framework for conducting this study (Sweeney & Griffiths, 2002, p.2; Cilliers, 1998, p.4; Rehorick & Bentz, 2008, p. 3). Hermeneutic phenomenology provided a means for capturing the essence of these interactions (Rehorick & Bentz). These interactions are fused with meaning, and language that are fundamental to sustaining life (Cilliers, 1998, p.3; Rehorick & Bentz, 2008, p. 4).

In this study, the simple rules of complex adaptive systems were the human level rules that were expressed by instincts, constructs, and mental models (Plsek and Greenhalgh, 2001). Such as the patient’s ideas, concerns and expectations of what the experience of living with CHD would be (Plsek & Greenhalgh). The rules are not explicit
and appeared irrational at times (Plsek & Greenhalgh). However, the rules demonstrated logical relationships between concepts in the model of the CAS (Cilliers, 1998, p.15).

Design

Phenomenology

Phenomenology is derived from an international historical movement of philosophical tradition that began with Edmund Husserl in the early twentieth century (Smith, 2008; Speziale, & Carpenter, 2007, p.78; Craig, 1998, p. 333). The focus of the movement began in Germany in the 1930’s, shifted to France in the 1960’s, and ultimately had a great part of its inspiration from the United States (Craig, 1998, p. 340; Smith). The phenomenological approach espouses: opposition to natural laws, opposition to speculative thinking, preoccupation with language, a technique of reflection on human experience, and analysis that produces descriptions and interpretations (Craig, 1998, p. 334). The researcher in this study sought to understand the lifeworld of the participants in an effort to understand the human experience or act of an older African American in the Midwest living with CHD.

The text that the researcher collected as data was condensed into words and phrases that were used to describe and interpret a unique human experience. Hence, contrary to the natural scientific techniques, this phenomenological approach did not seek to use reductionistic methods to control, test, or explain phenomena. The researcher did not seek to test a hypothesis or explain cause and affect relationships. Rather, the researcher’s focus was on language and how the participant used verbal and nonverbal communication to describe their world.
Phenomenology is the science of structures of personal experiences (Smith, 2008; Van Manen, 1990, p. 183). Intentionality is the central structure of that experience (Smith). An experience is directed toward an object (Smith). There are four main intercommunicating approaches to phenomenology: realistic, constitutive, existential, and hermeneutical (Craig, 1998, p. 334). Each approach has unique methods and defining characteristics.

Realistic phenomenology focuses on the structures of consciousness and intentionality (Craig, 1998, p. 334; Smith, 2008). Realistic phenomenology relies on the postulate that lived experiences occur in a world that is external to consciousness and is not created by consciousness (Smith). The leading figures in its development were Nicoli Hartmann, Roman Ingarden, Adolf Reinach and Max Scheler (Craig, 1998, p. 334). This approach emphasizes Husserl’s eidetic method, which allows the researcher to collect a systematic body of knowledge a priori by suspending beliefs in any actual facts during data collection (Craig, 1998, p. 335).

Constitutive phenomenology’s founding text is the first book of Husserl’s *Ideen zu einer reinen Phanomenologie und phanomenologischen philosophie* (Ideas pertaining to a pure phenomenology and to a phenomenological philosophy), published in 1913(Craig, 1998, p. 336). Constitutive phenomenology emphasizes accounting for objects in terms of the consciousness of them (Craig, 1998, p. 334). The main concern of this approach is to analyze the constitution of a matter which was refined by Dorian Cairns, Aron Gurwitsch, and Alfred Schultz (Craig, 1998, p. 334).

Martin Heidegger, Hannah Arendt, Jean-Paul Sartre, Maurice Merleau-Ponty and Simone de Beauvior were most influential in existential phenomenology (Craig, 1998, p.

Hermeneutic phenomenology emphasizes the role of interpretation in all spheres of life (Craig, 1998, p. 334). Hermeneutics is the study of interpretation in which the aim is to understand the author of the text (Van Manen, 1990, p. 179). Phenomenology is the attempt to describe and interpret the lifeworld (lived experience) (Van Manen, 1990, p. 11). The lifeworld is defined by Husserl as the natural attitude of everyday life as the original, pre-reflective, pre-theoretical attitude (Van Manen, 1990, p. 7). While all forms of phenomenology are derived from the “descriptive” phenomenology of Husserl’s second major work (Logical Investigations), hermeneutic phenomenology is both descriptive and interpretive (Creswell, 2003, p. 182; Omery, & Mack, 1995, p.149; Cohen & Omery, 1994).

Hermeneutic phenomenology is the approach that was used in this study. Martin Heidegger, Hans-George Gadamer, and Paul Ricoeur were the key players in this tendency (Craig, 1998, p. 334). Intentionality refers to the inseparable connectedness of the human being to the world (Van Manen, 1990, p. 181). According to the hermeneutic
phenomenological approach, the fundamental structure of consciousness is intentional and composed of the object that presents itself and the awareness of itself (Reisman, 2007, p. 28; Van Manen, 1990, p. 182). In other words, all thinking is always concerned with thinking of something and every action is directed or oriented toward an object (Reisman, 2007, p. 28; Van Manen, 1990, p. 182). Moreover, all awareness is conscious of something (Reisman, 2007, p. 28). This self-consciousness is pre-reflective; hence intentionality is only retrospectively possible (Reisman, 2007, p. 28; Van Manen, 1990, p. 182). It is not possible to have an experience and reflect on that experience while you are still in the moment of the experience (Van Manen, 1990, p. 182). As one begins to reflect on the experience, the emotions of the experience begin to fade during the analysis (Van Manen, 1990, p. 182).

Heideggerian phenomenology views the person as a “self” within the body. The participant’s world is shaped by the “self” and vice versa. Gadamer (a student of Heidegger) and Ricoer (studied Hussserl) further developed hermeneutic phenomenology by exploring: the role of language, the nature of questioning, the phenomenology of the human conversation, the significance of prejudice, historically, and tradition in the human project of understanding (Mulhall, 1996, p. x; Denzin & Lincoln, 2005, p. 27).

Social scientists and nurse researchers in the direct investigation and description of phenomena as experienced in life have utilized hermeneutic phenomenology (Crist & Tanner, 2003; Van der Zalm & Bergum, 2000). Hermeneutics utilizes reflective methods to uncover hidden meaning (Omery, & Mack, 1995, p. 149; Benner, 1994, p. 351). As an inductive research method, hermeneutic phenomenology enables access to phenomena that are often subconscious experiences (Creswell, 2003, p. 182). The experience of older
African Americans managing CHD is a complex nonlinear phenomenon that involves the interaction of multiple CAS that are continuously evolving. The hermeneutic phenomenological method enables the researcher to uncover the social phenomena holistically (Creswell, 2003,p. 182).

There are five assumptions of hermeneutic phenomenology. First, “human beings are social, and dialogical beings” (Benner, 1994,p. 71). Humans interact and build relationships through conversation. The object of conversations is often to explore or understand an issue and to reflect on themes and general meaning of the topic of discussion. Second, “understanding is always before us in the shared background practices; it is in the human community of societies and cultures, in the language, in our skills and activities, and in our inter-subjective and common meanings” (Benner, 1994,p. 71). The world is viewed as a meaningful set of relationships, practices, and language that are a result of cultural influence (Benner, 1994,p. 46). World is a priori, in the sense that it is understood and apparent in every instance of being-in-the-world (Benner, 1994,p. 46). It is the shared language, everyday skills and cultural practices that humans depend on for comprehension of the world (Benner, 1994,p. 46).

A third assumption is, “we are always already in a hermeneutic circle of understanding”; that is hermeneutic analysis is iterative in nature and finding meaning in text requires going back and forth between the overall interpretation and the details that stand out as significant for a specific reading (Benner, 1994,p. 71; Dreyfus, 1991, p.36). The new details can modify the overall interpretation and lead to the revelation of new significant details (Dreyfus, 1991, p.36).
Fourth, “Interpretation presupposes a shared understanding and therefore has a three-fold fore-structure of understanding” (Benner, 1994, p. 71). The fore-structure includes a fore having, a foresight, and a fore-conception (Benner, 1994, p. 72). Fore having is the background knowledge and understanding that we come to a situation with that gives it a practical familiarity (Benner, 1994, p. 72). Foresight is the point of view that results from our world experiences that we use to make an interpretation (Benner, 1994, p. 72). Fore-conception is the expectation of what to expect in an interpretation based on previous world experience (Benner, 1994, p. 72).

Last, “Interpretation involves the interpreter and the interpreted in a dialogical relationship” (Benner, 1994, p. 71). The interpreter brings his or her own understanding of a phenomenon to a situation. This understanding is a result of the interpreter’s life experiences. Therefore, the dialogue is ultimately guided by the interpreter’s previous understanding of the phenomenon of interest.

Hermeneutic phenomenology differs from other types of phenomenology in that it focuses on *Dasein*: the mode of being human or “being there” (Cohen, Kahn, Steeves, 2000, p. 5; Mulhall, 1996, p. 13; Benner, 1994, p. 36). According to Heidegger, humans are masters of their world, continuously accommodating to being-in-the-world, and prepared to do whatever is appropriate (Dreyfus, 1991, p. 104). Being-in-the-world or holistic background coping is the foundation of perception (Dreyfus, 1991, p. 104). Just as classical Husserlian phenomenology, this approach is concerned with human experience as it is lived (Creswell, 2003, p. 15).

There are several interpretations of the phenomenological methods that act as guidelines to this approach. This study referenced the steps as informed by Van Manen
The philosophical underpinnings of hermeneutic phenomenology as informed by Van Manen (1990, p.5) acknowledge individuals as being inextricably situated in their world (Crist, & Tanner, 2003). This methodology is concerned with the ability to be reflective, insightful, and sensitive to language and constantly open to experience (Van Manen, 1990, p. 2). The fundamental model of this study focused on the textual reflection of older African Americans on the day-to-day experience of managing CHD (Van Manen, 1990, p. 78). The researcher engaged in the six research activities seen as dynamically interrelated to interpretive research. These activities were utilized as guidelines for the development of research protocol and development of opening/probing questions (Van Manen, 1990, p.42).

First, the researcher chose a phenomenon to which she was seriously interested and committed (Van Manen, 1990, p.30). Second, the investigation was of an experience as it was lived rather than as it was conceptualized (Van Manen, 1990, p.30). Third, the researcher reflected on essential themes characteristic of the phenomenon (Van Manen, 1990, p.30). Fourth, the researcher described the phenomenon through written text (Van Manen, 1990, p.30). Fifth, the researcher maintained a strong and pedagogical relationship to the phenomenon (Van Manen, 1990, p.31). Last, the researcher considered the whole as well as the sum of its parts (Van Manen, 1990, p.31).

Phenomenologists ask questions about how people interpret lived experiences of chronic illness, growing old and dying (Cohen, Kahn, Steeves, 2000, p. 8). Complexity science theory suggests that the participants of any investigation are constantly collecting data from their environment, choosing what is relevant, and utilizing that information to guide its reactive and proactive behavior (Merry, 1995, p.183). The researcher used data
from the in-depth interviews in an attempt to uncover and describe the essential, invariant structure (or essence) of living through the diagnosis and treatment of CHD as an older African American. This study re-examined the taken for granted/forgotten experiences of older African Americans that affected their decision making as they managed CHD.

Setting

This study was conducted in a large metropolitan hospital (University Hospitals of Cleveland Case Medical Center) in the mid-western region of the United States. Between 2005-2007 the United States census bureau (USCB) estimated this city had a total population of 405,014 (USCB, 2009). Of that total, there were: 159,543 Whites, 214,037 Blacks, 33,524 Hispanics and 7,902 American Indian and Asians (USCB). Additionally, the facility has the second busiest emergency room in Northeast Ohio servicing 73,000 individuals from Cleveland as well as the surrounding areas (University Hospitals, 2009).

The 1032 bed tertiary care medical center partners with a private university (Case Western Reserve) to form a large biomedical research center (University Hospitals, 2009). The medical center is staffed by some of the nation’s foremost experts in cardiac and vascular surgery, electrophysiology, cardiovascular imaging, minimally invasive interventions, heart failure treatment and transplantation, arrhythmias, stem cell regeneration and prevention strategies and is ranked one of America’s best hospitals in six medical and surgical specialties (University Hospitals). The medical center has achieved magnet status by the American Nurse Credentialing Center for excellence in nursing services, exemplary nursing leadership, and quality patient care (University Hospitals). The facility has also received the Beacon award for critical care excellence by
the American Association of Critical Care Nurses and has been recognized as one of the nation’s top hospitals’ critical care units for their medical intensive care unit (University Hospitals). This institution has adopted the American Heart Association guidelines and protocols for the management of acute coronary syndrome.

Each of the cardiology clinics provides service to approximately 4,000 patients annually. The facility is equipped to provide comprehensive cardiac care for a variety of inpatient and outpatient medical and surgical services. The outpatient cardiology clinics consist of the medical team and nurse practitioners who have access to the referral services of the main hospital. Referral services include but are not limited to social workers, psychiatrists, physical therapists, occupational therapists, and dieticians.

Sample

The targeted population was African American male and female patients over age forty-five who have been admitted to the cardiac catheterization laboratory to diagnose the presence of CHD. The sample contained 4 males and 4 females. The goal of participant selection in hermeneutic phenomenology was to select individuals who had a shared experience of interest, yet are diverse enough from one another to yield a rich textual description of it (Van Manen, 1990, p.7). The purposive sampling method was chosen, and is the recommended sampling technique for this type of research method (Streubert & Carpenter, 2007, p.94; Denzin & Lincoln, 2005,p.451).

The sample size for the in-depth interviews was intentionally small to allow for breadth and depth of responses. The researcher checked for saturation among males and females. The size of the sample, not to exceed ten males and ten females was considered adequate when findings were clear and no new themes emerged (Crist, & Tanner, 2003).
Once the researcher reached the point in data collection and analysis in which no new ideas emerged, one additional set of interviews in each group beyond the point of saturation completed data collection. The achievement of saturation was be verified with the researcher’s colleagues.

**Inclusion Criteria**

The criteria for selection of participants were: African American males and females over ages 45 who were admitted to the cardiac catheterization laboratory with acute coronary syndrome. This age range had been chosen because most American men have their first cardiovascular event at ages 35 to 44, and women ages 45 to 54 (AHA, 2009). Additionally, CHD accounts for a higher proportion of CVD in men and women before age 75 (AHA, 2009). The aim of this study was to capture the perceptions and lived experiences of older African Americans managing CHD that was newly diagnosed.

Participants were required to be able to understand, read, write and speak English fluently. Informed consent had been obtained within six months of the initial diagnosis. Research has shown that older women who live alone, and lack social support before an acute MI are at a higher risk of mortality within the first six months, therefore the researcher attempted to collect data within that six month time period (Kerr, & Fothergill-Bourbonnais, 2002). The researcher sought to include participants who were admitted to the emergency room via ambulance or life flight with an acute myocardial infarction. Participants were required to be clinically stable at the time of data collection.

The researcher was aware that special efforts were needed to recruit and enroll minorities into research protocols, due to the racism they had likely experienced in the healthcare setting and society at large (Cohen, Kahn, Steeves, 2000, p. 43). The
researcher made every effort to ease any anxiety the participant may have had about the project by fully explaining the procedures, allowing ample time for questions, and by approaching them with respect.

Exclusion Criteria

The researcher excluded potential participants who were scheduled follow-up with the researcher’s outpatient cardiology clinical practice and would potentially be her clinical responsibility. This was intended to decrease the potential for any perceived coercion regarding the care they received (Cohen, Kahn, Steeves, 2000, p. 38). To better understand the experience of managing CHD, individuals with terminal medical conditions were excluded from the study. Potential participants with a diagnosis of dementia and any other cognitive impairment that would limit their ability to express themselves coherently were excluded from the study. The researcher described the planned procedures of the study to the participant and asked them to repeat the procedures back to the researcher. If the participant could repeat the planned procedure coherently to the researcher, then the researcher was assured of the participant’s understanding of the procedures.

Informed Consent

When obtaining the informed consent, the importance of each participant undergoing two interviews was reiterated. Therefore persons who were not willing or felt they were physically unable to undergo two in-depth semi-structured interviews were excluded. If the researcher found the client to become physically uncomfortable (exhibiting facial grimacing/ outward signs of pain) during the interviews, the researcher was prepared to reevaluate their participation in the study.
Researcher Presuppositions

The race, class, ethnicity, gender and professional role of the researcher had an effect on the interview (Denzin & Lincoln, 2005, p. 643). Not only was the researcher an African American female, but also she grew up in the same city as many of the participants and had the cultural knowledge necessary to accurately interpret and validate the experiences of participants. Additionally, the researcher had experience within the context of assisting an older family member as she managed the day-to-day health-related decision making of living with CHD.

Presuppositions

- Influenced by experience as African American female
- Influenced by experience as cardiology nurse practitioner
- Defines disparity as inequity in access/quality of care
- Did not anticipate participant openness with discussing thoughts of death and dying

Recruitment Procedure

The researcher met with the Director of the Center for Research and Innovation who is also the Medical Director of the cardiac catheterization laboratory (cath lab) to obtain permission to have access to patients who were admitted to the medical center for cardiac catheterizations. Additionally, the researcher met with the nurse manager of the cath lab to ask permission to request assistance from the staff in identifying African American patients with newly diagnosed CHD. Once permissions were granted the researcher met with the nurse practitioner and physician assistant who worked in the cath lab to explain the study and request support in identifying potential participants. Last, the
researcher met with the nurses in the cardiac intensive care unit to inform them of the study and ask for support with identifying potential study participants.

Routine visits were made by the researcher to the catheterization laboratory and coronary intensive care unit. The staff would tell potential participants about the research study and ask if the patient was interested in participating. If the patient said yes, the staff would introduce the patient to the researcher. The researcher would give a more detailed explanation of the study and confirm interest in participation. The researcher would ask the participant for permission to contact the patient in three to four weeks to set up an interview. Participants were informed of the need for them to choose an interview location that would allow for their privacy. All patients were reminded of their right to withdraw from participation at any time during the process.

Procedure

After informed consent was obtained, the demographic questionnaire was used to obtain information regarding self-identified racial identity, age, gender, marital status, religion, education, occupation, and income. The demographic data was helpful to confirm that the participants were members of the population of interest. The demographic data questionnaire was designed to capture participant characteristics that may not have been apparent during the interview. A roster of research participants was maintained until data analysis was completed. The identifying demographic data (name, birth date, etc.) was destroyed after the completion of data analysis.

The use of interviews in hermeneutic phenomenology was multipurpose. First, the interview was utilized to gain rapport with the participant and develop a conversational relationship, which encouraged reflection (Streubert & Carpenter, 2007, p.38; Denzin &
Lincoln, 2005, p. 643). Second, it was utilized as a means of facilitating the expression of the participant’s narratives of lifeworld experiences (Streubert & Carpenter, 2007, p. 95; Denzin & Lincoln, 2005, p. 642; Van Manen, 1990, p. 35). Third, this method allowed the researcher to compare data across interviews (Streubert & Carpenter, 2007, p. 96).

Data Collection

Nursing staff in the cardiac catheterization laboratory provided potential participants with handouts that briefly described the purpose of the study. Flyers with the contact information of the researcher were given to potential participants. Participants identified as having CHD underwent interviews spaced one week apart, or less (Seidman, 1998, p. 13). The time between the interviews allowed the participant to reflect on the previous interview (Seidman, 1998, p. 15). This model of phenomenological interviewing gave the researcher the opportunity to explore the meaning of the participant’s lived experience in the context of their natural setting (Seidman, 1998, p. 11).

