BIOPSYCHOSOCIAL-SPIRITUAL FACTORS IMPACTING AFRICAN AMERICAN PATIENTS’ CARDIAC REHABILITATION REFERRAL AND PARTICIPATION

by

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African Americans carry a heavier burden of cardiovascular risk factors and have higher rates of death from coronary heart disease than any other racial/ethnic group in the United States, yet they are also less likely to be referred to, participate in, or benefit from Cardiac Rehabilitation (CR). In order to investigate the demographic and biopsychosocial-spiritual factors impacting African American patients’ referral to and participation in CR, three research articles were completed: (a) a systematic review of the literature regarding this topic; (b) a descriptive phenomenological study designed to explore the lived experience of seven African American patients recovering from cardiac events and/or surgeries; and (c) a policy brief synthesizing the findings from a systematic review of the literature and a mixed methods study to offer policy-, programmatic-, and individual-level recommendations to best support African American patients’ recovery from cardiac events and/or experiences. The systematic review demonstrated a paucity of studies on the demographic and biopsychosocial-spiritual factors impacting African American patients’ CR referral and attendance. The studies that were identified demonstrated that, among African American patients, there was a lower likelihood for CR referral, a higher likelihood of enrolling in CR with more cardiovascular risk factors, and a lower likelihood of CR participation and completion due to factors related to low socioeconomic
status. The phenomenological study resulted in six emergent themes relevant to the lived experience of seven African Americans (4 men and 3 women) who had experienced a cardiac event and/or surgery: (a) Participants valued medical providers’ involvement during treatment and recovery; (b) Social support and participants’ need for it changed post-event/surgery; (c) Participants’ pre- and post-event/surgery experiences affected health outcomes; (d) Participants’ sense of agency affected their life perspectives and health behaviors; (e) Participants experienced inconsistent referral to and utilization of CR; and (f) Participants’ investment in faith was intensified or maintained. The policy brief emphasized the role of patients’ education and income levels in their likelihood to attend CR. Recommendations for improving cardiac outcomes for African American patients in the rural Southeast included systematizing orders for CR on discharge paperwork, assessing and accounting for patients’ levels of social support and spiritual resources, and coaching medical providers to reinforce treatment recommendations in a way that is understandable to patients and opens up discussion regarding potential biopsychosocial-spiritual barriers to implementing these recommendations.
BIOPSYCHOSOCIAL-SPIRITUAL FACTORS IMPACTING AFRICAN AMERICAN PATIENTS’ CARDIAC REHABILITATION REFERRAL AND PARTICIPATION

A Dissertation

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DEDICATION

This dissertation could not have been completed without the following godsend: a team of incredibly hardworking, generous people and the participants who agreed to be a part of this study. I would also like to dedicate this work to my mother, who nurtured my dreams and walked with me towards them, and to Sean who is my greatest dream come true.
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I want to thank the final member of my committee, Dr. Sharon Knight, for helping me to remember my anthropological self. Before I became a medical family therapist, I dreamed of being an anthropologist, riding a moped down dusty roads and gathering qualitative data in far away places. Our conversations unveiled for me that Greenville was my India. Take away the moped and add pavement to the streets, I could chase stories with the same fervor and curiosity. And, in gathering the stories of others, I would be weaving a story of my own. Thank you for helping me to see the beauty in this ever-changing tapestry of shared experience.
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Figure 2. Income and CR Attendance Participant Descriptives .................................................... 188
When I moved to Greenville, North Carolina in July 2012, I thought I knew what this place would hold for me. I had planned to study pediatric and adolescent genetic and chronic illness, a topic close to my heart. I had also planned to complete my degree and return to New England, the “homeland,” as soon as possible. Eastern North Carolina has confronted my plans and preconceived notions on many levels. When I first drove through the neighborhoods of Greenville, and began working in rural community health care, I realized how many people here were struggling with access to basic needs. In conversations with my mentor, Dr. Jennifer Hodgson, and my peers, I also realized how frequently access to resources was divided down racial/ethnic lines. Access to healthcare resources appeared to be no exception.

As I approached my dissertation topic in the fall of 2012, national factors were also at play. Just a few months prior to beginning the first year of my doctoral studies, the Patient Protection and Affordable Care Act (PPACA) had been upheld by the U.S. Supreme Court (CNN, 2012). Dr. Hodgson and I had a series of conversations about PPACA’s Readmission Reduction Program, which would leverage payment penalties against hospitals with high 30-day readmission ratios for myocardial infarction, heart failure, and pneumonia (Centers for Medicare & Medicaid Services, 2013). Two out of three of these targeted conditions were cardiovascular, so we wondered about what kind of primary, secondary, and tertiary resources would decrease rehospitalization for cardiac patients.

When I learned about Cardiac Rehabilitation (CR), I found an anchor point: a secondary treatment and prevention program that had been shown to offer dramatic benefits to cardiac patients. Whether patients were being referred to and were participating in this program seemed to be another story. Some of my preliminary reading pointed to a disparity that alarmed me.
Rates of cardiovascular disease were higher among African Americans than Non-Hispanic Whites, but rates of referral to and participation in CR were lower for this population. That African Americans were more vulnerable to disease but less able to access appropriate treatment struck me as profoundly unjust. I wanted to better understand this injustice, and I wanted to address it. This is the topic I would labor with for the next two-and-a-half years.

Over the course of the next year, I completed a systematic review (Chapter 2) of the existing literature on biopsychosocial-spiritual factors impacting African Americans’ referral to and participation in CR. This review demonstrated the paucity of research on this topic. I determined that a mixed methods study would allow me to: (a) investigate whether or not the factors deemed relevant to CR referral and participation in the general population were also relevant to African Americans, and (b) explore the factors that members of this population recovering from cardiac events and/or surgeries deemed relevant to their process of recovery.

As seems to often be the case, my study hit major methodological hurdles. And, as is also often the case, I learned just as much from these hurdles as I did from the data I was actually able to gather. My inability to recruit the number of African American participants I needed to do a comparative racial analysis has given me a great deal to ponder (see Chapter 5). However, due to this limitation in recruitment, my committee and I made the decision to revise the scope of my second article (Chapter 4) to reflect only the qualitative portion of my initially-mixed methods study.

One thing that has been constant in this process has been change. There has been an ongoing adaptation of myself and this study, throughout, and hopefully a positive evolution of both. I began my doctorate with a heart for one topic and developed a heart for another. I came to Greenville with the expectation that I could live here for two years and leave unchanged and,
luckily, I was wrong. Somewhere in the midst of this journey, I realized the ludicrousness of my preconceived notions and expectations. I realized the impossibility of staying the same. I had to let this place change me and change my heart. It has.

There is a poetic sense to this study, a conceptualization that has inspired me when numbers alone did not. I wanted to learn how “broken hearts” could be healed, not only through adherence to biological and physiological treatments but also through channeling social support, relieving psychological/emotional suffering, and connecting resources with need. If cardiovascular disease is a state of broken heartedness, interventions that are culturally competent and socially just are a form of love that can contribute towards that healing. Support from others, relief of suffering, access to resources—what are these other than love? This research is an offering and an act of love from my heart to the hearts of others.

It is my hope that readers will also let this work change them. This is an opportunity to be drawn into a very particular issue that may shed light on issues more pervasive. May we use what we learn to both heal and be healed.
References


CHAPTER ONE: INTRODUCTION

Cardiac Rehabilitation (CR) is a secondary prevention and treatment program that has been demonstrated to improve health outcomes for patients with cardiovascular disease (CVD) (Brown, Clark, Dalal, Welch, & Taylor, 2011; Heran et al., 2011). Unfortunately, CR referral and participation rates have remained low (Ayala, Xie, McGruder, & Valderrama, 2008; Suaya et al., 2007), especially for racial/ethnic minorities (Beswick et al., 2004; Evenson, Johnson, & Aytur, 2006; Suaya et al., 2007). African Americans, in particular, have a 20% higher age-adjusted death rate from coronary heart disease than Non-Hispanic Whites (CDC, 2013), and they are less likely than Non-Hispanic Whites to be referred to (Allen, Scott, Stewart, & Young, 2004; Gregory, LaVeist, & Simpson, 2006), participate in (Cannistra, O’Malley, & Balady, 1995; Evenson et al., 2006), or benefit from CR (Cannistra et al., 1995; Sanderson, Mirza, Fry, Allison, & Bittner, 2007).

Researchers studying referral rates for cardiovascular procedures and rehabilitation programs have found a relationship between race/ethnicity and the type of procedures/programs recommended for or received by patients (Gregory et al., 2006; Hannan et al., 1999; Ibrahim et al., 2003; Peterson et al., 1997; Schneider et al., 2001; van Ryn, Burgess, Malat, & Griffin, 2006). For example, African Americans are less likely to be recommended for (Ibrahim et al., 2003) and receive revascularization procedures (Hannan et al., 1999; Peterson et al., 1997; Schneider et al., 2001). Researchers have also demonstrated that cardiac patients who do not receive these procedures are, in turn, less likely to be referred for CR (Suaya et al., 2007). In relation to this indicator, other researchers have shown that being scheduled for a follow-up appointment with a cardiologist or cardiac surgeon is positively associated with a CR referral (Barber, Stommel, Kroll, Holmes-Rovner, & McIntosh, 2001).
On the level of CR participation among African Americans, researchers have identified a number of factors associated with poorer cardiovascular health and/or decreased likelihood of adopting heart healthy behaviors (e.g., recommended diet and exercise changes). These factors include depressive symptoms (Dickson, McCarthy, Howe, Schipper, & Katz, 2013; Dickson, McCarthy, & Katz, 2013), lower socioeconomic status (SES) (Blustein, Valentine, Mead, & Regenstein, 2008), and lower levels of social support (Grewen, Anderson, Girdler, & Light, 2003; Liu & Newschaffer, 2011; Tkatch et al., 2011). Some researchers have also argued that religious fatalism is a commonly held spiritual belief in the African American community, which can reinforce a passive approach to self-care (Dickson, McCarthy, Howe, et al., 2013; Johnson, Elbert-Avila, & Tulsky, 2005; Polzer & Miles, 2007) and fatalistic beliefs about cardiovascular risk factors and health (Dickson, McCarthy, Howe, et al., 2013).

While the aforementioned studies point to a handful of demographic, biological, psychological, social, and spiritual factors impacting cardiovascular health and health behaviors, none have looked at how these factors impact CR referral and participation for/among African American patients with CVD. Researchers have advocated for studies that measure the impact of larger system factors (e.g., protocol for referral, insurance coverage) on CR participation (Cortés & Arthur, 2006), as well as factors specific to racial/ethnic minorities in the development of interventions for patients with CVD (Cortés & Arthur, 2006; Davis, Vinci, Okwuosa, Chase, & Huang, 2007; Schneiderman et al., 2004). In accordance with these recommendations, this dissertation research aims to expand and enhance this area of the literature using a systemic Biopsychosocial-Spiritual (BPSS) theoretical approach (Engel, 1977, 1980; Wright, Watson, & Bell, 1996) and a mixed methods design, incorporating both quantitative and qualitative methods of data collection and analysis (Creswell, 2009).
This chapter introduces the background knowledge related to African Americans’ CR referral and participation. The extant literature on cardiovascular health and cardiovascular health behaviors for African Americans is presented using a BPSS approach. This chapter also includes a discussion of culturally-sensitive interventions for African Americans, the theoretical perspective and purpose of this research, and a brief description of the chapters contained in this dissertation proposal.

**Cardiovascular Health Disparities for African Americans**

From prevention and intervention to mortality rates, African Americans have experienced significant cardiovascular health disparities. In 2009, African Americans had a higher age-adjusted death rate from coronary heart disease than Non-Hispanic Whites (141.3 per 100,000 population for African Americans compared with 117.7 per 100,000 population for Non-Hispanic Whites) (CDC, 2013). As a population, African Americans also had a higher rate of hypertension (41.3% among African Americans compared to 28.6% among Non-Hispanic Whites during 2007–2010), but were less likely to have their hypertension controlled (42.5% of African Americans compared with 52.6% of Non-Hispanic Whites) (CDC, 2013).

Although these disparities are well documented, research on the development of interventions to address them is limited. Researchers have identified a need for interventions tailored to racial/ethnic minority patients with CVD and have made a call for studies that measure factors specific to these groups to assist in intervention development (Cortés & Arthur, 2006; Davis et al., 2007; Sanderson et al., 2007; Schneiderman et al., 2004). CR is an intervention for patients with CVD that has been validated for the general population but on which there has been little research regarding adaptation specifically for racial/ethnic minorities.
Cardiac Rehabilitation Referral and Participation

Outpatient CR is an American College of Cardiology/American Heart Association recommended program designed to treat multiple cardiovascular conditions and/or assist in the recovery from cardiac events/surgeries (i.e., myocardial infarction [MI], coronary artery bypass grafting [CABG], stable angina, heart valve repair/replacement, percutaneous transluminal coronary angioplasty [PCTA] or coronary stenting, heart/heart-lung transplant, congestive heart failure [CHF], coronary artery disease, diabetes, and/or peripheral artery disease [American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR), 2014]). Cardiac Rehabilitation consists of three phases, all or some of which a patient with CVD may participate in depending on his or her disease presentation and/or availability of programs: (a) Phase I—acute, inpatient treatment (one to 14 days), (b) Phase II—medically supervised outpatient treatment lasting three to six months, and (c) Phase III—minimally supervised or unsupervised maintenance (Jafri, 2004).

Although Phase I and III are also viable components of CR, Phase II CR is the phase generally emphasized in CR treatment and discussed in the literature. Phase II CR consists of the following: (a) physician-prescribed exercise training; (b) cardiac risk factor modification, including education, counseling, and behavioral intervention; (c) psychosocial assessment; (d) outcomes assessment; and (e) individualized treatment plan (AACVPR, 2014). For the purpose of this dissertation research, Phase II CR will also be the focus of discussion and “Cardiac Rehabilitation” and “CR” will be used to refer to this particular phase of treatment.

Cardiac Rehabilitation has been shown to reduce mortality rates related to CVD and other conditions (Heran et al., 2011), improve depression and anxiety symptoms in patients with CVD (Whalley et al., 2011), and lower rates of rehospitalization (Heran et al., 2011). However, only
about one third of eligible patients are referred to or participate in CR (Ayala et al., 2008; Cortés & Arthur, 2006; Suaya et al., 2007). Referral and participation rates are even lower for racial/ethnic minorities (Beswick et al., 2004; Suaya et al., 2007), including African Americans (Evenson et al., 2006; Gregory et al., 2006). Non-Hispanic Whites are twice as likely to receive a referral for CR than African American patients (Gregory et al. 2006), and are a third more likely to participate than other racial/ethnic minority groups (Suaya et al., 2007).

Considering the cardiovascular health disparities experienced by African Americans (CDC, 2013; U.S. Department of Health and Human Services–Office of Minority Health, 2012), these rates of referral and participation are particularly disturbing. One might hypothesize CR is not being made available and/or utilized by a population that is in dire need of it, and/or lack of referral to and participation in CR and other cardiovascular interventions is contributing to or compounding these disparities.

**BPSS Factors Impacting Cardiovascular Health Behaviors for African Americans**

The Biopsychosocial-Spiritual (BPSS) approach is a theoretical framework developed by Engel (1977, 1980) and adapted by Wright and colleagues (1996) to promote a holistic conceptualization of illness and health. According to Engel (1980), a patient’s experience is the result of the intersection of biological, psychological, and social factors operating on multiple levels of the system (i.e., societal-national level, cultural-subcultural level, community and family levels, and the individual level). Wright and colleagues (1996) highlighted spirituality giving way to the Biopsychosocial-Spiritual approach.

This dissertation research draws upon the BPSS approach as a foundational theoretical perspective. The BPSS approach is particularly germane to the current research as it allows for a holistic conceptualization of health, illness, and health behaviors by taking into account not only
biological factors (e.g., cardiovascular health diagnoses and disparities), but also psychological factors (e.g., depression, self-efficacy), social factors (e.g., social support, SES), and spiritual factors (e.g., religious/spiritual beliefs and community). The extant literature demonstrates the importance of each of these factors (biological, psychological, social, and spiritual) on African Americans’ cardiovascular health behaviors.

In addition to being the theoretical foundation for this dissertation research, the BPSS approach is used in the following section as a means of categorizing the different factors impacting cardiovascular health behaviors for African Americans. Because the research on African Americans patients’ health behaviors specific to CR is limited (Koehler, Hodgson, Dodor, Knight, & Rappleyea, 2014), this section looks at African American patients’ cardiovascular health behaviors more broadly.

**Biological Factors**

In addition to experiencing disparities in terms of cardiovascular health outcomes (CDC, 2013; U.S. Department of Health and Human Services–National Institutes of Health [DHHS–NIH], 2012), African Americans also experience disparities in medically-indicated care (Hannan et al., 1999; Ibrahim et al., 2003; Peterson et al., 1997; Schneider et al., 2001; van Ryn et al., 2006). When compared with Non-Hispanic Whites, African Americans were significantly less likely to receive CABG (Hannan et al., 1999; Peterson et al., 1997) or PCTA (Peterson et al., 1997; Schneider et al., 2001). Even when potentially confounding variables were controlled (e.g., age, disease status, or health risk factors), the ethnic/racial disparity in procedural recommendations and receipt by African American patients with CVD persisted (Hannan et al., 1999; Ibrahim et al., 2003; Peterson et al., 1997). It also appears that this disparity is the result of “underuse” of medically indicated procedures in African Americans rather than “overuse” in
Non-Hispanic Whites (Schneider et al., 2001). Further, because patients who received these procedures are also more likely to be referred to CR (Suaya et al., 2007), it is possible that racial/ethnic disparities at the level of surgical intervention, in turn, impact CR referral and participation.

Even when African American patients are referred to and participate in CR, Sanderson and colleagues (2007) have identified a “benefit gap” (p. 985) in that African American patients: (a) began CR with more cardiovascular risk factors than Non-White Hispanics and (b) ended CR with less improvement. Sanderson and colleagues (2007) recommended the development of population-specific interventions to address this gap. In addition to biological factors, psychological factors also have bearing on African American cardiovascular health behaviors, and specifically, implications for CR participation.

**Psychological Factors**

In the general population, depression and/or low mood have been associated with lower rates of CR participation (Casey, Hughes, Waechter, Josephson, & Rosneck, 2008; Malach & Imperato, 2004; Swardfager et al., 2011; Taylor, Wilson, & Sharp, 2011). Although the relationship between depression and CR participation within the African American population has not been studied, related research has demonstrated a negative association between levels of depression and heart healthy self-care practices among African American patients with CHF (Dickson, McCarthy, Howe, et al., 2013; Dickson, McCarthy, & Katz, 2013).

In contrast, high levels of self-efficacy in African American patients with CHF have been shown to be positively correlated with self-care (Warren-Findlow, Seymour, & Brunner Huber, 2012). Depression, self-care, and self-efficacy may all have implications for participation in CR, as an intervention promoting health behavior change, but unfortunately there have been no
studies investigating this particular relationship. The next section looks at social factors impacting cardiovascular health behaviors in African Americans.

**Social Factors**

In addition to biological and psychological factors, a number of social factors have implications for African Americans’ cardiovascular health behaviors. Racism, a societal-national factor experienced on the community, family, and individual levels, has been shown to increase cardiovascular risk factors for African Americans (Din-Dzietham, Nembhard, Collins, & Davis, 2004; Lewis, Aiello, Leurgans, Kelly, & Barnes, 2010). Physicians’ treatment recommendations have also been shown to be guided by assumptions regarding patients’ level of education and exercise preferences, and these assumption-guided recommendations have further compounded racial/ethnic disparities experienced by patients (van Ryn et al., 2006).

Culturally-specific health beliefs held by some African Americans may also influence self-care behaviors related to cardiovascular health (Dickson, McCarthy, Howe, et al., 2013; Ford, Kim, & Dancy, 2009; Warren-Findlow & Issel, 2010). For example, in three studies, cardiovascular risk factors or diseases were accepted as normative and/or unavoidable (Dickson, McCarthy, Howe, et al., 2013; Ford et al., 2009; Warren-Findlow & Issel, 2010). In their study of patients with CHF, Dickson, McCarthy, Howe, and colleagues (2013) noticed that this belief, along with the belief that stress increased CHF symptoms, was correlated with a more passive approach to self-care (e.g., “stay in bed,” “relax…let it pass,” p. 115). Although these researchers did not comment directly on CR, one can imagine how this sort of approach would be largely incompatible with CR participation and the activities it requires and promotes.

Researchers have also demonstrated the importance of patient-provider communication (Collins, Clark, Petersen, & Kressin, 2002; Lutfiyya, Cumba, McCullough, Barlow, & Lipsky,
2008; Shaw, Armin, Torres, Orzech, & Vivian, 2012) and social support from friends and family in promoting cardiovascular self-care in African American patients (Grewen et al., 2003; Liu & Newschaffer, 2011; Tkatch et al., 2011). With regard to patient-provider communication, Collins and colleagues (2002) found African American patients cited rapport-building and establishing trust in the provider as very important, especially before consenting to a procedure. With regard to social support, researchers uncovered a positive relationship between higher levels of support and improved cardiovascular health and cardiovascular health behaviors (Grewen et al., 2003; Liu & Newschaffer, 2011; Tkatch et al., 2011).

Finally, there appears to be a negative correlation between SES among African Americans and access to resources for self-care/cardiovascular health behaviors (Blustein et al., 2008; Wexler et al., 2008). For example, Wexler argued that limited resources may influence exercise behaviors more than differences in attitudes or beliefs about exercising. It may follow that individuals without access to resources for self-care will also be less likely to have resources to participate in CR and its recommended activities.

**Spiritual Factors**

Last but not least, spirituality has been shown to have a culturally-specific presentation among African Americans (Newlin, KnafI, & Melkus, 2002) and to be particularly important for many African Americans in the provision of medical and behavioral health care (Carter, 2002; Johnson et al., 2005). Unfortunately, the literature regarding the impact of spiritual factors on African American patients’ cardiovascular health behaviors is ambiguous. On the one hand, spirituality has been cited as an emotional coping strategy for managing the stress of cardiovascular health problems (Dickson, McCarthy, Howe, et al., 2013; Johnson et al., 2005; Warren-Findlow & Issel, 2010). On the other hand, religious fatalism (i.e., a belief that a higher
power has control over the events and outcomes of an individual’s life) may promote a passive approach to self-care (Dickson, McCarthy, Howe, et al., 2013; Polzer & Miles, 2007). This, in turn, may be problematic for participation in CR.

Some researchers working on cardiovascular studies and interventions for African Americans have successfully drawn upon the community spiritual resources, for example, by involving local churches in the study or intervention (Kalenderian et al., 2009; Peterson & Cheng, 2011; Plescia, Herrick, & Chavis, 2008; Yanek, Becker, Moy, Gittelsohn, & Koffman, 2001). However, in a study that compared attendance to a church-based and clinic-based exercise program for women, age was found to be the independent predictor of attendance rather than location (women ages 50-70 were more likely to attend) (Dornelas, Stepnowski, Fischer, & Thompson, 2007). Researchers have also cautioned those developing interventions from making the assumption that all African Americans are religious (Rucker-Whitaker et al., 2006).

The preceding section has reviewed various biological, psychological, social, and spiritual factors impacting African Americans’ cardiovascular health behaviors. The following section continues the discussion started here regarding the development and implementation of culturally-sensitive interventions for African American patients.

**Culturally-Sensitive Interventions for African American Patients**

The historical traumas African Americans have suffered at the hands of the White majority have been both countless and egregious. From a century of enslavement to legacies of exploitation by the medical and scientific research communities (e.g., Marion Sims’ experimental fistula operations on female slaves, the Tuskegee Syphilis study on lower SES African American males) (Washington, 2006), there is little wonder why African Americans may be cautious about involving themselves in current research studies and medical interventions.
While understandable, this reticence also presents a barrier to developing and improving interventions for African Americans; without recruiting and retaining members of this population, researchers are hard pressed to validate culturally-appropriate interventions and best practices which may ultimately serve to improve health outcomes and lower mortality rates.

Over the past two decades, the NIH has set forth guidelines for research requiring the recruitment of women and minorities in clinical research (DHHS–NIH, 2001). These guidelines have given researchers incentive to recruit minorities; however, they do not necessarily offer solutions to problems of recruitment and retention. Further, simply including minorities in studies does not necessarily support the development of interventions or best practices for these populations. Schneiderman and colleagues’ (2004) post hoc analysis of the Enhancing Recovery in Coronary Heart Disease Clinical Trial (ENRICHD) found significant treatment effects for White men receiving the intervention, but not for White women or minority men or women. These researchers argued it is essential that studies not only recruit and retain minority populations, but also “consider carefully the sociodemographic attributes of the population in designing the behavioral interventions” (Schneiderman et al., 2004, p. 481).

Researchers who have successfully recruited and retained minority participants have done so with careful attention to the needs and concerns of the population (Rucker-Whitaker et al., 2006; Sisk et al., 2008). Successful strategies for implementing a culturally-sensitive approach included, but were not limited to, using lay and/or race-concordant recruiters and study facilitators (Rucker-Whitaker et al., 2006; Sisk et al., 2008), having a flexible scheduling protocol, providing assistance with transportation, and encouraging participants to bring a support person with them (Sisk et al., 2008). Additionally, a series of focus groups with African American patients with CHF enrolled in the Heart Failure Adherence and Retention Trial
(HART) also identified that the social support provided by co-participants in the study was an important factor in promoting retention (Rucker-Whitaker et al., 2006).

Beyond issues of recruitment and retention, researchers have also turned their attention to the development of culturally-sensitive and effective interventions and best practices. The use of peer coaching alongside office-based clinical counseling in heart healthy behavioral changes has been shown to assist African American participants in reducing cardiovascular risks such as hypertension (Turner et al., 2012), while the use of community health advisors to provide health-based and social support has been recommended for African American patients with CHF (Durant et al., 2013). Some researchers have argued for incorporating spirituality/religion into interventions for African Americans (Kalenderian et al., 2009; Peterson & Cheng, 2011; Plescia et al., 2008; Yanek et al, 2001), while Rucker-Whitaker and colleagues (2006) have cautioned against researchers making a blanket assumption that all African Americans are religious. As a counterbalance to this caution, Rucker-Whitaker and colleagues (2006) also recommended that researchers do not avoid topics of religion/spirituality when developing and implementing interventions for African Americans as these may be potential storehouses of strength and resources for participants.

It is also worth noting that individuals who do not participate in studies or interventions may have found alternative ways to access the resources that the interventions were designed to provide. For example, a UK-based study of CR participation found that many individuals who did not participate in a CR program engaged in rehabilitative activities at home, such as exercise and lifestyle modification (Jones, Jolly, Raftery, Lip, & Greenfield, 2007). Unfortunately, Jones and colleagues’ (2007) study sample was predominately comprised of White British individuals and, therefore, cannot be generalized to racial/ethnic minorities. Studies investigating the at-
home or in-community rehabilitative activities of African American patients with CVD would be very instrumental in better understanding how to design relevant studies and interventions that build on existing individual and community strengths. This dissertation research is a step towards identifying population-specific factors for consideration in the development of CR referral protocol and programming for African Americans patients.

**Purpose and Design**

This dissertation research is a mixed methods concurrent transformative design (Creswell, 2009) developed to answer the following research question: “What demographic and biopsychosocial-spiritual factors impact CR referral and participation for/among adult African American patients with CVD?” The study will incorporate self-report surveys from African American and Non-Hispanic White patients with CVD (quantitative portion) and semi-structured phenomenological interviews with African American patients recovering from cardiac events and/or surgeries (qualitative portion). The qualitative portion of this study aligns with Husserl’s (1970) descriptive phenomenological approach and draws upon Colaizzi’s (1978) phenomenological analysis method.

Although the research question referenced above will guide the study as a whole, the research question for the qualitative portion of this study is: “What is the lived experience of African American patients recovering from cardiac events and/or surgeries?” While the quantitative portion of this study sought to identify larger system (e.g., referral practices, health care policies) and individual-level factors impacting both CR referral and participation for/among this population, the qualitative portion invited participants to identify their experiences with larger system and individual-level factors impacting their CR participation.
Summary

This chapter has introduced background knowledge and gaps in the literature on African Americans patients’ CR referral and participation. Through the lens of the BPSS approach (Engel 1977, 1980; Wright et al., 1996), cardiovascular health, health behaviors, and barriers impacting CR participation for African Americans will be studied to aid in the development and implementation of culturally-sensitive interventions for African American patients with CVD. The following chapters will include content relative to building the rationale, explaining the methodology, reporting the results, and recommending advancements in research, clinical care, healthcare policy, and for the field of Medical Family Therapy as related to this dissertation’s focus.

The second chapter is a systematic review of the literature on demographic and BPSS factors impacting African American patients’ CR referral and participation. The research question guiding this review was: “What demographic and biopsychosocial-spiritual factors impact CR referral and participation for/among adult African American patients with CVD?” This review was conducted by the lead researcher and yielded seven studies that fit the inclusion criteria. These seven studies demonstrated that African Americans patients have a lower likelihood for CR referral, a higher likelihood of enrolling in CR with more cardiovascular risk factors, and a lower likelihood of CR participation and completion due to factors related to low SES (e.g., lack of insurance, work conflicts, lower level of education) when compared with Non-Hispanic Whites. Among these studies, social and biological factors were investigated most frequently, psychological factors were investigated to a very limited degree, and spiritual factors were not investigated at all. Both the results from the seven studies and the low number of
articles that fit inclusion criteria reinforced the need for future studies that investigate the BPSS factors unique to African Americans patients’ CR referral and participation.

The third chapter details the methodology of this mixed methods dissertation research, consisting of a self-report survey given at two time points to patients with CVD (quantitative portion) and semi-structured phenomenological interviews with a subset of this patient sample—African Americans who experienced a cardiac event and were referred to CR but did not participate (qualitative portion). The research question guiding this dissertation as a whole was: “What demographic and biopsychosocial-spiritual factors impact CR referral and participation for/among adult African American patients with CVD?” The research question guiding the qualitative portion of this study was: “What is the lived experience of African American patients recovering from cardiac events and/or surgeries?” This study was designed in alignment with Husserl’s (1970) descriptive phenomenological approach and interview transcripts were analyzed using Colaizzi’s (1978) phenomenological analysis method.

Chapter four reports the qualitative results of this study. This represents a departure from the initially proposed methodology (mixed methods). Due to limitations in recruitment, the sample size collected for the quantitative portion was not large enough to power the proposed analyses. Therefore, the lead researcher and dissertation committee made the decision to revise the scope of chapter four to reflect the qualitative results only. Chapter five is a discussion of this study’s implications and recommendations for future interventions. It is in this final chapter that the preliminary quantitative results of this study are also presented.
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CHAPTER TWO: DEMOGRAPHIC AND BIOPSYCHOSOCIAL-SPIRITUAL FACTORS IMPACTING AFRICAN AMERICAN PATIENTS’ CR REFERRAL AND PARTICIPATION: A SYSTEMATIC REVIEW

Cardiac Rehabilitation (CR) is an American College of Cardiology/American Heart Association Class I treatment for multiple cardiovascular conditions and procedures (American Association of Cardiovascular and Pulmonary Rehabilitation, 2014). As a secondary prevention and treatment program, CR has been shown to offer participants significant physical and psychological health benefits, including reduced mortality related to cardiovascular and other health conditions, lower rates of hospitalization (Heran et al., 2011), and improved depression and anxiety symptoms (Whalley et al., 2011). Despite these results, CR referral and participation rates are generally low, with approximately one third of eligible patients referred or participating (Ayala, Xie, McGruder, & Valderrama, 2008; Cortés & Arthur, 2006; Suaya et al., 2007).

Cardiac Rehabilitation referral and participation rates are especially low for African American patients with cardiovascular disease (CVD) (Allen, Scott, Stewart, & Young, 2004; Evenson, Johnson, and Aytur, 2004; Gregory, LaVeist, and Simpson, 2006). Unfortunately, this disparity exists even though African Americans have higher cardiovascular risk factors and higher rates of mortality from coronary artery disease than Non-Hispanic Whites (Centers for Disease Control and Prevention [CDC], 2013). Presently, there is a gap in the literature regarding barriers and facilitators of CR referral and participation for racial/ethnic minorities (Beswick et al., 2004; Cortés & Arthur, 2006; Taylor, Wilson, & Sharpe, 2011).

In order to address this racial/ethnic disparity in care, it is essential to understand the multi-level systemic factors associated with African Americans patients’ CR referral and participation and to allow this understanding to inform future interventions. This systematic
review of the literature aims to identify extant knowledge and gaps in the literature regarding the
demographic and biopsychosocial-spiritual factors impacting CR referral and participation for
African American patients with CVD.

