EXPLORING THE EFFECTS OF BEING A PEER EDUCATOR ON AFRICAN AMERICAN BREAST CANCER SURVIVORS

by

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ABSTRACT

MELANIE J. ROUSE. Exploring the effects of being a peer educator on African
American breast cancer survivors. (Under the direction of DR. A. SUZANNE BOYD
and DR. DEE BALDWIN)

Efforts to reduce breast cancer-related health disparities amongst African American and White women have resulted in the development of breast cancer outreach programs that often include African American breast cancer survivors as peer educators. These programs have the potential to be beneficial for the survivors who serve as peer educators because of the potential to enhance self-efficacy beliefs through the spiritual foundation, the opportunity to be active in breast cancer outreach, exposure to other survivors and the sharing of illness narratives. Thus far, there is limited research available on African American breast cancer survivors who serve as peer educators. The purpose of this study was to explore the experiences of these survivors and the effect of the peer education program on the survivors' quality of life (QOL), health behaviors, and healthcare utilization. Following a grounded theory design, participants completed semi-structured interviews exploring their peer educator experiences, QOL, health behaviors, and healthcare utilization. Study findings reveal that overall participants had positive experiences as peer educators that often resulted in the participant finding her voice. Participation in the peer educator role was also found to positively influence the participants' QOL, health behaviors and healthcare utilization. The findings of this study are important in directing future research and understanding the potential benefits and/or risks of being a peer educator and may aid in the recruitment and retention of African American breast cancer survivors in these outreach programs.

DEDICATION

I dedicate this dissertation to my father who taught me never to give up.

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I am extremely thankful for all of the volunteers who chose to participate in this study and allowed me the opportunity to interview them. A special thank you goes to my entire dissertation committee: Dr. A. Suzanne Boyd, Dr. Dee Baldwin, Dr. David Langford, Dr. Jan Warren-Findlow, and Dr. Margaret C. Wilmoth. Thank you all for your time, thoughtful feedback, encouragement, and patience during this process. Each of you have challenged and inspired me in a way that I will forever be grateful.

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CHAPTER 1: INTRODUCTION

Survival rates for breast cancer among women in the U.S. continue to increase because of advances in the detection and treatment of breast cancer ("American Cancer Society. Breast cancer facts and figures 2011-2012," 2011; Lopez, Eng, Randall-David, & Robinson, 2005). As the number of women surviving breast cancer increases, the quality of that survival becomes an important issue for scholars, health professionals, and patients alike. This is especially true for African American survivors as these women often suffer from negative health outcomes at each stage of the breast cancer experience, including the survival stage (Barsevick, Bradley, Donnelly, & Micco, 2012; Bigby & Holmes, 2005; Bowen et al., 2007; Bradley, 2006; Du & Simon, 2005; Dunn, Agurs-Collins, Browne, Lubet, & Johnson, 2010).

1.1 African American Breast Cancer Survivors

Previous research indicates that African American breast cancer survivors are half as likely as their White American counterparts to have a mammogram after completion of treatment, and the duration of their medical follow-up care post-treatment on average is shorter, as well (Thompson, Littles, Jacob, & Coker, 2006). African American breast cancer survivors are also more likely to have lymphedema and report higher levels of pain post-treatment (Green, Hart-Johnson, & Loeffler, 2011; Morehead-Gee et al., 2012). These disparities can be attributed to several factors, such as a lack of access to and utilization of health services, co-morbidities, lower physical activity levels, and cultural values and beliefs unique to the African American population, including a mistrust of the healthcare system, in general (Du & Simon, 2005; Guidry, Torrence, & Herbelin, 2005; Hao et al., 2011; Kent et al., 2012; Masi & Olopade, 2005).