The researcher conducted two in-depth interviews designed to elicit candid responses regarding the experience of living with CHD. Two interviews separated by several days allowed the participant time to reflect on the topic at hand between interviews. The interviews were conducted in a natural setting of the participant’s choice. Open-ended in-depth interviews lasted between thirty to ninety minutes. The researcher called the participant in advance to confirm the date, time, and place chosen by the participant. The participant was reminded of the sensitive nature of the discussion and the importance of choosing a location in which confidentiality would be maintained. The participant was advised that he or she could change the meeting location at any time if they felt a threat of breach in confidentiality.
The first interview is focused on the life of the participant and the events that lead to their diagnosis of CHD (Seidman, 1998, p. 11). The participant was asked to reflect on their health experiences. Next the participant was asked what having the condition meant to them. The researcher also explored the details of living with CHD (Seidman, 1998, p. 12). The researcher began with questions regarding the type of physical activities the participant had been able to complete in the past and how this had changed since the diagnosis. The participant was asked to tell a story about a time when they realized that they had new physical limitations. The interview was concluded with the participant describing how the media influenced the management of their illness.

The second interview allowed the participant to reflect on the meaning of managing CHD and how it affected their lifeworld (Seidman, 1998, p. 12; Van Manen, 1990). Examples of questions included, “What happened when you were rushed to the hospital with the heart attack?” Next, the researcher asked elaborative probes, such as, “Where were you when the emergency occurred?” The researcher inquired about the participant’s relationship with their healthcare provider and how it had changed since the diagnosis. Finally, the researcher asked, about the negative and positive experiences resulting from the diagnosis. The researcher concluded with having the participant describe how they cope with the experience of living with heart disease.

The two in-depth interview strategy was chosen because it was congruent with the constructivist paradigm and research methodology. The researcher was the principal data collector. Being African American facilitated an advantage in establishing rapport with the participants. A culturally sensitive research approach was utilized, to ensure that the
way the participant’s understood and experienced their world was portrayed as accurately as possible (Denzin & Lincoln, 2005, p. 127).

The population of interest consisted of individuals who express the language of their tradition and culture similar to that of the researcher, therefore the researcher had an advantage in obtaining uninhibited audio-taped interviews (Cohen, Kahn, Steeves, 2000, p. 45). The researcher audio recorded interviews (Speziale, & Carpenter, 2007, p.96). The researcher recorded notes intermittently and unobtrusively, to document non-verbal communication, memo personal reactions and increase the accuracy of data collection during and following each interview (Streubert & Carpenter, 2007, p.96). At the time of each interview, willingness to participate was reaffirmed.

The researcher gained experience with qualitative research approaches as a graduate student in inquiry practicum and as a teaching assistant for a graduate level qualitative nursing research course. As a graduate level student, the researcher performed transcription of tape-recorded interviews. The researcher also had experience with checking transcriptions for errors for a focus group seminar in qualitative research. Additionally, the researcher gained experience with taking field notes as a teaching assistant participating in a focus group. The researcher transcribed and checked all transcription with the audio recordings and made corrections as needed. The researcher enlisted the assistance of an experienced phenomenologist as a second reader of data.

Data Management

The demographic data was collected and stored in a password protected computer file with access restricted to the researcher. The statistical package for the social sciences (SPSS) is the software package that will be utilized for the summary of demographic
data. This data was kept separate from the data collected during interviews. The identifying information was destroyed at the completion of data analysis. The researcher transcribed audio files into a Microsoft word program.

Data Analyses

An examination of the data began concurrently with data collection (Beck, 2008; Speziale, & Carpenter, 2007, p.96). Interviewing is the traditional technique utilized to capture and communicate a description of a lived experience (Cohen, Kahn, Steeves, 2000, p. 43; Van Manen, 1990, p.62). Furthermore, the researcher intended to illuminate the essence of managing CHD as an older African American (Van Manen, 1990, p.62). The goal of the analysis was to understand what being an older African American managing CHD is like for that person (Van Manen, 1990, p.62).

Hermeneutic phenomenology was utilized to identify recurring themes and patterns of meaning. The interviews were audio taped using two recording devices, in the event one should fail. The researcher transcribed the audiotapes. The transcription had a column to the right to allow the researcher to write notes regarding units of general meaning (Hyncer, 1985).

Bracketing and phenomenological reduction were utilized to elicit units of general meaning and allow openness to whatever meanings emerge (Beck, 2008; Hyncer, 1985). The researcher made a conscious effort to overcome her feelings, preferences, inclinations, and expectations and entered into the unique world of the person being interviewed (Beck ; Hyncer ; Van Manen, 1990, p.185). In the essence of reduction, it was important to see the particularity of the lived experience of each individual, as well as the universal essence that existed above and beyond the concreteness of the lived
meaning (Van Manen, 1990, p.185). Bracketing was the act of suspending one’s beliefs in order to study the structures of the lifeworld of the participant (Van Manen, 1990, p.175). The researcher’s response to the conversations was written in the margin or “bracketed” to allow the emergence of a meaningful interview (Hyncer). The researcher made a conscious effort to be open to the phenomenon through phenomenological reduction. There were several distinguishing levels of reduction.

Once the researcher bracketed presuppositions, a sense of the interview as a whole was acquired. To get a sense of the whole the researcher needed to listen to the entire tape several times in addition to reading the transcript several times (Beck, 2008; Hyncer, 1985). Specific units of meaning and themes emerged as the researcher became immersed in the context and content of the interview (Beck; Hyncer). Theme is the experience of focus and is the form of capturing the phenomenon one tries to understand (Van Manen, 1990, p.87). Careful attention was paid to the verbal and non-verbal communication (Hyncer).

The transcription was read multiple times and key words/phrases in the text were highlighted (Beck, 2008; Hyncer, 1985). The key phrases were summarized and clustered into categories and subsequently into themes. This process unearthed what the participant said by condensing a large amount of data into a few words (Hyncer). As the context of general themes became clear, units of meaning relating to the research question were identified (Beck; Hyncer). The researcher interpreted the data and chose an experienced phenomenologist to verify the units of relevant meaning. The researcher reviewed the units of meaning relating to the research question and eliminated any redundancies (Hyncer). Relevant units of meaning were separated into clusters of meanings (Hyncer).
Once the units of meanings were clustered, the researcher identified a common/central theme among the clusters (Hyncer). The clusters of meanings were given names (Beck). There were seven themes. Finally, a summary of each interview was written (Hyncer).

The approach was complementary to the CAS framework as it viewed the participant as “being” within a time framework that was influenced by their past, present and future. This post-constructuralist approach was chosen because the researcher agreed that validity was subject to possible revision by new evidence (Seale, 1999, pp.52). This approach acknowledged the participant as the only reliable source of information regarding the topic of interest. The participant was understood in the context of his or her own lifeworld. It was the researcher’s responsibility to accurately interpret the explanation provided by the participant. An audit log was maintained to enhance the confirmability of results from this study.

Trustworthiness

This qualitative study attended to three issues of trustworthiness. These issues of trustworthiness (parallel criteria) were: credibility, transferability, and dependability. As quantitative researchers rely on internal validity, qualitative researchers rely on trustworthiness and authenticity criteria to evaluate the adequacy of scientific inquiry (Guba & Lincoln, 1989, p. 233; Speziale, & Carpenter, 2007, p.49). Trustworthiness of the interview questions depended on the degree to which they elicited an exhaustive description of the participant’s lifeworld experience (Speziale, & Carpenter, 2007, p. 97).

Credibility

An essential criterion for establishing trustworthiness was establishing credibility (Ajjawi & Higgs, 2007; Guba & Lincoln, 1989, p. 237). Credibility was achieved when
there was a match between the constructed realities of the study participant and the reality represented by the researcher (Ajjawi & Higgs; Guba & Lincoln, 1989, p. 237). The techniques utilized to increase credibility in this study were: member checks, peer debriefing, negative case analysis, and progressive subjectivity (Guba & Lincoln, 1989, p. 237). The techniques most suitable for establishing credibility in this study are member checks, peer debriefing and negative case analysis.

Most importantly, once the summary was prepared, the researcher gave the participant the opportunity to confirm or correct their interpretations of what had been discussed. This is member checking (Guba & Lincoln, 1989, p. 238; Speziale, & Carpenter, 2007, p.49). Member checking involves having discussions with participants to seek feedback regarding the emerging analysis and the accuracy of its portrayal of their constructed realities (Guba & Lincoln, 1989, p. 238; Speziale, & Carpenter, 2007, p.49). The study was only credible if the participant recognized the descriptions as true to their own experiences and perceptions. If the participant did not identify the authenticity of the description, the researcher made revisions, until the participant’s experience was accurately represented. The researcher performed a member check after each initial interview to confirm an accurate representation of the participant’s thoughts and ideas.

The second interview essentially repeated the procedures delineated in the first interview. Once the second interview was analyzed and summarized, the researcher reviewed the data as a whole and made revisions as necessary (Hyncer, 1985). Thematic analysis was performed across cases to clarify common meanings. General and unique themes for all interviews were identified (Hyncer). The researcher constructed a composite summary of all the interviews to capture the essence of the phenomenon
(Hyncer). The research committee was consulted intermittently throughout this process to provide checks of the rigor and judgment of the researcher (Hyncer).

While maintaining confidentiality of the study, the researcher routinely completed the process of peer debriefing, this involved engaging a peer in extended and extensive discussions of the findings (Guba & Lincoln, 1989, p. 237). The researcher utilized this process to clarify questions regarding research findings and data interpretations with someone who did not have a vested interest. Peer debriefing was useful in exposing the tacit and implicit information the researcher possesses. The peer person also posed questions and comments that assisted the researcher in self-reflection and clarification of her role in the research study. The researcher would meet approximately once a week with a peer graduate student and discussed the emerging themes of her study.

Negative case analysis involved exploring elements of the data that contradicted emerging patterns in data analysis (Guba & Lincoln, 1989, p. 237). This assisted in refining the analysis until it accounted for the majority of cases presented in the study. The analysis of negative cases led to the revision, expansion, and confirmation of the emerging patterns in the analysis. This process continued until all known cases were accounted for (Guba & Lincoln, 1989, p. 238). A negative case was identified among the male and female participants. Progressive subjectivity was more difficult to accomplish due to the limited number of interactions the researcher had with the participants.

Transferability

While transferability was not the primary goal of this qualitative inquiry, it was taken into consideration. Transferability of qualitative inquiry is comparable to generalizability of quantitative inquiry (Guba & Lincoln, 1989, p. 241). The principle
technique for establishing transferability was thick description. The process of thick
description is one wherein the describer provided the context and themes found to be
critical to illuminating the essence of the experience (Guba & Lincoln, 1989, p. 241).

Confirmability

Confirmability refers to the degree to which the findings of the research study can be
corroborated or confirmed by others. This can be done via negative case analysis,
audit log, or simply rechecking the data. Once no new themes emerged in the data, the
researcher attempted to find a negative case among the participants recruited. The audit
log will also be available if needed.

Human Subjects

The healthcare system institutional review board approved the study protocol
April 13, 2011. The potential participants learned about the study from flyers provided by
the cardiac catheterization laboratory staff. Once the participant expressed an interest in
the study, the researcher contacted them. The benefits and risks were explained to each
participant. Each participant received an individual informed consent. Once informed
consent was obtained, the researcher began the interview at the time and place chosen by
the participant.

The researcher reviewed the study procedures with the participant to ensure full
disclosure. All participants were reassured their identities would not be disclosed in any
report to ensure confidentiality. The researcher was sensitive to the fact the targeted
population had experienced research misconduct in the United States after the institution
of the Nuremberg code and Helsinki declaration (Shampoo & Khin-Maung-Gyi, 2002,
Hence, the researcher was aware of the importance of re-establishing public confidence in scientific research, especially among African Americans.

Being interviewed regarding certain aspects of one’s life can be stressful for some individuals. Therefore, the participants were made aware of the interview procedures, including how many, how much time each interview would take, and the possible adverse psychological effects of the interview. The benefits of participating in the research, to the participant, their family, and other African Americans with similar conditions were discussed. A detailed explanation of how the researcher would protect their privacy and prevent the disclosure of any information that could identify the participant, was read to each participant (Denzin & Lincoln, 2005, p. 715).

Participants recruited for this study had at least one comorbidity. The researcher was an experienced cardiology nurse practitioner, and was trained to respond to any medical emergency (should one arise during the interview process). During the interview process, the researcher monitored participants for signs of physical discomfort and psychological distress. Had the participant exhibited restlessness, facial grimacing, or a change in respiratory pattern, the researcher would have requested a break. If the participant had exhibited signs of emotional distress, the researcher would have ended the interview (if necessary).

In this study open-ended in-depth interviews were used to collect data. The use of interview procedures did not place the participants at risk of physical harm. There was the potential for participants to experience emotional distress, however this did not occur. The participants were informed of their right to withdraw participation in the study at any time without loss of any benefits or services they would otherwise receive. The consent
form contained all the information listed above and was presented in a manner best understood by the participant.

All participants were provided information sheets detailing the aims of the research and research process. Participants were instructed to read an informational letter that: fully described the study, and contained the contact information for only the principal investigator (PI). The participants were given the opportunity to ask questions about the research and reminded they could withdraw from the study at any time without negative consequences. The researcher did not enroll participants who were directly under her care, to assure that there were no existing power relations between the researcher and participant that could be interpreted as coercion.

The researcher realized that the interview process could be emotionally and physically stressful. At the onset of the interview, the participant was reminded that he or she could take a break at any time. With over ten years of experience as a nurse in cardiology and gerontology, the researcher had advanced assessment skills that allowed her to detect nonverbal signs of pain, fatigue, and stress. The researcher would have encouraged the participant to take a break at the midpoint of the interview and end the interview if signs of physical or emotional distress were detected.

Research records were retained on the Case Western Reserve University campus. Confidential data and records were stored in a locked file cabinet in a research office that had limited access to the principle investigator. This included the consent forms, data collection forms and any documents containing names, addresses or any other identifying information. Original documents were not removed from the office. The principal
investigator was responsible for the storage and retention of confidentiality of the copied data and records relating to research.
Chapter 4

Results and Discussion

The purpose of this study was to explore the experience of older African Americans who suffered an acute coronary syndrome (ACS) and were managing newly diagnosed coronary heart disease (CHD). A hermeneutic phenomenological research method was chosen to enhance the understanding of the themes that affected day-to-day health-related decision making patterns of older African Americans who had suffered an acute coronary syndrome as they lived the experience of being diagnosed with a life threatening illness. Understanding the perceptions and experiences of African Americans living with coronary heart disease can offer health care providers additional strategies to improve disease management. This chapter will describe the emergence of themes, the results of this study, and discussion.

Sample Description

The sample in this research study consisted of four African American males and four African American females over age forty-five who presented to the cardiac catheterization laboratory with an acute coronary syndrome and newly diagnosed CHD. Two of the four men were married and all of the women were single or widowed (see Table 1). The age of participants ranged from 51 to 72 years. The average age of male participants was 59.5 years. The average age of female participants was 66 years.

Table 1. Demographic Data

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Sex</th>
<th>Marital Status</th>
<th>Religion</th>
<th>Education</th>
<th>Employment</th>
<th>Insurance</th>
<th>Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1</td>
<td>65</td>
<td>F</td>
<td>Widow</td>
<td>Jehovah</td>
<td>Diploma/</td>
<td>Retired</td>
<td>Medicare</td>
<td>0-20,000</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Witness</td>
<td>GED</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>A2</td>
<td>72</td>
<td>F</td>
<td>Single</td>
<td>Baptist</td>
<td>Some high school</td>
<td>Retired</td>
<td>Medicaid</td>
<td>0-20,000</td>
</tr>
<tr>
<td>A3</td>
<td>72</td>
<td>F</td>
<td>Widow</td>
<td>Christian</td>
<td>Some high school</td>
<td>Retired</td>
<td>Medicaid</td>
<td>0-20,000</td>
</tr>
<tr>
<td>A4</td>
<td>55</td>
<td>F</td>
<td>Single</td>
<td>Other</td>
<td>Diploma/ GED</td>
<td>Housekeeper</td>
<td>No insurance</td>
<td>20,000-39,999</td>
</tr>
<tr>
<td>B1</td>
<td>51</td>
<td>M</td>
<td>Divorced</td>
<td>Other</td>
<td>Vocational/ Trade school</td>
<td>Customer Service</td>
<td>Commercial</td>
<td>40,000+</td>
</tr>
<tr>
<td>B2</td>
<td>57</td>
<td>M</td>
<td>Single</td>
<td>Other</td>
<td>Some high school</td>
<td>General Laborer</td>
<td>No insurance</td>
<td>0-20,000</td>
</tr>
<tr>
<td>B3</td>
<td>59</td>
<td>M</td>
<td>Married</td>
<td>Other</td>
<td>Diploma/ GED</td>
<td>Retired</td>
<td>Commercial</td>
<td>0-20,000</td>
</tr>
<tr>
<td>B4</td>
<td>71</td>
<td>M</td>
<td>Married</td>
<td>Other</td>
<td>Diploma/ GED</td>
<td>Retired</td>
<td>Medicare</td>
<td>40,000+</td>
</tr>
</tbody>
</table>

The majority of the females (3) were retired with an income range of zero to $20,000. The one female who worked reported an income range of 20,000-39,999. Two of the four men were retired. One of the remaining two-reported unemployment status and the other worked full-time. Two of the men reported income ranges of zero to 20,000 while the other two reported an income range of 40,000 or more.

The participants in this study had similar education levels. Two women reported completing some high school and the other two received a diploma or general equivalency diploma (GED). The youngest of the men reported attending a vocational or trade school. Two men attained high school diplomas or a GED. Only one reported having some high school education without achieving a diploma or GED.
Results

There were six activities the researcher engaged in which are seen as dynamically interrelated to interpretive research. First, the researcher chose African Americans living with CHD as her phenomena of interest. Second, the researcher chose to interview participants’ one month status post-acute coronary syndrome to capture a sense of the experience as it is lived. Third, the researcher in collaboration with her qualitative expert and dissertation chair discussed what themes were essential to the experience of the phenomena of interest. Last, the researcher did a literature review to determine what characteristics most described the phenomena of being an African American with ACS and newly diagnosed CHD. It is important to note that there were two participants (A2, B4) who were on continuous oxygen therapy. The male participant’s (B4) wife assisted with his interview due to his propensity to experience dyspnea at rest. The wife and researcher were careful to confirm the participant’s perceptions and thoughts during and after the interviews.

A priori the researcher developed the line of questioning that would capture the essence of the lived experience of being an African American who experienced an acute coronary syndrome with newly diagnosed coronary heart disease and the process of making health-related decisions. This required multiple meetings with her dissertation committee, committee chair and qualitative expert. There were two research questions. First: What is the lived experience of managing CHD among African Americans? Second: What is the essence of health-related decision making among African Americans living with CHD?

Each participant completed two interviews. The first interview time ranged from 12
to 73 minutes. The second interview time ranged from 10 to 66 minutes. Each interview had an opening question with a line of more probing questions. After the researcher completed the first set of interviews, it became evident the order of open ended questioning from the first interview ultimately created redundancy in the answers of the second interview. The researcher consulted with her committee chair and qualitative expert. The decision was made to reverse the order of the questions. Hence, the questions for the first interview became the questions for the second interview and vice versa. This adjustment in the order of questioning affectively alleviated the redundancy in the results yielded.