Background Literature

Disparities in Cardiovascular Health/Health Behaviors for African Americans

The Biopsychosocial-Spiritual (BPSS) approach offers a model for conceptualizing the
intersection of multiple factors in health-related experiences and outcomes (Engel, 1977, 1980;
Wright, Watson, & Bell, 1996). Although a number of researchers have investigated
demographic, biological, psychological, and social factors impacting CR referral and
participation in the general population, there is a paucity of research on the factors impacting CR
referral and participation for African American patients. The following sections present the
available BPSS literature on African American cardiovascular disparities and population-specific
factors impacting cardiovascular health behaviors (see Figure 1).

Biological factors. Researchers have demonstrated that African American patients with
CVD are significantly less likely than Non-Hispanic White patients to receive coronary artery
bypass grafting (CABG) (Hannan et al., 1999; Peterson et al., 1997) or percutaneous
transluminal coronary angioplasty (PCTA) (Peterson et al., 1997, Schneider et al., 2001).
Because patients who received these procedures were also more likely to be referred to CR
(Suaya et al., 2007), it is possible that racial disparities at the level of surgical intervention
impacted CR referral and participation. Sanderson, Mirza, Fry, Allison, and Bittner (2007) have
also observed that African American patients who participated in CR began their programs with
more cardiovascular risk factors than Non-Hispanic White patients and ended CR with fewer
improvements (e.g., BMI level, waist circumference).
Psychological factors. Within the African American population with congestive heart failure (CHF), depressive symptoms have been shown to be negatively associated with engagement in cardiovascular self-care practices (Dickson, McCarthy, Howe, Schipper, and Katz, 2013; Dickson, McCarthy, & Katz, 2013). Dickson, McCarthy, and Katz (2013) found a high incidence (40%) of depressive symptoms among African American patients with CHF. They also documented an association between such symptoms and poorer self-care (Dickson, McCarthy, & Katz, 2013). In contrast to the detrimental effect of depression on self-care, Warren-Findlow, Seymour, and Brunner Huber (2012) demonstrated a correlation between personal self-efficacy and hypertension self-care in African American adults with hypertension.

Social factors. Racism is a harmful social factor impacting cardiovascular health for African Americans (Din-Dzietham, Nembhard, Collins, & Davis, 2004; Lewis, Aiello, Leurgans, Kelly, & Barnes, 2010; van Ryn, Burgess, Malat, and Griffin, 2006; Wyatt et al., 2003). A study by van Ryn and colleagues (2006) demonstrated that “physicians’ perceptions of patients’ education and physical activity preferences were significant predictors of their recommendations,” (p. 351) and that these physician behaviors further compounded racial/ethnic disparities experienced by patients at the individual level. Collins, Clark, Petersen, and Kressin (2002) also found that African American patients generally emphasized the importance of rapport-building and establishing trust in providers, especially before consenting to procedures.

Certain beliefs and practices may be held by African American communities and, in turn, impact cardiovascular health behaviors. Some researchers have argued that there is a tendency among members of these communities to normalize CVD or risk factors such as hypertension as natural or unavoidable (Ford, Kim, & Dancy, 2009; Warren-Findlow & Issel, 2010). Dickson, McCarthy, Howe, and colleagues (2013), in their study of African American patients with CHF,
reported that a fatalistic perspective about risk factors combined with the belief that stress caused CHF symptoms promoted a “passive approach (e.g. ‘stay in bed,’ ‘relax…let it pass’)” (p. 115). Some researchers have cautioned against confounding cultural differences with socioeconomic status (SES) differences, as beliefs and practices around self-care may ultimately reflect access to health information and resources (Blustein, Valentine, Mead, & Regenstein, 2008; Wexler et al., 2008).

At the community and family level, researchers studying the impact of social support on cardiovascular health among African Americans have identified a positive association between social support and improved cardiovascular health and healthy behaviors (Grewen, Anderson, Girdler, & Light, 2003; Liu & Newschaffer, 2011; Tkatch et al., 2011). In terms of cardiovascular health behaviors, Tkatch and colleagues (2011) reported that African American CR participants with larger social support networks had more health support and demonstrated healthier behaviors and higher coping self-efficacy than those who did not have such networks.

**Spiritual Factors.** Beyond these psychosocial factors, researchers have also demonstrated the importance of spirituality in health-related coping and decision-making for many African Americans (Dickson, McCarthy, Howe, et al., 2013; Johnson, Elbert-Avila, & Tulsky, 2005; Warren-Findlow & Issel, 2010). African American patients with CHF have been shown to draw upon both intrinsic spirituality (e.g., praying) and extrinsic spirituality (e.g. affiliation with a religious community) in their self-care behaviors (Dickson, McCarthy, Howe, et al., 2013). Conversely, some researchers argue spirituality may also be a risk factor by resulting in more passive, and thereby less effective, approaches to self-care (Dickson, McCarthy, Howe, et al., 2013; Polzer & Miles, 2007).
This systematic review sought to identify population-specific BPSS factors impacting CR referral and participation for African American patients. The following sections present the objectives, methods, and findings of this systematic review.

**Objectives**

The aim of this study was to: (a) complete a systematic review of the peer-reviewed literature related to demographic and BPSS factors impacting CR referral and participation for African American patients with CVD; (b) identify BPSS factors acting as facilitators of and barriers to CR referral and participation for this population; (c) identify gaps in the literature; and (d) make recommendations for future research studies and interventions to address cardiovascular health disparities for this population. The research question guiding this systematic review was: “What demographic and biopsychosocial-spiritual factors impact CR referral and participation for adult African American patients with CVD?”

**Method**

This review utilized Cooper's (2010) seven-step protocol for research synthesis. The lead researcher formulated the aforementioned research question and, using a combination of subject headings and keywords, searched the literature utilizing Medline via PubMed, PsycINFO via EBSCO, and CINAHL via EBSCO (see Table 1 for article search summary and Table 2 for subject heading equivalences across databases). The search strategy yielded 1,751 articles once duplicates were removed. Review of titles and abstracts left 40 articles for full text review. From these 40 articles, seven fit the inclusion criteria. A review of the reference lists of the final seven articles yielded no further applicable studies. A second reviewer performed the searches conducted in the initial review (see Figure 2 for flow chart summary of the search and review process). The quality of the seven articles was assessed using Hall, Ferreira, Maher, Latimer,
and Ferreira’s (2010) seven criteria for evaluating observational studies, adapted from criteria developed by Sanderson, Tatt, & Higgins (2007) and von Elm and colleagues (2007) (see Table 3 for criteria and summary of article quality). The results of analysis and integration of study outcomes are summarized in Table 4.

**Results**

The seven articles selected for this review explored the relationship between African American race/ethnicity and CR referral and participation. The results have been divided into four categories in keeping with the BPSS approach, with the addition of a section on demographic factors (i.e., sex/gender, race/ethnicity): (a) demographic factors; (b) biological factors; (c) psychological factors; and (d) social factors. No studies reported on spiritual factors, and some studies fell into more than one of the four categories.

**Demographic Factors: Rehabilitation Referral and Participation**

Three studies investigated the impact of race/ethnicity as a demographic factor on CR referral (Allen et al., 2004; Bittner, Sanderson, Breland, & Green, 1999; Gregory et al., 2006). Allen and colleagues (2004) recruited 253 women (108 African American and 145 White) who had experienced a cardiovascular event or procedure (i.e., myocardial infarction [MI], percutaneous coronary intervention [PCI], and CABG) and surveyed them within a month of discharge and again six months later. Allen and colleagues (2004) found significant racial disparities in referrals to CR, with African American women approximately half as likely (55%) to be referred when compared with White women.

Gregory and colleagues (2006) also investigated factors impacting CR referral in a sample of 1,933 patients (863 African American and 1070 White) who had experienced a cardiovascular event or procedure in the past year or had a diagnosis of recurrent CHF. Gregory
and colleagues (2006) interviewed participants within a year of discharge and found that White patients were two times more likely to receive a referral than African American patients. This finding remained statistically significant even after other variables (e.g., age, education, SES, insurance status) were held constant (Gregory et al., 2006).

In contrast to the above two studies, Bittner and colleagues (1999) did not find race to be a significant predictor of CR referral. The researchers reviewed CR enrollment screening logs of 1,329 patients (422 African American and 890 White) who were discharged from the hospital with a primary diagnosis of MI or angina or who had received CABG (Bittner et al., 1999). Although a higher percentage of White patients (9.5%) received a referral than those who were African American (7.4%), Bittner and colleagues (1999) reported that this difference was not statistically significant. Instead, two different demographic factors—in-county residence and younger age—were predictive of CR referral.

Five research teams investigated the impact of demographic factors on CR participation (Allen et al., 2004; Cannistra, O’Malley, & Balady, 1995; Evenson et al., 2006; Rankin, 2002; Young, Waller, & Kahana, 1991). Allen and colleagues (2004) found that enrollment (after receiving a referral) was proportionately lower among African American women than White women (9% compared to 19%, respectively). Evenson and colleagues (2006) also reported that, according to program directors’ estimates of their patient populations in 2004, only 9% of CR participants were African American compared to 90% of program participants who were White Non-Hispanic. Similarly, Rankin’s (2002) study of 76 female patients who had experienced a MI (81% White and 19% African American), reported that only 13 participants were enrolled at some point in CR during their yearlong study and that “all cardiac rehabilitation participants were white” (p. 405).
Young and colleagues (1991) also reported racial/ethnic disparities in CR participation. Their study included 246 participants (77 African American and 167 White), all of whom were patients who had experienced an MI. Young and colleagues (1991) found that, when compared with White MI patients, African American MI patients were less likely to be enrolled in CR, recommended for a catheterization, assigned a cardiologist, or to have received patient education on smoking or exercise.

In contrast with the four studies demonstrating racial/ethnic disparities negatively impacting African American patients’ CR participation rates, Cannistra and colleagues’ (1995) investigation found no statistically significant racial/ethnic disparity in CR completion. This study included 82 participants (35 African American and 47 White) who had had a cardiovascular event or procedure and were enrolled in a CR program. The researchers reported that the percentage of African American women who completed the program was lower than that of White women (51% and 64%, respectively), but this finding was not statistically significant (Cannistra et al., 1995).

Another salient demographic factor cited by Evenson and colleagues (2006) was sex/gender. Evenson and colleagues’ (2006) study was based on survey responses from CR program directors in North Carolina. Program directors were surveyed at two intervals (1999 and 2004) using a study-specific survey. Results from data collected in 2004 demonstrated a male majority among participants (65%). Data collected by these researchers did not measure CR referral and participation across sex/gender and race/ethnicity (Evenson et al., 2006).

The main limitation of these studies was the extent to which they addressed relationships between racial/ethnic disparities and reasons for CR referral and participation. For example, Evenson and colleagues (2006) did not explore the associations between race/ethnicity and other
BPSS factors impacting non-participation or drop-out. Similarly, Rankin (2002) investigated psychosocial and physical outcomes of MI recovery for female patients, but did not comment on how these factors impacted referral and participation for African American patients.

**Biological Factors: Referral and Participation**

Only two studies reported on biological factors impacting CR referral and/or participation (Bittner et al., 1999; Cannistra et al., 1995). In their study on referral rates, Bittner and colleagues (1999) found that a discharge diagnosis of MI or hypercholesterolemia was positively associated with CR referral. The researchers did not investigate the interaction between these biological factors and race/ethnicity (Bittner et al., 1999).

Cannistra and colleagues (1995) explored the impact of biological factors on CR participation and reported on the interaction of these factors with participants’ race/ethnicity. The researchers collected data on baseline risk factors (e.g., smoking, hypertension, diabetes, and body weight) at program entry and completion. Findings revealed that, compared with White women, African American women generally began the program with more cardiovascular risk factors and ended the program having experienced fewer benefits in terms of weight loss. However, CR was shown to benefit both African American women and White women in terms of improved functional capacity. Regardless of race, women identified medical illness as the most frequently cited cause of CR non-completion (Cannistra et al., 1995).

**Psychological Factors: Referral and Participation**

Only one study investigated the impact of psychological factors on CR referral and participation. Allen and colleagues’ (2004) study of White and African American female patients with CVD measured depression as a variable. According to these researchers, there was no statistically significant difference in rates of depression across races/ethnicities and no
interaction observed among the variables of depression, race/ethnicity, and CR referral or enrollment (Allen et al., 2004). In contrast, Rankin (2002) reported that, compared with White female patients with CVD, African American female patients with CVD had higher levels of mood disturbance. Rankin (2002) did not address how this may have contributed to the observed racial/ethnic disparity in CR participation.

**Social Factors: Referral and Participation**

Six studies investigated the impact of social factors on CR referral and participation (Allen et al., 2004; Bittner et al., 1999; Cannistra et al., 1995; Evenson et al., 2006; Gregory et al., 2006; Young et al., 1991). Therefore, social factors was the second largest category of studies after demographic factors.

Allen and colleagues (2004) reported that study participants’ income was a predictor of CR referral and enrollment, but statistical analyses on the interaction between income and race were insignificant. In contrast, Gregory and colleagues (2006) demonstrated that African American patients were more likely than those who were White to have Medicaid (17.9% compared to 4.1%, respectively) or be uninsured (4.4% compared to 2.8% respectively). The researchers also found that patients with private insurance had higher odds of CR referral than patients with either Medicare or Medicaid (Gregory et al., 2006). Bittner and colleagues (1999) observed a positive association between insurance coverage and CR referral but did not comment on the interaction of this predictor with race/ethnicity.

Evenson and colleagues (2006) found that 72% of program directors cited policy issues (e.g., “cost, financial, insurance,” p. 372) as the primary barrier to CR participation, whereas work conflicts were cited as the primary reason for enrolled participants dropping out of CR. Nearly a quarter of program directors surveyed also cited transportation as a barrier to
participation (Evenson et al., 2006). Like Bittner and colleagues (1991), Evenson and colleagues (2006) did not comment on the interaction of these variables with race/ethnicity.

In contrast with the above studies, Cannistra and colleagues (1995) investigated the interaction between social factors, race/ethnicity, and CR referral and participation. According to these researchers, 23% of African American women compared to 6% of White women reported withdrawing from CR due to work conflicts, and 12% of African American participants compared to 6% of White participants reported withdrawing due to personal reasons (Cannistra et al., 1995). It is not clear if “personal reasons” referred to lack of social support or other factors. Cannistra and colleagues (1995) hypothesized that withdrawal from CR due to work conflicts or personal reasons, “may also reflect the apparent lower socioeconomic status of black women in the program” (p. 892).

Young and colleagues’ (1991) study on CR participation specifically investigated the interactions between and among the variables of race/ethnicity, CR participation, and SES as defined by educational level. When both race/ethnicity and SES were included in analysis, Young and colleagues (1991) found that African American participants who were designated low SES ranked lowest in both health status and enrollment in CR. SES alone, however, did not account for disparities, as race/ethnicity still emerged as a predictive factor of enrollment (Young et al., 1991). For example, African American participants designated as high SES and White participants designated as low SES were on par in terms of likelihood of CR enrollment. Young and colleagues (1991) argued for the consideration of race/ethnicity and SES as confounding variables in cardiovascular health outcomes.
Discussion

The seven studies examined in this systematic review provided useful but limited insights into the demographic and BPSS factors impacting CR referral and participation for African American patients with CVD. Within this population, researchers have observed a lower likelihood for CR referral, a higher likelihood of enrolling in CR with more cardiovascular risk factors, and a lower likelihood of CR participation and completion due to factors related to low SES (e.g., lack of insurance, work conflicts, lower level of education) when compared with Non-Hispanic White patients. This review revealed the limited extent to which research investigations have explored interactions between BPSS factors, race/ethnicity, and CR referral and participation. For example, only three of the seven studies included in this review investigated the impact of the interaction between race/ethnicity and another BPSS factor on CR referral and participation rates (Allen et al., 2004; Cannistra et al., 1995; Young et al., 1991). Among the seven studies included in the review, researchers provided little information about psychological factors and no information on spiritual factors related to CR referral or participation for this population.

Lack of uniformity across studies made comparison and synthesis of study results difficult. For example, the research studies varied significantly in sample size, participant population (e.g., patients versus CR program directors), type of variables investigated, and method of measuring variables (e.g., patient self-report, provider/program director report, or chart review). Studies also varied somewhat in terms of quality (Table 3). The greatest variability was seen in the collection of follow-up data. Only four of the seven studies reviewed had a greater than 85% follow-up rate, limiting the degree to which inferences could be made about participants over time. Data collected at multiple time points post-cardiovascular event
would be especially useful for the measurement of CR participation, and specifically, completion. Finally, variability was also seen in use of multivariate analysis with adjustment for confounding variables and the reporting of outcome data at follow-up. Adjustment for confounds is especially important if, for example, CR referral and participation were influenced by a variable such as SES.

Considering the level of variability across methodologies in this systematic review of the literature, generalizations regarding factors impacting CR referral and participation for African American patients are not warranted. Rather, given the paucity of research on this topic, this discussion offers implications for future research and practice.

**Implications for Future Research and Practice**

While researchers have begun to investigate BPSS factors impacting CR referral and participation for African American patients with CVD, these findings are not comprehensive. Specifically, little research has been conducted on the impact of psychological and spiritual factors on CR participation for this population. Studies that investigate psychological factors are important considering the negative association between psychological factors, such as depression, and cardiovascular self-care (Dickson, McCarthy, Howe, et al., 2013; Dickson, McCarthy, & Katz, 2013). Similarly, studies that investigate spiritual factors are needed considering the relationship between spiritual factors, coping, and cardiovascular self-care for African American patients with CVD (Dickson, McCarthy, Howe, et al, 2013; Johnson et al., 2005; Polzer & Miles, 2007; Warren-Findlow & Issel, 2010;).

Studies on CR referral and participation for this population have included limited analysis on the interaction between race/ethnicity and other BPSS factors. Therefore, studies that employ path analysis or multiple regression to investigate the moderating relationships between
demographic or BPSS factors and CR referral and participation rates are strongly indicated. Such analyses would allow for a more nuanced understanding of interactions between variables and would also help to account for potentially confounding variables such as SES. Also, studies that are able to retain participants for follow-up would enable the collection of data across multiple time points, which would be useful for the investigation of CR completion.

Another gap in the research are qualitative studies that amplify the voices of African American patients with CVD. At this point, the voices of African American patients are virtually absent from the research. Although many of the studies in this review include data from patient self-report, the methodologies used did not allow participants to expound upon their individual experiences of rehabilitation. Qualitative methodologies that employ focus groups, observation, and/or individual interviews would enable researchers to identify issues impacting CR referral and participation that may not have been investigated in previous studies.

Research that supports the development of culturally-sensitive interventions for African American patients with CVD is needed. Although surveying individuals on their perspectives and experiences is a start, additional investigation of how this population defines its own needs and interests will increase the likelihood that future interventions will address those needs and interests. A mixed methods approach would offer researchers an opportunity to measure previously identified factors related to CR referral and participation and could potentially identify contextual issues that may not have been investigated.

Limitations

This systematic review has two important limitations. First, although the researcher employed many combinations of search terms to increase the likelihood of capturing every relevant article, a risk exists that relevant articles were missed or overlooked. The enlistment of
a second reviewer to check the work and the inclusion and exclusion decisions of the lead researcher reduced but did not eliminate the risk. Second, searches for this review were restricted to published articles in peer-reviewed journals that were written in English. Relevant articles that were currently in the process of being catalogued within research databases or were catalogued in non-peer reviewed or non-English language journals would not have been accessed for this review.

**Conclusion**

Currently, there is a paucity of research on the BPSS factors impacting CR referral and participation for African American patients with CVD. When compared with their Non-Hispanic White counterparts, African Americans suffer from poorer cardiovascular outcomes (CDC, 2013), yet this population is less likely to receive referrals or participate in CR. Not only does this represent a disparity, it also suggests an injustice in that a population most in need of an intervention has been shown to be less likely to receive it. A need exists for research that contributes to a BPSS understanding of African American patients’ cardiovascular health disparities and participation in cardiovascular health behaviors. Findings from this research, in turn, will help to correct this disparity and assist in the development of effective and population-specific interventions to promote CR referral and participation for African American patients with CVD.
References


Figure 1. BPSS Factors Negatively Impacting Cardiovascular Health and Cardiovascular Health Behaviors among African Americans. Key of abbreviations: CR = Cardiac Rehabilitation; CVD = Cardiovascular disease; SES = Socioeconomic status.

1 Hannan et al. (1999); Peterson et al. (1997); Schneider et al. (2001).
2 Sanderson, Mirza, et al. (2007).
3 Dickson, McCarthy, Howe, et al. (2013); Dickson, McCarthy, & Katz (2013).
4 Din-Dzietham et al. (2004); Lewis et al. (2010); van Ryn et al. (2006); Wyatt et al. (2003).
5 van Ryn et al. (2006).
6 Ford et al. (2009); Warren-Findlow & Issel (2010).
7 Blustein et al. (2008); Wexler et al. (2008).
8 Dickson, McCarthy, Howe, et al. (2013).
Table 1

**Article Search Summaries**

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Total for in-depth abstract/full text review from all databases: 40
Total articles that meet final criteria: 7
### Subject Heading Equivalencies by Database

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<th>PsycINFO via EBSCO</th>
<th>CINAHL via EBSCO</th>
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### Table 3

**Study Quality Criteria**

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<th>Study</th>
<th>Representative sample</th>
<th>Defined sample</th>
<th>Blinded outcome assessment</th>
<th>&gt; 85% follow-up rate</th>
<th>Appropriate outcome measures</th>
<th>Outcome data reported at follow-up</th>
<th>Multivariate analysis, w/ adj. for confounds</th>
<th>Total</th>
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</table>

Note: ‘1’ signifies that the author met the stated criteria, whereas ‘0’ indicates the criteria have not been met.

1 “Participants selected as consecutive or random cases” (Hall, Ferreira, Maher, Latimer, & Ferreira, 2010, p. 1103).
2 “Description of participant source and inclusion and exclusion criteria” (p. 1103).
3 “Assessor was unaware of prognostic factors at the time of outcome assessment” (p. 1103).
4 “Outcome data were available for at least 85% of participants at one follow-up point” (p. 1103).
5 “Appropriate choice of outcome measures” (p. 1103).
6 “Reporting of outcome data at follow-up” (p. 1103).
7 “Multivariate analysis conducted, with adjustment for potentially confounding variables” (p. 1103).
<table>
<thead>
<tr>
<th>Referral/ enrollment/completion</th>
<th>Sample size (n)</th>
<th>Participant characteristics: race/ethnicity and gender</th>
<th>Participant characteristics: Cardiovascular condition</th>
<th>Demographic and biopsychosocial-spiritual variable(s)</th>
<th>Findings</th>
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<td>AA and W women</td>
<td>MI, angina, PCI, CABG</td>
<td>Race/ethnicity; Income; depression</td>
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<td>Bittner et al. (1999)</td>
<td>Referral</td>
<td>1,329</td>
<td>AA and W men and women</td>
<td>MI, angina, CAGB</td>
<td>Race/ethnicity; distance to CR, insurance coverage, discharging physician's specialty</td>
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<td>Cannistra et al. (1995)</td>
<td>Attendance, completion</td>
<td>82</td>
<td>AA and W women</td>
<td>MI, angina, PCI, CABG, valve surgery; dx of cardiomyopathy, or multiple CV risk factors.</td>
<td>Race/ethnicity; Factors impacting CR participation = medical, work, personal, logistical</td>
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<tr>
<td>Evenson et al. (2006)</td>
<td>Attendance</td>
<td>61 = 2004; 45 = Both 1999 and 2004</td>
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<td>Eligible for CR</td>
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<td>AA and W men and women</td>
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Key of abbreviations: AA = African American; W = White; CR = Cardiac Rehabilitation; CV = Cardiovascular; CABG = Coronary Artery Bypass Grafting; MI = Myocardial Infarction; PCI = Percutaneous Coronary Intervention; Dx = Diagnosis; SES = Socioeconomic status
Figure 2. Flow Chart of Included Articles for Review.
CHAPTER THREE: METHODOLOGY

Although Cardiac Rehabilitation (CR), a secondary prevention and treatment program, has been demonstrated to improve physical and psychological health outcomes for patients with cardiovascular disease (CVD) (Brown, Clark, Dalal, Welch, & Taylor, 2011; Heran et al., 2011; Whalley et al., 2011), CR referral and participation rates have remained low, reflecting about one third of eligible patients (Ayala, Xie, McGruder, & Valderrama, 2008; Suaya et al., 2007). Cardiac Rehabilitation is especially underutilized by racial/ethnic minorities (Beswick et al., 2004; Evenson, Johnson, & Aytur, 2006; Suaya et al., 2007). African Americans have a 20% higher age-adjusted death rate from coronary heart disease than Non-Hispanic Whites (Centers for Disease Control and Prevention [CDC], 2013), but they are less likely than Non-Hispanic Whites to be referred to (Allen, Scott, Stewart, & Young, 2004; Gregory, LaVeist, & Simpson, 2006), participate in (Cannistra, O’Malley, & Balady, 1995; Evenson et al., 2006), or benefit from CR (Cannistra et al., 1995; Sanderson, Mirza, Fry, Allison, & Bittner, 2007).

This chapter presents the methodology for this mixed methods dissertation research on African American patients’ CR referral and participation. The researchers will provide the rationale for mixed methods research, as well as the design, data collection and procedures, the lead researcher’s and triangulated researcher’s statements of bias, and ethical considerations for this dissertation research. As a mixed methods study, this research was comprised of a quantitative and qualitative portion: (a) self-report surveys from African American and Non-Hispanic White patients with CVD (quantitative) and (b) audio-recorded, in-depth, open-ended phenomenological interviews (Colaizzi, 1978) with African American patients recovering from cardiac events and/or surgeries (qualitative). The overarching research question for this dissertation was: “What demographic and biopsychosocial-spiritual factors impact CR referral and participation for/among adult African American patients with CVD?” The research question
guiding the qualitative portion of this study was: “What is the lived experience of African American patients recovering from cardiac events and/or surgeries?”

**Mixed Methods Research**

Mixed methods researchers combine quantitative and qualitative research methods in order to address complex problems in the social and behavioral sciences (Creswell, 2009). According to Creswell (2009), a mixed methods approach may be especially instrumental when “the use of either quantitative or qualitative approaches by themselves is inadequate to address this complexity” (p. 203). In contrast, “combined use [of methods] provides an expanded understanding of research problems” (Creswell, 2009, p. 203). Historically, many researchers and theorists have considered quantitative and qualitative methods to be incompatible due to contrasting theoretical origins (i.e., positivism and constructivism, respectively) (Tashakkori & Teddlie, 1998). More recently, however, others have argued for a pragmatic approach founded in (a) paradigm relativism, “or the use of whatever philosophical and/or methodological approach works for the particular research problem under study” (p. 5) and (b) the compatibility thesis of quantitative and qualitative methods (Tashakkori & Teddlie, 1998). This pragmatism has opened the door for combined quantitative and qualitative approaches (Tashakkori & Teddlie, 1998).

Tashakkori and Teddlie (1998) have offered a broad definition of mixed methods studies: “studies that are products of the pragmatist paradigm and that combine qualitative and quantitative approaches within different phases of the research process” (p. 19). Creswell (2009) has provided a number of typologies for categorizing mixed methods studies based on the following aspects: (a) timing (i.e., sequencing of data collection methods); (b) weighing (i.e., amount of emphasis and/or importance given to each method); (c) mixing (i.e., when/how the
methods are mixed for study conceptualization and data interpretation); and (d) theorizing (i.e., the underlying theoretical perspective for the study). According to these typologies, the proposed study follows a concurrent transformative strategy (Creswell, 2009).

This concurrent transformative strategy was characterized by: (a) overlapping quantitative and qualitative phases (i.e., timing is concurrent); (b) variable weight given to each method; (c) connected data mixing (e.g., methods are connected or merged in the analysis process so findings from one inform findings from the other); and (d) guided by a theoretical lens that “is introduced in the introduction to a proposal, shapes a directional research question aimed at exploring a problem (e.g., inequality, discrimination, injustice), creates sensitivity to collecting data from marginalized or underrepresented groups, and ends with a call to action” (p. 212). According to Creswell (2009), this strategy is adopted to “give voice to diverse perspectives, to better advocate for participants, or to better understand a phenomenon or process that is changing as a result of being studied” (Creswell, 2009, p. 213). This study strongly aligned with the first two objectives of this strategy.

In accordance with a concurrent transformative strategy, the lead researcher conducted this study in overlapping phases with the quantitative and qualitative portions running concurrently. Greater weight was given to the quantitative portion, with the qualitative portion designed to supplement and provide insight into the quantitative data. The Biopsychosocial-Spiritual (BPSS) approach provided the theoretical lens that guided this study (Engel, 1977, 1980; Wright, Watson, & Bell, 1996). The BPSS approach conceptualizes health-related experiences through the consideration of multiple factors (i.e., biological, psychological, social, and spiritual) intersecting on different levels of the natural systems hierarchy (i.e., societal-national, cultural-subcultural, community and family, and individual levels [Engel, 1977, 1980]).
The researchers designed this study to not only investigate but also to make recommendations for rectifying a glaring health disparity in African Americans access to cardiovascular secondary prevention and treatment, specifically CR.

**Study Design**

A mixed methods approach was adopted to address the complexity of this research, and, specifically, a concurrent transformative strategy was selected in order to “give voice to diverse perspectives [and] to better advocate for participants” (Creswell, 2009, p. 213). This mixed methods concurrent transformative study (Creswell, 2009) incorporated self-report surveys from African American and Non-Hispanic White patients with CVD (quantitative portion) and semi-structured phenomenological interviews with African American patients recovering from cardiac events and/or surgeries (qualitative portion). The qualitative portion of this study was designed in alignment with Husserl’s (1970) descriptive phenomenology. The research question that guided the study as a whole was: “What demographic and biopsychosocial-spiritual factors impact CR referral and participation for/among adult African American patients with CVD?” The research question for the qualitative portion of this study was: “What is the lived experience of African American patients recovering from cardiac events and/or surgeries?”

This mixed methods dissertation research study consisted of a quantitative portion (read-aloud surveys) and a qualitative portion (audio-recorded, in-depth, open-ended phenomenological interviews). The lead researcher or research assistants enrolled patients with CVD in the study one to two days pre-discharge from an inpatient cardiac service. The quantitative portion consisted of two surveys. The “Time 1” (T1) portion of the survey was conducted in person, pre-hospital discharge immediately following study enrollment. The lead researcher or research assistants delivered the survey using a read-aloud process. The “Time 2”
(T2) portion was conducted approximately six weeks post-discharge also using a read-aloud survey process that was carried out over the telephone. The qualitative portion of this study consisted of open-ended, semi-structured phenomenological interviews with African Americans patients recovering from cardiac events and/or surgeries. Subsequent to completion of the six-week post-discharge survey (T2), the lead researcher or research assistants invited eligible participants to participate in the qualitative portion of the study. Additionally, eligible participants were also recruited for the qualitative portion of the study directly from a nearby CR facility. The lead researcher conducted all interviews by flexibly using an interview guide to ensure all participants addressed similar topics and issues related to their cardiac and CR perspectives and experiences.

The initial hypotheses for the quantitative portion of the study were:

1. African American race will be associated with lower incidence of revascularization procedures (i.e., coronary artery bypass grafting [CABG] or percutaneous coronary intervention [PCI]), and lower incidence of revascularization procedures will be associated with lower levels of CR referral.

2. African American race, lack of insurance, lower levels of education, unemployment, lower annual income, and no follow-up appointment with a cardiologist or cardiac surgeon will be associated with lower levels of both referral to and participation in (e.g., enrollment, attendance, and completion) CR.

3. Higher levels of anxiety, depression, and helpless inevitability, and lower levels of social support will be more strongly associated with lower levels of participation in CR among African American participants than among Non-Hispanic White participants.
This study was approved by the East Carolina University and Medical Center Institutional Review Board (IRB) before participant recruitment commenced (see Appendix A).