As the number of African American women surviving breast cancer increases, the quality of that survival is becoming more and more important. Quality of life (QOL) is a multidimensional construct that measures the degree of physical, emotional, functional, social, and spiritual well-being of an individual (Hennessy, Moriarty, Zack, Scherr, & Brackbill, 1994). There are a limited number of published studies that focus specifically on measuring the QOL of African American breast cancer survivors. Overall, these studies suggest that these survivors are more likely to have experienced impaired QOL and to have needs that are distinct from their White American counterparts, including becoming comfortable with the future, social and familial role adjustments, and access to health-related information (Ashing-Giwa, 1999; Rust & Davis, 2011) . The familial, social, occupational, and even, spiritual roles that these survivors play in their daily lives are important contributors to these needs (Fatone, Moadel, Foley, Fleming, & Jandorf, , 2007; Hamilton, Moore, Powe, Agarwal, & Martin, 2010; Hamilton & Sandelowski, 2004). For example, African American survivors may feel the need to serve as role models or advocates to help dispel the stigma of cancer as a death sentence within the African American community (Lopez et al., 2005). Or, they may feel a spiritual obligation to be a “witness” and give testimony of their breast cancer experience to others (Fatone et al., , 2007). Understanding the impact of these roles on the QOL of African American breast cancer survivors is important in the development and improvement of interventions that specifically target this population. In particular, the effect of serving as a peer educator in breast cancer-related programs has been largely ignored in the literature despite the potential impact of this role on the survivor's QOL (Boyd & Wilmoth, 2006; Hilaire, 2011).

1.2 African American Survivors as Peer Educators

In an effort to eliminate breast cancer disparities between African American and White women, several interventions have been developed and implemented specifically for African American women. Although the interventions may be structured differently, they often incorporate similar components, including religious or spiritual themes, education components, and incorporate African American breast cancer survivors as peer educators or peer supporters to other African American women (Boyd & Wilmoth, 2006; Shaw & Coggin, 2008; "Sisters Network, Inc: A National African American Breast Cancer Survivorship Organization," 2009; "The Witness Project: History," 2000). Although there is lack of research into the effect of this role on breast cancer survivors, research in other disciplines suggest peer education and support interventions have the potential to greatly impact the QOL of survivors who participate in these roles through the exposure to other survivors, the telling of their stories, and the health knowledge that can be gained (Bracke, Christiaens, & Verhaeghe, 2008; Davidson, Chinman, Sells, & Rowe, 2006; Solomon, 2004).

In these peer education programs, survivors often serve as the “witnesses” who tell the story of their breast cancer experience to their peers (Boyd & Wilmoth, 2006; "The Witness Project: History," 2000). Telling the story of their cancer experience can affect the survivor in potentially negative or positive ways. For some survivors, telling their story may cause increased stress and anxiety related to the illness and the fear of recurrence (Anderson & Geist Martin, 2003). Others, however, may have a more positive result and become empowered through telling their story. For these survivors, telling their story may give them a sense of control and a better understanding of themselves and their relationships with others (Anderson & Geist Martin, 2003).

1.3 Statement of the Problem

Increasingly, African American survivors are serving as peer educators in breast cancer support groups and breast cancer screening and prevention programs. In these programs, survivors often serve as “witnesses,” telling the story of their breast cancer experience to their peers (Boyd & Wilmoth, 2006; Erwin et al., 2003; "Sisters Network, Inc: A National African American Breast Cancer Survivorship Organization," 2009; "The Witness Project: History," 2000). These programs often incorporate various components, such as health education, the use of illness narratives, and exposure to other survivors that may greatly impact the survivor/peer educator (Boyd & Wilmoth, 2006; "Sisters Network, Inc: A National African American Breast Cancer Survivorship Organization," 2009; "The Witness Project: History," 2000). Each of these different program components, along with the requirements of the role itself, can potentially impact the QOL of the survivor. It is important that the experiences of the women who participate in these roles be explored in-depth so that the potential benefits and/or risks to the survivor can be assessed.