The researcher envisioned herself as the participant and reflected on the words used to describe the feelings participants reported as the scenario evolved. The researcher listened carefully to the words used to describe the phenomena. There was a focus on assuring congruence between the researcher’s perception of the meaning of those words and the participant’s meaning of those words. The researcher compared the experiences of the men among one another, the women among one another and the group as individuals.

Themes

Each participant chose the setting of their interview. Participants were asked to reflect on their experience of being diagnosed with ACS and CHD. The interviews were audio-taped. The audio-taped interviews were listened to multiple times to get a raw data which consisted of 16 transcribed interviews. The text was condensed into data words and phrases that were utilized to describe and interpret their experiences of being diagnosed with ACS and CHD and the act of making health-related decisions. The
researcher enlisted the assistance of an experienced qualitative nurse scientist as a second reader of the transcripts. There was agreement regarding the seven themes noted.

Research Question 1) What is the lived experience of managing CHD among African Americans? The patterns, which emerged were coded and clustered into a total of seven themes (see Table. 2). The first three themes pertained to research question 1:

Perception of illness; Changes in quality of life; Perception of care. Initially use of technology was classified under coping strategies however it was decided that the use of technology yielded a positive change in the quality of life. Hence, the final decision was to list the use of technology as a characteristic of the theme changes in quality of life.

These themes suggest arriving at health-related decisions for older African Americans is multi-factorial. The decision making process was reiterative with unpredictable results that were influenced by the main themes in this study. Hence, the presence or absence of a theme did not reliably predict a pattern in health-related decision making.

Table 2. Themes

<table>
<thead>
<tr>
<th>Theme I: Perception of Illness</th>
<th>Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perception of the urgent need for medical attention</td>
<td></td>
</tr>
<tr>
<td>Delay in care</td>
<td></td>
</tr>
<tr>
<td>Perception of the moment they were told they had or were having a heart attack</td>
<td></td>
</tr>
<tr>
<td>Perception of how medication effects their bodies</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme II: Changes in Quality of Life</th>
<th>Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in lifestyle</td>
<td></td>
</tr>
<tr>
<td>Use of technology</td>
<td></td>
</tr>
<tr>
<td>Loss of freedom</td>
<td></td>
</tr>
<tr>
<td>Perceptions of ability</td>
<td></td>
</tr>
<tr>
<td>Feelings about food</td>
<td></td>
</tr>
<tr>
<td>Feelings of stress</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme III: Perceptions of</th>
<th>Descriptors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doubts about care</td>
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<td>Theme I. Perception of Illness</td>
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**Perception of illness, changes in quality of life, and perception of care** are the themes resulting from data related to the first research question (table 3). The phrases in the text that led to the **perception of illness** were: “I really didn’t realize they were symptoms”; “I felt something was, was wrong but it didn’t make me go to the hospital”; “I felt like there was an elephant sitting in my chest”; “No, actually, he wasn’t rushed to the hospital for a heart attack. He was rushed to the hospital because of pneumonia. He had shortness of breath”.

**B1: Perception of the urgent need for medical attention/ delay in care.** A 51 year old male was asked to describe what made him decide to go to the hospital. He explains that he did not have the typical symptoms one would expect from an acute coronary syndrome. He stated, “I just felt. I felt something was, was wrong but it didn’t make me go to the hospital”. He reported that he realized his condition was serious when he was told that he would be transferred to another facility for additional testing. “That’s a dead

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giveaway that something”s wrong”, he said. He later complained about the bill he received for the cost of the transfer.

**B1: Perception of the moment they were told they had or were having a heart attack.** The 51 year old male (B1) stated he was in disbelief when he was told about his heart condition and that he had also suffered a couple of strokes. “Hey, you guys must be wrong. Or this is a temporary thing cause I”m like; I”m already under a doctor”s care. And I go faithful; I go religiously to my primary care doctor”.

The participant (B1) admitted he was incapacitated when he was admitted to the hospital. He considered it to be a temporary situation. Participant B1 reported that he did not have the typical symptoms of a heart attack nor a stroke and he had a hard time accepting the diagnosis.

**B1: Perception of how medication affected their body.** Participant B1 was a participant who reported going to the doctor “religiously”. He reported being vigilant about taking his medication every day and on time. When he became sick he was surprised and disappointed. Then he seemed to suspect there was a problem with his medication. He verbalized the hope that they could adjust his medication and send him home. He also verbalized suspicion regarding the efficacy of the medication. He states, “that medicine never tasted right anyways”. He laughed after making the statement but he seemed to feel as if the medication failed him.

**B2 (57 years old): Perception of the urgent need for medical attention/ delay in care.** The second male participant who was interviewed (B2) was a 57 year old male who was with his fiancé when he began to have chest pain while sitting on the couch. His fiancé is the one who told him to call 9-1-1. He was rushed to the hospital in an
ambulance. He stated that he was surprised when the doctor told him he was having a heart attack. He stated, “it didn’t seem like it”. He stated that he was afraid.

B2: Perception of how medication affected their body. The 57 year old male reported the medication he was taking made him dizzy. He reported that his cardiologist ignored him when he reported this side effect to him. At the time of the interview the participant reported that he was not taking his medications as prescribed. He stated they were expensive and, “I can’t afford that”.

B3: Perception of the urgent need for medical attention/ delay in care. The third male participant (59 years old) stated that he awakened with, “Severe chest pains”. He admitted that he had been having chest pain for three days leading up to the severity he experienced that morning. When he awakened with chest pain he stated his wife was the one who asked, “Do you think you need to go to the hospital”? He agreed and went to take a shower. He reported that he became dizzy and went back to the bed. “I told her to call 9-1-1”, he said.

B3: Perception of the moment they were told they had or were having a heart attack. Participant B3 described the scene as the emergency medical transporters (EMT) came into his home and transported him to the hospital via ambulance. He reported the transporters seemed to have no doubt that he was having a heart attack. He stated that he wasn’t afraid, “I just took it”. He stated that it was not his first near death experience.

B3: Perception of how medication affected their body. Participant B3 stated the doctor told him that his heart should be working at 60 %. “Now I’m down to 20”, he stated. He reported that the cardiologist told him he could improve with adjustments to his medication regimen and a little hard work. He reported that when he had a follow up
appointment with the cardiologist he was told his heart might not be as badly damaged as originally suspected.

The third male participant relied on his wife to put his pills in a pill organizer. He did not report any side effects or concerns regarding his medication regimen. He also reported that the nurses educated him on his medications during his hospitalization.

B4: Perception of the urgent need for medical attention/ delay in care. The fourth participant was a 71 year old male who was initially rushed to the hospital because of shortness of breath. He was diagnosed with pneumonia. At some point between 5 am and 3 pm he had a silent heart attack. When they found he was having a heart attack, he was admitted to the hospital. This participant was also diagnosed with lung disease during that admission. The lung disease was diagnosed as severe and the participant returned home on continuous oxygen therapy.

B4: Perception of the moment they were told they had or were having a heart attack. Participant B4 stated that he was having a lot of discomfort but, “I really didn”t know I was having a heart attack. I guess that”s why they, call it silent”. He adds, because I was having so much pain that I didn”t even notice.

B4: Perception of how medication affected their body. Participant B4”s wife set up his medication for him in an organizer. The participant and his wife spoke of the difficulties they had with the iron pill. They complained that the participant suffered severe constipation while taking the iron. They also discussed medications they felt were expensive but did not seem to be effective. Additionally, they reported concern regarding the side effects.
A1: Perception of the urgent need for medical attention/ delay in care. The first female participant was 65 years old. She stated, “to me it’s still unbelievable”. She stated that she never had signs that she was developing CHD. She reported that she was suspicious when she was first told that she was having a heart attack. “Well did they do this just because they can get some money”, she wondered. “It is just hard because I still don’t believe it happened to me”, she insisted.

Participant A1 reflected on the moment she began to have chest discomfort. She was attending a religious service and stated, “then all of a sudden I just started aching from all the way here (touching her chest), all the way down my arm, just a real funny tingling numbness and it went all up in my chest”. She stated that she returned home after the religious service, cooked dinner and went to sleep. “Don’t ask me why I didn’t think it was a heart attack and I went to sleep”, she explains. After she awakened, she began to eat and the discomfort returned. She described it as excruciating and intolerable. She did not call 9-1-1 because she did not want to be taken to the closest hospital. She reported that the hospital staff worked very quickly to treat her. She concluded, “I guess that’s the day I’ll never forget”.

A1: Perception of the moment they were told they had or were having a heart attack. “When they were doing the EKG they said, oh, you’re having a heart attack. And I just thought they were crazy”, A1 stated. “And they repeated and said oh yeah, you have, you’re having a heart attack. And next thing you know, like I said, they were rushing me in the back”, she explained. “I never thought about why I had this. I just accepted it”, she realized. She added, “But those machines ain’t got no reason to lie”.
A1: Perception of how medication affected their body. Participant A1 discussed her pre-existing depression. She began, “I can get pills. But pills don’t help you with thoughts. No, pills don’t help you with thoughts. No. I just function”.

A1 described an interaction with her primary care provider in which she disagreed with the medication he was prescribing. “He’s pretty good,” she stated. She described a scenario in which the cardiologist prescribed a new medication and her primary care doctor wanted to increase the dosage. She admitted that her blood pressure was elevated during the visit. She said that he explained why he wanted to change her medication. She emphasized, “And I keep trying to explain to you but how you going to take me from 5mg to 20mg”? She stated that he answered all her questions but when she returned home she was not satisfied with the response. “I called him up, and I say, I say, are you sure?” she asked. He says, “I’ve been your doctor for a long time. I know how to control your blood pressure don’t I”? She responded, “yeah, you do”. He said, “you take this. I’m not going to tell you anything wrong”. “I said ok. So, and now I take 25mg of lisinopril with 12.5mg of HCT. And he’s right”, she explained.

A2: Perception of the urgent need for medical attention/ delay in care. Participant A2 is a 72 year old female who was not aware that she was having a heart attack when she was rushed to the hospital. She reported that her friend called 9-1-1. She stated that she thought she was having an asthma attack.

A2: Perception of the moment they were told they had or were having a heart attack. She reported having difficulty remembering the exact moments surrounding her heart attack. Participant A2 had a history of lung disease; she had fallen and was unable to get up at the time the event occurred. The researcher of this study suspected that the
trauma of falling, likelihood of hypoxia and pain surrounding the event caused a
temporary lapse in memory.

_A2: Perception of how medication affected their body._ The second female
participant reported taking her medications as prescribed. She was living in a
rehabilitation facility at the time of the interview. She denied having concerns or
difficulty with any of her medications in the past or present “I really take any medicine”,
she stated.

_A3: Perception of the urgent need for medical attention/ delay in care._ The third
participant was home alone when she suffered a heart attack. She reported that her
daughter called her on the telephone and was concerned when she answered the phone.
Her daughter asked what she was doing when she answered the phone. The daughter
asked the participant, “why you sound so funny”? At some point during the call, the
participant stopped talking and the daughter called 9-1-1. Apparently the participant had
lost consciousness. She recalled regaining consciousness when the police began to knock
on her door. “This the first time I ever had any trouble with my heart. I ain’t never had no
trouble with it. And still don’t feel like I have none”, A3 noted.

_A3: Perception of the moment they were told they had or were having a heart
attack._ The ambulance took the participant to the closest hospital first and she was
transferred to the healthcare system’s main campus for coronary angiography. She
remembered some of the moments with humor and recalled the doctors joking about her
smiling. “I understand she was smiling cause she had the heart attack”, she recalled the
doctor saying. She was told she had a “little heart attack”. “I said, I had a heart attack?
Cause I been around people who had heart attacks (laugh). And the ones I been around
definitely wasn’t smiling”, she explained. “So I said, are you serious? I told him, I said are you serious (doctor’s name)? She asked? She continued, “I said, are you sure I had a heart attack? Well if I had a heart attack, why I don’t feel like I had one”? She said, “because you all saying I had a heart attack. I don’t feel nothing”.

A3: Perception of how medication affected their body. Participant A3 reported having problems with bleeding related to one of her medications. She did not complain about the side effects. She did not voice distrust regarding being prescribed the medications. She simply stated the occurrence of events. She reported one of the nurses in the hospital experienced a similar problem.

A4: Perception of the urgent need for medical attention/ delay in care. The fourth participant was a 55 year old female who did not seek immediate medical attention at the first sign of her heart problem. She went to the emergency room approximately one week after her first symptom. “I didn’t know it was a heart attack. Well, I think mentally, I kind of knew it was a heart attack”, she admitted. She reported having left jaw pain, and tightening in her chest.

“I just overlooked it”, she recalled the first time she had symptoms. “So then it happened again and I was driving”, she explained. She described bargaining, “if this happens again, then I’ll going to emergency”. She reported she was really scared when it happened again and she went to the emergency room.

Participant A4 worked in the hospital. She was upset when the nurse told her family she was having a heart attack. She stated the nurse was crazy and, “There was some information that she was telling my family when they got there that I didn’t want them to
know. Because I didn’t want them to worry. And I didn’t, and I didn’t feel like that was her place”.

**A4: Perception of the moment they were told they had or were having a heart attack.** The fourth participant reported that her feelings were hurt that she had a heart attack. “I was mad and sad that I was having a heart attack”, she said. She believed her heart attack was the result of not taking her blood pressure medications as prescribed. This had a profound effect on her perception of the effect of medications on her body. “I know I had not been taking my high blood pressure pills. I didn’t take them for like, maybe 2 weeks. So then I was mad at myself because I”m like… Well, you know, I caused it”, she explained. “I brought it on myself by not taking that and it contributed”, she conceded.

**A4: Perception of how medication affected their body.** The fourth female had accepted that she would have to take medication for the rest of her life. “I know it is serious medicine”, she stated. “So I”m not used to taking that type of medicine where I have to take it to survive”, she explained.

**Perception of illness** referred to perception of physical and mental changes due to the heart condition (see Table. 3). Every aspect of life was affected by this group’s perception of illness. Perception of illness had a direct effect on their perception of the need for urgent medical attention. Two of the women and two of the men did not have typical anginal symptoms. For those who had no symptoms there was often a delay in care, doubts about the care received and ambivalence toward the health care team.

For four participants who had symptoms, an initial hesitation to seek medical attention was conveyed. However, as symptoms reoccurred and persisted, individuals did
seek emergency medical attention. Despite the classic symptoms of a heart attack. Most of the participants expressed feelings of disbelief in the moment they were told they were having a heart attack.

Perceptions of how medication affected their bodies varied widely among participants. While some were indifferent, others reported that medication did not taste right, caused feelings of dizziness, and fatigue. For one participant who had her heart attack as a result of non-adherence to her blood pressure medication; there was a sense of lifetime obligation and fear. She stated that the biggest challenge she had faced since being diagnosed with heart disease was taking her medication.

For participants who had multiple chronic conditions the medication regimen was complicated. Some medications were dosed daily, while others were prescribed twice or three times a day. Most of the participants in this study required the use of aspirin, a cholesterol pill, a beta-blocker, and an ace inhibitor or angiotensin receptor blocker. Half of the participants in this study also had diabetes. Therefore their medication regimen was even more complex. For those who had additional co-morbidities, the challenge to manage medications was daunting.

Table 3. Distribution of “Lived Experience” Themes among Participants

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<th>Themes</th>
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| **Theme I: Perception of Illness** | • Perception of the urgent need for medical attention (n= 6)  
• Perception of the moment they were told they had or were having a heart attack (n= 4)  
• Perception of how medication effects their bodies |
Theme II. Changes in Quality of Life

Changes in quality of life is a theme that emerged from phrases such as: “You know, I’m doing, I’m dealing with a lot less as far as um, the, my quality of life. But I’m managing it because my alternative is to be having some funeral”; “So, it’s been a lifestyle change. It’s very depressing”; “My whole lifestyle. I don’t have a lifestyle”; “And there’s nothing else… Yeah, there’s really nothing else I can do other than cry”; “It just makes me more, more aware of what I do and… And what I eat and it’s the quality of life, period”. Participant B4: “Well, as you can see, I’m very active”, one of the male participants states. His wife interjects, “Meaning that he’s not”. “Meaning that my whole lifestyle changed. Meaning that my whole lifestyle changed. So, it’s been a lifestyle change. It’s very depressing”, he explains.

Perception of changes in quality of life. Participant B1 reflected on his efforts to modify his dietary intake, “I try to stay away from salt. That’s the number one enemy for
me”. He admitted, “I don’t like food. I really don’t like the taste of food but I eat it because I know I have to”.

B1 voiced his frustration, “because it’s affecting me. My whole lifestyle. I don’t have a lifestyle”. B1 reported difficulty adjusting to his heart problems. “I still have trouble realizing that’s what I’m having, or that that’s a problem. My mind just tells me something else is not right. I mean it’s hard to fathom heart failure”, he confessed. Participant B1 compared himself to others, “So I would just stay out there and dance. So when doctors mention heart failure, I be going well… Maybe mines is a little different type of a heart failure, if there is such a thing. So I was just saying well, I’m working through mine. And then I kept thinking, well some people have heart failure and they push themselves until they pass out. So I was trying to, trying to feel the difference”.

Participant B1 relied on his friend to get on the computer when he had questions about his health. “I’ll question my doctor if I think she hits a nerve. Find out the real answer, rather than from the computer”, he stated.

Participant B1 paid his bills over the computer. “It gives me numbers that I understand. And then I can just hit send or pay button, and pay”, he explained.

B1 (51 years old): Loss of freedom. Loss of freedom was an important theme for participant B1. He felt a loss of freedom beginning at the time of his admission to the hospital. He said,

They just told me that they were going to keep me here and that they would run some tests on me in the morning which would have been Saturday. And I thought that’s unusual to run a test on Saturday. Unless something is really wrong. So I said well, I’m here now. So much for my
vacation. Cause I was actually on vacation for a few days when I… You know, when I went to the hospital. And I’m thinking all along. Well I can just stop this and go home if I choose to. I still have power over me, even though I was strapped into the cart.

And uh, that thought and train of mind stayed with me throughout my whole stay at the hospital. The fact that I came voluntarily, I can leave voluntarily. Whenever I felt like leaving. I, It didn’t hit me that I wouldn’t be in shape to leave. That never occurred to me.

Participant B1’s physical limitations caused him to feel a loss of freedom. He talked about overcoming his challenges. He reflected on how he liked to dance. He said,

It frustrates me like… Because I know they’re up there every weekend and um… I’m, you know, I think about going. But I know I’m not quite ready for that. I’m, I’m not going to push that. Because I don’t want to knock people over (chuckle). Just trying to… because I feel I need to dance.

**B1: Feelings about food.** Participant B1 spoke of his challenges regarding dietary modification and feelings about food. He said,

But you know, you sometimes get in your head, you don’t want to hear exactly what the doctor is gonna say. Especially if you know, you haven’t been eating um… you know, on your right diet. And I hate when he tells me my blood sugar is high. And I’m like, I know that before I go there that, its high…cause I didn’t do right. So…

I said, I’m at home. I’m trying to work this out for myself. I said, “I don’t cook well”. It’s a lot of things I can do and cooking isn’t one of them. And
knowing how to put together…a, a schedule… to do so…is a very big challenge for me, for me. So I said, I have to just, sometimes, do the very best I can, cause I just don’t get to cooked a meal. I have to buy it, and get it to go. And bring it home or I, you know. Fine dining is not affordable for me like that.