Setting

The settings for this dissertation research were (a) a Southeastern academic medical center serving a population of nearly one and a half million people from a primarily rural and lower-income area, and (b) a nearby, affiliated CR facility. At the time of the study, over half of the medical center’s care was provided without payment, as either charity care, unreimbursed Medicaid care, or care through other need-based government programs. The medical center housed two cardiac inpatient units: a Cardiovascular Intensive Care Unit (CVICU) (24 beds, 8 of which were used for patients preparing for discharge) and a Cardiac Intermediate Unit (CIU) (56 beds all of which could be used for patients preparing for discharge). The CVICU typically served and discharged CABG and PCI patients, while myocardial infarction (MI) patients moved to the CIU before discharge and, therefore, typically discharged from the CIU. The CR facility was the only facility of its kind in the county where the academic medical center was located and was one of two CR facilities serving the county. The CR facility located in the academic medical center had 147 participants complete the CR program in the 2013-2014 fiscal year.

Participants

The participants in the quantitative portion of the study were patients with CVD preparing for discharge (i.e., discharge scheduled that day or within the next two days) from one of the two cardiac inpatient units housed within a Southeastern academic medical center. Patients were considered eligible for participation in the quantitative portion of the study if they met the following inclusion criteria: (a) English-speaking; (b) aged 18 and older; (c) prepared for discharge from a cardiac event or surgery for which CR was indicated (MI, coronary artery
bypass grafting [CABG], stable angina, heart valve repair/replacement, percutaneous coronary intervention [PCI] (including percutaneous transluminal coronary angioplasty [PCTA]), heart transplant, and/or coronary artery disease [adapted from American Association of Cardiovascular and Pulmonary Rehabilitation [AACVPR], 2014]); and (d) resident of a city or town in the county where the academic medical center was located. The researchers geographically restricted study participant recruitment, because the outcome variables of CR referral and participation were measured by consulting the electronic health record (EHR) and paper records of the two CR facilities that served that particular county.

Exclusion criteria for this study included: (a) a discharge diagnosis of heart failure or a heart-lung transplant (heart failure patients at this academic medical center were sometimes referred to pulmonary rehabilitation and heart-lung transplants patients could also be referred to pulmonary rehabilitation rather than CR) or (b) cognitive impairment that would interfere with the individual’s ability to consent to the study and participate in surveys and interviews. Upon enrollment, participants were asked to consent to T1 and T2 surveys and, if they met inclusion criteria, invited to participate in one audio-recorded, in-depth, open-ended telephone interview. However, the lead researcher or research assistants explained to the participant that he or she was not obligated to complete all portions of the study and could elect to discontinue enrollment at any point without consequence.

Anticipated enrollment for the quantitative portion of the study was 75 participants. Participants for the qualitative portion of the study were recruited (a) from an initial pool of 75 patients recovering from cardiac events and/or surgeries and (b) directly from a nearby CR facility affiliated with the academic medical center. Regarding recruitment from the initial pool of study participants, African American patients who were already enrolled in the study were
asked at the time of the six-week post-discharge survey (T2) if they were willing to participate in an audio-recorded, in-depth, open-ended interview of about one hour in duration. Additionally, participants were directly recruited from a nearby CR facility for the qualitative portion of the study. Eligibility criteria for participants recruited from the CR facility was identical to the eligibility criteria used for recruitment from the initial pool, with the following exception: a pre-discharge timeframe criterion was substituted for a post-discharge timeframe criterion. The researchers selected a time period of approximately two months post-discharge in order to ensure that participants who were recruited from the initial pool (at six to seven weeks post discharge) would be in the same stage of recovery as those recruited directly from the facility.

Participants were recruited and semi-structured interviews were conducted until the saturation of themes was reached. Saturation was affirmed when the analysis of additional data (in this case, participant interviews) yielded no new themes (Creswell, 2009). Although the number of interviews needed to reach saturation could not be predicted, Mason’s (2010) content analysis of qualitative studies provided some guidelines. In a review of 57 phenomenology studies, Mason (2010) found that the average number of interviews associated with a phenomenology was 25, while the median number was 20, and range was seven to 89. Due to the high specificity of the topic, anticipated homogeneity of the purposively selected sample, and the inclusion criteria for this phenomenological study, the researchers estimated that saturation would be reached within 8 to 12 interviews. The lead researcher planned to conducted one additional interview past the point of saturation to test comprehensiveness of themes (Morse, Barrett, Mayan, Olson, & Spiers, 2002).
Measures

The quantitative variables that were measured in this study were anxiety and depression using the Patient Health Questionnaire for Anxiety and Depression (PHQ-4; Kroenke, Spitzer, Williams, & Lowe, 2009); social support using the MOS Social Support Survey (Sherbourne & Stewart, 1991); helpless inevitability using the Religious Health Fatalism Questionnaire (Franklin, Schlundt, & Wallston, 2008). Patient self-report revealed the type of cardiac event and/or surgery the patient experienced and whether or not patients received and/or attended a post-discharge follow-up appointment with a cardiologist, cardiac surgeon, or primary care provider. The diagnosis at discharge was based on the EHR, and CR referral and participation in CR was based on the EHR and paper record data kept by the CR facilities serving the county in which the academic medical center was located. Data were also collected on the following demographic variables: sex/gender, age, race/ethnicity, insurance status, relationship status, highest level of education, employment status, household income, health insurance status, and number of household occupants. Permission was obtained for the use of the copyrighted measures (see Appendix B).

Independent Variables

Independent variables for this study included: (a) demographic information (e.g., sex/gender, age, race/ethnicity); (b) type of cardiac event/surgery; (c) follow-up appointment with cardiologist or cardiac surgeon; (d) anxiety; (e) depression; (f) social support; (g) helpless inevitability; and (h) diagnosis at discharge. The researchers used diagnosis at discharge as reported in the EHR to confirm the type of cardiac event/surgery indicated by patient self-report. In the event that diagnosis at discharge and patient self-report conflicted, the lead researcher deferred to the diagnosis at discharge listed in the EHR.
**Demographic information.** Demographic information was gathered from patients as part of the administration of the T1 survey. Information collected included sex/gender, age, race/ethnicity, insurance status, relationship status, highest level of education, employment status, household income, health insurance status, relationship status, and number of household occupants.

**Type of cardiac event/surgery.** Type of cardiac event/surgery was measured on the T1 survey with the question: “What was your recent hospitalization for?” The possible responses included: (a) heart attack (MI); (b) coronary artery bypass (CABG); (c) coronary stenting (“stent,” PCTA/angioplasty, or other PCI); (d) heart attack with revascularization (CABG, PCTA, or other PCI); (e) stable angina; (f) heart valve repair/replacement; (g) heart transplant; or (h) peripheral artery disease. Diagnosis at discharge (collected using the EHR) was used to confirm the type of cardiac event and/or surgery indicated by patient self-report on the T1 survey. In the event that diagnosis at discharge and patient self-report conflicted, the lead researcher deferred to the diagnosis at discharge listed in the EHR (see Hypothesis 1).

**Follow-up appointment with a cardiologist or cardiac surgeon.** The T2 survey asked participants about their attendance at a post-discharge follow-up appointment (yes/no) and with whom they had the appointment. For the latter question, the following options were given: (a) cardiologist; (b) cardiac surgeon; (c) primary care provider; and (d) other. Follow-up appointment and type of provider was included as an independent variable due to research that supported follow-up appointments with a cardiologist or cardiac surgeon as predictive of CR referral (Barber, Stommel, Kroll, Holmes-Rovner, & McIntosh, 2001) (See Hypothesis 2).

**Anxiety and depression.** The PHQ-4 (Kroenke, Spitzer, Williams, & Lowe, 2009) was included in both the T1 and T2 survey in order to measure symptoms of anxiety and depression.
Developed as a brief screener for anxiety and depression, the PHQ-4 is a composite of the PHQ-2 (brief screener for depressive symptoms) and the GAD-2 (brief screener for anxiety symptoms). The measure asked participants to rate the frequency with which they had been bothered by anxiety and depression symptoms over the past two weeks on a four-point Likert scale (0 = not at all, 1 = several days, 2 = more than half the days, 3 = nearly every day). Although this screener is not intended to be diagnostic, its effectiveness as an “indicator for further inquiry” (p. 613) has been demonstrated in the PHQ-2’s sensitivity (83%) and specificity (90%) for major depressive disorder (Kroenke, Spitzer, & Williams, 2003) and the GAD-2’s sensitivity and specificity for a variety of anxiety disorders (sensitivity = 88% for generalized anxiety disorder, 76% for panic disorder, 70% for social anxiety disorder, and 59% for posttraumatic stress disorder; specificity = 81-83% for above anxiety disorders) (Kroenke, Spitzer, Williams, Monahan, & Lowe, 2007).

The PHQ-4 has a Cronbach’s alpha (measurement of internal reliability) of 0.85 and has been demonstrated to correlate more strongly with results of longer screeners, such as the SF-20, in measuring mental health (Kroenke et al., 2009). The clinical cut off score for the PHQ-4 is 3 or more on the 0-to-12 point scale (normal = 0-2, mild = 3-5, moderate = 6-8, severe = 9-12) (Kroenke et al., 2009). Because the PHQ-4 asks participants to report on their experience over the past two weeks, the lead researcher or research assistants administered it as part of the T1 survey and also the T2 survey six weeks later.

**Social support.** Social support was measured on the T1 and T2 surveys using the MOS Social Support Survey (Sherbourne & Stewart, 1991). The MOS Social Support Survey is a multidimensional survey designed to measure four components of functional support: emotional/informational, tangible, and affectionate support, and positive social interaction. The overall social support index consisting of the four dimensions of support has high internal
reliability with a Cronbach’s alpha of 0.97 (Sherbourne & Stewart, 1991). In the development of this measure, the highest correlations were found between the overall social support index and variables of loneliness, marital functioning, family functioning, and mental health. Scoring is done on a 5-point Likert scale (1 = none of the time, 2 = a little of the time, 3 = some of the time, 4 = most of the time, 5 = all of the time). The stem “How often is each of the following kinds of support available to you if you need it?” is used to prompt answers to items. A sample item is, “Someone to help you if you were confined to bed” (Sherbourne & Stewart, 1991). Social support was measured in both the T1 and T2 surveys to ensure any changes in participants’ social support were noted and accounted for in analysis.

**Helpless inevitability.** Helpless inevitability was measured on the T1 and T2 surveys using the Religious Health Fatalism Questionnaire (RHFQ) (Franklin et al., 2008). The RHFQ was designed specifically for African American participants through a process that included consultation with focus groups and key informants within African American churches and pilot testing with 276 African American participants (Franklin et al., 2008). The RHFQ consists of three subscales that were identified using exploratory factor analysis of measure items: (a) divine provision; (b) destined plan; and (c) helpless inevitability. The latter subscale, helpless inevitability, was identified as “the subscale contributing the most to the prediction of health behaviors when compared to the other two subscales” (Franklin et al., 2008, p. 332). This subscale consists of two questions only, which likely contributes to its low Cronbach’s alpha of .52. When tested against Multidimensional Health Locus of Control (MHLC) (Wallston, 2005), helpless inevitability was positively and significantly correlated with MHLC’s measures of Chance Externality and Powerful Others. The two items which comprise this subscale are: “I don’t need to try to improve my health because I know it is up to God” and “I can control a small
health issue, but only God can control a big health issue” (Franklin et al., 2008). Helpless inevitability was measured in both the T1 and T2 surveys to ensure any changes in participants’ helpless inevitability were noted and accounted for in analysis.

**Dependent Variable Measures**

The dependent variable measures for this study were referral to and participation in CR per the EHR and paper records kept by the CR facilities. Referral to CR was defined as a medical provider’s referral that was submitted to a CR facility. It was noted if the patient received a letter from the CR facility and/or an inpatient consultation regarding CR after being identified as a patient eligible for CR services. However, the researchers did not consider the patient’s receipt of a letter or inpatient consultation only as a referral; rather, these were coded as recommendations. Referral was quantified as the dichotomous variable, “referred/not referred.”

Cardiac Rehabilitation participation was operationalized into three dichotomous variables: (a) enrolled (i.e., chart opened and assessment session scheduled for patient after confirming patient’s interest in participating)/did not enroll; (b) attended (i.e., attended assessment session and at least one subsequent CR session)/did not attend; and (c) completed (i.e., finished CR program according to CR facility assessment of patient completing the goals mutually determined by the patient and the CR staff)/did not complete. All participation variables were measured using the EHR and CR facilities’ paper records. Enrollment was measured six weeks post-discharge, while attendance and completion were measured five months post-discharge.

**Data Collection and Procedures**

**Recruitment, Enrollment, and Consent**

The researchers recruited participants who were awaiting discharge from the cardiac inpatient service that day or within the subsequent one to two days. The lead researcher or
research assistants consulted the EHR to determine which patients on the cardiac inpatient service were residents of the county from which participants were sampled for the study. Next, the nurses on the hospital unit where those patients were located were asked whether or not these patients were (a) preparing for discharge that day or within the subsequent one to two days and (b) had a diagnosis consistent with study inclusion criteria. Having located eligible patients’ rooms, the lead researcher or research assistant explained the study to each potential participant and asked whether or not he or she would be willing to participate in the study (see Appendix C for Recruitment Script). Those who were willing to participate were given the opportunity to enter a drawing for one of ten $25 gas cards to be drawn at the end of the survey data collection. Only participants who completed both the T1 and T2 surveys were eligible for the gas card drawing.

If participants were interested in entering their names into the drawing, the lead researcher or research assistants collected their name and contact information (telephone number, address) on separate sheets to be kept in a lockbox in a locked cabinet at the CIU, and later, a locked file cabinet in the research assistants’ locked office. Ten names were drawn from the participants who completed both the T1 and T2 surveys, and gas cards were mailed to the addresses provided. Regarding the qualitative portion of the study, participants who completed a telephone interview were automatically mailed a $25 gas card directly following the interview.

At the time of study enrollment, participants reviewed and signed the informed consent document after the lead researcher or research assistant addressed any questions or concerns (see Appendix D for informed consent document). The informed consent document included consent to participate in the T1 and T2 surveys and the audio-recorded, qualitative telephone interview, if the participant later met the inclusion criteria for the qualitative portion of the study. Contact
information, best times to call, and permission to leave a message were also obtained at the time of enrollment into the study and recorded on the study participant list. The enrollment process took approximately 10 to 15 minutes.

Data Collection

This study involved the collection of data from surveys, qualitative interviews, the academic medical center/CR facilities’ EHR, and the paper records kept by the CR facilities. The researchers ensured participants’ confidentiality by using sequentially assigned numbers in place of names to de-identify participants for the quantitative portion of the study. The lead researcher asked participants to select pseudonyms for themselves that were used in the transcript and the write-up of the analysis. A number was assigned to participants when they were enrolled in the study and was the only identifying information used on surveys and interview audio files and transcripts. The identifying numbers were recorded with the corresponding participant’s name and contact information and kept in a password-protected file on the lead researcher’s secure Pirate Drive.

Concerning storage of paper data, T1 surveys were initially stored in a lockbox in a locked cabinet on the CIU, but were later transported by the lead researcher or research assistant(s) in a lockbox to a locked file cabinet in the research assistants’ locked office. Transfer of surveys took place when the administration of the T2 surveys began at six weeks post-discharge, and continued approximately every six weeks for the remainder of the study. T2 surveys (paper) were also stored in the research assistants’ office while interview transcripts were stored a locked file cabinet in the lead researcher’s locked office. Interview audio files and digital versions of interview transcripts were password-protected and stored on the lead researcher’s secure Pirate Drive.
Phase 1: Surveys (Time 1 [T1] and Time 2 [T2]). The T1 survey (35 items) was administered when participants were preparing to discharge from the inpatient cardiac service that day or within the subsequent one to two days (see Appendix E for surveys). This survey took participants about 10 to 15 minutes to complete and consisted of demographic items (i.e., sex/gender, age, race/ethnicity, insurance status, relationship status, highest level of education, employment status, household income, health insurance status, relationship status, number of household occupants, and type of cardiac event/surgery the participant experienced), the PHQ-4 (Kroenke et al., 2009), the MOS Social Support Survey (Sherbourne & Stewart, 1991), and the helpless inevitability subscale from the Religious Health Fatalism Questionnaire (Franklin et al., 2008).

The lead researcher or research assistant administered the T2 survey (30 items) over the telephone approximately six weeks following each participant’s discharge date (see Appendix C for telephone script). The T2 survey took 10 to 15 minutes for participants to complete and consisted of questions about the individual’s receipt and/or attendance of a follow-up appointment, which provider that appointment was with (e.g., cardiologist, cardiac surgeon, primary care provider, or other provider), the date of any rehospitalizations, as well as a readministration of the PHQ-4 (Kroenke et al., 2009), the MOS Social Support Survey (Sherbourne & Stewart, 1991), and the helpless inevitability subscale from the Religious Health Fatalism Questionnaire (Franklin et al., 2008). Six weeks post-discharge was chosen for the administration of the T2 survey, because, at this point, participants should have had at least one follow-up appointment with a primary care provider, cardiologist, and/or cardiac surgeon per the academic medical center protocol.
If, in attempting to administer the T2 survey, the participant was not reachable upon the first telephone call, the lead researcher or research assistant attempted to contact the participant two additional times over the course of one week. If during the first or subsequent telephone call attempted, someone other than the participant answered the telephone, the lead researcher/research assistant identified herself by her first name and as a student researcher or research assistant who was following up with the participant. The lead researcher/research assistant asked if there was a better time to call back and also left a callback number. If no one answered and the participant had given permission for the lead researcher or research assistant to leave messages, a message and call back number was left by the caller regarding participation in the T2 survey. The lead researcher or research assistant left no more than two voicemail messages in the process of attempting to contact the participant. Messages were only left on the participant’s voicemail if he or she gave permission for this possibility during study enrollment.

The callback number given to participants was for a confidential telephone located in the research assistants’ office. During the survey data collection, only the lead researcher or research assistant answered calls on this line. Further, the voicemail connected to the line was password-protected and accessed by only the lead researcher and research assistant. If a participant called back and was administered the T2 survey after the one week designated for contacting and administrating the survey (six- to seven-weeks post-discharge), this was noted on the survey as a possible confound, due to the fact that a period of approximately six-weeks post-discharge was held as a constant in comparing participants’ responses from T1 and T2 surveys.

When the T2 survey had been successfully administered, the researchers paired T1 and T2 surveys using the sequentially assigned number given to each participant at the time of study enrollment. It was also at this point that participants eligible for the qualitative portion of the
study were asked if they were interested in scheduling an interview with the lead researcher. Interviews were conducted over the telephone and were scheduled in accordance with the participant’s availability, either directly following the T2 survey administration or at a later date.

In the case that a participant scored above the clinical cutoff score of three or above on the PHQ-4 during the administration of the T1 survey, the lead researcher or research assistant: (a) gave the participant a behavioral health resource sheet (see Appendix F) and (b) alerted a member of the participant’s care team to this concern so that the care team could coordinate appropriate resources and referrals for the participant prior to discharging the patient, as needed. If a participant scored above the clinical cutoff score on the PHQ-4 during the administration of the T2 survey, the lead researcher or research assistant: (a) explained that behavioral health support may be useful to patients experiencing mood changes after a cardiac event or surgery and (b) offered contact numbers for local behavioral health resources (see Appendix F).

**Electronic Health Record and paper records.** Data on CR referral and participation (e.g., enrollment, attendance, and completion) were collected using the EHR and paper records kept by the two CR facilities accessible to patients from the county where the academic medical center was located. The lead researcher and research assistants tracked referral data on a regular basis and documented CR enrollment at approximately two months post-discharge. By this time, participants should have had follow-up appointments with their primary care provider, cardiologist, and/or cardiac surgeon (per academic medical center protocol) and would have begun CR, if they had been referred and chose to act on the referral.

The lead research and research assistants measured CR attendance and completion at five months post-discharge. The lead researcher selected this time point based on the Centers for Medicare and Medicaid Services’ (2006) CR reimbursement structure (36-session program to be
completed over 12 to 18 weeks, or approximately four to five months post-discharge in the event that patients began CR several weeks after their cardiac event/surgery). In the event that a participant enrolled in CR after two months post-discharge, his or her enrollment data was corrected at five months post-discharge when attendance and completion data are collected.

Phase 2: In-depth, Open-ended, Semi-structured Interviews. The lead researcher conducted all audio-recorded, qualitative telephone interviews with African American participants who were recovering from cardiac events and/or surgeries. Following data collection, the lead researcher transcribed interviews and coded them in collaboration with a triangulated researcher and a peer debriefer until the saturation of themes was reached. Every interview began with the same grand tour question: “How would you describe your experience recovering from your cardiac event or surgery after being discharged from the hospital?” (see Appendix G for interview guide). A brief demographic questionnaire was also administered at the end of the telephone interview (i.e., type of cardiac event/surgery, sex/gender, age, race/ethnicity, insurance status, relationship status, highest level of education, employment status, household income, health insurance status, number of household occupants, receipt/attendance of a follow-up appointment, and re-hospitalizations following discharge) (see Appendix E for questionnaire).

The lead researcher facilitated the interviews, encouraging participants to expand on different elements of their experience. Participants were also informed that, upon completion of the interview, they would have the opportunity to participate in a member checking process (Creswell, 2009; Lincoln & Guba, 1985) once all interviews had been transcribed and coded and analysis was completed. Participants who wished to be involved in the member checking
process were provided a summary of the results to confirm that the results reflected the essence of their lived experience.

Data Analysis

This mixed methods dissertation research includes a phase 1 (quantitative) and phase 2 (qualitative) analysis. The phase 1 analysis consisted of regressions and path analyses of self-reported survey data from the initial pool of participants. The phase 2 analysis consisted of a phenomenological analysis of verbatim transcriptions of audio-recorded, in-depth, open-ended interviews conducted with African American participants who were recovering from cardiac events and/or surgeries. The phenomenological analysis entailed transcription and coding of audio recorded interviews using Colaizzi’s (1978) phenomenological analysis method.

**Phase 1.** For the quantitative portion of this study, the researchers used regressions and path analyses to examine the moderating effect of the independent variables (i.e., type of cardiac event/surgery, anxiety, depression, social support, and helpless inevitability) between race (i.e. African American or Non-White Hispanic) and the dependent variables of referral and participation (i.e., enrollment, attendance, and completion). The causal modeling technique of path analysis enables researchers to test the fit of a model consisting of the direct and indirect relationships between endogenous (dependent) and exogenous (independent) variables. Fit of the model is tested by comparing reproduced (theoretical) and empirical (observed) correlations and trimming the model of non-significant correlations (Mertler & Vannatta, 2009).

Separate path analyses were run for referral, enrollment, attendance, and completion. The following fit indices were used to test goodness of fit: Non-normed fit index, Chi-square tests, and Tucker Lewis TLI. A correlation table was also constructed to look at associations
between demographic variables (e.g., insurance status, relationship status, highest level of education, employment status, household income, etc.), and participant referral and participation.

**Phase 2.** For the qualitative portion of this study, the lead researcher transcribed, coded interview transcripts, and analyzed the coded data for themes using Colaizzi’s (1978) phenomenological analysis method. This method consisted of: (a) reading the transcripts; (b) identifying significant statements; (c) forming meaning statements from the significant statements; (d) clustering themes from the meaning statements and forming emerging themes; (e) creating an exhaustive description; (f) creating a statement of identification; and (g) validating the findings (Colaizzi, 1978).

**Reading the transcript.** Consistent with Colaizzi (1978), the researchers read the transcript in full “in order to acquire a feeling for [the participant’s descriptions of the phenomenon], a making sense out of them” (p. 59), before beginning to lift themes from the text.

**Identifying significant statements.** Next, in keeping with Colaizzi’s (1978) second step, the researchers identified and coded the statements that pertained to the phenomenon being studied. In this step, repetitions of the same theme were coded equally and statements grounded in specific context were coded in terms of “more general formulations” (p. 59) relating to the phenomenon.

**Forming meaning statements.** In the third step (Colaizzi, 1978), the researchers formed meaning statements from significant statements. This entailed the researcher using “creative insight” (p. 59) to “leap from what the [participants] say to what they mean” (p. 59). Colaizzi (1978) cautions researchers against being too strident in this step. In order to maintain fidelity to the phenomenon (and the participants’ experiences), the researchers ensured these statements
“discover and illuminate those meanings hidden within the various contexts and horizons of the investigated phenomenon which are announced in the original protocols [transcripts]” (p. 59).

**Clustering themes.** After steps one through three have been completed for each transcript, the researchers clustered common themes and subthemes that cut across participants’ experiences (Colaizzi, 1978). Once themes and subthemes were identified, the researchers “validated” themes by returning to the transcripts and asking themselves, “whether there is anything contained in the original protocols that isn’t accounted for in the clusters of themes” (p. 59). As recommended by Colaizzi (1978) the researchers maintained a “tolerance for ambiguity” (p. 61) in this stage by resisting the temptation to discount disconfirming evidence or “prematurely generating a theory which would merely conceptually-abstractly eliminate the discordance of [the researchers’] findings thus far” (p. 61).

**Creating an exhaustive description.** In the fifth step, “the results of everything so far [were] integrated into an exhaustive description of the investigated topic” (Colaizzi, 1978, p. 61). An exhaustive description was written as a list of statements that captured all the themes lifted from participants’ transcripts in the preceding steps (Colaizzi, 1978).

**Creating a statement of identification.** The statement of identification is intended to “formulate the exhaustive description of the phenomenon in as unequivocal a statement of identification of its fundamental structure as possible” (Colaizzi, 1978, p. 61). The researchers captured the essence of the participants’ lived experience in this one inclusive and overarching statement.

**Validating the findings.** Colaizzi’s (1978) final step is similar to member checking, as defined by Lincoln and Guba (1985) and Creswell (2009). In this step, the lead researcher consulted participants on the telephone about the exhaustive description. The lead researcher
asked participants whether or not the exhaustive description included the participants’ experiences. Additional findings gleaned at this final stage were incorporated into the study findings (Colaizzi, 1978).

**Verification Processes**

In accordance with Lincoln and Guba’s (1985) recommendations for trustworthiness of data, the researcher used verification processes to ensure credibility, transferability, dependability, and confirmability. The verification processes selected to ensure credibility included: (a) triangulation; (b) peer debriefing; (c) and member checking. Transferability was ensured through the use of thick description. Dependability and confirmability were ensured through maintaining an audit trail which included keeping a research log, a detailed accounting of the analysis process, writing analysis and interpretation memos, and maintaining a reflexive journal. Analysis and interpretation memos included reactions to the analysis process and emerging themes that surfaced through interaction with the data. The lead researcher kept a reflexive journal throughout the study in order to document continuing self-awareness of assumptions, biases, values, and beliefs.

Firstly, to ensure credibility, the lead researcher triangulated the data collection and analysis process. Triangulation strategies entailed using multiple sources of data collection and more than one researcher (Lincoln & Guba, 1985). Triangulation of data sources was achieved by interviewing multiple participants (Lincoln & Guba, 1985). Triangulation of analysts was achieved by involving a triangulated researcher in the analysis process. For every interview, the triangulated researcher coded approximately one quarter of the transcript pages, effectively auditing the lead researcher’s work. Next, the lead researcher and triangulated researcher met to
discuss and resolve differences in coding. If the lead researcher and triangulated researcher were unable to reach agreement, the peer debriefer was consulted.

Secondly, credibility was bolstered by using peer debriefing which took the form of ongoing conversations between the lead researcher and co-researchers. Peer debriefing entailed a peer researcher reviewing the lead researcher’s and triangulated researcher’s analysis “for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's [lead researcher’s and triangulated researcher’s] mind” (Lincoln & Guba, 1985, p. 308). The lead researcher consulted with the peer debriefer after initiating each phase of the analysis process and again upon each phase’s completion to ensure fidelity of the analysis process and that the themes were grounded in the data. The peer debriefer was also the third party consulted when the lead researcher and triangulated researcher were unable to reach coding agreement.

According to Lincoln and Guba (1985), transferability is the extent to which findings can be applied to other cases beyond the current research study. In this research, transferability was addressed through the use of thick description. Thick description in qualitative research refers to the thoroughly detailed presentation of findings to the extent that a reader can determine whether or not the findings would be transferable to other cases. In her write-up of the results, the lead researcher employed thick description by describing the context of the findings in great detail and grounding the findings in the words of participants.

Finally, to ensure dependability and confirmability, the lead researcher maintained an audit trail consisting of a research log, analysis and interpretation memos, and a reflexive journal. The research log contained documentation of contacts made throughout the research process and decisions made regarding protocol. Analysis and interpretation memos contained the lead researcher’s and co-researchers’ reflections and ideas regarding interpretation of the data.
Finally, the lead researcher engaged in reflexive journaling as a method of continual engagement with her own experiences vis à vis the research process. Reflexive journaling included the lead researcher’s reactions to and understanding of the participants and data, biases and insights, and her ongoing self-awareness in bracketing those biases. Selected entries from the lead researcher’s reflexivity journal are included in the write-up of this dissertation research (see Appendix H).

**Statements of Bias**

**Lead Researcher**

The lead researcher’s position both as a researcher and as a White, college-educated female from the Northeastern United States are salient to the conceptualization and implementation of this study. An important preliminary step in phenomenological research process is “bracketing” or identifying and “stepping away” from one’s biases to increase the likelihood that they will not interfere with data analysis (Bernard & Ryan, 2010, p. 259). According to Colaizzi (1978), questioning of one’s presuppositions regarding the phenomenon of study allows researchers to approach the study more objectively (Colaizzi, 1978). As Colaizzi (1978) defines it, “objectivity is fidelity to phenomena. It is a refusal to tell the phenomenon what it is, but a respectful listening to what the phenomenon speak of itself” (p. 52).

Throughout the conceptualization of this study, the lead researcher engaged in reflexivity or “conscious self-reflection on the part of the researcher to make explicit their potential influence on the research process” (Hennink, Hutter, & Bailey, 2011, p. 19). This process has included (a) ongoing reflexive journaling, and (b) a photo-reflexivity project that assisted the lead researcher in exploring her beliefs, assumptions, values, and biases associated with her dissertation topic. These activities have elucidated the following insights into the lead researcher’s perceptions: (a) a bias against health promotion interventions that are inaccessible to
socially disadvantaged patients; (b) an assumption that religion is important for many African Americans living in the Southeastern United States; (c) a belief that most disparities in health outcomes and health care can be explained by limited access to resources; and (d) a bias favoring early intervention for the management of health problems and the need for integrated medical and behavioral health care. The lead researcher challenged these biases and maintained an awareness of them throughout the study in order to manage the undue influence of these biases on herself as the qualitative research instrument and the study in general.

The lead researcher also engaged in ongoing reflexivity and peer dialogue regarding her position as a White researcher doing research with African American participants. Considering the historical trauma experienced by African Americans in the context of medical and scientific research (Washington, 2006), the lead researcher acknowledged the need for particular sensitivity in approaching both this research topic and research participants. First and foremost, she held an awareness of racial/ethnic disparities in power and privilege, and specifically, how her own White privilege could inadvertently silence others (e.g., McGoldrick & Hardy, 2008). She believed it was her charge to do everything possible to ensure that this silencing did not take place. In taking a stance of cultural humility and curiosity, tentatively offering ideas, asking questions to foster greater understandings, and including a methodological component that explored participants’ experiences as they understand them (phenomenology), she endeavored to promote minority voices within this socially complex dynamic.

**Triangulated Researcher**

When conducting research, it is important to examine and question biases that may involve particular topics within the study at hand. Becoming more aware of personal beliefs and values can help researchers recognize how their backgrounds may affect their perspective on
their research. The triangulated researcher’s position as a White, college-educated female in the South affected her perspective on health and health disparities in several ways. First, she realized that her race inherently allowed her opportunities and experiences that people of color may not have. A degree in Anthropology has enabled her to become more aware of limitations and restrictions that racial minorities may encounter in many environments, including healthcare settings. This has led the triangulated researcher to believe that African Americans may have to deal with implicit institutional oppression and inequality when trying to recover from a cardiac event or surgery. Consequently, the triangulated researcher believed that there were more complex issues for African Americans than for their White counterparts when considering how and why rehabilitation services were used after hospital discharge.

Additionally, growing up in a small Southern town reinforced the triangulated researcher’s beliefs about the importance of religion in a healthy life and family system. Living in the South for 23 years contributed to her understanding that the majority of families in this region value religion and the significance of prayer and reliance on God in the recovery process. Because of this, the triangulated researcher believed that an emphasis needed to be placed on having conversations about spirituality, perceptions about healthcare, and other factors that patients believed influenced their recovery (Statements of Bias also available in Appendix I).

**Ethical Considerations**

This study was designed with careful consideration for the wellbeing of the participants involved and in accordance with the ethical guidelines of the American Association for Marriage and Family Therapy and East Carolina University’s University & Medical Center Institutional Review Board. The risks to participants in this study were anticipated to be minimal (i.e., time and energy to complete surveys and interviews, possible discomfort with answering questions,
and/or negative emotions from talking about recovery experiences), and a number of safe guards were put in place to ensure participants’ safety.