1.4 Purpose of the Study

There is insufficient data on the experiences and effects of peer education on the African American breast cancer survivor/peer educator. This study on the effects of being a peer educator on African American women who are breast cancer survivors can contribute to a better understanding of the experiences of survivors who currently participate in this role. Therefore, the purpose of this study is to explore the experiences of peer educators/breast cancer survivors, as well as, the effect of the peer education/support program on their QOL, health behaviors and healthcare utilization.

1.5 Conceptual Framework: Bandura's Theory of Self-Efficacy

Self-efficacy beliefs play an integral role in an individuals' QOL in several different ways. First, self-efficacy influences the emotional and psychological well-being of an individual. Higher self-efficacy beliefs are associated with increases in self-confidence, self-esteem, and belief in one's ability (Bandura, 1997). High self-efficacy beliefs also positively influence health behaviors and healthcare utilization. Those who have high self-efficacy beliefs in their ability to perform positive health behaviors are more likely to be motivated to make those changes and are more likely to maintain them, resulting in more positive health outcomes (Ley et al., 2002). Among 56 breast cancer survivors, Ley and colleagues (2002) were able to demonstrate that survivors who participated in a self-efficacy enhancing group tended to have a higher quality of life than those who did not participate.

According to Bandura (1986), self-efficacy beliefs are created through personal experience, vicarious experience, social persuasion, somatic, and emotional states. There are several ways to strengthen self-efficacy, including providing encouragement, informative feedback, and exposure to peer-models and hearing their stories (Bandura, 1986). Peer outreach programs that incorporate African American breast cancer survivors as peer educators/supporters have the potential to meet some of the QOL needs of African American survivors by increasing the peer educators' self-efficacy (Bazargan, Kelly, Stein, Husaini, & Bazargan, 2000; Downing et al., 1999) The increase in self-efficacy may lead to an increase in positive health behaviors, which may, in turn, meet some of the QOL needs of survivors, including: increased physical activity, better eating habits, social and familial role adjustments, and access to breast cancer related health information. This is potentially due to the inclusion of the social support through exposure to other survivors, health knowledge through a health education component, and the African American tradition of "witnessing" through the illness narrative (Boyd & Wilmoth, 2006). Each of these concepts (social support, health education, and "witnessing") are common in breast cancer outreach programs and have been highlighted by African American survivors as a QOL need (Coggin & Shaw-Perry, 2006; Lythcott, Green, & Kramer-Brown, 2003; Moore, 2001; Powe et al., 2007).

The impact of these concepts on the health behaviors and QOL needs of the survivors may be influenced by several behavioral, affective, personal, and situational environmental factors. The *behavioral factors* include the individual's self-efficacy for performing preventive health behaviors and the *affective factors* include individual's level of anxiety and distress related to the repetition of the illness narrative and the burden of the role model/advocate role (Bandura, 1997). The *personal environmental factors* that may influence the health behaviors and QOL needs of survivors include self-efficacy for self-management of their health, the length of time and the amount of involvement in the programs, and the individual's spiritual/cultural belief in "witnessing" (Bandura, 1997; Holt & Klem, 2005). The *situational environmental factors* include the stage of their cancer, the length of time since the diagnosis and completion of treatment and the individual's health status. The benefits that may be gained through participation in peer outreach programs have the potential to increase African American breast cancer survivors' self-efficacy beliefs, the motivation for the adoption and maintenance of positive health behaviors and preventive healthcare utilization and, therefore, the QOL needs of survivors. Several concepts from Bandura's self-efficacy theory will be used to guide the development of this study, including: behavioral, cognitive, affective, and personal and situational environment.