Participant B1 continues to discuss the challenge of modifying his eating habits. He reminisces to when he could eat what and how much he wanted and how that time had passed. He felt as if he had made strides in figuring out what he could eat. He concluded that it was an ongoing battle.

**B1: Feelings of stress.** Participant B1 verbalized being stressed about his ability to perform his job. He didn’t think he was physically able to do his job any longer. He worried that he would not find an easier job that paid him as well. He told the interviewer,

So I have to, uh, I’m trying to keep my mind off of that. Because that just sinks me too. That just depresses me. Uh, if I think about how my quality of life is going, it’s going to change. It just depresses me to think of how it’s going to change. You know, I can’t…I can’t focus on, um… Things I knew I used to be able afford, and all this. Knowing that now I won’t be able to afford those things. Uh, it’s just… it’s just… a different change in the quality of life. A different way of uh… thinking. Uh, Mentally, it’s uh… frustrating. And I know, I got to get that off of me because the frustration stresses me. And if that stresses me, then I, I, that’s not going to work either. So I haven’t, I haven’t quite figured that out yet. So, it’s a
day-to-day.

*B2 (57 years old): Change in lifestyle.* Participant B2 didn’t verbalize much of a change in lifestyle since his heart attack. He reported that he slowed down. He said he would occasionally look for work. He seemed certain that his new physical limitations would not allow him to do the work he had done in the past.

*B2: Loss of Freedom.* This participant did not express a sense of loss of freedom. He reported driving people to stores and doctor’s appointments during his typical day. He also reported being told that he could walk for exercise. He was unemployed at the time of the interview and planned to file for disability. He seemed to be continuing his previous lifestyle with minimal behavior change. Participant B2 discussed his efforts to be physically active. He said,

Because I was waiting on asking the doctor what exercises can I do. And I asked him that he… He said, he said walk fifteen minutes. I haven’t even started that yet. I walk around in, you know, like… supermarkets. You know, when I was shopping… I take somebody shopping. Yeah, uh, other than that, I ain’t, as far as walking around the block. I ain’t start doing that.

*B2: Perceptions of ability.* Participant B2 did not express concerns about his physical ability other than his inability to perform the type of work he used to do. Also, he did not report the use of technology. He reported having some high school without receiving his diploma or a GED. Therefore, this participant may not have been a frequent user of technology. However, participant B2 did have strong feelings about food.
**B2: Feelings about food.** Participant B2 discussed his feelings about food. He said,

> My fiancé. She’s uh, won’t allow me a lot of sweets. Well, I appreciate that. Although… You know, I fuss and get mad sometimes. Like who do you think you is? I don’t say nothing. I, you know, just keep it inside but… I know she’s right. I know she’s right, and uh… and I appreciate that she… You know, handles, you know, certain types of food too… Meats. She don’t like fried foods. Stuff like that. Fatty foods.

Participant B2 reported his fiancé changed the way she cooked and would cook his food separately. He also talked about the food he used to eat. He described his favorite meals from various restaurants. “Man, I miss those though” he said.

**B2: Feelings of stress.** Participant B2 described how he coped with stress. He said,

> Right, that’s one way I deal with it. The most positive way. Cause uh, being around negative people, (he sighs) it just make me, make me feel worse, you know. I have to get away you know… sometimes. Be by myself and… Just chill, you know. Go down by the lake. And meditate.

**B3 (59 years old): Loss of Freedom.** The third male participant (B3) was semi-retired. He performed chores around the house prior to his heart attack. Participant B3 did not express a feeling of loss of freedom. He had not worked in a year and reported taking car rides with his wife for leisure activities. He also reported riding a stationary bike.

B3 stated some things changed but it did not seem to affect his day-to-day activities other than not being able to walk the dog and perform chores around the house. He reported that his sons took over those chores without being asked. “Say as far as
going out and even push the lawn mower and cutting my grass. I haven’t even done that since, uh my heart attack. They offer even, so far I haven’t walked the dog”, he stated.

**B3: Perceptions of ability.** Participant B3 was still having symptoms of shortness of breath and fatigue at the time of the interview. He explained that he cannot overexert himself. He stated that he would sit down if he got tired or short of breath. He stated,

Right now, I”m not, you know, strong as I, you know … I walk certain distances and I get tired. And I sit down. Yeah. Uh let’s see uh… Uh right now, I”m not, you know, strong as I, you know … Uh, I don’t try to do anything that’s real strenuous. No, no I can’t do that now. I have to be a little more careful. So, uh… I, uh, as Clint Eastwood said, “A man’s got to know his limitations.” So if I know that I am limited.

**B3: Loss of freedom.** Participant B3 did not verbalize using any form of technology to cope with his illness. He also had no complaints or feelings of loss of freedom. This participant did not verbalize changes in his perception of his physical or mental freedom.

**B3: Feelings about food.** Participant B3 relied on his nephew and his wife to prepare his meals. When discussing his feelings about food he said,

Oh, I’ve got, I’ve got a nephew that stays here with me. And, he, he went through the culinary school at Akron U. And he is a very good cook. That makes it easy. And he knows how to prepare food for diabetics. And so, I don’t worry about it. Just, he know what I can eat and what I can’t eat. He knows how it should be prepared so; I don’t even worry about it. So it’s, definitely done changed my eating habits. I uh, eating habits had
changed a little bit when I found out that I was diabetic. But it’s, now it’s, now it’s done got even more serious. Because so many of the things that uh, I was still eating being diabetic, I’m not going to eat at all now. Like staying away… Completely staying away from anything that’s fried. Uh, and so it’s definitely done changed my eating. How I eat, and my consumption of what I eat.

_B3: Feelings of stress._ Participant B3 did not express feelings of stress. He reported that he was not afraid when he was told he was having a heart attack. He made a religious reference about the lord providing when he was asked about finances. He did not openly express any feelings of stress.

_B4 (71 years old): Change in lifestyle._ Participant B4 had many changes to his lifestyle when he returned home from the hospital. He was practically bed bound. Walking from his bed to the bathroom required great effort and caused severe shortness of breath. He joked that he was very active and confirmed that he was not. He stated the lifestyle changes were very depressing. He noted that he was not on oxygen prior to his hospitalization, only to return home on continuous oxygen therapy.

_B4: Perceptions of ability._ The patient reported feelings of guilt regarding his wife having to take care of him. He needed assistance with the most basic activities of daily living (i.e. toileting). This caused stress for him and his wife, especially when he was experiencing constipation. He reported his change in lifestyle was depressing.

_B4: Use of technology._ B4 did not verbalize the use of technology. Participant B4 was seventy-one years old. The researcher suspected that he did not embrace the use of
technology due to age rather than cognitive ability. He reported reading a book for additional health information.

**B4: Loss of freedom.** Participant B4 and his wife previously discussed loss of freedom when they discussed his physical limitations. The wife also reported no desire to travel or do activities with him outside the home. The couple had not reported enjoying leisure activities outside the home together. This seemed to be no different from life before the heart attack. Participant B4 explained a feeling of loss of control and how he was coping with it. He stated, “I’ve always been very positive. So I just take it in stride really. You know, so… We have no control over the situation here. But just to deal with it”.

**B4: Feelings about food.** Participant B4 felt as though he was eating more since his cardiac event. “I eat… more now than I did before. But uh… I never was a big eater. I love vegetables. All types of vegetables”, he stated.

**B4: Feelings of stress.** Participant B4 reported his wife working so hard as a source of stress for him. He stated,

Well, I”m depressed because of the way that she’s working, now. She’s got 3 people right now. Myself, her aunt, and her sister. Her sister just had uh… Her sister just had a spinal operation. And she have to go by and check on her. And her aunt… And she”s got all types of problems. She have to go by there and check on her so… You know, it”s just… Constantly, her running. So I”m kind of stressed about that.

**A1 (65 years old): Perceptions of ability.** Participant A1 reported that her heart problem caused her more physical limitations than she had with her knee surgery. She
reported that she was still able to perform chores around the house after her knee surgery. She reported that she had to take frequent breaks while cleaning after her heart attack. She also reported she had to sit down after going up stairs before she could go back down. She realized the significant difference when she returned from shopping with her daughter. She reported, “I got home, and I thought that was the end of my mind. I was just like drained. Felt like I was gonna shut down, you know”?

A1: Use of technology. The only use of technology participant A1 reported using was an emergency radio. She wanted to keep it in her car in case of an emergency. She did not report using the computer. She did not report the use technology to access additional health resources.

A1 (65 years old): Loss of freedom. Participant A1 did not express feeling any loss of freedom. She discussed the possibility of moving to another state. She did not report her newly diagnosed condition as a barrier preventing her from relocating. She reported fatigue but did not report a loss of freedom due to new physical limitations.

A1: Feelings about food. Participant A1 reported a change in her eating habits. She stated,

I weighed myself the other day. I weighed 150 pounds. That’s uh, from last Monday. That’s a 5-pound weight loss. You know that’s a 5-pound weight loss. And I really don’t want to be losing weight like that. But I, I don’t even really have an appetite. I can drink a cup of coffee in the morning and then it dawned on me. You know, girl, you ain’t had nothing to eat. See. I just I don’t know if, if this is affecting my mind or what. I don’t eat a lot. I don’t do, really, I don’t do too much of nothing.
Participant A1 discussed her response to dealing with stress in her life. The dialogue included her use of food and feelings about food.

I might tell them to somebody (about the stress in her life). It used to be, and I’m going to just... And I mean, I would even regurgitate, and then I’d just go back to eating.

*A1: Feelings of stress.* Participant A1 reported her children were a primary source of stress. She said,

I just… Sometimes it’s so much easier to die cause I get so tired of taking care of things.

And even though I feel like my children want to see me… stay alive.

They… feel like… it’s somebody else that’s putting me…the stress upon me. Not them. It’s you know…. And in trying to help my daughter keep her children, so that they don’t get taken away from her. That’s a very stressful situation there.

*A2 (72 years old): Change in lifestyle.* Participant A2 reported that the heart attack did not affect her plans for the future. She lived a sedentary lifestyle due to her lung disease. She reported watching the television for enjoyment. It is important to note that she was unable to return to her home. She was sent to a skilled nursing facility for rehabilitation. After her rehabilitation she would be moved to an assisted living apartment.

*A2: Perceptions of ability.* Participant A2’s physical limitations prevented her from returning to the home she lived in prior to her hospitalization. She discussed her feelings regarding being unable to return to the home. She realized that she had new
physical limitations. Unfortunately, she had fallen and injured her hip while in the rehabilitation facility between interviews 1 and 2. She stated, “I can uh get up to wash myself and put my clothes on. You know, get dressed. Yeah. So now I’m… You know I broke my hip since then”. Ultimately, she was discharged to the assisted living apartment. She stated she would need help with cooking & cleaning.

A2: Feelings about food. Participant A2 reported having stress regarding what she could eat since her heart attack. She stated that she would eat whatever they would give her at the nursing home. When I asked if the assisted living apartment provided meals, she was uncertain of the answer.

A3 (72 years old): Change in lifestyle. The third female reported enjoying traveling for a leisure activity. She reported missing many social events with friends since her heart attack. The complications A3 experienced after her heart attack restricted her physically but she was also given doctor’s orders to limit activity. She followed the doctor’s instructions and was in the process of having an agency come into her home to help cook and clean.

A3: Perceptions of ability. A3 stated that she felt weak. She was upset that she was hospitalized and on bed rest for so long. She was concerned about her limited physical activity because of her history of spinal stenosis. She voiced the intention to restart rehabilitation.

A3: Use of technology. This participant did not verbalize using technology in her daily life. This may have been due to her age (72 years). She reported going to the library and reading books when seeking additional information regarding her health. She also voiced the intention to restart nursing classes in the coming semester of school.
A3: Loss of freedom: Participant A3 described her loss of freedom since her heart attack. She stated,

I’ve been kind of confined to the house.

And they don’t want to trust me trying to walk long ways. So I walk, like out to that doorway where you came in and back. Or I go around to the mailbox which is around the corner. Once a day. And then, when I’m sitting in here I have to sit an hour and then get up and walk around. In that hour, they told me. And then I don’t go as much. You know, I don’t like, get up and go to the mall.

I can’t get up and go to the store if I want.

I love travel… I do travel a lot. And I like to travel but… Naturally I can’t travel and, and… Now my one friend in Kentucky. I can’t go to her birthday this year because… That’s on the 12th. And I couldn’t go back to Chicago. And her birthday was on the 29th. July 29th.

A3: Feelings about food. Participant A3 had a plan to maintain her diet as she had been instructed to eat at the hospital. She took the hospital menu home and continued to prepare the same type of meals she received in the hospital. She also organized her food in such a way that she could prepare a meal in five to ten minutes. She stated her doctor was concerned about her being on her feet for long periods of time to prepare food. She said,

Cause I’m going by that menu. See on the menu, they got the carbs and everything marked. So I gets my… make my menu off of theirs.

They got the carbs marked. And then by certain foods they got the red
hearts. Then you know you can eat that. In other words, I been eating just what they gave me to eat in the hospital. I just went by their plan. If they gave it to me at the hospital, it must be ok. So I’m fixing my meals the same way they sent upstairs from the hospital. Now I can’t go wrong. Now if I go wrong, it’s, it’s what they did. I didn’t do it. You know?

A3: Feelings of stress. Participant A3 did not verbalize feelings of stress. When she was asked about stressful situations, she made reference to her religious beliefs. She stated that her children were grown up and she was widowed. She only had to take care of herself.

A4 (55 years old): Change in lifestyle. Participant A4 was a grandmother who lived with her daughter and grandchild. She reported that they took care of each other. She did not report additional physical disabilities since her heart attack. She stated she was afraid to be active shortly after her heart attack but she was almost back to her usual routine by the time of our interview.

A4: Perceptions of ability. Participant A4 reported that one of the cardiologists encouraged her to return to her usual physical activities. She gave an account of their conversation. She said,

Because (doctor name) talked to me. He was like, you can run a marathon now if you want to. He said, as long as you train for it.

You know, you can run. And he said, I would be happy if you come and tell me that you’re getting ready to run a marathon. So that kind of relaxed me. Knowing that I can do. You know, I can do certain things. Or, you know, strenuous things. And not worry about it.
I’m still skating… Going bowling next week.

_A4: Use of technology._ Participant A4 credited an email she received for educating her on the signs and symptoms of her heart attack. She stated that she kept important emails such as that one. She also reported going to a website to seek additional health information. She reported that her computer crashed shortly after the heart attack.

_A4: Loss of freedom._ Participant A4 reported feeling a loss of freedom since she had to take medication for the rest of her life. Taking the pills as prescribed was a daily stressor. She faulted herself for not taking her medication as prescribed as the reason for her heart attack. She became fearful of the consequences of missing her medication after her heart attack. Because of this, she kept a set of pills in the car.

For participant A4 there was a psychological loss of freedom. Her fears of having a reoccurrence of her heart attack caused notable stress and self-imposed physical limitations. Hence, she displayed an overlap of feelings of stress and loss of freedom. She reported feeling more comfortable being active by the time of our interview.

Quality of life worsened for all participants in this study. Being diagnosed with heart disease caused additional _feelings of stress_ and physical strain for African Americans who, in most cases, were already managing multiple chronic conditions. Changes in physical function increased tension resulting in their _perception of ability_. Impaired physical mobility translated into a _loss of freedom_ and _change in lifestyle_.

_Loss of Freedom_ seemed to occur almost immediately for some participants. “I still have power over me, even though I was strapped into the cart,” a male participant recollected. He later realized, “It didn’t hit me that I wouldn’t be in shape to leave. That never occurred to me.” Perceived loss of freedom was physical for some and emotional...
for others. For example, one participant stated, I was scared that I couldn’t really walk. And I couldn’t ride a bike. I just couldn’t do a lot of things”. These were not restrictions prescribed by her physician. These were her perceived limitations.

The impact of feelings about food could not be ignored. Simple day-to-day pleasures became task-oriented procedures that were essential for survival. One female participant considered the prescribed dietary changes an easy assignment and completely altered her diet to match what she received in the hospital. She accomplished this by taking the hospital menu with her to the grocery store. Another participant talked about food as if he were mourning the loss of a loved one. While another stated that he did not enjoy eating anymore, he just did so to survive. The most extreme case was a participant who would go almost the entire day without eating at all. The joy of eating seemed to be lost for the majority of individuals in this study.

All participants reported a change in the way in which they live. Some participants reported mild physical impairment that caused them to slow down. Others reported being discharged from the hospital to a nursing home with no hopes of returning to their former home. Traveling was restricted for most participants. Many rarely left home for reasons other than doctor appointments. The majority of the participants in this study reported at least a temporary restriction of recreational activities.

**Theme III. Perception of Care**

Perception of care involved the participant’s doubts about care received by staff or not. This included staff within the hospital as well as the staff who came into the home from the hospital. For some participants, there was overlap in feeling ignored by staff and having doubts about care. The phrases in the text that led to this theme were: “I feel
like… no, he ignored me”; “I got good care”; “They were conscientious” (referring to nursing care); “Because what the doctors knew, they didn’t say, or didn’t act like they knew. And it confused me. And it made me ponder about (primary care doctor name) now.”

**B1 (51 years old): Doubts about care and feeling ignored.** For participant B1 there was some overlap in doubts about the care he received and feeling ignored. He valued the honesty of the doctors. He thought the nurses were “real important”. He thought the nurse aides were important because they did things for him that he knew he could not do himself. He stated, “the reason the doctors are at the top of the list is because they’re going to actually tell you what’s wrong with you”.

He commented on the difficult type of work the healthcare staff performed. He said,

I couldn’t do that job. I compared their job. I was watching *every day*. And I would compare their job to what I would do. As far as dealing with customers and things of that. I wouldn’t, I couldn’t, do their job. They work hard. They work real hard. Whereas I could take a break if a customer gave me a hard time. I’m not going to get to the next house as fast. I’m just going to slow my role. Maybe go to the store. Something like that. And relax a little bit more. Whereas they have to go from one sick patient and when people sick, they get irritable. So you go from one sick person to the next sick person. You know, and if you got kids at home you clean up after them all the time. And now you got to come to work and clean up. I know you getting paid but it’s a difference.
Participant B1 did not like being reminded he was sick. He stated the hospital reminded him too much that he was sick. He did not like being unable to do things he would normally do. He stated,

And then I would be told, well you can’t get up because you know you, you, you fell down. Well, I’ve always heard from childbirth or from a little boy: If you fall down, you pick yourself up. And you try it again. You try and try until you can’t do it. So that mentality was that in the hospital too. Even though I’m feeling a little sick. I got to pick myself up. I am not going to get any better unless I do.

He discussed his relationship with his primary care provider. He talked about following the prescribed plan of care. He said,

And I don’t want to be, detrimental to my own health. So what I try. I started to meet him half way. I kind of learned to try to stay close to what he suggest because when I didn’t, something would go wrong and be too late. I talk to my doctor about everything. Even talk, I talked to him about when I couldn’t remember my grandkids name. And he was concerned. And that’s why he ordered the CAT scan.

(Primary care doctor name) is a pretty good doctor. I think. Um, it’s not that I feel real comfortable with (Primary care doctor name). It’s the fact that, I know he’s the doctor. And if I don’t know, then I throw it out to him and see what his opinion is on it. And he generally, will advise me.