Firstly, participants were informed that they could skip questions, take a break, stop a survey or interview, or discontinue study enrollment at any time. Secondly, if participants felt more comfortable having a family member or friend present for the survey administration or interview process, this allowance was granted. Thirdly, participants who scored above the clinical cutoff on the PHQ-4 (Kroenke et al., 2009) and/or experienced emotional distress during the survey or interview process were offered behavioral health resource information. If this occurred pre-discharge from the medical center, the participant was given a behavioral health resource sheet and the care team was informed of this concern so they could coordinate appropriate resources and referrals for the participant prior to discharging the patient, as needed; if this occurred post-discharge, the participant was given contact numbers for local behavioral health resources over the telephone [see Appendix G].

Additional safe guards were extended throughout the recruitment, enrollment, and data collection process, and included the de-identification of participant data, password-protecting documents and audio files and storing them on a secure server, storing paper documents in double-locked systems, and using sequentially assigned identification numbers (quantitative) or pseudonyms (qualitative) instead of participants’ names to identify electronic and paper data. It was the lead researcher’s primary concern that the participants involved in this study (as well as their family members) felt safe, supported, and able to ask for accommodations at any point in the research process.
Summary

This mixed methods concurrent transformative study was designed to investigate a disparity in CR referral and participation for/among African American patients with CVD. The inclusion of both a quantitative and qualitative portion allowed for: (a) the further investigation of demographic and biopsychosocial-spiritual factors that have been suggested to impact CR referral and cardiovascular health behavior participation for this population, and (b) the exploration of the lived experience of African American patients recovering from cardiac events and/or surgeries. This qualitative portion, in turn, assisted the lead researcher in identifying additional factors impacting CR participation for this population. Ultimately, the combined results of this mixed methods study were used to make policy-level and programmatic recommendations to support the development of interventions and best practices for African American patients with CVD.
References


CHAPTER FOUR: AFRICAN AMERICAN PATIENTS’ LIVED EXPERIENCE THROUGH CARDIAC EVENT/SURGERY AND RECOVERY

Heart disease is the number one leading cause of death in the United States (Centers for Disease Control and Prevention [CDC], 2011) and a “Healthy People 2020” target for improvement (U.S. Department of Health and Human Services [U.S. DHHS], 2014). Among African Americans, the rates of cardiovascular disease (CVD) risk and mortality are higher than for Non-Hispanic Whites, making CVD an even more troubling concern for this population. For example, during 2007–2010, African Americans had a higher rate of hypertension (41.3% among African Americans compared to 28.6% among Non-Hispanic Whites), and a lower rate of controlled hypertension (42.5% of African Americans compared with 52.6% of Non-Hispanic Whites) (CDC, 2013). Additionally, African Americans had a 20% higher age-adjusted death rate from coronary heart disease than Non-Hispanic Whites (141.3 per 100,000 population and 117.7 per 100,000 population, respectively) (CDC, 2013).

Cardiac Rehabilitation (CR) is a Class I secondary treatment and prevention program recommended by the American College of Cardiology/American Heart Association that has been demonstrated to improve health outcomes for patients with CVD (American Association of Cardiovascular and Pulmonary Rehabilitation [AACPR], 2014; Brown, Clark, Dalal, Welch, & Taylor, 2011; Heran et al., 2011; Kwan & Balady, 2012). However, only one third of eligible patients are referred to or participate in CR (Ayala, Xie, McGruder, & Valderrama 2008; Cortés & Arthur, 2006; Suaya et al., 2007). These rates are even lower for racial/ethnic minorities (Beswick et al., 2004; Suaya et al., 2007) and for African Americans, in particular (Evenson, Johnson, & Aytur, 2004; Gregory, LaVeist, & Simpson, 2006). In fact, Koehler, Hodgson, Dodor, Knight, and Rappleyea (2014) found in their review of the literature that African
American patients with CVD not only had a lower likelihood for CR referral, but also had a higher likelihood of enrolling in CR with more cardiovascular risk factors, and a lower likelihood of CR participation and completion due to factors related to low socioeconomic status (e.g., lack of insurance, work conflicts, lower level of education) when compared with Non-Hispanic White patients (Allen, Scott, Stewart, & Young, 2004; Bittner, Sanderson, Brelan, & Green, 1999; Cannistra, O’Malley, & Balady, 1995; Evenson et al., 2004; Gregory et al., 2006; Rankin, 2002; Young, Waller, & Kahana, 1991).

Although CR is the recommended intervention for recovery from CVD-related events and surgeries and for prevention of future events (AACVPR, 2014; Kwan & Balady, 2012), it appears to be less accessible to the African American population. Some researchers have hypothesized that different factors may contribute to this gap in health and care. Among African Americans, researchers have reported disparities in recommendation and receipt of medically-indicated care (Hannan et al., 1999; Ibrahim et al., 2003; Peterson et al., 1997; Schneider et al., 2001; van Ryn, Burgess, Malat, & Griffin, 2006); negative associations between depressive symptoms and cardiovascular self-care (Dickson, McCarthy, Howe, Schipper, & Katz, 2013; Dickson, McCarthy, & Katz, 2013); positive associations between depressive symptoms and CVD risk factors (Weinstein, Abraham, Diao, Zeno, & Deuster, 2011); positive associations between social support and improved cardiovascular health and health behaviors (Grewen, Anderson, Girdler, & Light, 2003; Liu & Newschaffer, 2011; Tkatch et al., 2011); and spirituality as a coping strategy for managing stress associated with CVD-related health problems (Dickson, McCarthy, Howe, et al., 2013; Johnson, Elbert-Avila, & Tulsky, 2005; Warren-Findlow & Issel, 2010), but also a potential source of fatalistic beliefs contributing to a passive approach to self-care (Dickson, McCarthy, Howe, et al., 2013; Polzer & Miles, 2007).
Little has been published on the demographic and biopsychosocial-spiritual factors impacting CR referral and participation among adult African American patients. In their systematic review, Koehler and colleagues (2014) identified only seven studies that addressed this topic. Among these studies, the impact of demographic characteristics (i.e., sex/gender, race/ethnicity) and biomedical and social factors on African Americans patients’ CR referral and participation were addressed most frequently (Allen et al., 2004; Bittner et al., 1999; Cannistra et al., 1995; Evenson et al., 2004; Gregory et al., 2006; Rankin, 2002; Young et al., 1991), psychological factors were addressed to a limited extent (Allen et al., 2004), and spiritual factors were not addressed at all (Koehler et al., 2014).

Because few studies have been conducted related to factors impacting African American patients’ CR referral and participation (Koehler et al., 2014), a descriptive phenomenological design (Husserl, 1970) was conducted to explore the lived experience of African American patients recovering from cardiac events and/or surgeries (including, but not limited to experiences related to CR referral and participation). The following section details the method of this study.

**Method**

Within descriptive phenomenology (Husserl, 1970), the researchers’ focus of inquiry is individuals’ subjective experience of reality. From this perspective, what individuals understand to be real is viewed as essential in making sense of their motivations and actions (Lopez & Willis, 2004). Because heart disease mortality rates in the rural Southeastern state where this study was conducted significantly surpassed national rates (168 deaths per 100,000 and 193.2 deaths per 100,000 for African Americans and Non-Hispanic Whites, respectively in 2009-2013 [NC DHHS, 2014]) and were 20% higher among African Americans than Non-Hispanic Whites, the
researchers determined that a qualitative method honoring the cultural landscape of those impacted was most appropriate. Therefore, the lead researcher selected a qualitative study designed to explore the following research question: “What is the lived experience of African American patients recovering from cardiac events and/or surgeries?” Approval was obtained from the East Carolina University and Medical Center Institutional Review Board (IRB) for this qualitative study as well as a larger mixed method study (see Appendix A–G).

**Participants**

A purposive sampling strategy was used to enroll participants from two different locations: (a) a Southeastern academic medical center serving a population of nearly one and a half million people and (b) a nearby, affiliated CR facility. Potential participants receiving care at the academic medical center and the local CR facility were identified as eligible for the study using data extracted from each facility’s electronic and paper record system. Participants were eligible if they were: (a) English-speaking; (b) African American; (c) aged 18 and older; (d) approximately two months post-discharge for a cardiac event or surgery for which CR was indicated (myocardial infarction [MI], coronary artery bypass grafting [CABG], stable angina, heart valve repair/replacement, percutaneous coronary intervention [PCI] (including percutaneous transluminal coronary angioplasty [PCTA]), heart transplant, and/or coronary artery disease [adapted from [AACVPR], 2014]); and (e) a resident of a city or town in the county where the academic medical center was located.

Exclusion criteria included: (a) a discharge diagnosis of heart failure or a heart-lung transplant (heart failure patients at this academic medical center were sometimes referred to pulmonary rehabilitation and those with heart-lung transplants could also be referred to
pulmonary rehabilitation rather than CR) and/or (b) cognitive impairment that would interfere with the individual’s ability to consent to the study and participate in surveys and interviews.

The lead researcher conducted the audio-recorded, in-depth, open-ended interviews until saturation of themes was reached. She understood saturation to have occurred when the analysis of additional data (i.e., participant interviews) yielded no new themes (Creswell, 2009). Ideally, a confirmatory interview is also conducted for the purpose of validating identified themes and decreasing the likelihood that themes were missed or overlooked in analysis (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Out of 15 eligible patients, seven patients participated in the study. Eight patients were not enrolled because the lead researcher or research assistant were not able to contact these individuals to schedule an interview or they could not be contacted at the time the interview had been scheduled or upon follow-up.

Participants were African American residents of cities or towns in the county where the academic medical center from which they were recruited was located. This county is primarily rural and lower income. Participants in the study included four men and three women who ranged in age from 37 to 64 years. The severity of their events and/or surgeries ranged from MI (heart attack) or stent placement only (done with a catheter and without a large incision), to a combination of MI and CABG (bypass surgery which requires the patient’s sternum to be opened and wired back together). For the seven study participants, CR status was as follows: two individuals had not been referred to CR and were not enrolled; three individuals had been referred but were pending medical action or clearance for enrollment or continued attendance; and two individuals were referred, enrolled, and attending (see Table 1 for participant demographics).
Participants were extended an incentive to participate in the study in appreciation of their time and energy. The incentive took the form of a $25 gas card directly mailed to participants following interview completion.

**Data Collection and Procedures**

**Enrollment and consent.** The researchers recruited five eligible patients from the academic medical center. After consenting to participate in the study prior to their discharge from the hospital (see Appendix D for informed consent), they were contacted by telephone six-weeks post-discharge to set up interviews. Six weeks post-discharge was chosen because, at this point, participants were anticipated to have had at least one follow-up appointment with a primary care provider, cardiologist, and/or cardiac surgeon per the academic medical center protocol and had the opportunity to receive a referral to CR or to discuss recovery alternatives with their medical provider(s).

Two patients were also recruited directly from the CR facility either by telephone or when a research assistant approached them directly at the CR facility at approximately two months post discharge. This time point was selected to ensure that individuals recruited from the initial pool of potential participants (contacted at six to seven weeks post-discharge) would be in the same stage of recovery as those recruited directly from the facility. If patients were contacted by telephone, a time was arranged for them to complete the informed consent face-to-face at the CR facility. Once consent was obtained, interviews were scheduled.

**Data collection.** The lead researcher conducted audio-recorded, in-depth, open-ended telephone interviews. Participants who were recruited directly from the CR facility were administered a demographic questionnaire (e.g., type of cardiac event/surgery, sex/gender, age, race/ethnicity) (see Appendix E for questionnaire) over the telephone. Participants recruited
from the academic medical center had also consented to a mixed method study of which this qualitative study was one portion. These participants’ demographic data were collected at the time of study enrollment (pre-discharge).

Prior to conducting the interviews, the lead researcher invited participants to select pseudonyms for themselves in an effort to mask their identity and protect their confidentiality. The lead researcher transcribed all interviews verbatim, and coded the transcripts with the help of a triangulated researcher and a peer debriefer (co-researcher) until thematic saturation was reached. Each interview began with the same grand tour question: “How would you describe your experience recovering from your cardiac event or surgery after being discharged from the hospital?” The lead researcher facilitated the interviews, flexibly using an interview guide to ensure all participants addressed similar topics and issues related to their cardiac and CR perspectives and experiences (see Appendix H for interview guide).

Data Analysis

After conducting each interview, the lead researcher transcribed, coded, and initiated data analysis using Colaizzi’s (1978) phenomenological analysis method. The analysis process consisted of reading the whole transcript, identifying statements that were significant to the phenomenon of study, and forming meaning statements to capture the participant’s meaning that informed the significant statements. Transcripts were coded successively as interviews were conducted. Saturation was reached when analysis of significant statements yielded no additional meaning statements. After all the transcripts were coded for significant statements and meaning statements, meaning statements were categorized by thematic clusters. This yielded 20 thematic clusters that were subsequently collapsed into six emergent themes (Table 2). Selected examples of narratives and emergent theme formation are included in Table 3. An exhaustive description
was developed to capture all the emergent themes identified by participants in narrative form. Finally, a statement of identification was formulated to communicate the essence of the participants’ lived experience.

Upon completion of the analysis, the results were validated by participants using member checking. For the purpose of member checking, the lead researcher called participants in order to read aloud an exhaustive description of findings and to request feedback. Five out of seven participants were reached and all five confirmed that the exhaustive description reflected their lived experience. One participant recommended a clarification in wording (i.e., that the inaccessibility of interventions discussed in Theme 3 should also be highlighted in Theme 5 for CR). This change was incorporated into the findings.

The analysis process achieved 100% inter-rater reliability among researchers. For every interview, a triangulated researcher coded approximately one quarter of the transcript pages, while the lead researcher coded the entire transcript. Next, the lead researcher and triangulated researcher reviewed one another’s work and met to discuss any coding differences. If less than 90% of coding was in agreement, the triangulated researcher was asked to audit the full transcript. The lead and triangulated researchers discussed each coded statement and, in instances in which the lead researcher and triangulated researcher were unable to reach agreement (10% of the time), the peer debriefer was consulted to assist with reaching consensus. The peer debriefer also reviewed each step of the analysis to ensure that it accurately reflected Colaizzi’s (1978) method and was grounded in the actual data and not the result of researcher assumptions or biases.

**Verification processes.** In accordance with Lincoln and Guba’s (1985) recommendations for trustworthiness of data, verification processes were undertaken to increase confidence in the findings. Three processes were implemented for the purpose of ensuring study
credibility: (a) triangulation; (b) peer debriefing; and (c) member checking. Firstly, triangulation involved the use of multiple sources (i.e. participants) in the collection of data and multiple researchers in the analysis of the data. Triangulation decreased the likelihood that findings were incidental to the participants contacted or the researchers analyzing the data. Triangulation of sources was achieved by interviewing multiple participants, while triangulation of researchers was achieved by involving a triangulated researcher and peer debriefer in the analysis process (Lincoln & Guba, 1985).

Secondly, peer debriefing took the form of ongoing conversations between the lead researcher and co-researchers. A peer debriefer was consulted in the case of coding disagreements between the lead researcher and the triangulated researcher, when the lead researcher sought consultation regarding the analysis, and to review each step of the analysis process. Thirdly, member checking entailed sharing the results of the study with participants so they could confirm that the findings were true to their lived experience. Upon enrollment, participants were informed that, after all interviews were completed, transcribed, coded, and analyzed, they would have the opportunity to participate in a member checking process of a summary of findings (Creswell, 2009; Lincoln & Guba, 1985). The researcher provided participants who wished to be involved in the member checking process with the study’s exhaustive description to affirm that the results reflected the essence of their lived experience.

Transferability refers to the likelihood that findings can be appropriately applied to other individuals outside of study participants. This requires that the findings be grounded in participants’ contexts in such a way that readers can understand how particular themes emerged in the interaction between the participants and these contexts. Transferability was ensured through the use of thick description, or rich and detailed explanations of participants’
experiences and was left to the reader to determine. Dependability and confirmability (i.e., the likelihood that the findings could be replicated and are not the result of researcher bias) were ensured through maintaining an audit trail which included keeping a research log, detailed accounting of the analysis process, interpretation memos, and a reflexive journal to document reactions to the analysis process and emerging themes that surfaced through interaction with the data (Lincoln & Guba, 1985) (see Appendix H).

**Findings**

Analysis of transcripts from seven participant interviews yielded 535 significant statements, 69 formulated meaning statements, 20 thematic clusters, and six emergent themes relevant to the essence of African American patients’ lived experience through cardiac event/surgery and recovery (see Table 2 for emergent themes and thematic clusters). The emergent themes were: (a) Participants valued medical providers’ involvement during treatment and recovery; (b) Social support and participants’ need for it changed post-event/surgery; (c) Participants’ pre- and post-event/surgery experiences affected health outcomes; (d) Participants’ sense of agency affected their life perspectives and health behaviors; (e) Participants experienced inconsistent referral to and utilization of Cardiac Rehabilitation; and (f) Participants’ investment in faith was intensified or maintained. The following section explores each emergent theme, as well as the thematic clusters categorized under it. It concludes with an exhaustive description and statement of identification that captures the lived experience of African American patients recovering from cardiac events and/or surgeries who were living in a primarily rural and lower-income county in the Southeast.
Participants Valued Medical Providers’ Involvement during Treatment and Recovery

Participants discussed the importance of medical providers’ help and expertise throughout and treatment and recovery process. Medical providers included doctors, nurses, and physical/occupational therapists in inpatient and outpatient settings. Participants valued both the functional and emotional support providers offered during and after participants’ hospitalizations. Participants expressed their appreciation for medical providers’ “dedication,” and also pointed out times when they needed additional support from medical providers.

Medical providers’ interventions impacted cardiac outcomes. Participants described experiencing medical crises prior to cardiac events/surgeries during which they sought medical providers for treatment of undiagnosed symptoms. At this time, medical providers were the source of vital information and interventions, often revealing for participants the cause of their symptoms. Participants noted that medical providers were often conservative in their interventions in that they observed patients first and considered less invasive treatments before proceeding to more invasive ones. Medical providers also adjusted participants’ medications, starting new medications and/or stopping existing ones, during and after hospitalizations. These elements of treatment directly impacted cardiac outcomes, from the types of intervention participants received to their recovery experiences.

Robert, a 60-year-old man, experienced an MI with the consequent placement of stents—a more conservative treatment, compared to CABG. He highlighted the aforementioned elements of medical treatment in his description of being hospitalized for, diagnosed with, and treated for heart problems. He recounted his experience by stating,

[When I went into the hospital for] pressure in my chest…that’s when I found out [I had heart problems]… After they [medical providers] did the tests and everything, they came
back, um, because I had a heart attack… They treat me, you know, they were treatin’ me and, then, uh, continuing to run tests, and… and give me medications, yeah… they didn’t do a bypass. They did, uh, well, the stent, I guess.

Lucy, a 41-year-old woman who experienced an MI and then received CABG, also noted that medical providers tried to select a more conservative intervention (stents) before determining that a larger intervention (CABG) was necessary. Lucy reported, “When I went in, um, they tried to do a stent but ended up having have heart surgery [CABG] because I had, um, three blockage that were severe.”

With regard to medical providers starting and stopping medications, participants explained that, although the process of tailoring medications was important and valued, it could present participants with unique challenges. Alberta, a 64-year-old woman who had stents placed, stated:

They [medical providers in hospital] changed all my medicine [for diabetes] and I, I still ain’t got that straight yet… They said my doctor could put me back on if they wanted to, but they were sayin’ that I was takin’ too much medication… They took me off all, and then at one point they said the medication I was takin’ for my diabetes, they didn’t use that type medicine in the hospital, so they used the type they used at the hospital.

Robert described a more straightforward process of having a stronger pain medication added to his medications post-discharge. He stated, “They added a couple of medications… Um, I got one that’s like a blood thinner, [for] heart. And, uh, and uh, a different- a stronger kind of pain pill than I usually was takin.” Robert viewed the addition of these medications as helpful.
Medical providers offered guidance on healthy lifestyle changes. Participants recalled medical providers guiding them on making healthy lifestyle changes after their cardiac event or surgery. These included heart-healthy diet and exercise modifications and recommendations to stop drinking and/or smoking. Participants expressed variability in the degree to which medical providers tailored guidance regarding activity level and exercise to the participants’ individual needs. Sometimes guidance took the form of general messages, whereas other times guidance was specific and hands-on. For example, participants Bruce, Mark, Michael, and Lucy were told to “just walk.” Lucy stated, “It was people [medical providers] that told me to, um, just walk… If I go to my doctors’ visits or something [they] just say, ‘Well, you need to make sure that you’re walkin.’” Bruce, a 60-year-old man who had stents placed, was told to, “just, uh, start taking it easy, if I don’t do nothing but just walk out to the mailbox and walk back, walk out to the mailbox and walk back, that will help build my strength up and everything and make my heart pump.”

In contrast to these general messages, Alberta described the existence of continuity of care from her surgeon to her physical therapist, all of whom referenced and guided her in exercises from the same pamphlet given to her by a nurse during her hospitalization:

The book that they gave me for to do the arm exercises, the leg exercises… And I did it [exercises] while I was in the hospital… I was even doing it before he [physical therapist] got here… The therapist come in. He helped me walk. I walked down the street. I did everything he asked me to do, and he said I done well with it… I had to do arm exercise, leg exercise, and then I walked down the street a block.
Notably, Alberta stated that she had also created her own continuity of care by doing exercises from the pamphlet between the time she was discharged and the time the physical therapist started home visits.

**Participants perceived support (functional and emotional) offered by medical providers.** In addition to guidance for healthy lifestyle changes, medical providers offered a combination of functional and emotional support to participants both during hospitalization and recovery. Functional support included adjusting medications, checking participants’ vitals and tolerance of treatment, putting in appropriate referrals, providing explanations of the treatment process to participants, and offering or making home visits (visiting nurses, physical/occupational therapists). Providers’ emotional support entailed offering encouragement to participants and positive feedback regarding participants’ cardiac event or surgical outcome and progress during recovery.

Often, support from medical providers served both functional and emotional purposes simultaneously. Miss Spunky, a 54-year old woman who experienced an MI, explained that her body had always been “very sensitive” to what she put on it or in it. Therefore, she appreciated her medical providers’ care with monitoring her reactions to new treatments and felt emotionally supported through the functionally supportive actions offered by her providers:

They, um, been thoroughly with, you know, the examination and medication and makin’ sure that, you know, that, uh, that they handle the, um, monitor my symptoms and, and reactions from the medicine. I mean, they’ve been a help for that, you know, consider how my body is: very sensitive to things. So, they, they’ve been kinda supportive.
For some participants, positive feedback seemed to also have a motivating effect, encouraging them to continue treatment recommendations through recovery. For example, Bruce stated: “My blood pressure was alright and [he] told me to keep doing what I’ve been doing [CHUCKLING]… With my, you know, with my diet and everything. Keep doing what I’m doing.” Other participants seemed to cite positive feedback as reassurance that they did not need additional resources such as CR, but were equipped to facilitate their own rehabilitation process. Robert stated, “Every time I went to the doctors they kept tellin’ me, ‘You’re doin’ good.’ And the last one I went to they said, ‘You, actually, you know, your heart’s good.’ Um, they did a blood test and an EKG, and they said that that it was all good.” This participant said he was accustomed to working out before his cardiac event/surgery and stated that he planned to ease back into working out on his own.

**Participants appreciated medical providers.** Participants expressed their appreciation for medical providers’ level of “dedication” to participants and their health. One participant, Bruce, also emphasized the good work that student doctors had done. Specifically, participants appreciated that medical providers seemed to invest personally in participants’ needs. Participants frequently spoke about medical providers “really caring” for them. Regarding the doctors and nurses who cared for him during his hospitalization, Bruce said, “You always know you’ve got somebody that’s got your back”. Michael, a 37-year-old man who experienced an MI and had had stents placed, stated that, although he had had previous experiences of discrimination based on his status as a Medicaid patient, he did not experience any such discrimination during hospitalization or post-discharge:
They really cared about me. I could tell the doctors really cared. They wanted me to get well…they kept telling me, um, you gotta do this, you gotta take your medicine. You can tell when someone actually care about you.

“Really caring” also meant that medical providers went above and beyond their job descriptions to care for participants. Michael recounted the way CR nurses and staff exceeded expectations in assisting with the coordination of his care: “They didn’t have to do all of that. They could have just told me to call my physician and set up an appointment, or I should call my doctor, but they did all the calling for me.”

Connected to participants’ sense of medical providers’ exceptional care was participants feeling that they were a part of a collaborative team with providers in which participants’ positive health outcomes were a shared goal. Participants’ appreciated that medical providers involved them in conversations about their care and explained to them what to do and what to expect medically. Bruce, who referred to his medical providers as “my doctors and nurse friends,” stated:

They just sit and listen, but they, and what they got to say, they gonna let you know what they’ve got to say, but they sit and listen to what you’ve got to say, too, and they try to explain what’s going on. . . [Their approach] make you feel good.

**Participants needed additional support from medical providers.** Although participants primarily spoke about the ways in which their medical providers had been exceptionally helpful, participants also pointed out things with which they would have liked additional support. Requests for additional support centered on post-event/surgery needs. Participants stated that it would have been helpful to have had more information about home-based recovery. For example, Lucy said that she and her family ended up buying a recliner after
they realized that she could not sleep comfortably in a regular bed for the first few weeks following discharge. According to this participant, the recliner most closely simulated a hospital bed by keeping her somewhat upright. She suggested medical providers consider “Lettin’ the family know, ‘You might want to try to look into rentin’ a recliner for the next couple weeks’… or something like that. You know, um, just things that they know patients will kinda struggle with for the first couple weeks.”

Social Support and Participants’ Need for It Changed Post-Event/Surgery

The second theme that emerged in the analysis of interview transcripts was the importance of social support during recovery. In particular, the social support given to participants, as well as participants’ need for or experience of social support, changed during this time. Participants’ social support networks included family members, friends, neighbors, and faith community members. Following participants’ cardiac events/surgeries, participants noticed an increase in both functional and emotional support from their networks in the form of help with daily activities of living, visits/check-ins, and encouragement. However, participants also expressed a sense of isolation or lack of social support at times, or they expressed challenges with certain types of social support or interaction that they did not deem helpful.

Social support was increased during recovery process. Following cardiac events/surgeries, many participants experienced their social networks rallying to support them. Functional support included assistance with activities of daily living (e.g., bathing, preparing meals), financial help when/if participants were unable to work for a significant amount of time, assistance with household chores and yard maintenance, and provision of home-based accommodations for recovery and gradual transitions back into normal routines. Lucy, who had also stated that her husband had bought a recliner upon her return home so she could sleep
upright, described the accommodations her family made around her return to college: “You can’t lift over 10 pounds, so, um, they would go with me… either my sons or my husband… Go to school with me and take my books into class and bring ‘em outta class…. ” Lucy reported feeling very supported by her family’s team effort in helping her return to school.

Emotional support from social networks included check-in telephone calls and/or visits, words of encouragement, and advice from others who had had similar cardiac experiences. As with the functional support, participants noted that the emotional support increased following their cardiac events/surgeries. Bruce stated that his adult children used to call him monthly, but “they done stopped that once a month once I wen through the hospital. They start calling a whole lot!...they ask about my appetite and everything.” According to participants, supporters also made check-in visits. During these visits supporters sometimes offered functional support and other times sat with the participant and/or offered words of encouragement. Michael stated that his family helped him by “just being there for me. Um, talking to me, um, not wanting me to stress, encouraging me to do things, encouraging me to walk.” Mark reported that he got good advice from his roommate who “had the same thing [cardiac event/surgery]” as the participant had, and thus, could guide him on the particulars of the recovery process.

**Sense of social isolation or limited support during recovery.**

According to participants, sense of isolation was often caused or compounded by lifestyle changes made post-event/surgery and participants’ physical limitations during their recovery process. Mark found that, upon following his medical providers’ recommendations to stop smoking and drinking, he lost contact with his friends with whom he used to engage in these activities. Although Mark recognized these were the “wrong kind of friends” to have if he wanted to adopt healthy lifestyle behaviors, he still expressed disappointment that they didn’t
come visit him in the hospital or post-discharge, stating, “the day after I had the heart
attack…they don’t come see me or nothing.’”

In a similar vein, Lucy felt isolation not due to losing friends, but due to feeling that her
friends did not share her new perspective on the consequences of unhealthy lifestyle behaviors:

Some people might have went through the struggle of battling with food, but they
haven’t went through the struggle of knowing that, okay this could really kill
you… Or it could shorten your life. So, basically, by them not realizin’ that, they
don’t take it as serious.

Although Lucy admitted that she “didn’t take [diet] as serious” before her MI and CABG, she
now felt distanced from those who had not had a similar change of perspective. She said, “I had
the realization and then coming back into normal world and normal society and everybody’s just
doin’ what they do,” she said.

Physical limitations also caused participants to feel isolated. In contrast to the example
above, this form of isolation was not a result of friends abandoning the participants, but rather
resulted from participants being unable to engage in their lives as they had been previously
acustomed. Lucy stated that social events were very difficult for her to attend in the first few
weeks following her discharge, because she was not able to move around the gatherings as she
formerly would have. According to Lucy, this left her feeling like she was an outsider at the
gathering, “watching life go by”—a stark contrast to her typical position as being what she
described as, “the center of attention”:

Everybody’s movin’ around socializing, and I’m kinda stuck in this spot waiting
for, ‘Okay, you wanna come talk to me?’ And have one person come talk to me a
little while, then they go off, and then I’m waiting for, ‘Okay, I’m just sitting
watching everybody’… it was kinda lonely. And it, uh, you felt like you was, like, missing a lot of things. Like, you kinda sittin’ there and you watching life go by.

Finally, some participants who were living far away from friends and family reported limited access to social support from these distant individuals. The geographical distance between participants and supporters predated participants’ cardiac events/surgeries, but the cardiac events/surgeries highlighted this distance. In these cases, participants leaned more heavily on their nearby supporters for assistance. For example, Robert stated that his family members lived “far, far away” in the Northeast and were only able to visit him for a short time during his recovery. While they were visiting, Robert said they helped with cooking. After they left, he said his fiancée “did everything.”

Challenges with social interactions and type of social support. Finally, participants expressed challenges with the type of support they received from supporters. This thematic cluster is distinct from the one preceding it; whereas the cluster above refers to sense of social isolation or limited social support, this cluster refers to the presence of social support that was in some way challenging for the participant. Participants reported that support that was “pitying,” disempowering, conflictual, or “humbling,” was challenging to them. Miss Spunky stated that she felt pitied when her family and friend looked at her “different” and spoke to her in a certain tone: “It’s like I’m being watched more, or, you know, [they say], ‘How you feelin? You feelin’ alright?’ [and I say], ‘Yeah, I’m fine!’”

Regarding disempowering support, Lucy did not feel supported when those around her provided her with words of encouragement but not with functional support:

So, a lot of times, like, I could tell somebody [about cardiac event/surgery] and they’d be like, ‘Oh okay, well, you got this, and you can do this.’ And the way
they kinda say it, seem like it’s kinda nonchalant, or, you know, ‘Yeah, you can
do it’ [UNDERWHELMED TONE]. And it’s like, ‘Okay, yeah, I’m telling you
this because, (a) I need a lifeline, I need you to, uh, come on, help me do this.’

According to Lucy, her cardiac event/surgery had “hit” her hard but had not affected
those around her in a similar way. As a result, her supporters were less likely to offer the
functional support she needed to implement healthy lifestyle changes and maintain them.

Support that was “humbling” or conflictual was also a challenge to participants
but was not necessarily seen as ultimately negative. Lucy stated that needing help from
her husband and children with activities of daily living was “humbling” and “a big, big
change…like for instance, you see your husband as your husband, but you don’t want
him to have to wipe you.” Support was conflictual when participants and supporters
disagreed on participants’ treatment recommendations. Lucy reported that, ultimately,
her difference of opinion with her husband regarding exercise (“I would try to walk the
half mile, and he was like, ‘That’s enough, you tired.’”) allowed her to find a “balance”
in implementing recommendations.

While participants reported challenges with social support and interactions, they also
reported that they did not always disclose their authentic feelings. Miss Spunky stated she made
a point of “acting joyful” when she felt pitied by others, “just to, uh, let ‘em know that you don’t
have to have pity [CHUCKLING], you know?” Similarly, Bruce said his friends at church did
not realize how sick he was before receiving his stent because of the smile he put on: “Even the
people at, at the church said – ‘cause I used to always smile so much they never thought I was
ever hurtin’ or anything because they said I kept such a smile.” This inauthenticity may have
made it more difficult for others to know that their support—or a different type of support and/or interaction—was needed.