1.6 Research Questions

The two primary objectives of this study are to (a) describe the experiences of African American breast cancer survivors serving as peer educators in Breast Cancer Outreach Programs and any potential benefits or risks associated with being a peer educator and (b) to explore the ways in which speaking about their breast cancer experience influences the self-efficacy, health behaviors and healthcare utilization, and ultimately QOL needs. To achieve these objectives, two research questions, along with a three sub-questions, were developed. These are:

1. What are the experiences of African American breast cancer survivors serving as peer educators in Breast Cancer Outreach Programs?
    a. What were their initial motivations and expectations for becoming a peer educator?
    b. How have these motivations and expectations changed or stayed the same in light of their experiences as peer educators?
    c. What positive or negative impact has being a peer educator had on the quality of life needs of peer educators who are also survivors?
2. How has being a peer educator influenced the health behaviors and healthcare

utilization of African American breast cancer survivors?

1.7 Relevant Definitions

- African American: Self-described as being an American of African descent
- Grounded Theory: A systematic qualitative research methodology that emphasizes the generation of theory from the data (Strauss & Corbin, 1994)
- Health Behaviors: any activity performed by an individual for the purpose of promoting, protecting or maintaining health (Stolley, Sharp, Wells, Simon, & Schiffer, 2006)
- Healthcare Utilization: Use of healthcare services and resources, including doctor visits and routine screenings, such as mammograms (Bowman, Rose, Deimling, Kypriotakis, & O'Toole, 2010; Breslau et al., 2010)
- Illness Narratives: An individual’s story about their own illness and its effect on their life (Frank, 1995)
- Peer Educator: An individual that provides knowledge, experience, emotional, social or practical support to other women with or without a breast cancer diagnosis (Funnell, 2010)
- Quality of Life (QOL): A subjective, multi-dimensional concept that incorporates a broad range of domains including: (a) physical, (b) functional, (c) emotional, (d) psychological, (e) social and (f) spiritual well-being (Hennessy et al., 1994)
- Self-efficacy: An individual’s belief that he or she is capable of carrying out activities in a certain manner to attain specific goals (Mosher, Duhamel, Egert, & Smith, 2010)
- Survivor: a term given at the time of cancer diagnosis based on the standard

definition of cancer survivorship (Smith et al., 2007)

1.8 Significance of the Study

There is insufficient data on the experiences of African American breast cancer survivors who serve as peer educators and the impact of that role on the survivors' QOL. Exploration of the experiences of those participating in this role and the QOL impact is important because these women provide services to their peers across the breast cancer continuum, including: (a) promoting breast cancer prevention and screening amongst African American women, in general, (b) serving as patient navigators or community health workers that provide breast cancer medication and treatment information and guidance for patients with breast cancer from the time of their diagnosis through the completion of treatment, and (c) providing support and health education for those who are in the post-treatment phase of breast cancer. Findings from this study may contribute to the recruitment and retention of survivors who participate in this role and suggest the ways in which their QOL is impacted by the role.

This study focuses on social factors and personal behaviors of individual African American breast cancer survivors who serve as peer educators. In this study the experiences of these peer educators will be explored, as well as, the effect of the role on the survivors' QOL, health behaviors, and healthcare utilization. This research is significant in that it extends the current knowledge base in the field and provides a foundation for further study of African American breast cancer survivors who serve as peer educators. Health services research is defined as a "multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviors affect access to health care, the quality and cost of health care and ultimately our health and well-being. Its research domains are individuals, families, organizations, institutions, communities and populations (Lohr & Steinwachs, 2002).” The results of this study will highlight social factors, personal behaviors, and program structures and processes that influence African American breast cancer survivors to initiate and continue participation in the peer educator role. These results can then be used to suggest factors that should be explored in more depth and provide direction for future research with this population.

There are also several cancer-related objectives highlighted in the *Healthy People 2020* report for which this research is significant ("Healthy People 2020," 2012). These objectives include increasing the proportion of survivors living 5 years or longer and improving the mental and physical health-related QOL among cancer survivors in general. *Healthy People 2020* includes breast cancer specific objectives as well. These objectives are to reduce the death rate, reduce late stage diagnosis, and to increase the proportion of women who receive breast cancer screenings according to recommended guidelines ("Healthy People 2020," 2012). The findings of this study will be useful in future research evaluating the impact of serving as a peer educator on these objectives amongst African American breast cancer survivors. This research will also be useful in informing the development, evaluation, and improvement of interventions that focus on these objectives and incorporate survivors as a part of the intervention.