Participant B1 reported that he would ask his doctor about dietary modifications and express concerns about his medication regimen. He stated,
Uh, I sometimes will mention certain medications. (Primary care doctor name), do I really need to take this medicine? Because I get sick after. He said, well, we can always arrange to take a different medicine that may not make you sick. But he says, generally what I prescribe for you, you need. I need. You need to be on it. And I’ll go ok. You know, I usually, I don’t fight with him about that part. Cause I figure, he knows a lot more about it than I know. As far as uh, all I need to do is tell him how my body is acting, or what the problem is, or I feel is the problem. And he generally works it out. Well, we missed it! We missed this last stroke.

Participant B1 felt as if the healthcare team was withholding information regarding his health or they did not know what was wrong with him. He stated he felt this way because,

You know, that’s the one thing that I find a little, not as encouraging about them. Sometimes they won’t answer the questions that you put before them. Maybe because they don’t know. But I would have liked to hear “I don’t know”, versus looking past you. And moving on to trying to fixing you up. I understand you’re going to fix me up. And I receive that. That you’re going to fix me up. But tell me, for the last 6 years, or 8 years, why am I on all these different medicines and I still get this problem that happens anyways. That part, if anything, I can’t. It baffles me, to the point, that I, I reluctantly, when they were telling me, in the hospital, that they’re gonna let me go once my blood thins out. I’m like, I’m not believing that. Because my blood should already be thin. I been on Coumadin, doctors,
for 8 years! My blood is thin, well wait, ok maybe it has to be a little thinner. I don’t know. But that’s what they should tell me. Don’t tell me that they have to thin my blood when I already know that I been on Coumadin and the Coumadin has been thinning my blood. And my INRs have been fine because whenever my INRs are too high (Primary care doctor name) will be on that phone and he leaves a message, now.

Participant B1 reflects back to a previous hospitalization at an undisclosed hospital in which he had a bad experience after discharge. This experience occurred after he had a stroke. The data are being included in this study because of its profound impact on his life experience and current worldview of the healthcare system.

I, and that’s what I wanted the nurses to do. Because the nurse did come a couple times. But, I don’t know. They didn’t show interest. Like they were interested in doing that (organizing his pills). Because a couple times I requested that.

They just did my vitals. And uh, I would ask. I would say well, I’m having trouble….uh understanding how to take my pills. And um…They would move on to something else. That confused me. I’m like, I thought that’s what they would want to do. So I wouldn’t take the wrong stuff. But that’s not, that’s not what…That’s why I said, I just said in my mind…I’m going to sit up here and die if I leave it to somebody else.

No…Uh. Uh…It’s almost like… they didn’t, they didn’t touch the pill part at all. They just did my vitals. So it made me learn how to do my pills.

And uh…I didn’t have to depend on the nurse. And, and I never bothered
her about the pill situation again. So in a sense it helped because it made me more independent. And I, I went to bed crying many nights because I couldn’t figure out… which pills uh…to take. I knew I was sick. And I knew I needed to take them. But I was afraid to take the pills. Because I didn’t know which, if, if I was taking the right ones.

B2 (57 years old): Doubts about care and feeling ignored. Participant B2 reported feeling like he was ignored by the cardiologist. He was complaining of symptoms he thought he was having from his medication. Since the cardiologist didn’t respond, he stated he would tell the endocrinologist when he went to see her. When asked about the relationship with the cardiologist, he replied, “Well, it ain’t tight yet. You know, cause uh I don’t know him”. He described the situation,

He didn’t say nothing. And then I told him, the medication you know, um, I was taking, was making me dizzy. He didn’t say nothing. He prescribed some more to give to me.

Participant B2 was not happy with the cleanliness of his room. He reported the cleaning staff did not come in regularly. He said,

They only came every once in a while to clean up. They should have come in more often and mop the floors, and you know and… Have you got to get up and walk around on that sticky dirty floor. Every once in a while they come and clean. Dump they trash and stuff.

B3 (59 years old): doubts about care and feeling ignored. Participant B3 had at least one previous hospitalization for a serious illness. When he reflected on being hospitalized with his heart attack he said,
The care I got at (hospital name)... It was good. It was excellent. I, I got no complaints. I had good nurses. That was on their job. They were consciences about that. And I had some young nurses. That’s just getting started. They was educating you. They spend their time educating on your medications. What it does. How that you should take it. And, I don’t know. They went through all of that with me. People say hospital food. I can’t even complain about that. So I guess the good lord gave me favor. I don’t know.

_B4 (71 years old): Doubts about care and feeling ignored._ Participant B4 expressed fear of being in the hospital alone. He seemed to be afraid that he would be ignored by the hospital staff if his wife left. He reported that his fears began when he witnessed another patient’s dissatisfaction with the care. He stated,

She was spending the night. My daughter was coming in a little more at the end. So I had better treatment, than, I think than a lot of the others. But I had one problem. I had to stop them from coming in all night doing blood work. Everything would be scheduled through the night. And I couldn’t get no rest. And I couldn’t get no rest. So I had to stop that.

Well, the nurses was good. The doctors was good. The food was lousy. Like I said, I think that because it was somebody around all the time. I heard a lot of people complaining and hollering. Screaming at the nurses and all that.

Yeah, because I figured that uh… If I didn’t have nobody there, I would be the one that was screaming too.
Because nobody came.

Now, I would say good.

What would it have been like if I didn’t have anybody there?

_A1 (65 years old): Doubts about care and feeling ignored._ Participant A1 seemed surprised that she was taken care of so quickly. She said, “I give (hospital name) credit they act just like that (snaps fingers). When I walked in, „cause I didn’t want to call 911, „cause if I call 911 they’d have took me to (hospital name), then I’d have to go through the ordeal of getting transferred down to (hospital name”).

Participant A1 reflected on her previous experiences in the health care system. She verbalized having a negative experience with a mental health care provider and a pharmacy. She discussed how these experiences changed her worldview of mental health providers and her utilization of pharmacies. She said,

At this point I’m scared to put anything in my mouth without them (her doctors) giving me a consent to do it. Because they have to know everything that I’m taking now and sometimes I don’t, I don’t know if the pharmacists… I don’t think they really understand that stuff don’t go together. Cause I can remember one time in dealing with the pharmacists I had a prescription and they gave me, something that was similar, but it wasn’t the same thing. Oh yeah, and I was highly upset.

Participant A1 talks about why she does not seek treatment for her depression. She related it to a bad experience she had with a previous provider. She recalled,

I’ve been in therapy and everything. And uh, sometimes it just seems futile. Because… I remember the last time I saw a doctor. When I was
working at (hospital name) and I went to see the doctor over there. And when he said, “well, if your husband is having an affair J, why don’t you have one”? I just thought that was so unprofessional. And I stopped going to see him. You know, and everybody had been saying this is… He was such a good doctor. He was such a good doctor. And he was not. I didn’t like that kind of advice.

I could be paying a bill and will tell them my whole life. And they will listen. They will listen. I don’t care. Because I have discovered in going to see a therapist, it doesn’t work. It doesn’t, it, it doesn’t work.

Participant A1 talked about her relationship with her cardiologist. Considered him to be nice, and pleasant. She said,

And, I like the fact that while he’s in the room, and he’s talking to me, he listens to me. Cause you get some of them ain’t heard nothing. I got one, where they don’t hear anything you say. So, I like the fact that he sit me there, examine me. Afterwards, he focus right in on me. I like the fact that when he was getting ready to send me home; he said I’m going to give you two options. He said, option one is I would prefer that you stick with me. He said, but I’m not that close. Or he said, option two is you can stay here and see somebody at the main campus. Or you can go in to the (clinic name). I told him, I said, you know, I liked his personality. He made me feel like, like I said, when I was talking to him, that he was listening to me. And then, even when he told me he was out in (city name) and I had never in my life been out in (city name). You know, so… But I, I chose to
stay with him.

_A4 (55 years old): Doubts about care and feeling ignored._ Participant A4 talked about the experience which led to her discontinuing her blood pressure medication. She had been dealing with hypertension for about 3 years. She said,

What happened was, I had went to one of the neighborhood clinics. And um, they took the blood pressure. And she went, wow, your blood pressure is really low.

The participant continued to tell the story about how she discontinued her blood pressure medication. She stated that she was supposed to continue taking it but did not. She seemed to blame the nurse. She said, “Maybe their equipment wasn’t right. Maybe she didn’t know what she was talking about. And I do believe that’s what it was”.

Participant A4 also reported having a negative interaction with the nurse at the hospital when she had her heart attack.

The nurse, she was crazy though. Yeah. She um… There was some information that she was telling my family when they got there that I didn’t want them to know.

Telling the family that information soon as they walk in. What’s wrong? Right. And oh yeah, well, the levels are high and that means she’s having a heart attack. You know, and… you know, and she just went on and on and on. She wouldn’t shut up.

Despite her negative experiences, participant A1 reported being satisfied with her care as a whole. She felt the staff took care of her quickly. When she voiced fear and the thought of refusing her heart cath, she said, “Uh, and they weren’t going to let me go…”
(Chuckle) So, you know. I like Dr. um… (doctor name) and the other doctor… uh, I can’t think (doctor name).

Several participants reported suspicion of receiving a diagnosis of heart disease because the hospital needed to make money. These suspicions quickly dissipated when participants acknowledged the urgency of the need for medical attention. All participants reported the perception of care in the initial moments of diagnosis as good or excellent. The presence of a theme or combination of themes did not reliably predict decision making patterns in these situations but were informative.

The majority of participants in this study had established primary care providers prior to their cardiac event. Most of the participants had the same primary care doctor for many years. Almost all participants had positive things to say about their doctors. Doctors were described as kind, pleasant, and some referred to their primary care doctor as a friend. Participant A1 said,

You know. Uh, my doctor is a Russian Jew. And I know from working in his office, that Jews take care of their own. You make them your friend, and you make a friend for the rest of your life. He is very kind and good to me.

None of these participants had health care providers of their same race or ethnicity. Therefore race/ethnicity concordance was not a contributing factor to the trust in the relationships that were discussed by the participants. The one participant who verbalized experiencing racism in the work place (which was a health care setting) also verbalized trust in her primary care provider who was Caucasian. Two of the four women in this study actively participated in shared health-related decision making with their primary
care physician. Two of the men also reported actively participating in health-related shared decision making.

There was only one participant who voiced dissatisfaction with his role in his care. This was a 57 year old African American male who had not utilized the health care system for many years. When asked about his last primary care provider he stated, “But he’s dead. I was told… been dead”. The participant verbalized the intention of following up with the cardiologist and endocrinologist who cared for him during his hospitalization.

The same participant also verbalized having had a positive experience in the intensive care unit. He reported feeling ignored by hospital staff when he was transferred to the medical cardiac floor. He stated that he asked for some water, “And they act like they didn’t hear me”. He also noted, “they had a nasty attitude at first. When I got in there”. He described how he began to sing as a way of coping with this stress. He reported that it was not long before the staff responded. “They came and uh, started, you know, attending to my needs and stuff. And they was very nice,” he states. His overall opinion of the staff was, “very nice, and helpful, and caring”.

Research question 2) What is the essence of health-related decision making among African Americans living with CHD? Health-related decisions were defined as any decisions the participants made which had an effect on their health status and the care they received. Participants were asked to reflect on their health-related decision making from the time when they first noted having a symptom of CHD. Health-related decision making was heavily influenced by the presence or lack of sources of support. The themes that emerged from this research question were impact of illness on others, personal fears and concerns, thoughts of dying and coping strategies (see Table. 4). The
emergent themes imply that participants made health-related decisions based on their respective financial situation and commitments to their sources of support. Sources of support were defined as the people the participant relied on to seek medical care and meet day-to-day health needs.

Table 4. Distribution of “Health-related Decision Making” Themes among Participants

<table>
<thead>
<tr>
<th>Themes</th>
<th>Descriptors</th>
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<tbody>
<tr>
<td>Theme IV: Impact of Illness on Others</td>
<td>• Reliance on others (N= 8)</td>
</tr>
<tr>
<td></td>
<td>• Concern for others (N= 8)</td>
</tr>
<tr>
<td></td>
<td>• Stress on relationships (n= 6)</td>
</tr>
<tr>
<td>Theme V: Personal Fears and Concerns</td>
<td>• Finances (n= 6)</td>
</tr>
<tr>
<td></td>
<td>• Concern for home (n= 6)</td>
</tr>
<tr>
<td>Theme VI: Thoughts of Dying</td>
<td>• Fear of death (n= 3)</td>
</tr>
<tr>
<td></td>
<td>• Thoughts of dying (n= 4)</td>
</tr>
<tr>
<td>Theme VII: Coping Strategies</td>
<td>• Spirituality (or lack of) (n= 7)</td>
</tr>
<tr>
<td></td>
<td>• Hope for the future (n= 4)</td>
</tr>
<tr>
<td></td>
<td>• Feeling depressed (n= 4)</td>
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Theme IV. Impact of Illness on Others

All participants in this study exhibited reliance on others. Participants usually relied on sources of support for transportation, assistance with activities of daily living (ADL) and instrumental activities of daily living (IADL). Reliance on others often caused feelings of stress for the participant as well as the sources of support. In most instances the sources of support assisted without complaint. In some situations the difficulties of the participant’s needs put a stress on their relationship. For instance, the wife of participant B1 (71 year old) reported she had difficulty coping with his episodes of
constipation. These episodes caused stress for her and her husband. As a result they discontinued his iron tablet. The participants reported worry or concern for others (their sources of support) and the stress their illness caused.

*B1 (51 years old): Reliance on others.* Participant B1 reported relying on his friend who was a school teacher to look up health information on the computer. He reported that she was more skilled to do the research. The stated he would make adjustments to his behaviors according to what they found or he would call his doctor to “find out the real answer”. This friend would also go to doctor appointments with him help the participant remember what the doctor said. She would sometimes write his questions down for him to take to the doctor. He stated, “my problem is retaining the information. So, as often as I can, I will take my friend with me. So that she can hear it as well. So she knows as much about my health as I do”. Additionally, she would drive for him when he needed to go out into the community.

Participant B1 also reported frustration with not being able to perform yard work and chores around the house. His daughter would tell him that he should not do that type of work anymore. He would become upset when he noticed the hedges needed to be trimmed. She offered to have someone trim take care of his yard. He said,

And I’ll go, I got all of the equipment in the garage. All I got to do is go over there and start it up and start cutting away and get it done. Instead of waiting on somebody. So it’s delaying me, as far as planning. I, I don’t even want to plan to do yard work anymore. It’s inconceivable for me to have somebody else to come do it. I have a riding mower. It worries others
more so than me. So I’m at the point I’m going to live until you die. You know.

*B3 (59 years old): Reliance on others.* Participant B3 reflected on the support of his sons,

Well, I’ve always known how my family felt about me. And they’ve always helped supported me and my wife. Which as far as I’m concerned, I’m blessed. Because of all 3 of my, my children, I’ve never had any problem out of any of them. And they all is independent, and responsible people.

Support that your family gives you. When you have, it’s big when, when you get sick. And your sons and stuff come by and take care of the things that you used to do. That you was able to do before you had a heart attack. They do it. Without you calling for them, or asking them. They come and do it. Uh, that’s, that’s the most rewarding, I think one of the most rewarding things since I had a heart attack.

*B4 (71 years old): Reliance on others.* Participant B4 commented on the stress he felt with trying to perform activities of daily living. He commented,

It’s still very stressful and I have a problem with standing for a short period of time. I still have a problem with the walking. Because I get short of breath. And uh… It’s uh… It’s going to be a slow process. I know that.

Well basically, my wife does all the work.

*A1 (65 years old): Reliance on others.* Participant A1 reported that she has never been able to rely on anyone. She stated that everyone in her life has relied on her. She
explained,

I’ve never been an invalid. I have never had anybody really take care of me. My first husband never took care of me. I was a single parent still with him. My second husband never took care of me. I always took care of me and my kids. And everybody that was around me, that was involved with me, it’s like I always took care of them. Nobody took care of me.

You know?

As much as I think they (her children) love me, when it comes to doing for their friends. I feel like I’m secondary.

_A3 (72 years old): Reliance on others._ Participant A3 had lived in Cleveland less than a year when she had her heart attack. One of her daughters lived nearby. Her daughter drove her where she needed to go. She said,

She (her daughter) was taking me to the grocery store.

Right now I have to. I can’t go out and drive. They don’t want me to do that. I can’t drive to the store. Or drive to the post office. So she takes me.

You know where before, I just jump in the truck & go on and come back. And do my work around the house. I was working here. I just moved here. But I can’t do that right now. Cause of my strength, you know. And they afraid I’m going to fall. So they sent somebody out to interview me yesterday. To get help, you know, right now.

It’s going to be like a, a nurse aide.

Participants in this study often expressed concern for their sources of support. _Concern for others_ was expressed as worry or concern for how the participant’s illness
had affected their sources of support. “I went up to the ER at Richmond. Uh, my friend drove me up there. And all along I”m thinking… I was more worried as to how would she get back” he explained.

**B1 (51 years old): Reliance on others.** Participant B1 relied on his girlfriend. His children did not live in the area. He said,

No, no I went up to the ER at Richmond. My friend drove me up there.

And all along I”m thinking, Umm, I was more worried as to how would she get back.

I think of my grandkids, my kids. And I just don”t, I just don”t want to give in to uh, being sick and can”t help yourself. I, I can”t. I never was like that and so I”m not gonna start that now. Um, pity type deal. No, I can, I can do it. I just, it”s just um…staying positive in the things that I can do.

Uh, the things I can do, I need to, to stay positive and do them. The things I can”t do, I have to realize my limit. My uh, limitations and, and maybe, uh have assistance in doing it. Um, so a big part is just having people around you who understand it. Who understand, and it”s, and it”s, for the most part I think I do. I, they”ll see um…some of my physical challenges and they know I didn”t have them before. And they may say well, dad just sit down. Or, or my sisters may say, just stay right there. I”ll get this or that for you. Uh, just cause I think, I think they look at the physical challenge that I”m kind of battling. And they know I”m not used to anything like that. And they, they”re always encouraging me, telling me,
it’s, it’s just going to take time. Uh…to, for everything to come together again.

Because I don’t know where I’m at… in life. I’m at… I’m not at the point of, of being able to just live. To, to, be able to just feel free, and don’t worry about stuff. That’s not… I, I worry. I do. And, and, it’s not… it’s not easy. And um, I worry about my kids, you know. And um, my siblings. You know, I, I, it’s just something on my mind constantly. I wish it wasn’t. I can’t, I can’t uh, control that. It’s just one day at a time for me. And once I get that understanding, I’ll be fine. It’s just that it’s a little slow at coming.

A1 (65 years old): Reliance on others. Participant A1 talked about her concern for her children. She expressed feelings of guilt for spoiling them. She expressed regret for not saying no. She stated,

And, and I watch my children. Many, there were times I worked 2 jobs. And I watch them. And, you know, I can’t see none of me in my children. I can’t see none of me in my children. With the stamina to achieve, to get what you want. And a lot of that is my fault. I made things easy for them. Maybe a little bit too easy. I had 8 children. And the 7 are spoiled. I’m talking about from the youngest to the oldest. They’re all spoiled. So sometimes I feel like, if I were to just die I wouldn’t have to, I wouldn’t have to deal with it. I, I just really don’t know how to say no. You know, cause I get tired of functioning for them. You know.

A2 (72 years old): Concern for Others. Participant A2 did not verbalize concern for
others. Prior to her heart attack she lived in a house with her son. She stated her son planned to move into a smaller place. The majority of her physical needs were met by the skilled nursing facility staff.