**Pre- & Post-Event/Surgery Experiences Affected Health Outcomes**

The third emergent theme identified how participants’ cardiac events/surgeries were not isolated health events but, rather, were a part of participants’ ongoing health experiences. During interviews, participants reported multiple health problems before events/surgeries, some of which directly compounded their heart problems. Post-event/surgery health outcomes were often positive, but participants also reported that some post-event/surgery treatments were either ineffective, inaccessible, or were not adopted by participants. For example, some participants expressed that they struggled to cover co-pays for prescribed medications or that their health insurance plan did not cover adjunctive treatments like weigh loss surgery.

**Participants had pre-event/surgery health problems.** Pre-event/surgery health problems endorsed by participants included prior cardiac events, atrial fibrillation, undiagnosed cardiac problems, high blood pressure, diabetes, obesity, knee problems, prior injuries, fibromyalgia, and depression. According to participants, these pre-existing health problems had kept participants from being able to live like they wanted to live. Michael stated that his obesity and knee problems made it difficult, and then impossible, to work at the physically strenuous job he had held. Miss Spunky stated that injuries from a car accident (approximately 10 years prior) and fibromyalgia “kinda, like, put a dent in my exercise.” Before being hospitalized and having a stent placed, Bruce stated:

I was having so much problems breathing sometimes that if I get excited, my chest would start hurting, so I can’t breath like I wanted to because my blood
pressure going up and down, up and down, I get tired quick, couldn’t-couldn’t hardly do nothing I wanted to.

Notably, health problems often resulted in participants’ limiting their activity levels, which some participants observed had an impact on their weight and physical endurance.

Participants also identified specific ways in which their pre-event/surgery health problems compounded their heart problems. Bruce explained that when pain from an existing shoulder problem would arise, he would “get aggravated, and it start me breathin’ hard, and then if I breathin’ extra hard that start messin’ with my heart [LAUGHING].” Lucy stated that the diet pills prescribed to her by a medical provider “produced” her heart attack, but she saw this as a blessing because it uncovered heart problems that could have killed her suddenly if they had continued to go unnoticed and unaddressed:

[The diet pills] helped my blood flow a little bit stronger, but it helped produce the heart attack… So, if it wasn’t for that, I could’ve died at any moment, because I didn’t know nothing about, um, the blockage, I have a heart problem.

Lucy explained that her father had died from a massive heart attack, and Lucy felt “that was getting ready to happen to me if, um, I didn’t have- didn’t take the diet pills and… it, it could have happened to me.”

Participants experienced post-event/surgery health improvements. Participants experienced some post-events/surgery health improvements that included successful recoveries from cardiac events/surgeries, needing fewer medications/interventions to manage health problems, and increased self-care. Robert stated that his recovery from his heart attack and stent placement was “quick and good… I guess it had to do with the medication and the doctor that did the surgery.” The medication Robert was referring to were “pain pills” that helped him in
early recovery. He stated the surgeon who performed his stent placement was one who had been recommended to him by others. Due to these factors, Robert stated that post-event/surgery he was “doin’ real good” and his medical providers had told him that everything “was all good” on the EKG.

Following cardiac events/surgeries, some participants experienced decreased need for medications and intervention. This was a result of both participants recovering from their cardiac events/surgeries and also achieving greater health than they had experienced before their hospitalization. Alberta stated that, as her health improved following her stent placement, she had fewer and fewer medical provider appointments to make. Alberta understood this to be sign that she was doing well enough that she did not need to be so closely monitored:

The nurse that came in, the therapy doctor and all that stuff that came into the home, they turned me loose all probably about two or three weeks ago… Only thing I gotta go to now is my heart doctor…To make sure that everything stays good.

After recovering from his stent placement, Bruce reported overall improvements in the way that he felt and reduction in the medications he was taking, including some that he was on before he had his surgery: “By my body adjustin’ to certain things and gettin’ stronger and stuff, I was able to get, you know them pills, off, off all the pills.”

Post-event/surgery limitations called for lifestyle adjustments. Participants emphasized that, following their events/surgeries, it was necessary to make adjustments to their home environments and routines to accommodate temporary and permanent limitations. For some participants, adjustments included different sleeping accommodations (i.e., lower beds and/or recliners that were easier to get in and out of for the first few weeks post-discharge), use
of a walker, riding in vehicles that were easier to get in and out of (i.e. larger versus compact vehicles), and help with carrying items over 10 pounds. Participants expressed a pervasive shift in how they moved through their days. Robert reported, “When you have a recovery you have to really take your time, get around slow and stuff like that, and make sure that you got proper rest.”

Participants stated that their previous personal and familial health experiences contributed to their adaptability and resilience in not only making these accommodations but accepting them. Lucy stated that her experience being a caregiver to loved ones and having a history of personal health problems (i.e., diabetes, fibromyalgia, and knee surgeries) helped her to have a “strong mind” during her recovery process. According to Lucy, the “humbling” support she received (e.g., needing her husband and children to help her with activities of daily living) “could make you depressed” if one had not been strengthen by previous health-related experiences.

**Some interventions ineffective or inaccessible post-event/surgery.** Some post-event/surgery treatments were ineffective, inaccessible, or not adopted by participants. Thus, participants experienced ongoing physical and/or psychological limitations. First, participants reported difficulties with some medications prescribed to them post-event/surgery. Alberta stated that her medical providers adjusted her diabetes medications while she was in the hospital but that these adjustments were problematic after she was discharged. Alberta hypothesized this may have been because the medications were adjusted when she was in the hospital and was “not eating.” She stated that, nearly two months post-discharge, her medical providers were still “trying to get it [the medication] straight.” Medication side effects and interaction effects were also a concern for participants. Bruce stated that the combination of medications he was taking post-discharge “was messin’ with me bad.” Bruce described this as a physical (e.g., stomach aches), as well as psychological (e.g., feeling like he was “floating”) experience. He reported
feeling much better after he was well enough to taper down his medications; he found that taking fewer medications made him feel better.

Participants’ access to treatments was sometimes compromised by their ability to pay for them. Difficulty of access, then, had bearing on whether or not participants were compliant with medical providers’ treatment recommendations. Michael described his sense of depression (manifested, he stated, by feelings of hopelessness) when he found he could not afford the medication that he had been prescribed for his heart:

> They was tellin’ me in the hospital it [the medication] was like $100. They gave me a free month the first time, and then the nurse gave me like a $50 co-pay card. So, I was thinking, I got $50 from my, one of my family members and he took me up there to get the medicine, and told me $290 and my heart just dropped. I like, ‘No way I can afford this.’

Luckily, Michael reached out to his medical providers and was able to secure the medication. Other participants, however, felt their inability to access care compromised their health both pre- and post-event/surgery. Lucy stated that she had been battling with her insurance company to get approval for weight loss surgery for years. Lucy believed the surgery would help her drop the weight that her medical providers told her would kill her in the next 10 years. She stated, “I’ve been trying to get that [weight loss surgery] even before the, the heart attack. But, um, by them not taking care of that, then they spent over $200,000 on a heart surgery that mighta coulda been avoided.” At the time of the interview, Lucy was actively involved in CR and had made significant changes to her diet. Although she reported that her weight had not changed, she felt she was getting stronger.
A fourth theme that emerged from interview transcripts was the impact of participants’ sense of agency on their life perspectives and health behaviors. Participants experienced distress when they felt they had little or no control over their health outcomes. In contrast, when participants felt like agents in their own health and care, they were proactive about advocating for their needs. This agency took the form of participants choosing to opt in or out of treatment recommendations and how they would incorporate these recommendations into their lives. It also took the form of participants treating cardiac events/surgeries as “wake-up calls” that inspired them to take control of their lives and pass their newfound wisdom onto others.

**Unpredictability of health challenges and outcomes affected distress level.**

Participants reported feeling distressed when they were faced with the unpredictability of their treatments and/or health outcomes. Distress included anxiety about having limited control over and knowledge of their cardiac events/surgeries and outcomes; fear that engaging in exercise would trigger another cardiac event; frustration when physical limitations precluded being able to exercise as instructed by medical providers; being unsure of medications’ physical and psychological effects; and feeling depressed as a result of unforeseen health-related hardships. Words participants used to describe their anxiety about limited control regarding their cardiac events/surgeries and outcomes included “scary,” “fightful,” “overwhelmed,” and “hard to accept.”

Miss Spunky explained the way in which she could become preoccupied with the possibility of a second cardiac event, post-discharge:

I thought about, you know, ‘Is this gonna happen again?’ That, that stays in my mind a lot [CHUCKLING], you know. Yeah, I’m, I’m concerned about it happenin’ again, or, I mean, I’m anticipating – it’s like every time I feel a little
pain, I’m anticipatin’ that, ‘Okay, this may be happenin’. And um, so that’s, that’s the challenge that I’m facin’ now as, as far as that.’

Miss Spunky stated that, to cope with this concern, it helped her to “stay positive on it. Tryin’ to not let it bother me…it’s something that keep naggin’ but nothin’ that I stay focused on. Miss Spunky also continued to exercise in spite of this fear, with the help and support of her CR nurses and staff (although she stated that even before she went to CR, she was exercising at home because she was “determined…to build my strength back up”).

Participants had different levels of proactivity about health and recovery process.

Participants varied in the extent to which they engaged proactively in the implementation of their care. Whereas some participants researched and implemented recommended diet and lifestyle changes both pre- and post-intervention (sometimes even before medical providers had recommended that they do so), others stated that they passively chose not to implement these changes even though they knew that they “should.” In regard to the latter point, Mark stated, “I know what I should be doing: get up and walk around more often.” When asked what kept him from walking more, Mark said, “Nothing. I’m just lazy. I sleep a lot.” When questioned further, Mark explained that some of his medications made him groggy and a variety of other health problem caused him physical limitations. Even in the context of these factors, however, Mark’s approach appeared more like a passive decision to not engage in recommended changes rather than an active decision to opt out.

In contrast, Robert explained his active decision to opt out of certain care. Robert explained that his recovery was so successful that he declined home health care after his first appointment with a visiting nurse. He reported, “They came one time, and I didn’t, actually, I
didn’t need ‘em.” Regarding exercise, this participant stated that he had high comfort level with exercise from working out for years prior to his cardiac event/surgery and, therefore, felt he did not need guidance with exercise. He stated that his medical providers had not talked to him about CR, but even if they had, he felt he did not need guidance on starting up exercise again post-event/surgery, because “I pretty much know how to ease my way back in it, like I’m doing.” It is notable here that Robert’s proactivity was expressed in opting out of (not into) treatments.

**Cardiac events/surgeries led to lifestyle changes.** Participants reported that their cardiac events/surgeries led them to actively make lifestyle changes. These changes involved shifts in both perception and behavior, and included feeling inspired to get more serious about health following the wake-up calls of cardiac events/surgeries; perceiving weight changes as connected to greater health and wellbeing and engaging in behavioral modifications to manage weight; having a new appreciation for peace and quiet; and accepting and making peace with health-related limitations. In regard to the “wake-up call” of cardiac events/surgeries, participants explained that they got more “serious” about their health and their lives when they realized that their behavior leading up to their cardiac events and/or surgeries could have killed them. Mark said that had he not changed his health behaviors (including drinking and smoking) following his MI, “I really wouldn’t have, you know, probably would’ve die young…This might have been a wake-up call.”

Both Michael and Lucy stated that their cardiac events/surgeries jolted them into improving their lifestyle behaviors, especially their diets. Michael expressed that his MI precipitated health behavior changes. He said,
[The MI] changed the way I do a lot of things. Um, it made me take life a little bit more serious...just make sure I take my medication all the time. Don’t eat- watch what I eat…

Basically, I was just eating everything.

Lucy stated her wake-up call came when her medical provider told her (after her MI and before her CABG) that, “if I do not change and get the weight off, that he don’t see me lasting another 10 years after the surgery.” Before her MI, Lucy reported that,

[I] didn’t take it [consequence of unhealthy diet] as serious. I was like, ‘Okay, I know that I need to get some weight off. I know that this is a problem.’ But until something serious happened, ‘Okay, now I know it’s really a problem, I really got to deal with this.’

Participants also expressed that they cultivated a new appreciation for peace and quiet following their cardiac events/surgeries. Mark explained that, before his MI, “I liked noise… But now that I’ve been sick and I got better, I love the quietness… I can sit on the porch, I don’t hear a lot of profane language and stuff.” Mark described this change as occurring alongside a change in the type of people with whom he socialized. According to Mark, when he stopped drinking and smoking, he also became distant from friends with whom he shared these activities. Presumably, these activities were “noisier” and stood in contrast to the “peaceful” lifestyle the participant adopted post-discharge. Although this participant stated he used to like this noisier lifestyle before his cardiac event, afterwards he shifted to valuing quietness.

In a related vein, participants also noted that they learned to make peace with their health-related limitations post-event/surgery. Alberta explained that she let go of the expectation that she would be able to complete all household tasks on her own. Instead, she focused on whether or not these tasks got done and not on whether or not she was the one to do them: “Somebody will do it for me, so I don’t worry about it… Long as it gets done, I didn’t worry about it.
Whether I can do it or not.” Robert stated that his ability to accept his limitations post-event/surgery helped him to move forward in his recovery. He reported,

I just had to accept the fact of what was going on, and, and then I dealt with it… whatever’s gonna be is always the way it’s gonna be. By thinking that way, you know, that, that helps out a lot to me.

Although, at first glance, perspectives of acceptance can seem like a passive process of letting go, participants described acceptance as an active process of learning contentment and adaptability in the face of change.

**Passing on new knowledge was a part of participants’ recovery process.** Finally, participants stated that they not only gleaned knowledge from the experiences of their cardiac events/surgeries, they also shared this new knowledge with others. In particular, participants gave health advice to their children regarding their children’s and future grandchildren’s health-related behaviors. Lucy reported that it was very important to her that her two teenage sons internalize healthy lifestyle behaviors, so they would not be faced with the same challenges she had experienced. “I teach ‘em lessons,” she said. Lucy’s lessons began after the wake-up call of her cardiac event/surgery and included information on sugar addiction, diabetes, and healthy cooking and eating. For example, she told her sons,

You gotta kinda retrain your tastebuds, in a sense,’ So it ain’t always, ‘Okay, I want sugar, sugar, sugar.’ I said, ‘cause, um, ‘You see people out here who don’t have fingers, toes, hands, arms, legs, and they lost it to diabetes.

Lucy stated that as a result of her lessons, her sons had started cooking healthfully for the family and would even help her keep track of her own healthy eating goals.
Participants Experienced Inconsistent Referral to and Utilization of Cardiac Rehabilitation

Participants reported a great deal of variability in referral to and participation in CR. Those who were referred to and participated in CR reported positive experiences. Those whose medical providers did not talk to them about CR and/or did not explain to them what CR was in a way that participants could understand generally did not participate. Other barriers to CR participation included not being referred to CR or waiting on medical providers for action/clearance to begin or continue the program. An additional pathway to referral was learning about CR word-of-mouth in the community, but participants stated they would have preferred to have learned about CR from medical providers. Participants stated that they were grateful for the support offered by CR nurses and staff, but sometimes found the presence of other patients “gloomy” and/or unmotivating.

**Participants experienced health-related successes with CR.** Participants who were referred to and participated in CR reported positive experiences with health-related successes and support from CR nurses and staff. Alberta appreciated the program so much that she stated, “I would like that the program could last, you know, forever!” Lucy stated that she thought CR was “very important to help you get, get stronger and back to, not just your own life that you had before heart surgery, but a better life.” After finishing CR, she planned to transfer the exercise program she had developed at CR to a local gym. Miss Spunky also reported that CR “did a tremendous help as far as gainin’ energy back and wantin’ to do things.” In addition to the support provided by CR nurses and staff, she also cited availability of equipment as a benefit to participating in CR versus exercising at home.

Functional and emotional support from CR nurses and staff was an important component of participants’ positive experiences. Miss Spunky also reported this support was a reason CR
was preferable to exercising at home: “being around the people that, you know, watchin’ you and pushin’ you and encouragin’ you [CHUCKLING]… Yeah, they [CR nurses and staff] was- they fun.” Michael also stated that CR nurses and staff went above and beyond his expectation of medical providers when they helped him to coordinate his care with other outside providers.

**Participants experienced barriers to CR participation.** Participants also experienced barriers to CR participation. These included not being referred to CR, medical providers not talking to participants about CR, not understanding what CR was, or waiting on medical providers for action/clearance to begin or continue the program. Some participants had not heard of CR or had a very vague understanding of what it was. Mark was aware that one of his medical providers had put in a CR referral for him and he was scheduled to attend, but he had a difficult time articulating exactly what CR was: “He [medical provider] had wanted me to do somethin’. Uh, some, uh . . oh, man, I can’t explain it…What is it?” Michael, who had attended an initial assessment session at CR still had difficulty explaining what it was, despite this first visit and meeting with CR nurses and staff: “Um, once I went in there I see that they exercise- I saw a lot of exercise equipment… I mean, I just see a lot of exercise equipment, I know they do- they weigh you and everything like that.”

Lucy stated that she happened to learn about CR word-of-mouth from a woman whom she met at a salon. According to Lucy, the woman had recently had cardiac surgery, had attended CR, and “told me [Lucy] how nice the people was and told me to go ask my doctor about it.” As a result of this chance conversation, Lucy sought a referral from her medical providers using her online patient portal. She reported that she was given a referral, and then successfully enrolled in, attended, and completed CR. Although Lucy stated that she was
grateful to have learned about CR in one way or another, she also reported being disappointed that none of her medical providers had told her about this resource:

Nobody hadn’t told me about it, um, hadn’t said anything about there’s a rehab place for it. Nothing... I think that they should let the people know. Especially right before [discharge]- at the hospital would be great, because somebody have it on their discharge papers. You know, some type of way to, to let people know that ‘These services are available, check into it.’

While participants spoke positively about the support received from CR nurses and staff, they were neutral to negative about interactions with other CR patients. Participants stated that they did not interact with other patients; they interacted only with the CR nurses and staff. Despite lack of interactions, the presence of other CR patients was described as threatening participants’ motivation to exercise or engage in CR. Miss Spunky stated that other patients she observed at CR were less motivated and/or less able to exercise than her and this contributed to a “gloomy” feeling. She reported, “I have to keep my focus on this therapy, and... because- well, I’m not sayin’ all of ‘em in there [are] like that, but usually complaints. It’s just, some just complain…”

Similarly, Michael reported that when he attended his initial assessment session at CR, he observed that he was one of the youngest patients present. He stated that this was particularly upsetting to him: “When I started the rehab thing, um, no disrespect, but when I ain’t seen nothing but older people in there, like grandmoms and granddaddys, and I look at my age, I’m saying to myself, ‘I shouldn’t be in here.’...Yeah, it’s kinda, first day I went there I probably wanted to cry to myself. I was like, ‘Oh man.’” As Michael described it, his observations of other CR patients highlighted for him the
untimely nature of his cardiac events/surgeries. Although CR was by no means a causal agent in creating this reality for Michael, the fact that it triggered this realization for him may have negatively impacted his associations with CR.

**Participants’ Investment in Faith was Intensified or Maintained**

A sixth and final theme that emerged in transcripts was the intensification or maintenance of participants’ investment in their faith throughout the recovery process. Participants reported ongoing personal and familial involvement in their faith communities. Some even reported the resolution of pre-event/surgery spiritual challenges. According to participants, their faith was a source of strength and gratitude during their recovery. Specifically, participants stated that giving their troubles to God helped them to cope with challenges of their recovery. They also expressed their praise to God for giving them life.

**Involvement in faith and faith communities.** Participants maintained involvement in their faith and faith communities throughout their recoveries. Some participants reported that their faith community members came into the hospital to visit and pray with them following cardiac events/surgeries. After discharge, participants stated that faith community members continued to support them, and participants resumed attending faith-based services and functions as soon as possible. Lucy described pushing herself to attend a church service in which her sons were involved approximately a week post-discharge, even though her medical providers had cautioned her against leaving the house for the first week.

Some participants also reported that, following their cardiac events/surgeries, involvement with their faith intensified. This included more frequent considerations about faith-based questions and one’s relationship with God and seeking spiritual guidance and counsel from others. Bruce reported that, during his recovery, he experienced spiritual “frustration” related to
his faith in God and his worries for himself and other people. Bruce met periodically with his pastor, who helped Bruce learn “What to believe, how to believe, and how to put it in faith.” Through these spiritual conversations, Bruce reported that he was able to put his worries for self and others in faith. As a result, he also reported better health overall. Bruce stated:

Don’t have to do, deal with too many pills, don’t have to deal with a whole lotta people, and their problems and stuff. I’ve just been doing a whole lot, lot better… I ain’t supposed to worry about nobody else’s problems. All you have to do is just pray about it and just leave it alone.

**Faith was a source of strength and gratitude for participants.** As was the case with Bruce in the example above, participants cited faith as a source of strength and gratitude during their recovery. Participants stated that they gave their troubles to God. For Miss Spunky, saying to herself “God got it” helped her let go of health-related worries. Mark stated that the best advice his roommate, who had also gone through a cardiac event, had given him was: “Put it [faith] in the hands of the Lord.” Alberta stated that, when she first learned that she had had a MI, she was able to “calm back out” by drawing on her faith in God. She stated, “He’s was gonna take care of me.” Lucy reported that, in addition to drawing upon previous personal and familial health experiences for resilience (developing the “strong mind”), her religion and belief in God helped her with this. Robert added:

Every time, you know, stuff’d go wrong, I’d think about my spiritual relationship with God, and, um, and, um, the prayer, and, uh, it’s just, like, I, I had no, no fear in believing that I would be alright, you know?

Participants also offered praise to God for giving them life. Michael emphasized the gratitude he had for God in giving him the opportunity to see his children grow up:
“Everyday I wake up I pray, I thank God everyday I wake up. I mean, that’s the way I look at it… I mean, I got a 7-year-old son and an 18-year-old daughter.” When asked about spiritual factors associated with his recovery process, Mark answered, “Well, I’m still livin’. That’s spiritual… I’m just still livin’. The Lord kept me here.” At the close of his interview, Mark stated, “I thank God everyday… For bringing me back alive and everything… He really helped me.” God and participants’ faith in God were not only described as the primary source of participants’ strength, these were also described as the very power by which their hearts were still beating.

**Exhaustive Description**

After themes were identified from participants’ interview transcripts, an exhaustive description was developed. This consisted of a list of statements that capture all the emergent themes and which reflected the richness of the participants’ lived experiences (Colaizzi, 1978). The exhaustive description formulated for this study was as follows:

African American participants recovering from cardiac events and/or surgeries did so with the support of their medical providers and social networks. Medical providers (i.e. doctors, nurses, physical/occupational therapists) were valued for help and expertise, from treating cardiac events/surgeries to guiding participants in making healthy lifestyle changes (e.g., diet, exercise, substance use) during recovery. Support from medical providers was both functional and emotional and included adjusting medications, checking in with participants, putting in appropriate referrals, and giving encouragement and explanations of treatment. Participants expressed appreciation for the “dedication” of medical providers and also pointed out times when they would have liked additional support from them. For example, some participants
desired recommendations on how to make appropriate accommodations at home after discharge, whereas others desired information regarding availability and utility of CR programs.

Support from participants’ social networks (i.e., family members, friends, neighbors, and faith community members), as well as participants’ need for this support, changed during recovery. Participants’ social networks offered increased functional and emotional support, including help with daily activities of living, visits/check-ins, and encouragement. However, participants also expressed experiences of social isolation and lack of support stemming from various factors, including making lifestyle behavior changes (resulting in alienation from individuals who continued to engage in unhealthy behaviors), having limited mobility at social gatherings, and being geographically distant from family and friends. During recovery, participants were sensitive to the type of social support they received; support that was “pitying,” “humbling,” conflictual, or disempowering was challenging for participants. Participants were not always authentic with their social networks in expressing their health experience and needs.

Participants’ health outcomes following cardiac events and/or surgeries were impacted by health-related experiences before and after the events and/or surgeries. Participants reported multiple health problems before events/surgeries, some of which directly compounded participants’ heart problems. Post-event/surgery, participants made adjustments to their home environments and routines to accommodate temporary and permanent limitations. Previous personal and familial health experiences contributed to participants’ adaptability and resilience. Some positive improvements resulted from cardiac events/surgeries (i.e., recoveries were successful, fewer medications/interventions were needed to manage health problems, self-care increased), but some post-event or surgical treatments were ineffective, inaccessible, or not
adopted by participants, and participants experienced ongoing physical and/or psychological limitations.

Participants’ sense of agency impacted life perspectives and health behaviors. Participants experienced distress when they felt they had little or no control over their health outcomes (e.g., medication had unknown side-effects and exercise was frustrating due to limitations or a source of fear as a possible trigger for another cardiac event). When participants felt like agents in their own health and care, they were likely to proactively advocate for their needs by choosing to opt in or out of treatment recommendations and how they would incorporate treatment recommendations into their lives (i.e., exercising at CR versus exercising at home). With this stance of agency, participants saw cardiac events and/or surgeries as “wake-up calls” that inspired them to take control of their lives. They expressed new perspectives on what was important in their lives and to their health. They also communicated to others their wisdom and knowledge about living healthfully.

According to participants, referral to and utilization of CR was inconsistent. Participants who were referred to and participated in CR reported positive experiences. Participants whose medical providers did not talk to them about CR generally did not participate. Other barriers to CR participation included not being referred to CR, not understanding what CR was, CR being inaccessible due to lack of insurance coverage, waiting on medical providers’ action to begin the program, or experiencing health problems that required medical clearance for program continuation. Learning about CR word-of-mouth in the community was an additional pathway to participants’ referral and participation in CR, although participants stated they would have preferred to have learned about CR from medical providers. Participants who participated in CR expressed appreciation for the encouragement and motivation to exercise from CR nurses and
staff. In contrast, the presence of “gloomy” or less motivated or able patients at CR threatened to compromise participants’ motivation.

In addition to the importance of biomedical, psychological, and social factors during and after recovery, participants’ investment in their faith was either intensified or maintained throughout this process. Participants reported ongoing personal and familial involvement in their faith communities, and even the resolution of some pre-event/surgery spiritual challenges. Participants identified their faith as a source of strength and gratitude during recovery. They reported that giving their troubles to God helped them to work through their recoveries and move forward in their lives.

**Statement of Identification**

A statement of identification is intended to reduce the exhaustive description to the essence of participants’ lived experience. The statement of identification that emerged from this study incorporated multiple aspects of the description into one inclusive and overarching statement. The statement of identification for this study was as follows:

Participants who felt supported as agents in their own health care were likely to actively engage in their recovery by implementing treatment recommendations or alternatives to recommendations (e.g. exercising at home versus CR, managing symptoms with lifestyle changes instead of with prescribed medications). Participants’ previous health histories and involvement in their faith had important bearing on recovery experiences and outcomes, as did perceived support from medical providers and individuals who comprised their social networks.

**Discussion**

The themes revealed in this phenomenological study offer important considerations for the recovery process of African American patients who have experienced a cardiac event and/or
surgery. Several themes highlighted the importance of medical provider respect, encouragement, and direct involvement in care as well as the role of the participants’ pre-existing and continuing health problems during their illness and recovery experience. Although participants did not always follow through on treatment recommendations (e.g., exercising as indicated), they generally expressed a great deal of appreciation and respect for their medical providers, as well as a desire to incorporate their professional recommendations into their lives if possible.

These findings were similar to those from previous researchers who have demonstrated the importance of medical providers building rapport and bringing culturally-sensitive health understandings to their communication with African American patients (Collins, Clark, Petersen, & Kressin, 2002; Lutfiyya, Cumba, McCullough, Barlow, & Lipsky, 2008; Shaw, Armin, Torres, Orzech, & Vivian, 2012). Participants in this study took these previous findings a step further in emphasizing the importance of medical providers demonstrating a personal investment in patients’ wellbeing. Participants praised medical providers for their “dedication,” “really car[ing]” about them, and going above and beyond the requirements of their job to help them improve their health.

How or whether or not medical providers offered post-event/surgery recommendations to participants had important implications for follow-through. For example, when participants were not referred to CR and/or their medical providers did not discuss CR with them in a way that they could understand, participants stated that they did not participate in CR. Barriers to CR also included participants waiting on medical providers’ action to begin the program or health problems that required medical clearance for program continuation.

While the literature confirmed the existence of racial/ethnic disparity in the rates of CR referral and participation of African American patients (Allen et al., 2004, Gregory et al., 2006),
this study illuminated some potential sources of this disparity: level of health literacy (i.e., for some participants referrals were only made after participants directly requested them; if patients did not know what to request, they may have been less likely to received a referral) and severity of health problems upon initiating CR (i.e., participants with multiple health problems were more likely to require waiting for action/clearance from medical providers to begin or continue CR).

There is a need for studies that build on these findings by investigating the impact of different types of referral conversations with African American patients on their likelihood to participate in CR. Studies on the impact of patients’ medical limitations, medical providers’ referral activity, and alternative ways African American patients with CVD may effectively recover at home are also warranted.

Participant agency was also an important factor identified in the emergent themes and participants’ health outcomes addressed by participants in this study. When participants believed they could serve as agents in their own health and care, they were proactive about advocating for their needs (i.e., requesting CR referrals, changes in medication, and/or other medical interventions). Participants were most distressed about and passive in their health and care when they felt that they had little or no control over their cardiac treatments and outcomes. Participants who understood what was happening to them and why, and who also had a good understanding of what they could do to affect change in their health, were more apt to make active decisions about how to implement treatment recommendations into their lives. This has been confirmed in the literature in studies investigating a passive approach to self-care. Dickson, McCarthy, Howe, and colleagues (2013), for example, found that African American patients who believed cardiovascular risk factors or disease were normative or unavoidable adopted a more passive approach (e.g., “stay in bed,” “relax…let it pass,” p. 115).
Notably, a sense of agency did not automatically mean that participants would adopt recommendations; in some cases, agency appeared to give participants the confidence to choose alternative ways to obtain the resources medical interventions were designed to offer (e.g., exercising at home versus exercising at CR). However, seeking alternative ways to obtain treatment was often less problematic than participants passively choosing inactivity. This, again, highlights the importance of medical providers engagement in building rapport and trust with patients. When participants felt involved in their treatment and recovery process, they were more likely to take an active role in implementing self-care and healthy lifestyle changes.

Additionally, the support received by medical providers, family members, friends, neighbors, and faith community members played vital and ongoing roles in participants’ recovery experiences. The positive association between social networks and cardiovascular self-care has been well documented in the literature (Grewen et al., 2003; Liu & Newschaffer, 2011; Tkatch et al., 2011). However, participants in this study also stated that the mere presence of others did not automatically result in feeling supported as agents in their own care. In some cases, friends were seen as negative influences who continued to make the unhealthy lifestyle choices that the participant was striving to change (e.g., drinking, using drugs, eating unhealthy foods). In other cases, participants perceived social networks’ emotional support as “pitying” or exercising alongside other less motivated and/or less able patients as discouraging. Studies investigating the impact of different types and/or sources of social support on patients’ post-event/surgery health behaviors would be useful in implementing best practices for this population.

Finally, participants expressed that their hospitalizations and recoveries were important times for them spiritually. This observation was in keeping with other researchers’ findings
regarding the importance of spirituality as a coping strategy for African Americans managing stress associated with cardiovascular health problems (Dickson, McCarthy, Howe, et al., 2013; Johnson, Elbert-Avila, & Tulsky, 2005; Warren-Findlow & Issel, 2010). However, existing studies have not investigated the relationship between African Americans’ spiritual beliefs and CR referral and participation. Participants stated that during their recoveries they not only maintained their spiritual involvement, but also often intensified it, sometimes even resolving some pre-existing spiritual challenges. Some researchers have posited that fatalistic beliefs associated with African American patients’ religions can contribute to a passive approach to self-care (Dickson, McCarthy, Howe, et al., 2013; Polzer & Miles, 2007). Participants in this study did not endorse this finding. Rather than a source of passivity, the participants portrayed spirituality as a source of agency for them in accepting what they could not change in order to actively engage in the areas of their lives in which they did have control.

**Limitations**

There are several limitations of this study. Firstly, although the experiences of the individuals in this study may hold true for other individuals recovering from cardiac events and/or surgeries, generalization of findings is not possible, particularly across demographic lines. Participants in this study were not only racially but also regionally homogenous. Secondly, all the participants in this study expressed a strong affiliation with their faith. It is possible that these findings, then, are reflective of African American patients who living in the Southeastern United States or who self-identify as religious and/or spiritual and may not apply to African American patients recovering from cardiac events/surgeries who do not identify in this way.