This study will incorporate a grounded theory design so that the development of a conceptual model of the phenomenon will be grounded in the experiences of the participants. The study findings will be useful in understanding the potential benefits and/or risks of being a peer educator and the potential impact of peer education programs on the health behaviors and healthcare utilization of the survivors. In addition, these findings will also be useful in informing health service research policies aimed at improving the quality of survivorship of African American breast cancer survivors, including policies that incorporate peer education/peer support as complementary to traditional healthcare services.

CHAPTER 2: LITERATURE REVIEW

Breast cancer is an enduring condition characterized by physical, psychological, and social concerns that can continue for years after the initial treatment is completed due to the lasting effects of the cancer treatment and the potential for cancer recurrence (Bloom, Petersen, & Kang, 2007). These concerns include the disruption in the survivor's ability to fulfill their roles within family and society. This disruption often results in changes in the attitudes, perspective and outlook, meaning, and interpersonal interactions of the cancer survivor (Carpenter, Brockopp, & Andrykowski, 1999; Mathieson & Stam, 1995). Survival rates for breast cancer among women in the U.S. continue to increase due to advances in the detection and treatment of breast cancer. However, African American women continue to have higher mortality rates as compared to other racial/ethnic groups ("American Cancer Society. Breast cancer facts and figures 2011-2012," 2011; Lopez et al., 2005).

As the number of women surviving breast cancer increases, the quality of that survival becomes an important issue for scholars, health professionals, and patients alike. This is especially true for African American survivors who often suffer from more negative health outcomes at each stage of the breast cancer experience when compared to other racial and/or ethnic groups (Bigby & Holmes, 2005; Bowen et al., 2007; Bradley, 2006; Dunn et al., 2010; Morehead-Gee et al., 2012). Between 2003 and 2007, African American women were found to have an overall breast cancer mortality rate of 32.4, which is higher than the White American women mortality rate of 23.9. The higher mortality rate among African American women occurred despite them having a lower overall incidence rate than white women (116.1 vs. 125.4, respectively) ("American Cancer Society. Cancer Facts and Figures for African Americans 2011-2012," 2011). The 5-year relative survival rate among African American women is also lower than that for White American women, with 78% of African Americans and 90% of White Americans who were diagnosed between 1999 and 2006 surviving five years ("American Cancer Society. Cancer Facts and Figures for African Americans 2011-2012," 2011; Mackenzie, Carlson, Munoz, & Speca, 2007).

Disparities in the mortality and incidence rate of breast cancer among African American and White American women may reflect other disparities that exist in various stages of the breast cancer experience. More often, African American women are diagnosed with late stage breast cancer and present with co-morbidities, such as diabetes, heart disease, and high blood pressure, and more aggressive tumors that are difficult to treat ("American Cancer Society. Cancer Facts and Figures for African Americans 2011-2012," 2011). African American women with breast cancer are more likely to experience delays in time from an abnormal screening test result and breast cancer diagnosis, as well as delays in time from diagnosis to treatment initiation (Campbell, 2002; Fedewa et al., 2011). Previous research also indicates that African American women are less likely to undergo guideline-based surgical treatments and adjuvant therapy (Morris, Rhoads, Stain, & Birkmeyer, 2010). In addition to these disparities, African American survivors are half as likely as their White American counterparts to have a mammogram after completion of treatment and the duration of their medical follow-up care post-treatment on average is shorter, as well (Thompson et al., 2006). These disparities can be attributed to several factors, such as a lack of access to and/or utilization of health services and cultural values and beliefs unique to the African American population, including a mistrust of the healthcare system, in general (Du & Simon, 2005; Dunn et al., 2010; Guidry et al., 2005; Masi & Olopade, 2005; Matthews, Tejeda, Johnson, Berbaum, & Manfredi, 2012)