*A3 (72 years old): Concern for Others*

She (her daughter), she work. That’s her job. She, they nurses. She just come and help me and, right now, she would like to come in if (name of agency) allow her. She would like to come in 2 or 3 days.

But now the only reason, the lady said she can get paid. She have to be working. The agency she working for have to be registered with (name of agency).

Participant A3 reflected on a time when a nurse had a negative experience with a patient. The study participant seemed to have empathy for the nurses who cared for her and their challenges in meeting the needs of more difficult/complicated patients.

*A4 (55 years old) Concern for Others.* Participant A4 recalled the incident that caused her to be angry with the nurse in the emergency room. She said,

There was some information that she (the nurse in the emergency room) was telling my family when they got there that I didn’t want them to know. Because I didn’t want them to worry. And I didn’t, and I didn’t feel like that was her place.

Men who were in relationships relied on their significant other for assistance with acquiring health information, organizing medications, cooking meals, and assisting with ADLs and IADLs. All of the women in this study were widowed or single. The women typically relied on their children as sources of support. The diagnosis of heart disease
often imposed stress on relationships as participants struggled to regain physical ability and return to baseline activates.

B1 (51 years old) Concern for Others. Participant B1 expressed concern for his children as they tried to help him cope with his illness. He remembered a time when he called his son while he was having an anxiety attack. He was upset because he couldn’t remember if he had taken his bedtime pills. He was trying to decide if he should take them again. His son told him, no. He suggested he skip the pills for that night and make sure not to forget to take them the next night. He feared his dad would over medicate himself. The participant felt he had become too dependent on his son. He feared what would happen if his son put the pills together wrong. He stated,

And that frustrated me to the point where I, I’m thinking: man even, I can’t even figure out what pills to take. I’m in really bad shape. So I, after going through with him a little bit. He says, well dad, um, I’ll be home in 3, 3 days or something like that. And I’m like well, 3 days, I’ll be dead from taking the wrong medications. But what it made me do, is the next day, is to sit down…and put my pillbox together. All those different pills. I put it together, the way I could understand it at the time. Uh, to someone else, it might not make sense. But for me, it made sense to do it a certain way…off of reading the list of pills I had to take, and how often.

And…that took me the whole day to do that. But I figured it out, and I’ve been doing them since.

It did, uh but, what it also did, was I became too dependent on him.

Because he was putting them together. And I was like, well, what if he
putting them together wrong? And I said, well, the best way, and because I didn’t want him to feel guilt putting them together wrong. And something happen. And I’m like no. So I said, well, I need to put them together, so if something happen, he don’t have to take the blame for putting them together wrong. I put them together. So I learned. I sat down, and I learned. And I stayed there, and made out 2, 3 weeks at a time.

I knew they were important to take. But I couldn’t think. Um…I, maybe, probably needed somebody here. But everybody have such busy lives…That I couldn’t uh, uh, say to them I, I really need for you to stay here. Because they don’t, they don’t, my kids don’t live here.

**B1 (51 years old): Stress on relationships.** Participant B1 had an intimate friend who he relied on to help him manage his chronic illnesses. He talked about the stress his illness put on their relationship. He said,

Uh, it’s just that, I do have a friend…um, I don’t know how it really uh, affects her. It uh, it affects her because she left one time. From the, just the uh, the, the rheumatoid. Uh, because I couldn’t move around, and was always hurting. And uh, she was taking me back and forth to the doctor. And I could see how it was wearing on her. And I could see, uh she would tell me little things, like her family wasn’t in the, you know, didn’t like it. Because they saw how it affected her. And she wanted to kind of move on with life. And I’m, at a standstill. Because I’m trying to get better. And uh, So I had to just kind of just push, and I pushed her away. So I told her, I said maybe you should just go. I’ll be, I’ll be ok. And uh, she did. Uh, she
left. Yeah, I missed her. And things like that. But I figured that she
probably will do better uh, away than with me. Because, I think she was
looking for a brighter future, I think, and mine, mine, wasn’t as, as bright.

*B3 (59 years old): Stress on relationships.* Participant B3 talked about intimacy
with his wife. He seemed to be implying that there were issues with intimacy before he
had his heart attack. He stated,

Some things I wasn’t doing as much as I used to do. And may not be
doing at all now, but… But it haven’t, it haven’t changed. No. No. Uh,
relationships seem to be… the same as it was before I had the heart attack.

*B4 (71 years old): Stress on relationships.* Participant B4 wife commented
on how the experience had affected her. She admitted that she warned the
husbands in order to protect the wives. She stated that the husbands were stubborn
and did not listen to their wives. The participant talked about his friends wanting
to visit him. He said, “Well usually, I uh, my relationship with friends has usually
been pretty good. Matter of fact it”s become too much”.

*A3 (72 years old): Stress on relationships.* Participant A3 was widowed. She
verbalized having step-children through marriage. She reported these individuals were
self-sufficient adults. She did not mention her father but stated her mother was deceased.
As a single African American female she expressed no feelings of stress on relationships.

**Theme V. Personal Fears and Concerns**

Personal fear and concern is a theme which developed as a result of participants
reporting fears regarding their ability to pay their bills, and maintain their home. There
was also fear of death and thoughts of dying. While the majority of the participants in this
study were retired, there were several who were too young to retire. Concern regarding finances reflected concern for how the newly diagnosed illness would affect their financial status (or not).

One participant reported that he was relieved that his illness occurred after his retirement. Two (B1, B2) of the four men in this study who were not retired were eligible for disability after suffering their heart attack. Interestingly, the other two men would have also qualified for disability (but were retired). All of the men reported some level of concern regarding the effect of managing and living with CHD on their finances.

Several of the participants reflected on their work ethic. These individuals discussed how they tried to pass on their values to their children. For those who “worked all of their life”, it was difficult to retire prematurely or apply for disability. “You know, once you go disability, you, you’re done. As far as uh, making goals and so forth like that,” participant B1 stated. This participant often felt preoccupied with feelings of financial insecurity.

Unfortunately, one of the working age participants (B2, 57 years old) did not have a job. He had been searching for work with no success. Since the heart attack, he had applied for disability. He had been out of the hospital for approximately one month at the time of the interview. The participant had already stopped taking his medications. He stated “I got them on hold. I took it one time. Cause I could only afford, uh, to buy one bottle”.

*B1 (51 years old): Finances.* Participant B1 openly expressed his concern for his finances. He initially focused on getting out of the hospital and returning to work. He did not have sick time and worried he could lose his job. He said,
I’m thinking well… you know…Ok; I’m going to let them do what they got to do to find out what”s wrong with me. And I”m thinking it can be fixed without surgery or anything like that so that I can go to work on Monday. That would come into my head. Uh…the people”s faces that I work with. I was thinking, how are they gonna respond to me being sick and I just came off of being sick. With the rheumatoid. I was off 3 months. So I”m like, well I don”t have any sick time. I don”t have any sick time to be sick. So if I”m sick, I”m not gonna have a job to return to. And, and I could only think about. I, I”ve been there twenty something years. I don”t, I”m like; I don”t know how to do anything else.

Participant B1 reflected on how he spent his money. He seemed willing to sacrifice his health in order to maintain financial stability. He was cautious not to be wasteful when spending his money. He paid for what was important first ( i.e. utilities, my house payment). He said,

If I could breathe, I had better go to work because nobody was going to feed me. So, I did so. Just to help pay the… You know, I have to pay bills. So I, that, that made breathing was secondary. If I was going to breath and move I”d have had to go to work. After that series of stroke, it was a little bit different. Because I already had twenty something years in, total… uh, the first job I had. So I had over thirty something years of working. My brain wouldn”t let me relax on that. Even though I felt like, I did enough work. I worked a long time. And I felt, not that I thought wanted somebody to give me anything. I know that”s not going to happen.
Participant B1 talked about the pressure he felt to return to work at a time when he did not feel physically ready to return. This previous experience seemed to affect his view on returning to work after his recent hospitalization. He said,

“...my job was telling me I need to go back to work. Because of, you know, of my age. I wasn’t going to. You know, once you go disability, you, you’re done. As far as uh, making goals and so forth like that. So I did. I went back to work.

Participant B1 talked about returning to work when he knew he was not physically ready. “I didn’t even let my job know that I was in, in the hospital. I used vacation time”, he admitted. Participant B1 was a single man. He said, “There is nobody else there to help pay a bill or anything”. He stated there were many times when he did not feel well and, “I had to look past that”. He continued to believe in his ability to do the job. “Which is what I, what I did”, he said.

B2 (57 years old): Finances. The participant reported being unemployed. He reported he would have more difficulty seeking a job due to his heart condition. He stated, “I’m trying to get some medical assistance from the welfare. Financial”. He also reported concern over the cost of his medications. He commented on the expense of the medications. The participant responded, “Oh they real expensive. A hundred dollars and, a bottle and stuff. I can’t afford that.

B3 (59 years old): Finances. Participant B3 talked about his financial situation. He said, “I been working since I was 16 years old. I worked 33 years for Lincoln Electric.”
And I came out March 6 of 0-9. I went to voluntary separation. Retirement. I can’t draw 100% of my pension, ’til I’m 60 years old. And if I mess with it anywhere before I’m 60, I lose 4% on each year. That would be about 13 months, before I will apply for a full pension. So, I done, I done went over a year already. With not working. The longest span in my life that I done went without… Without not working. And to tell you the truth, I’m not looking forward to work no more anyway. I’m not worried. So I, you know, all my children is grown. I been able to send all of them to college. These are my grandchildren that you’re seeing now. And so, if I don’t, if I don’t have it now, I never will have it. So I’m not that concerned about that. I told them at church a few weeks ago. I say, I just pray for, pray to the lord for health and strength. So, for the financial part of it. I say, like I told my wife, I say well, we get there at the right age, I say, that gone be taken care of anyway. If we still here. So, my outlook on it now. Hey, the lord will provide.

A1 (65 years old): Finances. Participant A1 made few comments regarding finances. She said,

To me it’s still unbelievable. I don’t, because there were no signs beforehand that this was going on and, uh, first I was just kind of wondering dang, well did they do this just, ’cause they can get some money? It is just hard, ’cause I still don’t believe it happened to me.

Concern for home referred to the participant’s ability to care for the home. This usually included cleaning, yard work, and cooking. Concerns for caring for the home
were expressed by male and female participants. Males were typically concerned with maintaining the outer appearance of the home while females focused on maintaining the interior of the home. *Concern for the home* also consisted of the ability to pay for the home.

*B2 (57 years old): Concern for home.* Participant B2 did not speak much regarding concern for providing for his home. He was unemployed and it seemed his fiancé was the primary financial provider. When asked, “How has it affected your role as a provider or a caregiver”? He replied, “Well, like I said. It has slowed down a lot of progress, you know. You know, as far as unemployment benefits”.

*B3 (59 years old): Concern for home.* Participant B3 previously reported his sons assisted with yard work and walking the dog. His nephew cooked meals for him and his wife. The researcher observed the home was well maintained. Therefore it seemed the participant’s support system adequately compensated for his needs regarding maintaining his home.

*B4 (71 years old): Concern for home.* Participant B4 and his wife did not report a concern for their home. Their home was well maintained. The participant’s wife pointed out the home improvements the participant completed before becoming ill. The researcher concluded the couple found a way to maintain their home without his physical assistance. The wife reported a plan to return to work if financial assistance was needed to pay for his medication. The participant did not seem to be in agreement with this plan.

*A1 (65 years old): Concern for home.* While participant A1 reported taking longer to complete chores around her home, she did not report concern regarding inability to complete the tasks. She stated she needed to take a break when completing chores
requiring moderate exertion such as climbing stairs and raking leaves. She did not report any financial concern for maintaining her home.

_A4 (55 years old): Concern for home._ Participant A4 lived with her daughter and granddaughter. When asked about her role as a provider she stated she and her daughter helped each other out. She did not specifically mention chores or financial responsibilities for the home. She did not report having difficulty paying her bills or affording medications. She did state that she purchased her medication before she paid her bills.

**Theme VI. Thoughts of Dying**

Fear of death and thoughts of dying was a significant theme among participants. One participant (A1) reported she would accept dying in her sleep. She seemed to view death as an escape from the troubles she experienced with her children. Some participants (B1, B2, B3, and A1) reported having previous near death experiences and thoughts of dying. Phrases which led to the theme of fear of death and dying were “I”m going to sit up here and die”, “I was so close to death”, and “that”s what”s going to kill me”.

_B1 (51 years old): Thoughts of Dying._ Participant B1 spoke of death and dying. He said,

I just said in my mind…I”m going to sit up here and die if I leave it to somebody else (referring to setting up his pill box).

I”m not trying to prove anything to anybody. That death thing is knocking at my door (referring to returning to work too quickly after a physically compromising illness). And I didn’t want to, you know, I, uh, ignore it. I
want, I want to know, address the issues that I have. And I didn”t know if, uh, and I don”t think my job would be receptive to that.

You know, I”m doing… I”m dealing with a lot less as far as um… the… My quality of life. But I”m managing it because my alternative is to be having some funeral. And I”m not trying to, to help anyone pay for a funeral. So I just… I just try to, uh… Just take it… just take it one day at a time.

B2 (57 years old): Thoughts of Dying. The participant stated he felt fear however he did not explicitly state he was afraid of dying. The participant talked of near death experiences toward the end of the same interview. He spoke of them as if he had many. It would seem that death might have been a fear or concern when he learned he was having a heart attack.

B3 (59 years old): Thoughts of Dying. Participant B3 stated he didn”t have any fear when told he was having a heart attack. He said,

Well, I wasn”t afraid. There was no fear. Uh, I just, I just, I just took it.

You know it”s, because it wasn”t the first experience I had had with uh… I had, uh, uh, uh an appendix that burst on me. Six years ago. Uh, so, I went in… And I was… uh hey; I was so close to death…I, I, by me having that kind of experience…uh…and like I said. The shadow of death was on me… Then…I, So I didn”t feel any fear uh, when the doctor told me I was having a heart attack. I just took the information and I just lay there.

B4 (71 years old) Thoughts of Dying. Participant B4 and his wife did not speak of concerns regarding him dying. His wife stated, “You know, but then on the other hand.
As we live, we know, we shall, shall die”. She made that statement after her husband reported concern about her working so hard to take care of so many family members who had been sick or recently died. He spoke of his family history and stated, “Now on my father. I feel that I, you know, I had picked up their longevity”. The wife and participant acknowledged that his state of health was not good. Participant B4’s wife said, “Ok. So this, the lung disease now, is, is the primary cause of his uh, distress now. You know, it’s really, you know, it’s, if’s really bad”.

**A1 (65 years old): Thoughts of Dying.** Participant A1 spoke often of her thoughts of death and dying. She said,

I kind of think it reminds me that I can die because it actually was my second brush with death. Because last September I had the blood clot and I got to the hospital just in time for that and actually that was, you know. So within seven months I’ve had two brushes with death.

Participant A1 talked about how she thought she would die. She denied having thoughts of suicide. She said,

Cause I’m not going to be one that’s a hypochondriacs. Thinking I’m having a heart attack and I’m not having a heart attack. And I don’t want them to get familiar who (participant A1 name) is walking through that door. You know, here she come again. So, and, and I actually… I actually do believe that’s what will kill me.

And then I tell my children if I don’t see you in the morning you know… And I will. And I will tell them. You know, I don’t feel good. I’m, you know, you might not see me in the morning, you know.
And even though I feel like my children want to see me... stay alive. They... feel like... it’s somebody else that’s putting me...the stress upon me. Not them. It’s you know.... And in trying to help my daughter keep her children, so that they don’t get taken away from her. That’s a very stressful situation there. So sometimes I feel like, um, if I was dead, then I wouldn’t have to be bothered with them. I wouldn’t have to... function no more.

So sometimes I feel like, if I were... to just die... I wouldn’t have to... I wouldn’t have to deal with it. I, I just really...don’t know how to say no. You know, cause I get tired of functioning... for them. You know.

No. I mean, I do, I uh. There are times when, I don’t care if I die. But I, I’m not... To me that’s kind of like a coward’s way out (suicide). You know, it, it really is. If I would have died during the heart attack, it would have been ok.

_A2 (72 years old): Thoughts of Dying._ Participant A2 did not discuss any feelings of fear or thoughts of dying. The only time she seemed to feel fear was when she had to have the cardiac catheterization. She reported her brother helped ease those concerns.

_A3 (72 years old): Thoughts of Dying._ Participant A3 discussed her thoughts of being fearful. She said,

No. No, I don’t like fear. Ain’t nothing to be afraid of. What I’m going to be afraid of? I know god got my back. I’m not worried about it. I’m not afraid of nothing. I just feel truthfully, Can I say? I just feel that uh, the
lord got my back. And there’s nothing going to happen, that he not going
to allow to happen.

_A4 (55 years old): Thoughts of Dying._ Participant A4 spoke of her fear of death and thoughts of dying. She stated she was “really scared”. “Because I’m like, oh my god… I don’t want to die”, she explained. She later stated, “So I’m not used to taking that type of medicine where I have to take it to survive”. She elaborated, “So that, that scares me every day. Yeah. That I will probably just drop dead or something. So I make sure, you know, I, it’s by my bed. And I have a little container”, she stated when referring to her pills. She reported being most afraid of dying and not taking her pills. She said, “I could have been shopping and just dropped dead or something”.

**Theme VII. Coping Strategies**

The majority of participants (n=7) in this study stated that spirituality had an influence on their decision making. Many participants relied on spirituality for strength in times of uncertainty. Prayer was often used as a coping mechanism. _Spirituality_ not only influenced health-related decisions but decisions for preference in providers.

_B1 (51 years old): Spirituality._ Participant B1 expressed spirituality in combination with hope for the future. His spirituality reinforced his hope for the future. This was apparent with his views regarding reflecting on his short term and long term expectations of what the future would bring. However, this participant does not make reference to a specific religious affiliation or set of beliefs. He said,

The fact, I just thought, well, I’m going to have these tests ran. They’re going to see what’s wrong. And bad heart or not, I didn’t care. I was getting up Monday and was going to leave and go to work. Well as it turns
out, that it was good to think, ok, to think that way. I felt, because it kept, it gave, it kept me looking forward. Forward to getting out of here. Versus.

Oh, oh, me. And… you know, start feeling sorry for myself. I wasn’t going to do that. I was… I’m going to get well in a couple of days.

Miracles happen and I was due a miracle.

*B2 (57 years old): Spirituality.* Participant B2 seemed to feel that his heart attack may have been god’s way of getting his attention. He reported fearing death even though he should not. “I mean, as a Christian I shouldn’t be. But I asked the lord to take that fear from me cause he didn’t give us no spirit of fear”, he explained.

*B3 (59 years old): Spirituality.* Participant B3 spoke about his spirituality and how it affected his decision making. He stated,

And so… If I don’t, if I don’t have it now, I never will have it. So I’m not that concerned about that. Or… I told them at church a few weeks ago. I say, I just pray for, pray to the lord for health and strength. So, for the financial part of it. I say, like I told my wife. I say well, I say, we get there at the right age, I say, that that gone be taken care of anyway. If we still here. So, my outlook on it now. Hey, the lord will provide.

*B4 (71 years old): Spirituality.* Participant B4 reported spirituality but did not report a religious affiliation when supplying demographic data. He did not mention the effect of spirituality on his decision making. This participant did not mention attending any particular religious ceremony nor did he report watching a worship service on television.