Thirdly, it is a recommended practice to conduct an additional interview past the point of saturation to confirm that all themes have been identified (Morse et al., 2002). This confirmatory
interview was unable to be secured due to availability of eligible patients for recruitment. While a triangulated researcher and peer debriefer strongly believed that saturation was achieved, it is possible that apparent saturation was reached before themes were exhausted and an additional interview would have confirmed this.

**Conclusion**

This qualitative study investigated the lived experience of African American patients recovering from cardiac events and/or surgeries in the context of a primarily rural and lower-income county in the Southeast. Findings underscored the importance of medical provider and social network support during the treatment and recovery process, the impact of participants’ pre- and post-event/surgery health on their event/surgery outcomes, the need for greater consistency and clarity in CR referrals and recommendations, and the role of participants’ sense of agency and spirituality as sources of strength during recovery. In providing care for African American patients recovering from cardiac events and/or surgeries, medical providers and social network members should capitalize on patients’ agency, faith, and former resilience to health challenges in order to restore—and, hopefully, improve—health and wellbeing. Moreover, there is a need for studies investigating the typology and outcomes of physician-patient referral conversations, patients’ pre-existing and continuing medical and physical limitations, professional and personal sources of support, and spiritual beliefs and resources on African American patients’ likelihood of participation in CR.
References


Table 1

Participant Demographics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Event/Surgery</th>
<th>CR Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bruce</td>
<td>Male</td>
<td>60</td>
<td>Stents</td>
<td>No referral, not enrolled</td>
</tr>
<tr>
<td>Mark</td>
<td>Male</td>
<td>60</td>
<td>MI</td>
<td>Referred, enrollment pending medical action</td>
</tr>
<tr>
<td>Michael</td>
<td>Male</td>
<td>37</td>
<td>MI, Stents</td>
<td>Referred, enrollment pending medical action</td>
</tr>
<tr>
<td>Alberta</td>
<td>Female</td>
<td>64</td>
<td>Stents</td>
<td>Referred, enrolled, attending</td>
</tr>
<tr>
<td>Lucy</td>
<td>Female</td>
<td>41</td>
<td>MI, CABG</td>
<td>Late referral, enrolled, attending, nearly completed</td>
</tr>
<tr>
<td>Robert</td>
<td>Male</td>
<td>60</td>
<td>MI, stents</td>
<td>No referral, not enrolled</td>
</tr>
<tr>
<td>Miss Spunky</td>
<td>Female</td>
<td>54</td>
<td>MI</td>
<td>Referred, enrolled, continued attendance pending medical action</td>
</tr>
</tbody>
</table>
### Emergent Themes and Thematic Clusters

<table>
<thead>
<tr>
<th>Emergent Themes</th>
<th>Thematic clusters</th>
</tr>
</thead>
</table>
| Participants valued medical providers’ involvement during treatment and recovery | a) Medical providers’ interventions impacted cardiac outcomes  
|                                                                                | b) Medical providers offered guidance on healthy lifestyle changes  
|                                                                                | c) Participants perceived support (functional and emotional) offered by medical providers.  
|                                                                                | d) Participants appreciated medical providers  
|                                                                                | e) Participants needed additional support from medical providers                                                                 |
| Social support and participants’ need for it changed post-event/surgery        | a) Social support was increased during recovery process  
|                                                                                | b) Participants experienced sense of social isolation/limited support during recovery  
|                                                                                | c) Participants experienced challenges with social interactions and type of social support offered during recovery |
| Participants’ pre- and post-event/surgery experiences affected health outcomes | a) Participants had pre-event/surgery health problems  
|                                                                                | b) Participants experienced post-event/surgery health improvements  
|                                                                                | c) Participants’ post-event/surgery limitations called for lifestyle adjustments.  
|                                                                                | d) Participants experienced some interventions as ineffective or inaccessible post-event/surgery |
| Participants’ sense of agency affected their life perspectives and health behaviors | a) Unpredictability of health challenges and outcomes affected distress level  
|                                                                                | b) Participants had different levels of proactivity about health and recovery process.  
|                                                                                | c) Cardiac events/surgeries led to lifestyle changes  
|                                                                                | d) Passing on new knowledge was a part of participants’ recovery process                                                                 |
| Participants experienced inconsistent referral to and utilization of Cardiac Rehabilitation | a) Participants experienced health-related successes with CR  
|                                                                                | b) Participants experienced barriers to CR participation                                                                 |
| Participants’ investment in faith was intensified or maintained                | a) Participants and families were involved in their faith and faith communities  
|                                                                                | b) Participants experienced faith as a source of strength and gratitude for participants                                                                 |
Table 3

Selected Examples of Narratives and Emergent Theme Formation

<table>
<thead>
<tr>
<th>Significant Statements</th>
<th>Formulated Meanings</th>
<th>Thematic Clusters</th>
<th>Emergent Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>“That doctor would be affirming to telling me points, what’s gonna happen and what shouldn’t happen, and if it happens, what, what to do if it happens…It make you feel good.”</td>
<td>Participants appreciated medical providers telling them what to do and what to expect medically.</td>
<td>Participants appreciated medical providers</td>
<td>Participants valued medical providers’ involvement during treatment and recovery</td>
</tr>
<tr>
<td>“Oh Lord yeah, I had people clean my house, cook for me, too. My brothers come in, they would sit when my husband couldn’t be here. I had an aunt come and live with me for two weeks after my husband went back to work. And then, my grandkids, they come and they help out. I had a bundle of help. I, I couldn’t ask for any more. I really didn’t have to do anything.”</td>
<td>Family members increased emotional and functional support to participants through intervention and during recovery</td>
<td>Social support was increased during recovery process</td>
<td>Social support and participants’ need for it changed post-event/surgery</td>
</tr>
<tr>
<td>“‘Cause I was taking a lot of pain pills for my shoulder and stuff. And when my shoulder started hurtin’ real bad it would start my heart hurtin’… I get aggravated, and it start me breathin’ hard, and then if I breathin’ extra hard that start messin’ with my heart”</td>
<td>Participants experienced co-morbid health problems (medical and behavioral health, and related medications) that compounded and/or contributed to the diagnosis of heart problems.</td>
<td>Participants had pre-event/surgery health problems</td>
<td>Participants’ pre- and post-event/surgery experiences affected health outcomes</td>
</tr>
<tr>
<td>“I was going to, um, exercise at home myself [if Cardiac Rehabilitation was not available]… Cause I was, I was gonna be determined, either way, regardless, I was, I was determined, you know, to build my strength back up.”</td>
<td>Participants were comfortable exercising before cardiac events/surgeries and were motivated to exercise afterwards.</td>
<td>Participants had different levels of proactivity about health and recovery process</td>
<td>Participants’ sense of agency affected their life perspectives and health behaviors</td>
</tr>
</tbody>
</table>
“My first time going, you know they talk to you, I see a nurse, and they asked you were you having problems, and I told them I’ve been depressed, I’ve been having chest problems, so they called my doctor immediately, and need to come in the next day for appointment, so the doctor talked to me, checked my heart out. So, I guess I’m just waiting to hear back from the rehab place.”

Participants received referral to Cardiac Rehabilitation but waited for medical provider action or clearance to begin or continue program.

Participants experienced barriers to Cardiac Rehabilitation participation.

Participants experienced inconsistent referral to and utilization of Cardiac Rehabilitation.

“Every time, you know, stuff’d go wrong, I’d think about my spiritual relationship with God, and, um, and, um, the prayer, and, uh, it’s just, like, I, I had no, no fear in believing that I would be alright, you know?... I had no fear that everything would be alright.”

Surrendering troubles to God gave participants the strength to get through challenges during their recovery.

Participants experienced spirituality as a source of strength and gratitude.

Participants’ investment in faith was intensified or maintained.
CHAPTER FIVE: PROMOTING ACCESS TO CARDIAC REHABILITATION FOR AFRICAN AMERICAN PATIENTS: A POLICY BRIEF

Heart disease is not only the number one leading cause of death in the U.S. (Centers for Disease Control and Prevention [CDC], 2013), it is a disease particularly threatening to African Americans. African Americans have a 20% higher age-adjusted death rate from coronary heart disease than Non-Hispanic Whites (141.3 per 100,000 population for African Americans compared with 117.7 per 100,000 population for Non-Hispanic Whites) (CDC, 2013), putting this population even further from the “Healthy People 2020” (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion [DHHS–ODPHP], 2014a) objective of lowering the death rate to 103.4 per 100,000 people by the year 2020.

Nationwide, rates of cardiovascular disease (CVD) risk, incidence, and mortality are higher among African Americans than Non-Hispanic Whites (CDC, 2013; U.S. Department of Health and Human Services–National Institutes of Health [DHHS–NIH], 2012). In terms of CVD risk factors, African Americans were more likely than Non-Hispanic Whites to have hypertension but less likely to have their hypertension controlled (CDC, 2013). African Americans also have a 45% higher prevalence of myocardial infarction (MI) in those 35 to 44 years of age than Non-Hispanic Whites in the same age group (DHHS–NIH, 2012).

Cardiac Rehabilitation (CR) is a secondary prevention and treatment program that has demonstrated improvement in health outcomes for patients with CVD (Brown, Clark, Dalal, Welch, & Taylor, 2011; Heran et al., 2011; Whalley et al., 2011). It is an American College of Cardiology/American Heart Association Class I treatment for multiple cardiovascular conditions and procedures including MI (Antman et al., 2004), chronic stable angina (Anderson et al., 2007; Gibbons et al., 2003), coronary bypass grafting (Hillis et al., 2011), heart failure (Hunt et al.,
2009), percutaneous coronary intervention (Levine et al. 2011), and peripheral artery disease (Hirsch et al., 2006). Unfortunately, CR is significantly underutilized, with only about one third of eligible participants being referred to or participating in CR (Ayala, Xie, McGruder, & Valderrama, 2008; Cortés & Arthur, 2006; Suaya et al., 2007).

In addition, researchers have found race/ethnicity to be predictors of both CR referral and participation (Gregory, LaVeist, & Simpson, 2006; Suaya et al., 2007). According to Gregory and colleagues (2006), “White patients [were] two times more likely to be referred than Black patients [to CR]” (p. 707). With regard to participation, Suaya and colleagues (2007) reported that “Whites were 33% more likely to receive CR than nonwhites after adjustment for age and sex” (p. 1655). Researchers on a study of CR participation in North Carolina found that the vast majority of program participants (90%) in both 1999 and 2004 were Non-Hispanic Whites and only a small minority (9%) were African Americans (Evenson et al., 2006). Considering North Carolina’s state population is 22% African American (U.S. Census Bureau, 2013) and African Americans in North Carolina have higher coronary heart disease mortality rates than Non-Hispanic Whites (NC DHHS, 2014), the proportionally low percentage of African American CR participants is striking.

Researchers have observed that those African American patients who participate in CR begin their programs with more cardiovascular risk factors than Non-Hispanic Whites (e.g., hypertension and diabetes) and also end CR with less improvements than Non-Hispanic Whites across a variety of measures (e.g., BMI level, waist circumference, and hemoglobin A1C) (Sanderson, Mirza, Fry, Allison, & Bittner, 2007). Sanderson and colleagues (2007) argued for further research on this “benefit gap” (p. 985) for African Americans and recommended amelioration through the development of population-specific interventions. Thus, the purpose of
this policy brief is to (a) draw on available research to substantiate a case for tailoring CR to the needs of the African American population and (b) make recommendations for outpatient treatment of CVD in African Americans.

Method

Between 2012 and early 2015, the authors conducted a systematic review of the literature (Koehler, Hodgson, Dodor, Knight, & Rappleyea, 2014) and a mixed methods study (Koehler et al., 2015) in order to: (a) identify existing literature on the demographic and biopsychosocial-spiritual factors impacting African American patients’ CR referral and participation; (b) investigate these factors; and (c) explore emergent themes associated with this population’s recovery from cardiac events and/or surgeries.

The systematic review of the literature followed Cooper’s (2010) seven-step protocol for research synthesis to answer the following question: “What demographic and biopsychosocial-spiritual factors impact CR referral and participation for adult African American patients with CVD?” Three databases—Medline via PubMed, PsycINFO via EBSCO, and CINAHL via EBSCO—were searched using a combination of subject headings and keywords (see Table 1 for summary of search terms and equivalencies by database). These searches yielded 1,751 articles once duplicates were removed. From these articles, 40 were identified for full review and then read in consideration of criteria for final inclusion. A second reviewer was also enlisted to check the first author’s steps and to provide inter-rater reliability for the articles admitted into the review.

The mixed methods study was a two-phase quantitative and qualitative study consisting of: (a) self-report surveys completed by patients with CVD who were discharging from the hospital following cardiac events and/or surgeries (quantitative) and (b) semi-structured
phenomenological interviews with African American patients recovering from cardiac events and/or surgeries (qualitative). The research question guiding the study as a whole was: “What demographic and biopsychosocial-spiritual factors impact CR referral and participation for/among adult African American patients with CVD?”

Inclusion criteria for the study were: (a) English-speaking; (b) aged 18 and older; (c) being prepared for discharge from a cardiac event and/or surgery for which CR is indicated (MI, coronary artery bypass grafting [CABG], stable angina, heart valve repair/replacement, percutaneous coronary intervention [PCI] (including percutaneous transluminal coronary angioplasty [PCTA]), heart transplant, and/or coronary artery disease [adapted from American Association of Cardiovascular and Pulmonary Rehabilitation [AACVPR], 2014]); and (d) a resident of a city or town in the county where the academic medical center was located.

Exclusion criteria included: (a) a discharge diagnosis of heart failure or a heart-lung transplant (heart failure patients at this academic medical center were sometimes referred to pulmonary rehabilitation and heart-lung transplants may also have been referred to pulmonary rehabilitation rather than CR) and/or (b) cognitive impairment that would interfere with the individual’s ability to consent to the study and participate in surveys and interviews.

The qualitative portion of this study was designed in alignment with Husserl’s (1970) descriptive phenomenology, in which the focus of inquiry was on individuals’ subjective experiences of reality as they defined those experiences (Lopez & Willis, 2004). The above criteria for the quantitative portion were held consistent for the qualitative portion with the additional inclusion criterion of African American race. The following research question guided the qualitative portion of the research: “What is the lived experience of African American patients recovering from cardiac events and/or surgeries?”
Results

The results from the mixed methods study confirmed and helped to expand upon Koehler and colleagues’ (2014) systematic review findings, which highlighted the importance of social and biological factors in African American patients’ CR referral and participation. Quantitative results from the mixed methods study highlighted the importance of social factors, specifically the relationship between CR attendance and participants’ household income and highest level of education. Qualitative results yielded six emergent themes, three of which centered on social factors, two on biological factors, and one each on social and spiritual factors. These qualitative findings derived from a broader investigation of African American patients’ recovery from cardiac events and/or surgeries (and less specifically of CR referral and participation), but again highlighted the effect of social and biological factors on this population’s experience of recovery following cardiac events and/or surgeries.

Systematic Review Findings

According to Koehler and colleagues (2014), the seven studies that fit the systematic review’s eligibility criteria demonstrated that African American patients had a lower likelihood for CR referral, a higher likelihood of enrolling in CR with more cardiovascular risk factors, and a lower likelihood of CR participation and completion due to factors related to low socioeconomic status (e.g., lack of insurance, work conflicts, lower level of education) when compared with Non-Hispanic Whites.

In addition to identifying social and biological factors salient to CR referral and participation, Koehler and colleagues (2014) found psychological factors were cited to a limited extent in the literature. One study demonstrated no interaction among variables of depression, race/ethnicity, and CR referral or enrollment (Allen, Scott, Stewart, & Young, 2004). In contrast,
another study demonstrated higher levels of mood disturbance in African American female patients with CVD compared to White female patients (Rankin, 2002). Unfortunately, this study did not investigate the interaction between mood disturbance and the observed racial/ethnic disparity in CR participation (Rankin, 2002). Spiritual factors were not identified at all in the articles identified for this systematic review (see Table 2 for a summary of included articles). While these findings may indicate that social and biological factors were most salient to CR referral and participation for African American patients with CVD, they may also indicate a lack of comprehensive studies on the many and varied factors contributing to these phenomena.

**Quantitative Findings**

Demographic data was collected from 50 patients (14 African American, 35 White, and 1 Asian American; see Table 3 for participants’ demographic information) recovering from cardiac events and/or surgeries in a primarily rural and lower-income county in the Southeast. Data was tested for linearity, normality, and homoscedasticity. There were no missing data. Normality plots (standardized residuals plotted against standardized predicted values) demonstrated that data points were scattered randomly about the regression line. To test for outliers, Mahalanobis distances were calculated and compared against the chi-square critical value for 50 cases; all calculated distances were well below the critical value. Based on observations from these tests, data appeared to be normal.

Chi-square tests for independence were run to investigate the relationship between independent variables (i.e., race, relationship status, insurance status, employment status, highest level of education, and household income) and dependent, outcome variables (i.e., recommendation, referral, enrollment, and attendance). These variables were operationalized as follows: (a) recommended = patient received a letter from the CR facility and/or had an inpatient
consult in which CR was recommended; (b) referred = patient received a documented, formal referral from medical provider for CR; (c) enrolled = chart opened and assessment session scheduled for patient after confirming patient’s interest in participating; and (d) attended = patient attended assessment session and at least one subsequent CR session. Chi-square tests were selected in order to run preliminary analyses on a small sample (N = 50). Income data was recoded from increments of $10,000 (e.g, less than $10,000, $10-19,000) to low, medium, and high based on the national poverty guidelines (U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2014) and average annual household income in the U.S. (DeNavas-Walt & Proctor, 2014).

Chi-square tests indicated no significant association between race and recommendation, referral, enrollment, or attendance. Significant associations, however, were found between highest level of education and attendance ($\chi^2[4, N = 50] = 8.638, p = .07$) and between annual household income and attendance ($\chi^2[5, N = 50] = 6.225, p = .044$) (see Figures 1 and 2 and Table 4 for descriptive statistics on the education, income, and attendance). These findings suggest that while race did not have a direct bearing on CR referral or participation, education level and household income may have bearing on who attends CR after being referred.

It should be noted that there was a limitation in the way outcome data was collected. Recommendation, referral, enrollment, and attendance were measured at approximately two months post-discharge. It is possible that the outcome variables measured at this time point later changed, for example if a participant received a late referral or a referral was made but not immediately acted on due to medical or psychosocial barriers to participation.
Qualitative Findings

In order to gain a richer understanding of the barriers to participating in CR for African American patients, the lead researcher conducted interviews with seven African American participants who were in the process of recovering from cardiac events and/or surgeries. Analysis of resultant transcripts, using Colaizzi’s (1978) phenomenological analysis method, yielded six emergent themes related to African American patients’ lived experience of cardiac event/surgery recovery. The emergent themes were: (a) Participants valued medical providers’ involvement during treatment and recovery; (b) Social support and participants’ need for it changed post-event/surgery; (c) Participants’ pre- and post-event/surgery experiences affected health outcomes; (d) Participants’ sense of agency affected their life perspectives and health behaviors; (e) Participants experienced inconsistent referral to and utilization of Cardiac Rehabilitation; and (f) Participants’ investment in faith was intensified or maintained (see Table 5 for emergent themes, definitions, and selected quotations).

As is common to phenomenological studies, an exhaustive description was developed to help consolidate the participants’ experiences into a cohesive narrative incorporating the emergent themes. Overall, what was reflected in the findings was the importance of medical providers (i.e. doctors, nurses, physical/occupational therapists) and social networks (i.e., family members, friends, neighbors, and faith community members) in supporting participants through cardiac events/surgeries and recovery. Medical providers were valued for their help and expertise, from treating cardiac events/surgeries to guiding participants in making healthy lifestyle changes (e.g., diet, exercise, substance use) during recovery. Support from participants’ social networks, as well as participants’ need for this support, changed during recovery and included help with daily activities of living, visits/check-ins, and encouragement.
The findings also revealed that participants’ health outcomes following cardiac events/surgeries were impacted by health-related experiences before and after the events/surgeries. Participants reported multiple health problems before events/surgeries, some of which directly compounded participants’ heart problems. Some participants experienced post-event/surgery improvements; others had post-event/surgery limitations that called for lifestyle adjustments. Participants’ sense of agency during intervention and recovery impacted life perspectives and health behaviors. When participants felt like agents in their own health and care, they were more likely to proactively advocate for their needs by choosing to opt in or out of treatment recommendations and how they would incorporate these into their lives (i.e., exercising at CR versus exercising at home).

According to participants, referral to and utilization in CR was inconsistent. When participants were referred to and participated in CR, they reported positive experiences. Participants whose medical providers did not talk to them about CR generally did not participate. Other barriers to CR participation included not being referred to CR, not understanding what CR was, or waiting on medical providers for action/clearance to begin or continue the program. Learning about CR word-of-mouth in the community was an additional pathway to referral and participation, although participants stated that they would have preferred to have learned about CR from medical providers. Participants who attended CR expressed appreciation for the encouragement and motivation to exercise that CR nurses and staff provided. In contrast, the presence of “gloomy,” less motivated patients at CR threatened to compromise participants’ motivation.

In addition to the importance of biomedical, psychological, and social factors during and after recovery, participants’ investment in their faith was either intensified or maintained
throughout this process. Participants reported ongoing personal and familial involvement in their faith communities, and even the resolution of some pre-event/surgery spiritual challenges. Participants identified their faith as a source of strength and gratitude during recovery. They reported that giving their troubles to God helped them to work through their recoveries and move forward in their lives. Participants also praised God for giving them life.

**Invisible Findings: Reflections on Data Collection**

Before discussing the implications of these findings, the invisible findings of this study warrant some discussion. When this mixed method study was first conceived, the lead researcher had hoped to have a large enough sample to perform a comparative racial analysis. Unfortunately, over the course of an eight-month-recruitment at a Southeastern academic medical center, relatively few participants were recruited (N = 58, 8 of whom were later deemed ineligible for the study for a final N = 50), and, more notably, only 13 of those 50 were African American.

The county in which this academic medical center is located is comprised of approximately 61.1% White and 34.6% African Americans. Given these proportions, one could expect to see approximately 18 African American in a sample of 50 recruited participants. Further, considering the proportionally higher burden of CVD on African Americans in comparison to Non-Hispanic Whites, 18 would be a conservative estimate.

There are several speculations as to why fewer-than-anticipated African American patients were available for study recruitment (i.e. hospitalized in the academic medical center where this study was based during the eight month recruiting period and eligible for enrollment per the study’s inclusion criteria). Firstly, it is possible that the African American individuals in need of CVD care either did not seek their care at the academic medical center where this study
was based or did not seek care at all. Another medical center may have been preferred by African Americans in this community, or was more accessible financially, geographically, or otherwise. However, considering the distant proximity of other facilities with a cardiac specialization in this region, this is unlikely. Regarding not seeking care, researchers have reported disparate findings on treatment seeking behaviors for African American patients with CVD. Some findings suggest that African Americans patients with congestive heart failure (CHF) are more likely than Non-Hispanic Whites to seek medical support for symptoms (Artinian, Magnan, Sloan, & Lange, 2002). Other researchers reported that African American heart failure patients delayed treatment-seeking longer than Non-Hispanic Whites (Evangelista, Dracup, & Doering, 2002).

Secondly, it is also possible that this study’s exclusion criteria of CHF may have cut back on African American participants in this study. Congestive heart failure was an exclusion criterion for this study because, at this academic medical center, patients with CHF were sometimes referred to pulmonary rehabilitation rather than CR. Whether or not medical providers were more or less likely to refer to pulmonary rehabilitation versus CR (and whether or not patients were more likely to participate in one over the other) was a question beyond the scope of this brief. However, considering the support for CR as an effective intervention (Brown et al., 2011; Heran et al., 2011; Whalley et al., 2011), further exploration is warranted.

Thirdly, the challenge of recruiting African Americans into medical and scientific research studies is both well documented and understandable given the counts of historical and medical trauma committed against this population (Washington, 2006). It is possible that more African Americans opted out of this study for fear of exploitation. Although the National Institutes of Health have set forth guidelines for research requiring the recruitment of women and
minorities in clinical research (DHHS–NIH, 2001), these do not offer solutions to problems of recruitment and retention.

**Implications and Recommendations**

Healthy People 2020’s administrators have set a goal to “increase the proportion of adult heart attack survivors who are referred to a cardiac rehabilitation program at discharge” (DHHS–ODPHP, 2014b). Although CR is just one of many possible interventions that may improve health outcomes, it is currently the best practice secondary treatment and prevention program for patients with CVD (AACPR, 2014; Brown et al., 2011; Heran et al., 2011; Kwan & Balady, 2012). Therefore, the following recommendations put emphasis on CR referral and participation, while also offering broader suggestions for improving outcomes for African American patients with CVD.

These recommendations should also be considered within the context of this study’s quantitative findings. Chi-square tests did not demonstrate a significant relationship between race and CR referral, enrollment, or attendance. Instead, survey participants’ highest level of education and annual household income were significant predictors of attendance. Both education and income levels are measurements of socioeconomic status. Further, the distribution of education and income levels often fall down racial/ethnic lines, with lower levels of education and income disproportionately represented among racial/ethnic minorities. In a larger sample, an association may have been observed between race and attendance due to the indirect and confounding effects of education and household income levels on attendance. The following recommendations, therefore, are made with an awareness to the socioeconomic disparities disproportionately experienced by African Americans. However, some policy recommendations may also be useful for non-African American populations confronting similar disparities.
1. Although patients ultimately determine whether or not they choose to follow through on medical providers’ treatment recommendations, it is essential that hospitals/medical centers: 
(a) adopt automatic CR orders for patients discharging with CR eligible diagnoses; (b) have orders printed on discharge summaries; and (c) disseminate information regarding CR to non-medical settings (e.g., flyers or pamphlets in grocery stores, beauty salon, churches). Implementing automatic orders at discharge increases the likelihood that post-discharge care is systematic and consistent. Orders should also be printed clearly on discharge summaries and written and explained in a way that is clear to patients and their caregivers (i.e., taking into account literacy levels and, specifically, health literacy). Finally, making information regarding CR available to people within their communities may increase utilization of this resource by bolstering patient awareness of CR.

2. The 2014 Medicare expansion of CR coverage to include patients with CHF was a boon for CR access (Centers for Medicare & Medicaid Services, 2014). However, implementation of national guidelines is still inconsistent state to state and often program to program. Differences in reimbursement from private insurance companies also increase the challenge despite the presence of an eligible diagnosis. Policy administrators on the state and national level can support legislation that increases CR coverage and reimbursement, while not-for-profit hospital/medical center administrators may consider extending philanthropy towards sponsoring outpatient CR care for eligible patients.

3. Regarding treatment recommendations, patients’ comorbid medical and mental health conditions, as well as their former and ongoing experiences in the medical world, should be considered. Medical providers can do this by asking patients, either at the inpatient or outpatient level, what barriers to health and/or implementing treatment recommendations
they have experienced in the past (e.g., access to medical and behavioral health care, lack of social support and/or motivation). This may give medical providers a context in which to present their own recommendations. This information may also be relevant in assisting medical providers and patients to successfully troubleshoot these barriers together.

4. In both inpatient and outpatient settings, medical providers should be encouraged to reinforce CR orders and to communicate these, and other treatment recommendations, clearly to patients. Further, recommendations to participate in CR should be backed with documented, formal referrals. Some hospitals and CR facilities offer inpatient CR consults or send letters to patients post-discharge regarding CR. These recommendations may be compelling for some patients, while others may view them as suggestions only, and still others may not have the level of health literacy required to turn this suggestion into action. Also, in the case that patients are referred and must wait on medical providers for action/clearance to begin or continue CR, it is important that patients understand why they are waiting (e.g., for insurance coverage to be verified, for a medical concern to be assessed before a patient begins or resumes exercise) and who will be contacting them regarding their action/clearance. When patients are helped to understand treatment recommendations and the process surrounding the implementation of these recommendations, they are more likely to feel like collaborators in their own health and care. As a result of this, they may also be more likely to incorporate treatment recommendations into their lives in sustainable and helpful ways.

5. Medical providers and members of patients’ support networks can capitalize on the power of agency by involving patients directly in their care by giving explanations, choices, and empowering support (i.e., assisting patients in gaining higher levels of independence and improved health and self-care). This may take the form of medical providers, families, and
patients sitting down together to gather data on potential barriers; filling gaps in understanding; addressing misunderstandings regarding treatment recommendations; and developing, implementing, and reinforcing care plans. Although family office visits may strike medical providers as time consuming, this approach may result in more efficient and effective care in the long-term.

6. It is extremely important that patients’ levels of social support are assessed and accounted for before patients are discharged. The physical limitations and emotional experiences of recovery can be in and of themselves isolating. If patients are also geographically distant from family or friends, feel set a part from their communities, or do not have the financial means to access needed care, this isolation can be compounded. Measures to connect patients with functional (e.g., home health care) and emotional support (e.g., contact with others who have recovered from similar events/surgeries) may help patients to gain access to important resources, including CR.

7. Medical providers, social network members, and program developers should also take into account the importance of patients’ perceptions of support. Support that felt pitying, conflictual, or disempowering to participants was viewed negatively. In other words, the mere presence of others (even well-meaning others) did not automatically result in patients feeling supported as agents in their own care. For example, participants stated that it was challenging to exercise alongside others who were less motivated and/or less able to exercise than themselves. This may be an important consideration for CR classes and for formatting/programming of support groups or other group-level interventions. Some patients may benefit from being paired with a peer who is further along in recovery than they are.

8. Medical providers and social network members should check in with patients about the big-
picture questions with which they are grappling. Providing space for patients to discuss existential questions can combat isolation and can also help with care planning, as these larger questions are also often related to a patients’ sense of agency in their lives, health, and care. A provider or supporter might ask, “How are you making sense of this? What has this experience meant for you and your life?” Finally, if a patient is already involved in a faith community, this can be a tremendous resource. Program developers may consider building on existing relationships between patients and their faith communities by partnering with these communities to offer exercise-based programs or other interventions promoting healthy lifestyle changes. The following studies offer additional recommendations on weaving spirituality/religion into interventions for African Americans: Kalenderian et al., 2009; Peterson & Cheng, 2011; Plescia et al., 2008; Yanek et al, 2001.

The above recommendations have been made particularly with African Americans in mind and may be applicable to other populations experiencing similar health disparities. In implementing these recommendations, hospital/medical center administrators, medical providers, and social network members should maintain awareness to the context of oppression in which African American patients have been steeped. As a population, African Americans have experienced countless medical and historical traumas in the United States, from a century of enslavement to exploitation by medical and scientific research communities (e.g., Marion Sims’ experimental fistula operations on female slaves, the Tuskegee Syphilis study on lower SES African American males) (Washington, 2006). Given this history, African Americans may be understandably cautious about participating in research studies and/or medical interventions. Here the importance of care, understanding, establishing trust, and building rapport with this population is paramount, especially for medical providers (Collins, Clark, Petersen, & Kressin,
2002; Lutfiyya, Cumba, McCullough, Barlow, & Lipsky, 2008; Shaw, Armin, Torres, Orzech, & Vivian, 2012). The role of policy change is also essential in creating a sociopolitical climate in which the above provider and patient level changes can be best supported.