There are a limited number of studies that focus on the quality of life (QOL) of African American breast cancer survivors. Studies that do focus on the QOL of African American breast cancer survivors suggest that these survivors are more likely to have impaired QOL and to have needs that are distinct from their White American counterparts (Ashing-Giwa, 1999; Aziz & Rowland, 2002; Russell, Von Ah, Giesler, Storniolo, & Haase, 2008) . These needs include becoming comfortable with the future, social and familial role adjustment, and being a role model/advocate (Powe et al., 2007). The familial, social, and occupational roles that African American breast cancer survivors play in their daily lives is an important contributor to these needs (Fatone et al., 2007; Hamilton & Sandelowski, 2004). Understanding the impact of these roles on the QOL of African American breast cancer survivors is important in the development and improvement of interventions that specifically target this population.

Few studies have explored the effect various social and familial roles have on African American breast cancer survivors’ QOL. In particular, the effect of serving as a peer educator in breast cancer-related programs has largely been ignored. Increasingly, African American survivors are serving as peer educators in breast cancer support groups and breast cancer screening and prevention programs. These programs often incorporate various components, such as health education, the use of illness narratives, and exposure to other survivors, that may greatly impact the survivor/peer educator (Boyd & Wilmoth, 2006; "Sisters Network, Inc: A National African American Breast Cancer Survivorship Organization," 2009; "The Witness Project: History," 2000). The purpose of this chapter is to summarize the current literature on the QOL of African American breast cancer survivors and to discuss the potential impact participation in the peer educator role may have on their QOL. The implications of research in this area will also be highlighted.

2.1 Quality of Life for Breast Cancer Survivors

Quality of life is a subjective, multi-dimensional concept that incorporates a broad range of domains including: (a) physical, (b) functional, (c) emotional, (d) psychological, (e) social and (f) spiritual well-being (Hennessy et al., 1994). Each domain assesses a different aspect of an individual's sense of well-being and ability to manage day-to-day activities (Ashing-Giwa, 2005). Studies exploring the QOL of breast cancer survivors have found that factors such as the perception of illness and treatment, health behaviors, socioeconomic status, self-expectations, risk appraisals, cultural values and beliefs, as well as life experiences greatly influence the QOL of survivors (Ashing-Giwa & Lim, 2010b; Powe et al., 2007).

QOL for breast cancer survivors, in general, is associated with cancer recurrence, the use of adjuvant therapy, the type of breast surgery used, socioeconomic status, access to quality healthcare, and psychosocial factors, including: (a) general health perception, (b) depression, (c) self-consciousness about appearance, (d) avoidance of thoughts about cancer, (e) physical health, and (f) familial, social, and occupational role limitations. Survivors often experience increased physical and psychosocial symptoms, fatigue, and social and occupational changes (Bowen et al., 2007; Paskett et al., 2008). In general, survivors' QOL tends to improve within the first two years post-diagnosis to be only slightly lower than that of women of similar age without a diagnosis of breast cancer (Bowen et al., 2007; Casso, Buist, & Taplin, 2004; Dorval, Maunsell, Deschenes, Brisson, & Masse, 1998; Geiger et al., 2006). Among long-term survivors who have not had a recurrence of cancer and have positive psychosocial functioning, their QOL is often similar to that of women without breast cancer (Dorval et al., 1998). There is, however, a subgroup of survivors who continue to experience poor QOL beyond two-years post diagnosis. This group is comprised of 20-25% of all breast cancer survivors. Predictors of poor QOL in this group include higher age, lower income, co-morbidity, undergoing a mastectomy, and receiving chemotherapy (Bowen et al., 2007; Bower et al., 2006; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998).