*A1 (65 years old): Spirituality.* Participant A1 noted her religious affliction was
Jehovah’s Witness. She noted first having symptoms of her heart attack while she was at her place of worship. She also reported fear of negative consequences for not being focused on the ceremony she attended. However, during the interview she did not directly or specifically mention how her spirituality affected her decision making.

_A2 (72 years old): Spirituality._ Participant A2 did not discuss spirituality. She noted Baptist as her religious affiliation on her demographic data sheet. She did not mention attending any religious ceremonies or watching any religious ceremonies on television during the interview.

_A3 (72 years old): Spirituality._ When asked about her fears, participant A3 said, I”m not afraid of nothing. I just feel truthfully I can say, I just feel that uh… The lord got my back. And there”s nothing going to happen, that he not going to allow to happen. But if you start thinking negative, then you”re putting yourself in a trick web of deception, now. You”re fooling yourself now. Because now, you”re saying. Well, you”re going to get bitter, and this, and that. But no. I keep a positive attitude. God want me healed. I will be healed but I have to go through stuff. And I realize that. Everybody do. Sooner or later, everybody going to go through something. And ain”t but one doctor in that hospital breathing. And that”s (doctor name). Cause he”s a Christian. Do you know (doctor name)?

_A4 (55 years old): Spirituality._ There were times when participants described feeling depressed but they would also convey hope for the future. When their situations seemed bleak, many participants in this group turned to prayer. With regard to spirituality, this female participant stated that when she is feeling sad, afraid, or worried
she prays. She then stated there is nothing else she can do other than cry. “Miracles happen and I was due a miracle” another participant (B1, 51 years old) announced.

**B1 (51 years old): Hope for the future.** Participant B1 talked about his intimate relationship and how his illness affected them and their relationship. He seemed to show a lack of hope for the future when he said,

But I figured she that she probably will do better uh, away than with me.

Because uh… Uh, because, I think she was looking for a brighter future, I think, and mine, mine, wasn’t as, as bright.

**B2 (57 years old): Hope for the future.** Participant B2 talked about his hope to become a gospel singer with a record deal. “I can’t do that now, until I get all my strength back. Until the lord says so” he explained. He discussed his plans to, “speed up the progress of getting married”. He stated it was “God’s will”. He added, “the lord been good to me all my life”.

**B3 (59 years old): Hope for the future.** Participant B3 spoke of his hope for the future. “So, he said, with a little hard work, and rehab and what not, I should be able to lead a normal life”, he said. He looked forward to “be able to go up and down the steps without being out of breath”. His hope for the future motivated him to change his eating habits. However, he made sure to state, “As you get older, you begin to understand that your, the days before you is less”.

**B4 (71 years old): Hope for the future.** Participant B4 and his wife did not verbalize hope for the future. Of all the participants, B4 suffered the most significant disabilities. Simple activities of daily living required a great deal of effort and caused extreme fatigue. The couple never talked about the possibility of the participant dying but
they did not talk about the future either.

**A1 (65 years old): Hope for the future.** Participant A1 reported a lack of hope for the future. “So sometimes I feel like, if I were to just die, I wouldn’t have to deal with it. I just really don’t know how to say no. You know, cause I get tired of functioning for them (her children). You know”.

**A2 (72 years old): Hope for the future.** Participant A2 never made reference to her hopes and dreams for the future. She reported having a sedentary lifestyle. She enjoyed watching television. She did not report leaving home for any leisure activities outside the home. Her comorbid lung disease had limited her activity for a long period of time.

**A3 (72 years old): Hope for the future.** Participant A3 reported that her heart attack did not affect her hope or plans for the future. “It haven’t affected me at all because I’m signed up to get into college. I was in college when I was in Chicago”, she explained. She reported attending school to become a nurse.

**A4 (55 years old): Hope for the future.** Participant A4 reported having hope for the future and that she had returned to enjoying the leisure activities she enjoyed prior to her heart attack. She listed skating, bowling, and riding a bike. However, she reported thoughts of her heart attack and a fear of reoccurrence were “still in the back of my mind. It will never leave”.

**B1 (51 years old): Feeling depressed.** When participant B1 thought of how his quality of life would change if he could no longer work he stated, “That just sinks me too. That just depresses me”. He continued, “It just depresses me to think of how it’s going to change”. He didn’t want to focus on, “Things I knew I used to be able afford”. He anticipated a lower quality of life.“ Uh, Mentally, it’s frustrating”, he admitted. He
reported the thoughts of how his life would change were frustrating and stressful.

*B2 (57 years old): Feeling depressed.* Participant B2 did not report signs or symptoms of depression. He reported turning to his religion when he had “negative experiences”. “I just started singing, and that was one, one of my ways of dealing with that negative stuff”, he stated.

*B3 (59 years old): Feeling depressed.* Participant B3 did not express any feelings of sadness or depression. He reflected on a previous near death experience and the near death experiences of his mother and his wife. He also talked of a grandchild who was born on his birthday and at the time of his near death experience. He explained that she died prematurely. He reflected on how his past experiences prepared him for the experience of his heart attack. The participant’s previous suffering of emotional pain and sorrow affected, maybe even desensitized, transformed, or modified his response to his most recent traumatic event (the heart attack).

*B4 (71 years old): Feeling depressed.* Participant B4 reported his lack of physical activity changed his lifestyle. “It’s very depressing”, he confessed. “Well, I’m depressed because of the way that she’s working, now”, he added. He reported concern that his wife was helping take care of three people. He listed himself, her aunt, and her sister. His wife reported witnessing his emotional pain. “I see him hurting a lot”, she recalled.

*A1 (65 years old): Feeling depressed.* Participant A1 reported previously receiving therapy to treat her depression. She stated, “It just seems futile”. She was not interested in taking pills to treat her depression. She felt, “Pills don’t help you with thoughts”. She summarized by stating, “No. I just, I just function”.

*A2 (72 years old): Feeling depressed.* Participant A2 reported she felt sad about
not being able to return to her home. She reported having heart disease was stressful. Participant A2 did not report signs or symptoms of depression.

_A3 (72 years old): Feeling depressed._ Participant A3 denied feeling sad or depressed. “I said, well, what do you want me to do cry? I don’t have nothing to cry about. And I’m not hurting so I don’t have nothing to be sick about. I’m not sick, she exclaimed. She elaborated, “The lord got my back. And there’s nothing going to happen, that he not going to allow to happen”. She talked about the healing power of thinking positive. “God want me healed. I will be healed but I have to go through stuff. And I realize that. Everybody do. Sooner or later, everybody going to go through something”, she said.

_A4 (55 years old): Feeling depressed._ When participant A4 was asked how she coped when she feels sad, she said, “I just pray. And there’s really nothing else I can do other than cry. I don’t really talk it over with uh, anyone”. She elaborated, “I’ve sort of gotten past it but I still feel sad about it. Knowing that something is wrong with my heart. Knowing that I had to have a procedure done. You know, knowing that it was um, a heart attack. That’s what makes me sad”.

Coping strategies for the participants included prayer, singing, telling their story to strangers, taking advice from sources of support, spending time with people who were positive/ encouraging, and observing trans-generational role models. Every participant reported having spiritual beliefs. Most participants (n=6) acknowledged turning to prayer when situations seemed hopeless. Even the participants, who reported feeling hopeless and wishing for death in their sleep, reported a desire to live.

Five of the eight participants reported uncertainty regarding the etiology of their
initial symptoms. Feelings of uncertainty played a major role in perception of illness. Several of these participants reported repeatedly contemplating the need to seek medical attention. Uncertainties of etiology often lead to a delay in care. In some cases sources of support convinced participants to seek medical care. The sources of support in this study were family, friends, neighbors, co-workers, significant others, and health care providers. The sources of support were people the participant relied on to seek medical care for day-to-day needs (or lack thereof). Essentially, these people encouraged the participant.

Discussion

What is the lived experience of managing CHD among African Americans? The results of this study show that African Americans respond to ACS and CHD similar to other ethnic/racial groups. Most of the participants in this study voiced a trusting partnership with the healthcare providers in disease management, reported performing self-management skills, and a strong sense of spirituality and resilience. Unique culturally influenced attributes for this racial/ethnic group were their manifestation of depressive symptoms, and lack of social support among the females.

Contrary to many studies in which racial/ethnic differences in trust were examined, this study found all participants verbalized trust in their primary care providers and cardiologists who performed their cardiac catheterization (Armstrong, Ravenell, McMurphy & Putt, 2007; Halbert, Armstrong, Gandy, & Shaker, 2006; Lee, Tamayo-Sarver, Kinner, & Hobgood, 2008). Similar to the Jacobs, Rolle, Ferrans, Whitaker, & Warnecke (2006) study, interpersonal competence and technical competence facilitated trust. Hence lack of interpersonal skills, and technical incompetence, led to distrust due to perceived focus on profit, racism, and being ignored. Benkert, Peters, Clark, & Keves-
Foster (2006) notably showed a strong positive correlation between perceived racism and mistrust. One participant in this study displayed distrust in an Asian provider similar to that noted in Benkert, Peters, Clark, & Keves-Foster (2006). She stated the doctor was not friendly.

Many of the participants in this study had positive things to say about their primary care provider. Several participants (B1, A1, and A3) verbalized having caring feelings beyond the usual patient-provider relationship for their primary care provider. Two of these participants also verbalized strong positive feelings for the cardiologist who cared for them during their myocardial infarction.

Several participants verbalized episodic doubts about care when they perceived their questions regarding their health status and cause of illness were not adequately answered. The participants often verbalized their doubts openly to providers. This communication usually facilitated discussions and resolved feelings of doubt. There was an even greater level of trust in physicians who shared spiritual beliefs with their patients. This would be congruent with the results of Armstrong et al., (2008) which showed the need to further differentiate distrust in values versus distrust in competence.

Medical mistrust among African American males in this study reflected the results of the Hammond (2010) study which found the majority of male participants had contact with a physician within the last 12 months. Most male participants (75%) reported complete satisfaction with the quality their interaction. As in the Hammond study the majority of participants reported the physician listened to their concerns and addressed their needs appropriately (75%), explained health information in a way they could understand (100%), and no participant reported feeling rushed through their
appointment. They (100%) also verbalized feeling free to discuss any issue of concern without restriction.

A dominant behavior affecting participation in health-related decision making was the performance of self-management skills. The participants who desired an active role in health-related decision making verbalized requesting health information from their health care team. These same participants viewed themselves as a partner or teammate with their physician and other health care providers. Additionally these participants were knowledgeable about their illness and verbalized the frequency of testing required to monitor their disease state. This may explain the increased utilization of screening tests and preventive health services noted for participants who preferred more involvement in health-related decision making as noted in Heisler et al., 2009; Musa, Schultz, Harris, Silverman, & Thomas, 2009.

Participants in this study who reported an active role in health-related decision making reported overall satisfaction with the care they received during hospitalization. The remaining participants reported feeling ignored (B2) or had no desire to have a role more active than the one they had (A2, A4). The participants who had no desire for a more active role in health-related decision making seemed to lack confidence in their knowledge & ability to do so.

Understanding how African Americans cope with CHD is important as the health care system shifts toward a patient-centered model of care. While coping strategies varied among participants, spirituality was a consistent theme for all. Spirituality was a characteristic that every participant in this study reported having. Spirituality was defined as the sensitivity or attachment to religious values for the purpose of this study (Merriam-
Webster, 2011). Attitude toward the health care team, practice of self-management, and hope for the future were also influenced by spirituality. While discussing religious beliefs with patients is generally not advised, it may give patients a sense of physician moral and ethical values. Participants in this study valued hospital staff that was caring and showed concern for their needs.

As in the Harvey & Cook (2010) and Polzer Casarez, Engbretson, & Otswald (2010) studies, spirituality was practiced by reading books written by spiritual leaders that contained advice on coping with illness, attending church, praying, and communicating with church members. One coping strategy, which was consistent with nearly all participants, was the use of prayer. In this study prayer seemed to be a tool used to relieve anxiety and depression when there seemed to be no other alternative. This use of prayer was similar to a church-based nurse-managed resource center that used prayer with a stress management technique to help clients look at stress from a spiritual perspective (Fehring & Frenn, 1987).

Contrary to one research study, this group of African Americans recovering from an acute coronary event did not display gender differences in health information needs. All males and half the females in this study perceived a gap between health information they wanted and what they perceived they received (Stewart et al., 2004). The topic they desired more information on was the cause of their heart attack. Most of the participants planned to inquire about the health information they wanted at their next doctor’s appointment.

At least four of the participants in this study reported depressive symptoms. For two of the four, the depression was pre-existing. The participants who reported these
symptoms did not have any overt signs of depression. They smiled and laughed during the interviews. Most were dressed for the day (as opposed to wearing pajamas). Depression is not something that is included in the nursing assessment after a myocardial infarction at most institutions. Nor is it something healthcare providers routinely screen for at the first office visit after an ACS. All of the participants followed up with their cardiologist as recommended within the first four weeks after their hospitalization.

*What is the essence of health-related decision making among African Americans living with CHD?* This study found older African Americans with CHD reported multiple themes affected health-related decision making. Health-related decisions were made based on their knowledge of their illness, new physical disabilities, feelings of guilt of impact on sources of support, health care provider partnership, and previous near death experiences. There was some overlap in themes that resulted from each research question.

Nearly all participants in this study preferred an active role in health-related decision making contrary to some previous studies (Levinson, Kao, Kuby, & Thisted, 2005). Most of the men (3) and half of the women (2) in this study preferred an active role in health-related decision making. The ones who preferred an active role verbalized having one. All but one of the participants in this study verbalized satisfaction with their current role in deciding which treatments were best for them. This is contrary to the study in which Kremer, Ironson, Scheidman and Hautzinger (2007) found fifty-eight percent of participants felt they had not achieved their desired level of decision making. Participants acknowledged the need for information regarding their health status, disease condition, and recommended therapy to be properly prepared to make the best decision.
Perception of illness was a theme that impacted the essence of the phenomena as well as health-related decision making. Perception of illness was crucial to health-related decision making. The individual’s perception of their medical condition is the basis of disease management. Many of the participants in this study reported a desire for full disclosure of their health information. It was important for them to understand why they had CHD and the chance of a clinical reoccurrence. The participants wanted to understand their medical condition to the best of their ability. The men and women in this study utilized additional resources (books, the internet, and advice from sources of support) to obtain additional information regarding their health conditions.

In this study a new disability was almost certain for older African Americans recovering from an acute coronary event. This finding corresponded with the results of Xie et al. (2008). Participants with CHD had lower rating of mental health, physical health, and health utility (Xie et al., 2008). There were racial/ethnic differences and disparities in health-related quality of life (HRQoL), health status, and mortality that were not well understood and remained unexplained after adjustments for socioeconomic and demographic characteristics (Xie et al., 2008).

Many participants in this study suffered significant mobility impairments after their hospitalization. All participants who reported new physical limitations reported an undesired change in lifestyle. Many were forced to forgo extracurricular activities at least temporarily. Limitations on physical activity led to feelings of loss of freedom and loss of control over one’s life as well as their physical being. The perceived loss of independence and worsening health status often led to feelings of depression and hopelessness. One participant utilized technology to pay his bills rather than the traditional methods. This
choice decreased the risk of unsafe driving and the anxiety he felt when going into the community alone.

Participants often expressed feelings of guilt for the impact of their illness on others. All of the participants in this study verbalized having family members as sources of support. A previous study also showed how social support plays a key role for African Americans in management of chronic illness and self-management behaviors (Tang, Brown, Funnel, & Anderson, 2008). Many participants in this study verbalized appreciation for the efforts made by their sources of support. Fortunately, most of these participants had children who were independent adults. Two female participants lived with adult children. One would no longer be able to live in the home they shared together. Two male participants had wives but both men were in situations where they were retired/semi-retired. Therefore their new limitations would not change the amount of household income. Nonetheless, the cost of medications was a significant additional expense.

Another theme that affected participant health-related decision making was previous near death experiences and reflections on death. Several participants reported a history of at least one near death experience. Additionally several participants reported fear of sudden death in a public place and reflected on how life for others would be if they died. This fear affected their decisions to go out to public places and whether they would venture out alone.

Fear of dying and reflection on death are two themes, which also emerged in the Coyle (2009) study. Surviving a heart attack led participants to have feelings of uncertainty, fear of recurrence, and ongoing symptoms, which were not well understood
by the participants (Coyle, 2009). This was also true for several (63%) participants in this study. The same participants who voiced fear of dying voiced feelings of intermittent anxiety and/or depression. These fears reinforced adherence to medication regimens.

While the sample size of this study was small, the results make a significant contribution to the literature. The African Americans in this small sample demonstrated medical trust, self-management skills & viewed their provider as partners in disease management. Many participants in this study did not show overt signs of depression but the symptoms were reported during the interviews. These are issues that warrant further investigation.
Chapter 5

Summary

The purpose of this study was to explore the themes that affected the day-to-day health-related decision making patterns of African Americans who had experienced an acute coronary syndrome and were managing newly diagnosed coronary heart disease (CHD). Understanding the lived experience of African Americans with coronary heart disease can offer health care providers additional strategies to improve management of CHD. This study found health-related decision making among African Americans to be multifactorial. This chapter will summarize the results of this study and discuss how it contributes to the literature.

A hermeneutic phenomenological approach was utilized to explore two research questions. 1.) What is the lived experience of managing coronary heart disease among older African Americans? 2.) What is the essence of health-related decision making among older African Americans living with CHD? These questions were explored using two audio-taped 30-60 minute open ended in-depth interviews per participant.

The sample consisted of eight African American (males =4 and females =4) over age 45 who were admitted to the cardiac catheterization laboratory with acute coronary syndrome in a large metropolitan hospital for the evaluation and treatment of CHD. Purposive sampling was utilized. The size of the sample was considered adequate when findings were clear and no new themes emerged. Bracketing and phenomenological reduction were utilized to elicit units of general meaning and allow openness of the meanings that emerged. Once the researcher reached the point in data collection and analysis in which no new ideas emerged, one additional set of interviews in each group
beyond the point of saturation completed data collection. The achievement of *saturation* was verified with the researcher’s qualitative expert.

**Pertinent Findings**

*What is the lived experience of managing CHD among African Americans?* The lived experience of African Americans managing CHD was defined by three factors: the state of co-morbid conditions, medical trust, and physical ability. The state of comorbid conditions at the time of the cardiac event had a large impact on the participant’s experience with coronary heart disease. Coronary heart disease was not always the illness that had the greatest impact on the participants in this study. Participant B1 reported his rheumatoid arthritis and cerebrovascular disease had a greater impact on his physical ability. Two other participants (A2, B4) were more physically limited because of their lung disease.

Conversely, being diagnosed with CHD was emotionally traumatic for participant A4. She developed a fear of being physically active. The thought of forgetting to take her medication and discontinuing antiplatelet therapy after one year was also disturbing to her. One of the cardiologists who cared for her helped alleviate some of these fears. This cardiologist is the same person who convinced her to proceed with her heart catheterization though she initially wanted to decline. It would seem that this cardiologist developed a trusting relationship with the participant in a short period of time.

Most participants in this study verbalized trust in primary care providers and the cardiologist who performed their cardiac catheterization. Medical trust was important to how African Americans experienced coronary heart disease. Trust was jeopardized when there were inconsistencies in the health information participants received and when their
questions or concerns were not directly addressed. As with any relationship, there were
times when trust was questioned but these issues were easy to resolve because
participants reported having good communication with their primary care provider. The
majority of participants reported they would call their provider if they had a question or
concern.