**Conclusion**

This policy brief has offered recommendations for the treatment of African American patients recovering from cardiac events and/or surgeries. From CVD risk factors to prevalence, interventions, and outcomes, African Americans as a population experience significant gaps in health, health care, and access to treatment. It is the hope of the researchers writing this brief that policy, programmatic, and individual-level changes will be made to help lift the burden of disease and close the gap in care for this population. There is little use to a best practice intervention if it is not accessible to a population who needs it most. This brief is a call to meeting a healthcare need with a resource, through advocacy, understanding, and care.
References


185


doi:10.1002/14651858.CD002902.pub3

Figure 1. Education and CR Attendance Participant Descriptives.
Figure 2. Income and CR Attendance Participant Descriptives.
Table 1

*Summary of Search Terms and Equivalencies by Database*

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<th>Medline via PubMed</th>
<th>PsycINFO via EBSCO</th>
<th>CINAHL via EBSCO</th>
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<tr>
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<td>Heart Surgery; “Cardiac Surgical Procedures”</td>
<td>Surgery, Cardiovascular; Heart Surgery</td>
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<td>Cardiovascular Disorders</td>
<td>Cardiovascular Diseases</td>
</tr>
<tr>
<td>Cardiovascular Surgical Procedures</td>
<td>Heart Surgery; “Cardiovascular Surgical Procedures”</td>
<td>Surgery, Cardiovascular; Heart Surgery</td>
</tr>
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<td>Cardiovascular Disorders; Heart Surgery; “Coronary Artery Bypass”</td>
<td>Coronary Artery Bypass</td>
</tr>
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<td>Coronary Arteriosclerosis</td>
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<td>Coronary Disease</td>
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<td>Heart Diseases</td>
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</tr>
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<td>“Heart Failure”</td>
<td>Heart Failure</td>
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<td>“Myocardial Ischemia”</td>
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<td>Rehabilitation</td>
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</tr>
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<td>Rehabilitation Centers</td>
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<tr>
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<td>Heart Surgery; “Thoracic Surgery”</td>
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</table>
Table 2

Article Summaries

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<th>Referral/enrollment/attendance/completion</th>
<th>Sample size (n)</th>
<th>Participant characteristics: race/ethnicity and gender</th>
<th>Participant characteristics: Cardiovascular condition</th>
<th>Demographic and biopsychosocial-spiritual variable(s)</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Allen et al. (2004)</td>
<td>Referral/enrollment</td>
<td>253 AA and W women</td>
<td>MI, angina, PCI, CAGB</td>
<td>Race/ethnicity; Income; depression</td>
<td>AA women half as likely to be referred to CR; AA = lower enrollment; Income = predictor of referral/enrollment; no interaction between race and income or race and depression.</td>
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<td>Bittner et al. (1999)</td>
<td>Referral</td>
<td>1,329 AA and W men and women</td>
<td>MI, angina, CAGB</td>
<td>Race/ethnicity; distance to CR, insurance coverage, discharging physician’s specialty</td>
<td>9.5% of W participants were referred compared with 7.4% of AA participants but this difference was not statistically significant.</td>
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<td>Cannistra et al. (1995)</td>
<td>Attendance, completion</td>
<td>82 AA and W women</td>
<td>MI, angina, PCI, CAGB, valve surgery; dx of cardiomyopathy, or multiple CV risk factors.</td>
<td>Race/ethnicity; Factors impacting CR participation = medical, work, personal, logistical</td>
<td>AA women = more CV risk factors at program entry; more likely to not complete CR and cited work conflict and personal reasons; less likely to lose weight from CR than W women. Both AA and W women = improved functional capacity with CR.</td>
</tr>
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<td>Evenson et al. (2006)</td>
<td>Attendance</td>
<td>61 = 2004; 45 = Both 1999 and 2004 CR program directors in NC</td>
<td>Eligible for CR</td>
<td>Race/ethnicity; gender; availability of transportation</td>
<td>CR participants = 90% W, 9% AA; 72% of program directors cited policy issues as primary barrier to participation; work conflicts = primary reason for drop-out.</td>
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<td>Race/Ethnicity</td>
<td>Diagnosis/Condition</td>
<td>Race/Ethnicity; Insurance Status</td>
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<td>----------------</td>
<td>---------------------</td>
<td>---------------------------------------</td>
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<td>Gregory et al. (2006)</td>
<td>Referral</td>
<td>1,933</td>
<td>AA and W men and women</td>
<td>MI, revascularization, in past year; Dx of HF</td>
<td>W participants = 2x more likely to be referred to CR; AA participants more likely to have Medicaid or no insurance than W participants.</td>
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<td>Rankin et al. (2002)</td>
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<td>MI</td>
<td>Race/ethnicity</td>
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<td>Young et al. (1991)</td>
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<td>AA and W men and women</td>
<td>MI</td>
<td>Race/ethnicity, SES</td>
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Key of abbreviations: AA = African American; W = White; CR = Cardiac Rehabilitation; CV = Cardiovascular; CABG = Coronary Artery Bypass Grafting; MI = Myocardial Infarction; PCI = Percutaneous Coronary Intervention; Dx = Diagnosis; SES = Socioeconomic status
### Table 3

**Survey Participants’ Demographic Information**

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<th>Characteristics</th>
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<tr>
<td>female</td>
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<tr>
<td>male</td>
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<td>Income</td>
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<td>high ($60-149,000)</td>
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Table 4

*Survey Participants’ Income, Education, and Cardiac Rehabilitation Attendance*

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<td>1</td>
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</tr>
<tr>
<td><strong>Income</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>low ($0-19,000)</td>
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<td>0</td>
</tr>
<tr>
<td>medium ($20-59,000)</td>
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<tr>
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<td>10</td>
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<td>62.5</td>
</tr>
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<td>Definition</td>
<td>Selected quotation</td>
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</tr>
<tr>
<td>------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Participants valued medical providers’ involvement during treatment and recovery</td>
<td>Medical providers (i.e. doctors, nurses, physical/occupational therapists) offered interventions, support, and guidance to participants during treatment and recovery. Participants expressed gratitude for this support and sometimes requested additional support.</td>
<td>“They [medical providers] really cared about me. I could tell the doctors really cared. They wanted me to get well…they kept telling me, um, you gotta do this, you gotta take your medicine. You can tell when someone actually care about you.”</td>
<td></td>
</tr>
<tr>
<td>Social support and participants’ need for it changed post-event/surgery</td>
<td>Support from participants’ social networks (i.e., family members, friends, neighbors, and faith community members), as well as participants’ need for this support, changed during recovery. Support from social networks included help with daily activities of living, visits/check-ins, and encouragement. Sometimes participants felt isolated by lack of social support, physical limitations, or new lifestyle changes.</td>
<td>“You can’t lift over 10 pounds, so, um, they would go with me… either my sons or my husband… Go to school with me and take my books into class and bring ‘em outta class….”</td>
<td>“Everybody’s movin’ around socializing, and I’m kinda stuck in this spot waiting for, ‘Okay, you wanna come talk to me?’ And have one person come talk to me a little while, then they go off … it was kinda lonely. And it, uh, you felt like you was, like, missing a lot of things. Like, you kinda sittin’ there and you watching life go by.”</td>
</tr>
<tr>
<td>Participants’ pre- and post-event/surgery experiences affected health outcomes</td>
<td>Participants’ health outcomes following cardiac events/surgeries were impacted by health-related experiences before and after the events/surgeries that sometimes directly compounded heart problems. Some participants experienced post-event/surgery improvements; others had post-event/surgery limitations that called for lifestyle adjustments.</td>
<td>“I was having so much problems breathing sometimes [pre-surgery] that if I get excited my chest would start hurting, so I can’t breath like I wanted to because my blood pressure going up and down, up and down, I get tired quick, couldn’t hardly do nothing I wanted to.”</td>
<td>“‘Cause I was taking a lot of pain pills for my shoulder and stuff. And when my shoulder started hurtin’ real bad it would start my heart hurtin.’ And [medical providers] took me off that right there [post-surgery]. Now that I’ve been doing a whole lot better ‘cause I take me a Tylenol either, and a Bayer and I’m a’ight.”</td>
</tr>
<tr>
<td>Participants’ sense of agency affected their life perspectives and health behaviors</td>
<td>Participants’ sense of agency during intervention and recovery impacted life perspectives and health behaviors. When participants felt like agents in their own health and care, they were more likely to proactively advocate for their needs by choosing to opt in or out of treatment recommendations and how they would incorporate these into their lives (i.e., exercising at CR vs. exercising at home).</td>
<td>“It [cardiac event/intervention] changed the way I do a lot of things. Um, it made me take life a little bit more serious...just make sure I take my medication all the time. Don’t eat- watch what I eat… Basically, I was just eating everything.”</td>
<td></td>
</tr>
<tr>
<td>---</td>
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<td></td>
</tr>
<tr>
<td>Participants experienced inconsistent referral to and utilization of Cardiac Rehabilitation</td>
<td>Participants whose medical providers did not talk to them about CR generally did not participate. Other barriers to CR participation included not being referred to CR, not understanding what CR was, or waiting on medical providers for action/clearance to begin or continue the program.</td>
<td>“Nobody hadn’t told me about it, um, hadn’t said anything about there’s a rehab place for it. <em>Nothing</em>... I think that they <em>should</em> let the people know. Especially right before [discharge]- at the hospital would be <em>great</em>, because somebody have it on their discharge papers. You know, some type of way to, to let people know that ‘These services are available, check into it.’”</td>
<td></td>
</tr>
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</table>
| Participants’ investment in faith was intensified or maintained | Participants reported ongoing personal and familial involvement in their faith communities, and even the resolution of some pre-event/surgery spiritual challenges. Participants identified their faith as a source of strength and gratitude during recovery. | “Every time, you know, stuff’d go wrong, I’d think about my spiritual relationship with God, and, um, and, um, the prayer, and, uh, it’s just, like, I, I had no, no fear in believing that I would be alright, you know?”
|  |  | “Everyday I wake up I pray, I thank God everyday I wake up. I mean, that’s the way I look at it…I mean, I got a 7-year-old son and an 18-year-old daughter.” |
APPENDIX A: IRB APPROVAL

Notification of Initial Approval: Expedited

From: Biomedical IRB
To: Aubry Koehler
CC: Jennifer Hodgson
Date: 4/17/2014
Re: UMCIRB 14-000159

Cardiac Rehabilitation Referral and Participation for/among African American Patients
I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 4/16/2014 to 4/15/2015. The research study is eligible for review under expedited category #5,6,7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

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<td>Koehler.RequestforPrepwork.pdf</td>
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<td>Koehler.Surveys.2.11.14.doc</td>
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</table>

The Chairperson (or designee) does not have a potential for conflict of interest on this study.
Notification of Amendment Approval

From: Biomedical IRB
To: Aubry Koehler
CC: Jennifer Hodson
Date: 11/25/2014
Re: Ame10_UMCIRB 14-000159
UMCIRB 14-000159
Cardiac Rehabilitation Referral and Participation for/among African American Patients

Your Amendment has been reviewed and approved using expedited review for the period of 11/25/2014 to 4/15/2015. It was the determination of the UMCIRB Chairperson (or designee) that this revision does not impact the overall risk/benefit ratio of the study and is appropriate for the population and procedures proposed.

Please note that any further changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. A continuing or final review must be submitted to the UMCIRB prior to the date of study expiration. The investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamp on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

<table>
<thead>
<tr>
<th>Document</th>
<th>Description</th>
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<tbody>
<tr>
<td>Koehler.Demographicquestions.docx(0.01)</td>
<td>Surveys and Questionnaires</td>
</tr>
<tr>
<td>Koehler.InformedConsent.QualOnly11.20.14.doc(0.04)</td>
<td>Consent Forms</td>
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</table>

The Chairperson (or designee) does not have a potential of conflict of interest on this study.
APPENDIX B: PERMISSION TO USE MEASURES

Permission to Use PHQ-4

Screener Overview

Recognizing signs of mental health disorders is not always easy. The Patient Health Questionnaire (PHQ) is a diagnostic tool for mental health disorders used by health care professionals that is quick and easy for patients to complete. In the mid-1990s, Robert L. Spitzer, MD, Janet B.W. Williams, DSW, and Kurt Kroenke, MD, and colleagues at Columbia University developed the Primary Care Evaluation of Mental Disorders (PRIME-MD), a diagnostic tool containing modules on 12 different mental health disorders. They worked in collaboration with researchers at the Regenstrief Institute at Indiana University and with the support of an educational grant from Pfizer Inc. During the development of PRIME-MD, Drs. Spitzer, Williams and Kroenke, created the PHQ and GAD-7 screeners.

The PHQ, a self-administered version of the PRIME-MD, contains the mood (PHQ-9), anxiety, alcohol, eating, and somatoform modules as covered in the original PRIME-MD. The GAD-7 was subsequently developed as a brief scale for anxiety. The PHQ-9, a tool specific to depression, simply scores each of the 9 DSM-IV criteria based on the mood module from the original PRIME-MD. The GAD-7 scores 7 common anxiety symptoms. Various versions of the PHQ scales are discussed in the Instruction Manual.

All PHQ, GAD-7 screeners and translations are downloadable from this website and no permission is required to reproduce, translate, display or distribute them.
Permission to Use MOS Social Support Survey

Social Support Survey: RAND Medical Outcomes Study

This brief, self-administered Social Support Survey instrument was developed for patients in the Medical Outcomes Study (MOS), a two-year study of patients with chronic conditions. It is easy to administer to chronically ill patients, and the items are short, simple, and easy to understand. It may also be appropriate for use with other populations.

Available Documents

MOS Social Support Survey Instrument

- Survey Instrument (HTML)
- Survey Instrument (PDF)

Permissions Information
All of the surveys from RAND Health are public documents, available without charge.

Translations
Many of the surveys listed are available in other languages. If you are interested in translating any surveys into another language, see our translation guidelines.

Questions or Comments?
Email us at RAND_Health@rand.org
Permission to Use Religion Health Fatalism Questionnaire

RE: Use of RHFQ

Schlundt, David G <david.schlundt@vanderbilt.edu>
Wed 01/01/2014 11:20 AM

To: [email redacted]; Wallston, Ken <ken.wallston@Vanderbilt.edu>

You forwarded this message on 05/26/2014 12:06 PM.

1 attachment

I believe I can say on behalf of Dr. Franklin that it is OK to use the questionnaire for your research. In Table 2, the factor loading for the items are presented. Use the bold-faced loadings to define subscales. There are three subscale (divine provision, destined plan, and helpless inevitability). You can also sum all the items into a total score.

Let me know if you have other questions
I have attached a formatted version of the items
Recruitment Script

Hi, Ms./Mr. {insert name}. My name is Aubry Koehler and I am a student at ECU. I am working on a study that looks at which medical services cardiac patients use while they are recovering from a cardiac event (like a heart attack) or surgery (like a stent placement). I am wondering if it would be alright if I sit down with you and tell you a little more about this study, so you can make the decision whether or not you would like to participate.

[If the patient agrees for the PI to continue with the recruitment process, she will do so. If the patient does not agree, the PI will thank the patient for his or her time and leave the room].

This study has a few different parts to it. If you agree to participate today, I will ask you to sign a form documenting your agreement, and then I will read a survey to you and mark down your answers. The survey asks some questions about you like your age, gender, mood, social support, and spirituality. This survey will take about 15 minutes. Six weeks after you go home, either my research assistant or I will call you to ask you some of the same questions and some new questions about the medical services you have used. During this phone call, you may be asked to be a part of an individual interview to learn more about their experience. If you are asked to participate in an interview we would schedule a time and place of your choosing to have the interview. Individuals who complete an interview will be given a $25 gas card for their participation directly following the interview.

Because we want to learn more about how participants use medical services, we would also need to be able to check your Vidant Medical Center electronic health record and paper records at Vidant Health Groups to see what services you use. Only with your consent to participate in the study, will my research assistant and I check your health records up until eight months after your discharge. This private information will not be shared with anyone outside of
the research team. We will never use your name or any other information that could be used to identify you when we publish or present the study’s results. If you provide us with your contact information, we can mail you a summary of the results as well.

Individuals who decide to participate in this study, and who complete both surveys (today and six weeks from now), will be entered in a drawing to win a $25 gas card. This is a small gift to show our appreciation for your time. If you would like to be entered in the drawing, we will take your name and contact information down today. Then, after we finish giving surveys to all the participants, we will draw 10 names, call you if your name was drawn, and send you the gas card. If you are asked to participate in an interview and complete the interview we will automatically give you a $25 gas card immediately after you finish the interview.

Please know that your decision whether or not to participate will not affect your care in any way. We want you to feel comfortable saying “no” if you decide not to participate. Also, if you do decide to participate, know that you may choose to stop participating in the study at any time. It is your choice and you always have the right to change your mind.

I have just summarized the basic information in the informed consent document. If you would like, you can read it in its entirety, or I can read it to you. What would you prefer?

[If the patient asks to have the informed consent document read to him or her, PI will do so. If the patient elects to read the informed consent document him or herself, the PI will not read the informed consent document verbatim].

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Do you have any questions about what I have just told you? Do you have any concerns? [PI will pause for questions and concerns. If patient has questions or concerns, PI will answer and address them to the best of her ability. If patient does not have questions or concerns, PI will continue with recruitment process].

Would you like to participate? If so, we will need you to sign this informed consent document to show your agreement.

[If patient agrees to participate, he or she will sign the informed consent document and a copy will be given to him or her for later reference. If the patient declines to participate, the PI will thank him or her for her time and leave the room].
Telephone Script (for T2 survey)

Hello, Ms./Mr. {insert name}. My name is Aubry Koehler and I am an ECU student working on a study that looks as use of medical services by cardiac patients during their recovery. I met with you before you left the hospital, and at that time you agreed to participate in this study and answered a survey. *OR* My name is Michelle Tracy and I am a research assistant working on a study that looks at use of medical services by cardiac patients during their recovery. My colleague, Aubry Koehler, met you before you left the hospital. At that time, you agreed to participate in this study and answered a survey about yourself, and your mood, social support, and spirituality.

Today, I would like to ask you some questions about the medical services you have been using since you left the hospital. They are the same survey questions you answered when you were in the hospital. This will take about 15 minutes. Is it alright if I continue?

[If the participant agrees, the PI/Research Assistant will administer the survey. If the participant does not have time at the moment, the PI/Research Assistant will ask if there is a better time to call back.]

[After completing the survey questions]. Thank you so much for participating in the survey.

[If participant entered his/her name in the $25 gas card drawing]. Once we enrolling participants (in approximately two months), we will be drawing names for the $25 gas cards. If
your name is drawn, we will call you, and then send you the gas card at the address you provided when you entered your name.

[If participant is eligible for an interview]. Also, you may remember when you first agreed to participate in this study, that Aubry said some participants will be asked to participate in an individual interview. You were identified as someone we could learn a lot from and would like to interview you about your experience recovering from a cardiac event (like a heart attack) or surgery (like a stent placement). Interviews will be facilitated by me and Aubry/my Research Assistant. They will last about one hour and will take place over the phone at a time of your choosing. Participants who complete an interview will be given a $25 gas card to compensate them for their time. Are you interested in scheduling an interview with us?

[If participant is willing to schedule an interview, the PI/Research Assistant will work with the participant to select a time for the interview. This may be during the T2 survey call or another time scheduled by the participant. If the participant is unwilling to schedule an interview, the PI/Research Assistant will thank the participant for his or her time].
Title of Research Study: Cardiac Rehabilitation Referral and Participation for/among African American Patients
Principal Investigator: Aubry N. Koehler, MA, LMFTA
Institution/Department or Division: Child Development & Family Relations
Address: 108 Rivers Building, Mail Stop 505, East Carolina University, Greenville, NC 27858
Telephone #: (252) 737-1415
Study Sponsor/Funding Source: N/A

Researchers at East Carolina University (ECU), Vidant Medical Center, and Vidant Medical Groups study problems in society, health problems, environmental problems, behavior problems, and the human condition. Our goal is to try to find ways to improve the lives of you and others. To do this, we need the help of volunteers who are willing to take part in research.

Why is this research being done?
The purpose of this research is to better understand what medical services cardiac patients use while they are recovering. The decision to take part in this research is yours to make. By doing this research, we hope to learn what kind of factors affect the type of medical services cardiac patients with different backgrounds use.

Why am I being invited to take part in this research?
You are being invited to take part in this research because you are getting ready to discharge from the hospital after a cardiac event (such as a heart attack) or a cardiac surgery (such as a bypass or stent placement). If you volunteer to take part in this research, you will be one of about 200 people to do so.

Are there reasons I should not take part in this research?
I understand I should not volunteer for this study if I am: (a) a non-English speaker, (b) under 18 years of age, (c) a non-Pitt County resident, (c) being discharged with a diagnosis of heart failure or following a heart-lung transplant, and/or (d) cognitively impaired such that it may interfere with my ability to consent to the study and participate in surveys and interviews.

What other choices do I have if I do not take part in this research?
Participation in this research project is voluntary. You may choose not to participate at any time.

Where is the research going to take place and how long will it last?
The research will occur at the following times and places: today at Vidant Medical Center, over the phone for a follow-up call, and again over the phone if you are selected for an interview. If you do volunteer to participate, you will complete a short survey today (estimated to take about 15-20 minutes). Then, about six weeks after you go home from the hospital, we will call you to ask you some follow-up questions about your recovery (estimated to take about 10-15 minutes). During that phone call, we may ask you if you would be willing to participate in an individual audio-recorded, over-the-phone interview so we can learn more about your personal recovery experience (estimated to take about one hour). The total amount
of time you will be asked to volunteer is between 30 minutes and one hour and 30 minutes depending on whether or not you are selected for an interview.

What will I be asked to do?

You are being asked to do the following:

- Complete a short survey that I will read aloud to you today. This survey asks about your demographic information (age, gender) and also about your mood, your social support, and your spiritual beliefs.
- Complete a short follow-up survey over the phone when we call you approximately six weeks after your hospital discharge. This survey asks about your mood and medical services used during your recovery.
- Allow us to view your electronic health record and paper records kept by Vidant Medical Center/Health Groups to see what medical services you used for your recovery (until eight months after this discharge).
- If you are selected for an audio-recorded interview, we will inform you during the six-week follow-up call. At that time, you may elect to complete the interview during the phone call or schedule another time for the phone interview. During the phone interview, we will ask you about your personal experience recovering from a cardiac event. We will type up your audio-recorded interview for analysis and keep it in a password-protected file. Audio files will be password-protected and stored on a secure server at East Carolina University.
- If you participate in a phone interview and are willing to be involved in the process of double-checking the results (“member checking”), we will contact you over the phone and read you a summary of the results. This will give you an opportunity to share any additional information or help us make corrections. Audio files will be erased after they are typed and the member checking process is completed. The typed interviews will be stored electronically on a secure server at East Carolina University, accessed only by my computer, which is password-protected. The typed interview documents will be kept in a locked filing cabinet in my locked office. Documents will be shredded and electronic files containing identifying information will be erased six years after the project is completed.

What possible harms or discomforts might I experience if I take part in the research?

There are possible risks (the chance of harm) when taking part in this research. This research will require your time and energy to complete. Some participants who have completed surveys and interviews on topics of mood, social support, and spirituality may experience discomfort with answering questions. Some participants may also experience negative feelings (such as anger, fear, grief, or sadness) from being asked to recall and talk about a difficult time (such as recovering from a cardiac event). Please know you may always ask to “skip” questions you are not comfortable with answering. You can also ask to stop a survey or interview at any time. Additionally, you may choose to have a family member or friend present during the survey or interview if this makes you feel more comfortable.

In the case that you experience negative emotions or your survey answers indicate that you are experiencing symptoms of anxiety or depression, we will help connect you with behavioral health resources that you may choose to use. If you are still in the hospital when this occurs, we will let your care team know so they can connect you with appropriate resources. If you are out of the hospital when this occurs, we will give you contact information for resources over the phone or in person.

What are the possible benefits I may experience from taking part in this research?

We do not know if you will get any benefits by taking part in this study. Hopefully, this research will help us learn more about how to best serve cardiac patients from different backgrounds. There may be no personal benefit from your participation but the information gained by doing this research may help
others in the future. However, other people who have participated in this type of research have experienced benefit from being able to talk about their experience with researchers. By participating in this research study, you may also experience these benefits.

**Will I be paid for taking part in this research?**
We will not be able to pay you for the time you volunteer while being in this study. However, you do have the opportunity to enter your name into a drawing for a $25 gas card. Participants who complete both the survey today and the follow-up survey six weeks after you leave the hospital are eligible for this drawing. After the survey data collection, we will do the drawing and will notify you and send you the gas card if your name was drawn. If you are asked to participate in an interview and you complete the interview, you will be mailed a gas card at the time of interview completion. Participants who are interested in being entered into the drawing will give their name and contact information (phone number, address) today.

We would also like to share the results of this study with you. If you are interested in receiving a summary of the results from this study, we are more than happy to send you a copy. Please provide an email address or mailing address here:

______________________________________________________________

**What will it cost me to take part in this research?** It will not cost you any money to be part of the research. This research study is not for profit and is being completed as part of the Principal Investigator’s degree requirements. All researchers are donating their time to the study.

**Who will know that I took part in this research and learn personal information about me?**
To do this research, ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- The University & Medical Center Institutional Review Board (UMCIRB) and its staff, who have responsibility for overseeing your welfare during this research, and other ECU staff who oversee this research.
- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
- People designated by Vidant Medical Center and Vidant Health
- Additionally, the following people and/or organizations may be given access to your personal health information and they are: Vidant Cardiovascular and Pulmonary Rehabilitation (Greenville, NC), Vidant Cardiovascular and Pulmonary Rehabilitation (Washington, NC)

**How will you keep the information you collect about me secure? How long will you keep it?**
Your name will only be attached to this informed consent document and a list kept by the Principal Investigator of the study participants. Surveys will be identified by an assigned number and kept in a locked file cabinet. A list of study participants with contact information and your assigned number will be listed in a password-protected file on a secure server at East Carolina University. If you are selected to participate in an audio-recorded interview, the audio file will be password-protected and stored on a secure server at East Carolina University. Hardcopies of your typed interview will be stored in a locked file cabinet. Your name will not be attached to these materials. Audio files will be erased after the interviews are typed and the member checking process is completed (if you are willing to be involved in the process of double-checking the results, we will contact you over the phone or in person to read you a summary of the results so you can provide feedback). Findings from this study may be used for other professional presentations or publications (e.g., articles, book format). In all presentations and
publications, your identifying information will never be used. After this study is complete, documents will be shredded and electronic files containing identifying information will be erased six years after the project is completed.

What if I decide I do not want to continue in this research?
If you decide you no longer want to be in this research after it has already started, you may stop at any time. You will not be penalized or criticized for stopping. You will not lose any benefits that you should normally receive.

Who should I contact if I have questions?
The people conducting this study will be available to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at (252) 737-1415 (Thursday and Fridays, 9AM-5PM) or the Principal Investigator’s Supervisor, Jennifer Hodgson, PhD, at (252) 328-1349 (Monday-Friday, 9AM-5PM).

If you have questions about your rights as someone taking part in research, you may call the Office for Human Research Integrity (OHRI) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the OHRI, at 252-744-1971 and the Vidant Medical Center Risk Management Office at 252-847-5246.

I have decided I want to take part in this research. What should I do now?
The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

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<th>Participant's Name (PRINT)</th>
<th>Signature</th>
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Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person’s questions about the research.

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UMCIRB HIPAA Privacy Authorization

East Carolina University (ECU)/Vidant Medical Center (VMC): Research Participant Authorization to Use and Disclose Protected Health Information for Research

For use only with the research consent form for UMCIRB#: 14-000159

Principal Investigator: Aubry N. Koehler, MA, LMFTA
Title: Cardiac Rehabilitation Referral and Participation for/among African American Patients

Location where research will be conducted
The members of the research team will conduct the research study at:
☐ East Carolina University (ECU) ☒ VMC ☐ ECU & VMC ☐ Other: Vidant Cardiovascular and Pulmonary Rehabilitation (Greenville, NC & Washington, NC),

When taking part in research, protected health information (PHI) is collected, used, and shared with others who are involved in the research. Federal laws require that researchers and health care providers protect your PHI. Also, federal laws require that we get your permission to use collected PHI for the research. This permission is called authorization.

In order to complete the research project in which you have decided to take part, the research team needs to collect and use some of your PHI as described below.

What types of protected health information (PHI) about me will be used or disclosed?

ECU Health Care Component: Vidant Health Entity:
☐ ECU Physicians [☒] Entire Vidant Health system
☐ School of Dental Medicine [☐] Vidant Medical Center
☐ Speech, Language, and Hearing Clinic [☐] Other Vidant Health Entity (please list):
☐ Human Performance Lab [☐]
☐ Physical Therapy [☐]
☐ Student Health [☐]
☒ Other ECU Health Entity [☐]
(please list): Dept of Child Development & Family Relations

Type of ECU Records:
☐ Medical/clinic records [☐]
☐ Billing records [☐]
☐ Lab, Pathology and/or Radiology results [☐]
☐ Mental Health records [☐]
☐ PHI previously collected for research [☐]
☒ Records generated during this study [☐]
☐ Other:

Type of Vidant Records:
[☒] Medical/clinic records [☐]
[☐] Billing records [☐]
[☐] Lab, Pathology and/or Radiology results [☐]
[☐] Mental Health records [☐]
[☐] PHI previously collected for research [☐]
[☐] Records generated during this study [☐]
[☐] Other:

Who will use or disclose my PHI?
[☒] Principal Investigator
[☐] Other members of the research team
[☐] Other providers involved in your care during research procedures, outpatient/inpatient stays during which research is being performed, or physician office visits during which research is being performed.

Who will receive my PHI?
[☐] Sponsor or other funding source to provide oversight for entire research project
[☒] Research investigators to conduct and oversee the research project
Principal Investigator and research team members to participate in the various research activities

FDA or other regulatory agencies to provide regulatory oversight

UMCIRB to provide continuing review of the research project

Institutional officials in connection with duties for monitoring research activity

Other providers involved in your care during research procedures, outpatient/inpatient stays during which research is being performed, or physician office visits during which research is being performed.

Researchers at other sites—List sites:

Data and Safety Monitoring Board and its staff

Contract Research Organization and its staff

Other: People designated by Vidant Medical Center and Vidant Health System

We will share only the PHI listed above with the individuals/agencies listed above. If we need to share other PHI or if we need to send PHI to other individuals/agencies not listed above, we will ask for your permission in writing again.

**How my PHI may be released to others:**

ECU and VMC are required under law to protect your PHI. However, those individuals or agencies who receive your PHI may not be required by the Federal privacy laws to protect it and may share your PHI with others without your permission, if permitted by the laws governing them.

**What if I do not sign this form?**

You will not be eligible to participate in this study if you do not sign this Authorization form.

**How may I revoke (take back) my authorization?**

You have the right to stop sharing your PHI. To revoke (or take back) your authorization, you must give the Principal Investigator your request to revoke (or take back) your authorization in writing. If you request that we stop collecting your PHI for the study, you may be removed from the study. If you are removed from the study, it will not affect your ability to receive standard medical care or affect payment, health plan enrollment or benefit eligibility. PHI collected for the research study prior to revoking (or taking back) your Authorization will continue to be used for the purposes of the research study. Also, the FDA (if involved with your study) can look at your PHI related to the study even if you withdraw this authorization.

**Restrictions on access to my PHI:**

You will not be able to see your PHI in your medical record related to this study until the study is complete. If it is necessary for your care, your PHI will be provided to you or your physician.

**How long may the PHI about me be used or disclosed for this study?**

Research information continues to be looked at after the study is finished so it is difficult to say when use of your PHI will stop. There is not an expiration date for this authorization to use and disclose your PHI for this study.

If you have questions about the sharing of PHI related to this research study, call the Principal Investigator, Aubry N. Koehler, at phone number (252) 737-1415 or the Principal Investigator’s Supervisor, Jennifer Hodgson, PhD, at (252) 328-1349. Also, you may telephone the University and Medical Center Institutional Review Board at 252-744-2914. In addition, if you have concerns about confidentiality and privacy rights, you may phone the Privacy Officer at Vidant Medical Center at 252-847-6545 or the Privacy Officer at East Carolina University at 252-744-5200.
**Authorization**
To authorize the use and disclosure of your PHI for this study in the way that has been described in this form, please sign below and date when you signed this form. A signed copy of this Authorization will be given to you for your records.

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<th>Name of Participant or Authorized Representative (print)</th>
<th>Signature</th>
<th>Date</th>
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If an Authorized Representative has signed on behalf of a Participant please print on the line above the authority of the Legal Representative to do so (*such as parent, court-appointed guardian, or power of attorney)*.

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<th>Person Obtaining Authorization</th>
<th>Signature</th>
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Informed Consent for Qualitative-Only Participants

East Carolina University

Informed Consent to Participate in Research
Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: Cardiac Rehabilitation Referral and Participation for/among African American Patients
Principal Investigator: Aubry N. Koehler, MA, LMFTA
Institution/Department or Division: Child Development & Family Relations
Address: 108 Rivers Building, Mail Stop 505, East Carolina University, Greenville, NC 27858
Telephone #: (252) 737-1415
Study Sponsor/Funding Source: N/A

Researchers at East Carolina University (ECU), Vidant Medical Center, and Vidant Medical Groups study problems in society, health problems, environmental problems, behavior problems, and the human condition. Our goal is to try to find ways to improve the lives of you and others. To do this, we need the help of volunteers who are willing to take part in research.

Why is this research being done? The purpose of this research is to better understand what medical services cardiac patients use while they are recovering. The decision to take part in this research is yours to make. By doing this research, we hope to learn what kind of factors affect the type of medical services cardiac patients with different backgrounds use.