It is most important to note there was no patient-physician race/ethnicity
concordance for any participant in this study. Meaning all of the participants had primary
care providers and cardiologists who were not African American. Additionally, many
participants verbalized the importance of having a provider with good interpersonal
skills. Two participants (B2, A4) did not seem to expect a relationship beyond patient and
provider with their physician. These two participants reported non-adherence to medical
advice and prescribed medication regimens prior to their heart attack. Though previous
studies have reported a positive association between race concordance and cardiac
medication adherence among African Americans, the findings of this study support the
idea that patient-physician concordance is not necessary to improve adherence to
recommended therapies in the disease management of African Americans with CHD.
More importantly, the results of this study support the theory that a good interpersonal
relationship between patient and provider improve the likelihood of adherence to
recommended therapies in the disease management of African Americans with CHD.

*What is the essence of health-related decision making among African Americans
living with CHD?* Health-related decisions were made based on the participant’s
knowledge of their illness, new physical disabilities, feelings of guilt of impact on
sources of support, provider partnership and previous near death experiences. Being
unable to perform the same tasks as they did before was a challenging experience for many African Americans in this study. Suffering a new physical disability resulted in giving up activities participants enjoyed (driving, roller skating, bowling, line dancing etc.). Disabilities put participants at increased risk for injury in their homes (falls). Many participants reported feeling confined to their homes. Symptoms ranged from mild shortness of breath and fatigue to feeling as if the participant was going to “shut down”.

Men were more likely than women to have a spouse or significant other as their support person. The women typically relied on their children or siblings for support. In two of these cases the women were widows. Children and siblings were not as easily accessible as a spouse or significant other who (in the majority of cases) lived in the same home as the participant. The researcher believed this provided an additional challenge to women as they adjust to new physical impairments and lifestyle changes. These circumstances put them at increased risk for negative health outcomes due to lack of social support.

**Limitations**

This study had several limitations. The setting was a single academic medical center in the Midwest. Consequently our findings are not generalizable to all African Americans with newly diagnosed coronary heart disease. The African Americans who chose to participate in this study may have been participants who were more likely to perform self-management skills. Participants in this study may have had different experiences based on the economic situation in Cleveland, Ohio during an economic recession. The economic situation in Cleveland, Ohio more likely had an effect on the participants who were working than the ones who were retired.
This study took place in a large academic hospital with highly skilled healthcare professionals. This hospital had the second busiest emergency department in Northeast Ohio. This may have resulted in a sicker population of potential participants as compared to the general population of African Americans with newly diagnosed CHD. Thus the participants may have had more complicated clinical presentations or more severe disease states.

The researcher who conducted these interviews worked as a cardiology nurse practitioner at the hospital where the research was conducted. The participants in this study may have answered the research questions differently than they would have if the interviewer had no affiliation with the hospital providing care. The participants may have answered more positively or more negatively based on their knowledge of the background of the interviewer. Additionally, there were limited interactions between the researcher and participants. This may have had an effect on the researcher’s ability to develop a trusting relationship with the participants.

Implications

African Americans with newly diagnosed CHD need to make many health-related decisions. When a patient is admitted to the hospital with CHD it is important to assess their decision making preference. Helping patients identify decisions they will need to make regarding care prior to discharge can have a positive impact on health outcomes. In order to improve patient outcomes, the nurse should help the patient identify behaviors that will need modification and help the patient identify steps they can take toward behavior change. It is important that the nurse assist the patient in the planning and implementation of behavior change in order to manage the newly diagnosed disease.
Most importantly, the nurse will need to help the patient identify measurable goals to meet by a defined time period.

In this study there were several implications for understanding the determinants of medical trust. Medical mistrust is defined as the mistrust of health care organizations and health care professionals (Hammond, 2010). Medical mistrust has been associated with African Americans being less satisfied with care, non-adherence to recommended treatment, and underutilization of health care facilities (Hammond, 2010). The interpersonal relationship between the patient and the health care team is important in establishing medical trust.

The interpersonal relationship between a cardiologist and a patient is determined by fewer interactions than that of a primary care provider. Furthermore, the initial interaction between a cardiologist and patient with an acute coronary syndrome is established in the midst of time restriction, the pressure of a medical emergency and fear of procedural complications. This situation can be equally stressful for both the provider and patient. The course of the hospital stay is often short. Patients are subject to longer stays when there are complications or uncontrolled existing medical conditions. With all of these issues being considered, there is less time and fewer interactions for a cardiologist to establish a meaningful relationship with the patient prior to the time of discharge. These issues decrease opportunities to establish a trusting relationship and increase the chance of a patient not showing up for a follow-up appointment.

**Contribution to Nursing Science**

Understanding the thoughts and feelings of African Americans as they respond to a newly diagnosed disease is important to nursing science. The nurse scientist needs to
understand how this phenomenon is different for African Americans. Based on the results of this study, it is important for nurses to assess the patient for symptoms of depression. Many participants in this study reported feeling down or depressed. None of the participants reported being evaluated or treated for depression after their CHD was diagnosed. It would appear that symptoms of depression may be under detected in this population.

Second, it was concerning that participants reported incidents where they felt as if they were being ignored. Acute care settings can be very busy however it is important for every patient to feel as if their needs are being met. Nurses should routinely check to make sure that the patient feels as if their needs are being met. Previous research studies show that African Americans can misinterpret being ignored as a sign of racism (Woodard et al., 2005).

Nurse researchers want to know if there is a difference between the way African American’s perceive the care they receive and why. The results of this study demonstrate that there may be a different response to being diagnosed with CHD. African Americans did voice the fear of being misdiagnosed or mistreated but the trust was easily regained with good interpersonal communication and the staff’s display of clinical expertise.

This qualitative study makes a unique contribution to nursing research. The rich textual data captures the African American’s perception of their body as it changed; their mind as they interpreted what was happening to them; and their environment as they attempted to navigate with new physical impairments. Every participant contributed a unique perspective to the study despite the common challenges they each faced. Every participant’s life was irreversibly altered by the event that caused their hospitalization.
Many of the participants in this study empathized with the role of the nurse as a member of the healthcare team. They enjoyed having the opportunity to have private conversations with the nurse. Most participants verbalized complete satisfaction with nursing care provided during the hospital stay. The nurse-patient relationship can be very influential in motivating patients and promoting positive behavior change. This role is underutilized.

This research focused on the lived experience of African Americans with newly diagnosed CHD. The selection of this population allowed a deeper understanding of the initial perceptions African Americans had when coping with an ACS and new diagnosis of CHD. The participants in this study displayed feelings of trust and satisfaction with providers of Caucasian, Latin, and Asian descent. Additionally, choosing African Americans with acute ischemic events allowed insight into the urgency felt by the participants. It also exposed the difficulty an individual may have in accepting the diagnosis when they had no symptoms.

Policy

The results of this study reveal that African Americans want to be informed about their health status. The participants wanted access to their health care information and most wanted to have a role in health-related decision making. More importantly, the participants were attracted to providers who seemed to listen and respond to their concerns. This was especially important when the participant voiced concerns regarding the prescribed medication regimen. Therefore it is important to focus on policy change that will empower the patient to have their desired level of related health decision making.
The researcher of this study would like to focus on policy change in the transition of care from hospital to home and self-management strategies. The results of this study show there is still a need for a smoother transition from hospital to home. Many participants in this study had complications or questions and concerns regarding their plan of care. There were also times when the hospital physician’s plan of care did not seem to correlate with the primary care provider’s plan of care.

The patients in this study viewed their primary care provider as the primary person to develop their plan of care. There were other times when participants voiced concern that the primary care provider did not receive the same information regarding why the patient was hospitalized and what the follow-up treatment should be. Additionally, there were times when the primary care physician did not receive the correspondence or notification of their patient’s hospitalization. This was frustrating to the patient and presumably the provider. The problem becomes more concerning when there are multiple providers involved which was true for the majority of the participants in this study (88%). Poor transitions of care can lead to medical errors, medication-related problems and poor quality of care. The researcher of this study proposes implementing policy to establish accountability for communicating a plan of care from provider to provider.

It is proposed that each health care facility in the United States establish contact with the facility or community provider from whom the patient was received at the time of admission. This communication is to be documented in the medical record. It is proposed that the facility provider contact the primary care provider or sending facility (facility that sent the patient) prior to time of discharge to discuss the plan of care and
proposed schedule for follow-up. Additionally, a national performance measure should be
developed to encourage improved communications during transitions of care.

The IOM performed an analysis to identify the sources of disparity in healthcare
(IOM, 2001, p. 180). The sources were identified according to the effect of their decision
making on health outcomes. The decision making of patients was identified as
paramount, followed by providers, utilization managers, and health care system
administrators (IOM, p. 180). Developing policy focusing on the patient decision making
would have the biggest impact on patient outcomes.

The results from this study support the idea that older African Americans with
newly diagnosed CHD can successfully perform self-management tasks if given the
proper support during the initial implementation. The researcher of this study proposes
changing the care model of institutions throughout the country to a patient-centered
model which offers: Self-management education classes, identification of an
interdisciplinary team whom the patient can contact at any time with questions or
concerns about their care, and opportunities for continued education on health promotion
and disease prevention topics. The care provided by the team should also include a
holistic approach to care which includes meeting the spiritual needs of the patient.

Previous research found the clinician’s decision to order noninvasive or invasive
cardiac testing was the most influential factor leading to racial/ethnic disparity in the
evaluation and treatment of CHD (Bashore et al., 2001). Since that time the American
Heart Association has developed recommended protocols to eliminate disparity in the
treatment of heart disease resulting from the clinician’s decision. Mission: Lifeline is a
national initiative initiated by the American Heart Association (AHA) which is designed
to minimize the time lag between symptom identification to coronary intervention (AHA, 2011).

All of the hospitals in the United States should have appropriate protocols and standing orders for the identification and treatment of acute coronary syndromes. These protocols should be in place in the intensive care units and emergency room departments throughout the country. There should be quality improvement processes in place to track data, monitor, report, and improve treatment provided for the targeted population. It is recommended that an interdisciplinary team within the hospital review this data quarterly.

While there were only 8 participants in this study, the results of this study show that African Americans are benefiting from protocols that guide clinician decision making. The hospital in which these participants were admitted has the stated protocols. It would seem these protocols may be effective in eliminating racial/ethnic discrimination in the evaluation and treatment of CHD among African Americans. It is important to note that all of the participants in this study received coronary angiography. If we have found a way to address disparity due to clinician decisions then the patient’s decision making should be the focus of future interventions.

*Practice*

This research gives nurses new insight into the African American’s response to ACS and CHD. This is important because the nurse often functions as a disease management coordinator. It is the nurse who is tasked to encourage the modification of the health-related behaviors of African Americans with CHD. The public views the nurse as someone who can help empower patients in health-related decision making & self-management. Nurses provide this service through patient educate on illness, disease
prevention strategies, and health promotion strategies. As the health care systems are transitioning to patient-centered care, the nurses are expected to provide patient centered care using self-management strategies. It is through these self-management strategies that nurses can support and empower patient decision making.

The researcher of this study would suggest that nurses begin discussing goal setting for behavior modification with patients as soon as possible. Make sure the patient’s needs are met and that they do not feel as if they are being ignored. Assess the patient for pre-existing depression. Identify patients who are at risk for depression to the medical team. Offer the patient the opportunity to tell their story about their ACS. Ask them how they plan to manage their disease. Even if the patient is not certain, it will encourage them to think about their plans for their care.

Florence Nightingale’s theory is relevant today and always. The nursing metaparadigm and nursing science has the patient as its central focus. The participants in this study reported being observant of the environment and when they felt the environment was unsanitary it caused emotional distress. Participants were observant of nurse hand washing techniques and the cleanliness of their environment. They were also concerned with the privacy of their environment. It is important for nurses to control and maintain the patient’s environment when they are vulnerable to infectious disease as is the situation status post angiography and in intensive care settings.

For some participants the environment was psychologically stressful because the high-tech care they received caused a lack of rest. This was a result of being awakened in the early morning hours for blood draws. Psychological stress also resulted when there was not good communication between the cardiologist and the primary care physician.
The nurse can assist by assessing for these psychological stressors and addressing them as appropriate. Rest is an important aspect of healing and addressing these psychological stressors will promote the healing process.

Assessment of the patient’s environment includes an assessment of the patient’s home situation. The results of this study show that female participants are at increased risk for lack of social support. It is common for a patient to be discharged to return home on a different medication regimen than the one they were admitted on. The nurse has the ability to assess the patient’s knowledge and skill to take medications as prescribed. She can offer educational materials and educate the patient as needed. If the patient anticipates problems, the nurse can begin to assess the financial barriers that may prevent the patient from taking medications as prescribed. The nurse can also begin the search for patient assistance programs. This is especially important when the patient has multiple chronic conditions.

Holistic practice values the subjective experience of individuals and the nurse becomes a therapeutic partner in patient care. According to the American Holistic Nurses Association (AHNA), all nursing practice that has healing the whole person as its goal is holistic nursing (AHNA, 2011). The use of hermeneutic phenomenology in this study allowed the researcher to explore the participant’s perception of body, mind, and spirit as they managed the experience of living with CHD. The results of this study provide insight into the importance of nurses fostering therapeutic and trusting relationships with patients.

Contrary to what may have been taught in nursing school, it is okay to talk about religion if the health care provider shares common beliefs with the patient. If not, it
should not stop the health care provider from supporting and assisting the patient’s desire to fulfill spiritual needs and religious practices. Moreover, it is okay to have a friendly relationship with the patient if both parties are comfortable with the exchange of information. Of course it is important for nurses to maintain professionalism. However, there is no harm sharing details regarding educational background or family stories as long as it does not conflict with the nurse’s professional duties and obligations to patient care.

Every interpersonal interaction is important. Every participant in this study commented on the care they received from nursing staff. Almost all participants (6) were completely satisfied with their nursing care. Many participants noted the time that was taken to educate them on issues related to managing CHD (i.e. disease symptoms, medications). Hence, nursing should focus on incorporating time for therapeutic listening and motivational interviewing.

**Recommendations for Future Research**

The researcher of this study would like to propose a research project that would have the goal of improving the patient’s ability to perform self-management skills. The researcher believes self-management strategies could be more effective for African Americans if used in combination with motivational interviewing. Motivational interviewing is technique that is guided by four principles: resisting the right reflex, understand and explore the patient’s motivation for change, therapeutic listening (with empathy), and empowering the patient (Rollnick, Miller, & Butler, 2008, p. 7). This would allow the nurse to establish a collaborative relationship to honor the autonomy of
the patient. This form of counseling was found to be effective in the management of many illnesses including CHD (Rollnick, Miller, & Butler, 2008, p. 6).

Based on the results of this study the researcher would recommend developing a research study using a nurse-managed motivational interviewing intervention to support self-management strategies for African Americans with newly diagnosed CHD. This study shows that African Americans are capable of self-management. Yet previous studies have shown self-management strategies to be less effective for this population. Therefore the researcher proposes a quasi-experimental clinical trial using purposive sampling to enroll 100 participants of various racial/ethnic backgrounds from at least two medical centers into a study that would use a motivational interviewing technique as the intervention. The population would be divided evenly into two groups. Both groups would be instructed on self-management strategies. The goal of the sampling of multiple ethnic groups at more than one setting is to obtain a larger more representative sample across settings. The goal of the second research project is to obtain additional data about health-related decision making that will be used to develop an intervention study.

One group would receive a motivational interview from a nurse every month starting prior to discharge from the healthcare facility. The participants would set goals for self-management prior to the day of discharge. The nurse would review their progress in meeting their goals prior to each motivational interview. The success of the intervention would be determined by: (1) the participant meeting their goals, (2) positive behavior change, (3) the participant’s satisfaction with the care provided, (4) the participant’s self-rating of their ability to manage their illness.
Examining Health-related Decision Making Patterns of African Americans with Coronary Heart Disease (Interview 1)

Research Questions:
What is the lived experience of managing CHD among African Americans?

What is the essence of health-related decision making among African Americans living with CHD?

Interview 2
Opening question

1. What happened when you were rushed to the hospital with the heart attack?

Probes:
   a. Where were you when the emergency occurred?
   b. What were your symptoms?
   c. Who were you with?
   d. How were you told that you were having a heart attack?
   e. Who told you that you?
   f. What were your thoughts?
   g. How did you feel?
   h. How were you transported to the hospital?

2. How has this condition affected your plans for the future?

Probes:
   a. To what extent has your illness affected those closest to you?
   b. How has it affected your role as a provider or caregiver?
   c. What has been most challenging?
   d. What has been most rewarding?
   e. What emotions do you feel?
   f. What are you most afraid of?
   g. How do you cope with these feelings?
3. Tell me about your experiences with the healthcare system.

Probes:
   a. List the top 5 good experiences that you have had in the health care system.
   b. List the top 5 bad experiences that you have had in the health care system.
   c. Did the staff meet your expectations?
   d. If you could change one thing about the experience, what would it be?

4. What kind of relationship would you say that you have with your primary health care provider?

Probes:
   a. How do you determine how often do you visit the doctor?
   b. What do you talk about during your office visit?
   c. What would you like to talk about during your office visit?

5. What type of health-related decisions does your primary health care provider encourage you to participate in?

Probes:
   a. Which health-related decisions would you prefer to allow your doctor to have the final decision?
   b. What health-related decisions would you like to have the final decision?
Examining Health-related Decision Making Patterns of African Americans with Coronary Heart Disease (Interview 2)

Research Questions:
What is the lived experience of managing CHD among African Americans?

What is the essence of health-related decision making among African Americans living with CHD?

Interview 1
Opening question
1. What has it been like for you to have heart disease?

Probes:
   a. Tell me about the symptoms you have?
   b. How has your day-to-day life changed because of the heart disease?
   c. What does your family say about your heart problems and taking care of yourself?
   d. Who else do you know who has heart disease?
   e. What kinds of things do you talk about related to having heart disease?
   f. What has been most difficult since you were told you had heart disease?

2. Tell me how you decide what to do to take care of your health?

Probes:
   a. Who influences your decisions about what to do to take care of yourself?
   b. Who do you get advice from about your heart disease?
   c. What resources do you use when you are seeking additional information?
   d. What things do you think about to decide:
      How to spend your money
      What medicine you take and when;
      What to eat;
      What activities to take part in;
What exercise you do.

3. Tell me what you do when you have chest pains.

4. Tell me what you do when you are short of breathe.

5. What kind of decisions did you have to make (about your job, relationships, leisure activities), after you found you had heart disease.
References


American Heart Association. (n. d.) Mission: Lifeline is the American Heart Association’s national initiative to advance the systems of care of patients with ST-segment elevation myocardial infarction (STEMI) and all AMI patients. Retrieved April 4, 2011 from http://www.americanheart.org/downloadable/heart/1238103222717ML_Criteria.pdf


Conigliaro, J., Whittle, J., Good, C.B., Hanusa, B.H., Passman, L.J., Lofgren, R.P.,


http://epublications.marquette.edu/cgi/viewcontent.cgi?article=1027&context=nursing_fac&sei-redir=1#search="wholistic+nursing"


HTH Engineering Incorporated. Start-stop dictation and transcription systems retrieved July 2, 2009 from


Lillie-Blanton, M., Brodie, M., Rowland, D., Altman, D., & McIntosh, M. (2002). Race,


February 1, 2009 from http://www.nhlbi.nih.gov/resources/docs/ses.txt