Why am I being invited to take part in this research? You are being invited to take part in this research because you are an African American patient currently recovering from a cardiac event or surgery. You are being asked to participate in the qualitative (interview) portion of a larger study that also has a quantitative (survey) component. If you volunteer to take part in this research (qualitative interviews), you will be one of about 12 people to do so.

Are there reasons I should not take part in this research? I understand I should not volunteer for this study if I am: (a) a non-English speaker, (b) under 18 years of age, (c) a non-Pitt County resident, (c) being discharged with a diagnosis of heart failure or following a heart-lung transplant, and/or (d) cognitively impaired such that it may interfere with my ability to consent to the study and participate in an interview.

What other choices do I have if I do not take part in this research? Participation in this research project is voluntary. You may choose not to participate at any time.

Where is the research going to take place and how long will it last? The research will occur at the following times and places: today at the Cardiac Rehabilitation facility, when you will be guided through the informed consent paperwork (15 minutes) and then over the phone for an interview, including a demographic questionnaire (about an hour). This will total about an hour and 15 minutes. If you agree to participate in “member-checking” (a process of double-checking the results; we will contact you over the phone to read you a summary of the results so you can provide feedback), this will be an addition 15-30 minutes, for a total of one hour and 15 minutes to one hour and 30 minutes.
What will I be asked to do?
You are being asked to do the following:

- Allow us to view your electronic health record and paper records kept by Vidant Medical Center/Health Groups to see what medical services you used for your recovery (for the next six months only).
- Participate in an audio-recorded, over-the-phone interview. During this interview, we will ask you about your personal experience recovering from a cardiac event or surgery. We will also ask you some demographic questions about yourself and the follow-up care you have received. We will type up your audio-recorded interview for analysis and keep it in a password-protected file. Audio files will be password-protected and stored on a secure server at East Carolina University.
- If you participate in an interview and are willing to be involved in the process of double-checking the results (“member checking”), we will contact you over the phone and read you a summary of the results. This will give you an opportunity to share any additional information or help us make corrections. Audio files will be erased after they are typed and the member checking process is completed. The typed interviews will be stored electronically on a secure server at East Carolina University, accessed only by my computer, which is password-protected. The typed interview documents will be kept in a locked filing cabinet in my locked office. Documents will be shredded and electronic files containing identifying information will be erased six years after the project is completed.

What possible harms or discomforts might I experience if I take part in the research?
There are possible risks (the chance of harm) when taking part in this research. This research will require your time and energy to complete. Some participants may experience discomfort or negative feelings (such as anger, fear, grief, or sadness) from being asked to recall and talk about their recovery experience. Please know you may always ask to “skip” questions you are not comfortable answering. You can also ask to stop an interview at any time. Additionally, you may choose to have a family member or friend present during your interview if this makes you feel more comfortable. In the case that you experience negative emotions during the interview and would like to seek professional support, we will help connect you with behavioral health resources that you may choose to use. We will give you contact information for resources over the phone.

What are the possible benefits I may experience from taking part in this research?
We do not know if you will get any benefits by taking part in this study. Hopefully, this research will help us learn more about how to best serve cardiac patients from different backgrounds. There may be no personal benefit from your participation but the information gained by doing this research may help others in the future. However, other people who have participated in this type of research have experienced benefit from being able to talk about their experience with researchers. By participating in this research study, you may also experience these benefits.

Will I be paid for taking part in this research?
We will not be able pay you for the time you volunteer while being in this study. However, we do want to thank you by offering you a $25 gas card for your participation. We will mail this to you after the completion of your interview. If you are interested in receiving a gas card, please provide your mailing address here:______________________________________________________________

We would also like to share the results of this study with you. If you are interested in receiving a summary of the results from this study, we are more than happy to send you a copy. Please provide an email address or mailing address here:______________________________________________________________
**What will it cost me to take part in this research?** It will not cost you any money to be part of the research. This research study is not for profit and is being completed as part of the Principal Investigator’s degree requirements. All researchers are donating their time to the study.

**Who will know that I took part in this research and learn personal information about me?**

To do this research, ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- The University & Medical Center Institutional Review Board (UMCIRB) and its staff, who have responsibility for overseeing your welfare during this research, and other ECU staff who oversee this research.
- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
- People designated by Vidant Medical Center and Vidant Health
- Additionally, the following people and/or organizations may be given access to your personal health information and they are: Vidant Cardiovascular and Pulmonary Rehabilitation (Greenville, NC), Vidant Cardiovascular and Pulmonary Rehabilitation (Washington, NC)

**How will you keep the information you collect about me secure? How long will you keep it?**

Your name will only be attached to this informed consent document and a list kept by the Principal Investigator of the study participants. The audio file of your interview will be password-protected and stored on a secure server at East Carolina University. Hardcopies of your typed interview will be stored in a locked file cabinet. Your name will not be attached to these materials. Audio files will be erased after the interviews are typed and the member checking process is completed (if you are willing to be involved in the process of double-checking the results, we will contact you over the phone to read you a summary of the results so you can provide feedback). Findings from this study may be used for other professional presentations or publications (e.g., articles, book format). In all presentations and publications, your identifying information will never be used. After this study is complete, documents will be shredded and electronic files containing identifying information will be erased six years after the project is completed.

**What if I decide I do not want to continue in this research?**

If you decide you no longer want to be in this research after it has already started, you may stop at any time. You will not be penalized or criticized for stopping. You will not lose any benefits that you should normally receive.

**Who should I contact if I have questions?**

The people conducting this study will be available to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at (252) 737-1415 (Thursday and Fridays, 9AM-5PM) or the Principal Investigator’s Supervisor, Jennifer Hodgson, PhD, at (252) 328-1349 (Monday-Friday, 9AM-5PM).

If you have questions about your rights as someone taking part in research, you may call the Office for Human Research Integrity (OHRI) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the OHRI, at 252-744-1971 and the Vidant Medical Center Risk Management Office at 252-847-5246.
I have decided I want to take part in this research. What should I do now?
The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

<table>
<thead>
<tr>
<th>Participant's Name (PRINT)</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

**Person Obtaining Informed Consent**: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person’s questions about the research.

<table>
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UMCIRB HIPAA Privacy Authorization

East Carolina University (ECU)/Vidant Medical Center (VMC): Research Participant Authorization to Use and Disclose Protected Health Information for Research

For use only with the research consent form for UMCIRB#: 14-000159

Principal Investigator: Aubry N. Koehler, MA, LMFTA

Title: Cardiac Rehabilitation Referral and Participation for/among African American Patients

Location where research will be conducted

The members of the research team will conduct the research study at:

- East Carolina University (ECU)
- VMC
- ECU & VMC
- Other: Vidant Cardiovascular and Pulmonary Rehabilitation (Greenville, NC & Washington, NC)

When taking part in research, protected health information (PHI) is collected, used, and shared with others who are involved in the research. Federal laws require that researchers and health care providers protect your PHI. Also, federal laws require that we get your permission to use collected PHI for the research. This permission is called authorization.

In order to complete the research project in which you have decided to take part, the research team needs to collect and use some of your PHI as described below.

What types of protected health information (PHI) about me will be used or disclosed?

<table>
<thead>
<tr>
<th>ECU Health Care Component:</th>
<th>Vidant Health Entity:</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ] ECU Physicians</td>
<td>[ ] Entire Vidant Health system</td>
</tr>
<tr>
<td>[ ] School of Dental Medicine</td>
<td>[ ] Vidant Medical Center</td>
</tr>
<tr>
<td>[ ] Speech, Language, and Hearing Clinic</td>
<td>[ ] Other Vidant Health Entity</td>
</tr>
<tr>
<td>[ ] Human Performance Lab</td>
<td>(please list):</td>
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<tr>
<td>[ ] Physical Therapy</td>
<td></td>
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<tr>
<td>[ ] Student Health</td>
<td></td>
</tr>
<tr>
<td>[ ] Other ECU Health Entity</td>
<td>(please list): Dept of Child Development &amp; Family Relations</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type of ECU Records:</th>
<th>Type of Vidant Records:</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ] Medical/clinic records</td>
<td>[ ] Medical/clinic records</td>
</tr>
<tr>
<td>[ ] Billing records</td>
<td>[ ] Billing records</td>
</tr>
<tr>
<td>[ ] Lab, Pathology and/or Radiology results</td>
<td>[ ] Lab, Pathology and/or Radiology results</td>
</tr>
<tr>
<td>[ ] Mental Health records</td>
<td>[ ] Mental Health records</td>
</tr>
<tr>
<td>[ ] PHI previously collected for research</td>
<td>[ ] PHI previously collected for research</td>
</tr>
<tr>
<td>[ ] Records generated during this study</td>
<td>[ ] Records generated during this study</td>
</tr>
<tr>
<td>[ ] Other:</td>
<td>[ ] Other:</td>
</tr>
</tbody>
</table>

Who will use or disclose my PHI?

- [ ] Principal Investigator
- [ ] Other members of the research team
- [ ] Other providers involved in your care during research procedures, outpatient/inpatient stays during which research is being performed, or physician office visits during which research is being performed.

Who will receive my PHI?

- [ ] Sponsor or other funding source to provide oversight for entire research project
- [ ] Research investigators to conduct and oversee the research project
Principal Investigator and research team members to participate in the various research activities
FDA or other regulatory agencies to provide regulatory oversight
UMCIRB to provide continuing review of the research project
Institutional officials in connection with duties for monitoring research activity
Other providers involved in your care during research procedures, outpatient/inpatient stays during which research is being performed, or physician office visits during which research is being performed.
Researchers at other sites—List sites:
Data and Safety Monitoring Board and its staff
Contract Research Organization and its staff
Other: People designated by Vidant Medical Center and Vidant Health System

We will share only the PHI listed above with the individuals/agencies listed above. If we need to share other PHI or if we need to send PHI to other individuals/agencies not listed above, we will ask for your permission in writing again

How my PHI may be released to others:
ECU and VMC are required under law to protect your PHI. However, those individuals or agencies who receive your PHI may not be required by the Federal privacy laws to protect it and may share your PHI with others without your permission, if permitted by the laws governing them.

What if I do not sign this form?
You will not be eligible to participate in this study if you do not sign this Authorization form.

How may I revoke (take back) my authorization?
You have the right to stop sharing your PHI. To revoke (or take back) your authorization, you must give the Principal Investigator your request to revoke (or take back) your authorization in writing. If you request that we stop collecting your PHI for the study, you may be removed from the study. If you are removed from the study, it will not affect your ability to receive standard medical care or affect payment, health plan enrollment or benefit eligibility. PHI collected for the research study prior to revoking (or taking back) your Authorization will continue to be used for the purposes of the research study. Also, the FDA (if involved with your study) can look at your PHI related to the study even if you withdraw this authorization.

Restrictions on access to my PHI:
You will not be able to see your PHI in your medical record related to this study until the study is complete. If it is necessary for your care, your PHI will be provided to you or your physician.

How long may the PHI about me be used or disclosed for this study?
Research information continues to be looked at after the study is finished so it is difficult to say when use of your PHI will stop. There is not an expiration date for this authorization to use and disclose your PHI for this study.

If you have questions about the sharing of PHI related to this research study, call the Principal Investigator, Aubry N. Koehler, at phone number (252) 737-1415 or the Principal Investigator’s Supervisor, Jennifer Hodgson, PhD, at (252) 328-1349. Also, you may telephone the University and Medical Center Institutional Review Board at 252-744-2914. In addition, if you have concerns about confidentiality and privacy rights, you may phone the Privacy Officer at Vidant Medical Center at 252-847-6545 or the Privacy Officer at East Carolina University at 252-744-5200.
**Authorization**

To authorize the use and disclosure of your PHI for this study in the way that has been described in this form, please sign below and date when you signed this form. A signed copy of this Authorization will be given to you for your records.

<table>
<thead>
<tr>
<th>Name of Participant or Authorized Representative (print)</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

If an Authorized Representative has signed on behalf of a Participant please print on the line above the authority of the Legal Representative to do so (*such as parent, court-appointed guardian, or power of attorney*).

<table>
<thead>
<tr>
<th>Person Obtaining Authorization</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>
APPENDIX E: SURVEYS

“TIME 1” (T1) SURVEY
To be administered at the time of study enrollment, pre-discharge.

Date:
ID #:

1. What was your recent hospitalization for?
☐ Heart attack (MI)
☐ Coronary artery bypass (CABG)
☐ Coronary stenting (“stent,” PCTA/angioplasty, or other PCI)
☐ Heart attack with revascularization (CABG, PCTA, or other PCI)
☐ Angina
☐ Heart valve repair/replacement
☐ Heart transplant
☐ Peripheral artery disease

2. What is your sex/gender?
☐ Female
☐ Male
☐ Other

3. What year were you born?
______________

4. How would you define your race/ethnicity:
☐ American Indian or Alaskan Native
☐ Asian or Asian American
☐ Black or African American
☐ Hawaiian or Other Pacific Islander
☐ Hispanic or Latino/Latina
☐ Non-Hispanic White

5. What is the highest level of education you have completed?
☐ Did not complete High School
☐ GED/High School graduate
☐ Some college
☐ College graduate
☐ Graduate school
6. How would you describe your current employment?
☐ Employed for wages – full time
☐ Employed for wages – part time
☐ Self-employed
☐ Out of work for more than 1 year
☐ Out of work for less than 1 year
☐ A homemaker
☐ A student
☐ Retired
☐ Unable to work

7. What is your total yearly household income?
☐ Less than $10,000
☐ $10,000 to $19,000
☐ $20,000 to $29,000
☐ $30,000 to $39,000
☐ $40,000 to $49,000
☐ $50,000 to $59,000
☐ $60,000 to $69,000
☐ $70,000 to $79,000
☐ $80,000 to $89,000
☐ $90,000 to $99,999
☐ $100,000 to $149,000

8. What type of health insurance do you have?
☐ None
☐ Private insurance (i.e., Blue Cross Blue Shield)
☐ Medicaid
☐ Medicare
☐ Other Public Assistance
☐ Other (please indicate)

9. How would you describe your current relationship status?
☐ Married
☐ Divorced
☐ Widowed
☐ Separated
☐ Never been married
☐ In an unmarried relationship, living together
☐ In an unmarried relationship, not living together

10. How many people are in your household?
__________________
BEHAVIORAL HEALTH QUESTIONS

Please answer the following four questions (Question #11 - #14) according to this prompt:
Over the last 2 weeks, how often have you been bothered by any of the following problems?

11. Little interest or pleasure in doing things
☐ Not at all
☐ Several days
☐ More than half the days
☐ Nearly everyday

12. Feeling down, depressed, or hopeless
☐ Not at all
☐ Several days
☐ More than half the days
☐ Nearly everyday

13. Feeling nervous, anxious, or on edge
☐ Not at all
☐ Several days
☐ More than half the days
☐ Nearly everyday

14. Not being able to stop or control worry
☐ Not at all
☐ Several days
☐ More than half the days
☐ Nearly everyday
### SOCIAL SUPPORT QUESTIONS

Please answer the following questions (Question #15 - #33) according to this prompt: How often is each of the following kinds of support available to you if you need it?

<table>
<thead>
<tr>
<th>Question</th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. Someone you can count on to listen to you when you need to talk</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Someone to give you information to help you understand a situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. Someone to give you good advice about a crisis</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Someone to confide in or talk to about yourself or your problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Someone whose advice you really want</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. Someone to share your most private worries and fears with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21. Someone to turn to for suggestions about how to deal with a personal problem</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. Someone who understands your problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. Someone to help you if you were confined to bed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. Someone to take you to the doctor if you needed it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. Someone to prepare your meals if you were unable to do it yourself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>26. Someone to help with daily chores if you were sick</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>27. Someone who shows you love and affection</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>28. Someone to love and make you feel wanted</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>29. Someone who hugs you</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>30. Someone to have a good time with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>31. Someone to get together with for relaxation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
32. Someone to do something enjoyable with

33. Someone to do things with to help you get your mind off things

SPIRITUALITY QUESTIONS
Please answer the following two questions (Question #34 and #35):

34. I don’t need to improve my health because I know it is up to God.
☐ Strongly Disagree
☐ Disagree
☐ Neither agree nor disagree
☐ Agree
☐ Strongly agree

35. I can control a small health issue, but only God can control a big health issue.
☐ Strongly Disagree
☐ Disagree
☐ Neither agree nor disagree
☐ Agree
☐ Strongly agree
“TIME 2” (T2) SURVEY
To be administered during the six-week post-discharge follow up call.

Date:  
ID #:  

MEDICAL/BIOLOGICAL QUESTIONS
1. Were you scheduled for a follow-up medical appointment after you were discharged from the hospital?  
☐ Yes  
☐ No  
☐ Unsure  

If you answered ‘Yes’ to the above question, please answer the following three questions (Question #2 and #3).

2. Who was the appointment with?  
☐ Primary care provider  
☐ Cardiologist  
☐ Cardiac surgeon  
☐ Other  

3. Did you go to this appointment?  
☐ Yes  
☐ No  
☐ Unsure  

4. Have you had any rehospitalizations since you were first discharged?  
☐ Yes  
☐ No  

5. If you answered ‘yes’ to Question #5, what was this rehospitalization for?
______________________________________________________________________________
BEHAVIORAL HEALTH QUESTIONS
Please answer the following four questions (Question #6 - #9) according to this prompt:
Over the last 2 weeks, how often have you been bothered by any of the following problems?

6. Little interest or pleasure in doing things
☐ Not at all
☐ Several days
☐ More than half the days
☐ Nearly everyday

7. Feeling down, depressed, or hopeless
☐ Not at all
☐ Several days
☐ More than half the days
☐ Nearly everyday

8. Feeling nervous, anxious, or on edge
☐ Not at all
☐ Several days
☐ More than half the days
☐ Nearly everyday

9. Not being able to stop or control worry
☐ Not at all
☐ Several days
☐ More than half the days
☐ Nearly everyday
### SOCIAL SUPPORT QUESTIONS

Please answer the following questions (Question #10 - #28) according to this prompt: How often is each of the following kinds of support available to you if you need it?

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<tr>
<td>26. Someone to get together with for relaxation</td>
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<td>2</td>
<td>3</td>
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<td>5</td>
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</table>
27. Someone to do something enjoyable with

28. Someone to do things with to help you get your mind off things

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SPIRITUALITY QUESTIONS
Please answer the following two questions (Question #29 and #30):

29. I don’t need to improve my health because I know it is up to God.
☐ Strongly Disagree
☐ Disagree
☐ Neither agree nor disagree
☐ Agree
☐ Strongly agree

30. I can control a small health issue, but only God can control a big health issue.
☐ Strongly Disagree
☐ Disagree
☐ Neither agree nor disagree
☐ Agree
☐ Strongly agree
DEMOGRAPHICS QUESTIONNAIRE
To be administered to qualitative-only participants at time of interview

Date:
ID #:

1. What was your recent hospitalization for?
☐ Heart attack (MI)
☐ Coronary artery bypass (CABG)
☐ Coronary stenting (“stent,” PCTA/angioplasty, or other PCI)
☐ Heart attack with revascularization (CABG, PCTA, or other PCI)
☐ Angina
☐ Heart valve repair/replacement
☐ Heart transplant
☐ Peripheral artery disease

2. What is your sex/gender?
☐ Female
☐ Male
☐ Other

3. What year were you born?
______________

4. How would you define your race/ethnicity:
☐ American Indian or Alaskan Native
☐ Asian or Asian American
☐ Black or African American
☐ Hawaiian or Other Pacific Islander
☐ Hispanic or Latino/Latina
☐ Non-Hispanic White

5. What is the highest level of education you have completed?
☐ Did not complete High School
☐ GED/High School graduate
☐ Some college
☐ College graduate
☐ Graduate school
6. How would you describe your current employment?

☐ Employed for wages – full time
☐ Employed for wages – part time
☐ Self-employed
☐ Out of work for more than 1 year
☐ Out of work for less than 1 year
☐ A homemaker
☐ A student
☐ Retired
☐ Unable to work

7. What is your total yearly household income?

☐ Less than $10,000
☐ $10,000 to $19,000
☐ $20,000 to $29,000
☐ $30,000 to $39,000
☐ $40,000 to $49,000
☐ $50,000 to $59,000
☐ $60,000 to $69,000
☐ $70,000 to $79,000
☐ $80,000 to $89,000
☐ $90,000 to $99,999
☐ $100,000 to $149,000

8. What type of health insurance do you have?

☐ None
☐ Private insurance (i.e., Blue Cross Blue Shield)
☐ Medicaid
☐ Medicare
☐ Other Public Assistance
☐ Other (please indicate)

9. How would you describe your current relationship status?

☐ Married
☐ Divorced
☐ Widowed
☐ Separated
☐ Never been married
☐ In an unmarried relationship, living together
☐ In an unmarried relationship, not living together

10. How many people are in your household?

__________________
11. Were you scheduled for a follow-up medical appointment after you were discharged from the hospital?

☐ Yes
☐ No
☐ Unsure

If you answered ‘Yes’ to the above question, please answer the following three questions (Question #2 and #3).

12. Who was the appointment with?
☐ Primary care provider
☐ Cardiologist
☐ Cardiac surgeon
☐ Other

13. Did you go to this appointment?
☐ Yes
☐ No
☐ Unsure

14. Have you had any rehospitalizations since you were first discharged?
☐ Yes
☐ No

15. If you answered ‘yes’ to Question #5, what was this rehospitalization for?
______________________________________________________________________________
APPENDIX F: BEHAVIORAL HEALTH RESOURCES

Behavioral Health Resources (for participants pre-discharge)

Some patients who are recovering from a cardiac event or surgery (for example, a heart attack, a bypass, or a stent) may have feelings of anxiety, depression, or emotional distress:

- **Anxiety symptoms**—Feeling worried, nervous, or on edge
- **Depression symptoms**—Feeling down, sad, “blue,” or hopeless
- **Emotional distress**—Feeling of angry, fearful or scared, frustrated, or grief-stricken.

Today, when I asked you about how you are doing, some of your answers told me that you may be experiencing anxiety or depression symptoms. What I am going to do is let your care provider know that you are experiencing these symptoms. That way, he or she can help connect you with behavioral resources in the hospital that you chose to use.

After you discharge, I encourage you to do the following to make sure you get the support you need:

1) Let your primary care provider and/or cardiologist know that you are experiencing feelings of anxiety, depression, or emotional distress.

2) Let your trusted family members and friends know that you are experiencing feelings of anxiety, depression, or emotional distress.

3) Contact a behavioral health provider with whom you can meet and discuss your feelings.

Here are some local resources:

a. ECU Family Therapy Clinic, 612 East 10th St., Greenville, NC (252) 737-1415.
   Provides therapy to individuals, couples, and families on a sliding-fee scale.
b. ECU PASS Clinic, Rawl Building Room 311 (ECU Main Campus), East 5th St., Greenville, NC, (252) 737-4180. Provides therapy to individuals on a sliding-fee scale.

c. PORT Human Services, 2602 Courtier Dr., Greenville, NC (252) 752-0483. Provides individual, couple, family, and group therapy for those with a mental health and/or substance abuse diagnosis. Accepts private insurance, Medicare, and Medicaid. Non-insured individuals may be able to receive free services.

d. East Carolina Behavioral Health, (877) 685-2415. ECBH is Pitt County’s Local Managed Care Entity (MCO). A MCO is a storehouse for behavioral health resources. Call their access crisis line (above) for more information.

4) If you ever feel you are in crisis and need help immediately, here are some important contacts:

   a. REAL Crisis Intervention (252) 758-4357. 24/7 crisis line. Provides over-the-phone counseling and referrals.

   b. Call 911 or go to your nearest emergency room.
Behavioral Health Resources (for participants post-discharge)

Some patients who are recovering from a cardiac event or surgery (for example, a heart attack, a bypass, or a stent) may have feelings of anxiety, depression, or emotional distress:

- **Anxiety symptoms**—Feeling worried, nervous, or on edge
- **Depression symptoms**—Feeling down, sad, “blue,” or hopeless
- **Emotional distress**—Feeling of angry, fearful or scared, frustrated, or grief-stricken.

Today, when I asked you about how you are doing, some of your answers told me that you may be experiencing anxiety or depression symptoms. I encourage you to do the following to make sure you have the support that you need:

1) Let your primary care provider and/or cardiologist know that you are experiencing feelings of anxiety, depression, or emotional distress.

2) Let your trusted family members and friends know that you are experiencing feelings of anxiety, depression, or emotional distress.

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b. Call 911 or go to your nearest emergency room.
APPENDIX G: INTERVIEW GUIDE

Introduction

Thank you so much for meeting with me and my research assistant today. I am working on this project because I want to better understand the experience of people recovering from a cardiac event (e.g., heart attack, hospitalization for angina). This project is part of my requirements for my doctoral program at East Carolina University. I am meeting with you because I am particularly interested in the recovery experience of African American patients with CVD after they are discharged from the hospital following a cardiac event.

There are no right or wrong answers; please share information as it comes to mind. What you share with me today will be used only for this project. When I write about the results of my project (in the form of an article, book, and or presentation), I will not use your name or information that could be used to identify you. The consent form you signed when we first met in the hospital is your written agreement for the interview today. Please know that you may decide not to continue with the interview at anytime, or you may choose to “skip” a question if you do not feel comfortable answering it. Just let me know and we will move on, or stop the interview completely. This interview will take about an hour and will be audio recorded. Do you have any questions about the process before we begin?

Grand Tour Question

How would you describe your experience recovering from your cardiac event or surgery after being discharged from the hospital?
Probing Questions

- What has having a heart problem meant to you?
- What are some challenges you have faced in your recovery process?
  - Have you experienced any physical challenges?
  - Have you experienced any emotional challenges
  - Have you experienced any social challenges?
  - Have you experienced any spiritual/religious challenges?
- What successes have you experienced?
- How have you experienced the follow-up appointments with your cardiologist or primary care provider after being discharged from the hospital?
  - How would you describe how you have been treated?
  - How were your questions/concerns addressed?
  - What concerns do you continue to have?
- What is your understanding about how you can best recover from your heart problem?
  - What messages or information have you gotten from your health care provider?
  - What messages or information have your gotten from others?
    - What messages or information have your gotten about diet?
    - What messages or information have your gotten about exercise?
- Did any of your health care providers discuss cardiac rehabilitation (CR) with you?
  
  ***Follow up probes:*** Which health care provider? When was it?
  - What do you think is the importance of CR to your recovery?
  - What were your intentions about participating in CR?
  - Did you have any concerns about CR?
o Did you think about/engage in any alternatives to CR?

• What home remedies (non-medical strategies), if any, have been a part of your recovery process?

• How have you been helped or supported by others in your process of recovering?
  o How have health care providers like doctors, nurses supported you?
  o How have other health people supported you?
  o How have family members supported you?
  o How have friends supported you?
  o How has your community supported you?
  o How has your church/faith community supported you?

• What services (or assistance) have you needed but have not received to help you with recovery?
  o What could health professionals like doctors and nurses have offered after discharge to help you with your recovery?

• What else you would like to share about your recovery experience?
APPENDIX H: REFLEXIVE JOURNAL SELECTED ENTRIES

2/17/14
“A lot of my reflexivity, at this point, is about the process of getting my research started, rather than about how I will interface with participants or the data. The photo-reflexivity project had me writing more pointedly about participants and data, which I imagine I will do more of (and will need to do more of) when I move along in my research. At this point, the bulk of my reflexivity is about being aware of my own fears and the more objective limits of time, and pushing forward in the most judicious way possible.”

7/18/14
“Just finished our first qualitative interview. So excited! As Sean would say, I am super stoked on it! Right after we finished, I said to Michelle, “How about that black hole of cardiac rehab?” People just don’t know. And the tragic thing is, this person would have been a great candidate physically (Michelle says) and also in terms of compliance with medical recommendations. He seems to have great rapport with his doctors, so I imagine if they recommended CR he would be there in a second.”

9/27/14
“Tonight I called #037 to finish our interview. He has been difficult to reach and then, once I reach him, his stamina has been low for the interview. A man answered the phone and I greeted him by [the participant’s] name, but he corrected me, saying that my participant was back in the hospital. Poor guy. It made me sad and also feel kind of hopeless about helping people. Here I am talking to him and really offering no help. It’s a slap-in-the-face reminder of how sick these
people are, too, and how precious and short life is. I need to live while I do this dissertation because it’s not going to keep me warm at night.”

11/20/14

“I went back through the significant statements I underlined in #009 and underlined more inclusively. I had thought I was underlining only statements directly related to my research question/phenomenon of study, but really it’s anything even peripherally related. It’s overwhelming how much DATA there is to work with—I’m not sure how to begin coding it. One step at a time. I am bogged down by the embarrassment of riches in my life—doing things I love but often too much of them. SIMPLIFY.”

12/16/14

“I am juiced and eager to write. Last night, I dreamed I was an anthropologist collecting data on a moped. That is my essence of researcher self! A freedom and excitement. I have lost that in the mire of my dissertation, but I think I am regaining it when I visualize getting back on course with the original purpose of my dissertation—to amplify marginalized voices. I can do that through the qualitative. The qualitative is my vector.”
APPENDIX I: STATEMENTS OF BIAS

Lead Researcher

The lead researcher’s position both as a researcher and as a White, college-educated female from the Northeastern United States are salient to the conceptualization and implementation of this study. An important preliminary step in phenomenological research process is “bracketing” or identifying and “stepping away” from one’s biases to increase the likelihood that they will not interfere with data analysis (Bernard & Ryan, 2010, p. 259). According to Colaizzi (1978), questioning of one’s presuppositions regarding the phenomenon of study allows researchers to approach the study more objectively (Colaizzi, 1978). As Colaizzi (1978) defines it, “objectivity is fidelity to phenomena. It is a refusal to tell the phenomenon what it is, but a respectful listening to what the phenomenon speak of itself” (p. 52).

Throughout the conceptualization of this study, the lead researcher engaged in reflexivity or “conscious self-reflection on the part of the researcher to make explicit their potential influence on the research process” (Hennink, Hutter, & Bailey, 2011, p. 19). This process has included (a) ongoing reflexive journaling, and (b) a photo-reflexivity project that assisted the lead researcher in exploring her beliefs, assumptions, values, and biases associated with her dissertation topic. These activities have elucidated the following insights into the lead researcher’s perceptions: (a) a bias against health promotion interventions that are inaccessible to socially disadvantaged patients; (b) an assumption that religion is important for many African Americans living in the Southeastern United States; (c) a belief that most disparities in health outcomes and health care can be explained by limited access to resources; and (d) a bias favoring early intervention for the management of health problems and the need for integrated medical and behavioral health care. The lead researcher challenged these biases and held an awareness to them throughout study conceptualization to manage undue influence of these biases on the study.
The lead researcher has also engaged in ongoing reflexivity and peer dialogue regarding her position as a White researcher doing research with African American participants. Considering the historical trauma experienced by African Americans in the context of medical and scientific research (Washington, 2006), the lead researcher acknowledges the need for particular sensitivity in approaching both this research topic and research participants. First and foremost, she held an awareness of racial/ethnic disparities in power and privilege, and specifically, how her own White privilege could inadvertently silence others (e.g., McGoldrick & Hardy, 2008). She believed it was her charge to do everything possible to ensure that this silencing did not take place. In taking a stance of cultural humility and curiosity, tentatively offering ideas, asking questions to foster greater understandings, and including a methodological component that explores participants’ experiences as they understand them (phenomenology), she has endeavored to promote minority voices within this socially complex dynamic.
References


Triangulated Researcher

When conducting research, it is important to examine and question biases that may involve particular topics within the study at hand. Becoming more aware of personal beliefs and values can help researchers recognize how their backgrounds may affect their perspective on their research. The triangulated researcher’s position as a White, college-educated female in the South affects her perspective on health and health disparities in several ways. First, she realizes that her race inherently allows her opportunities and experiences that people of color may not have. A degree in Anthropology has allowed her to become more aware of limitations and restrictions that racial minorities may encounter in many environments, including healthcare settings. This has led the triangulated researcher to believe that African Americans may have to deal with implicit institutional oppression and inequality when trying to recover from a cardiac event or surgery. Consequently, the triangulated researcher feels that there are more complex issues for African Americans than for their White counterparts when considering how and why rehabilitation services are used after discharging from the hospital.

Additionally, growing up in a small Southern town has reinforced the triangulated researcher’s beliefs about the importance of religion in a healthy life and family system. Living in the South for 23 years has contributed to her understanding that the majority of families in this region value religion and the significance of prayer and reliance on God in the recovery process. Because of this, the triangulated researcher feels that an emphasis needs to be placed on having conversations about spirituality, perceptions about healthcare, and other factors that patients believe influence their recovery.