2.2 African American Breast Cancer Survivors

Many of the previously discussed studies on QOL of breast cancer survivors included few African American participants or did not explore breast cancer survivorship by race. For example, Ganz and colleagues (1998) study of health-related QOL and sexual functioning among breast cancer survivors included 122 African American women out of a total sample size of 864 but did not explore the results of their study by race. In another example, Bower and colleagues (2006) study of fatigue in breast cancer survivors included a sample size of 817 but did not report the racial/ethnic demographics of the sample. It is important that research in this area be stratified by race because factors that are known predictors of lower QOL in various domains among breast cancer survivors are more prevalent within the African American community, in general and, among African American breast cancer survivors, specifically (Bigby & Holmes, 2005; Eversley et al., 2005; Hao et al., 2011; Matthews et al., 2012; Powe et al., 2007). Therefore, race may be representative of other risk factors for QOL impairment, such as lower socioeconomic status, physical activity levels, and cancer screening rates, as well as, limited or lack of access to quality healthcare (Bigby & Holmes, 2005; Campbell, 2002; Giedzinska, Meyerowitz, Ganz, & Rowland, 2004; Matthews et al., 2012). Race may also be a proxy for co-morbidity, late stage diagnosis, more aggressive tumors, and increased use of mastectomy without reconstruction and chemotherapy (Bigby & Holmes, 2005; Eversley et al., 2005; Giedzinska et al., 2004; Matthews et al., 2012). However, even when controlling for these risk factors, African American race continues to have a significant impact on QOL (Campbell, 2002; Paxton et al., 2012; Powe et al., 2007). This may be because race reflects the unique cultural beliefs, values, and shared experiences of individuals within the African American community, including real or perceived racism/racial discrimination (Hamilton, Agarwal, Carter, & Crandell, 2011; Powe et al., 2007; Russell et al., 2008). These beliefs, values, and shared experiences play a significant role in how the individual responds to each stage of the breast cancer experience, from prevention to mortality, and greatly impact QOL at each stage (Aziz & Rowland, 2002; Bigby & Holmes, 2005; Campbell, 2002; Kagawa-Singer, Padilla, & Ashing-Giwa, 2010; Powe et al., 2007).

Taken together, studies exploring breast cancer survivorship by race demonstrate that African American survivors may be at greater risk than their White American counterparts for QOL impairment (Aziz & Rowland, 2002; Giedzinska et al., 2004; Hao et al., 2011; Matthews et al., 2012). In a prospective population-based, multicenter, multiethnic study by Bowen and colleagues (2007), researchers found that African American survivors reported significantly lower physical functioning compared to their

White American counterparts. In this study, the mean score for African American participants on the Medical Outcomes Study short form 36 physical component was found to be 43.5 compared to a mean score of 47.0 for White American participants (*P*=0.01). Paskett and colleagues (2008) found similar results in their observational study that included comparisons of breast cancer survivors and women without breast cancer. The findings of their research study demonstrate that while both African American and White American cancer survivors had poorer physical functioning and general health than women without breast cancer, African American breast cancer survivors had significantly worse physical functioning and general health than their White American counterparts.

Other studies show that African American breast cancer survivors are more likely to experience fatigue, keloid formation, and increased risk for lymphedema and role limitations than their White American counterparts (Giedzinska et al., 2004; Russell et al., 2008; Schootman, Deshpande, Pruitt, Aft, & Jeffe, 2010). The disparities found in these research studies are partially attributable to African American survivors' increased risk for late stage diagnosis, the presence of co-morbidities, increased use of chemotherapy and mastectomy, and the intensity of the treatment due to the late stage diagnosis (Bigby & Holmes, 2005; Bowen et al., 2007). African American survivors are also more likely to be overweight or obese, have a poor diet and participate in low levels of physical activity (Bigby & Holmes, 2005; Morehead-Gee et al., 2012; Schootman et al., 2010).

While the literature has demonstrated that African American breast cancer survivors do experience some QOL impairment in comparison to their White American counterparts, some studies have demonstrated areas in which African American breast cancer survivors actually fare better than their White American counterparts. Ashing-Giwa and Lim (2010a) conducted a cross-sectional study among a population-based sample of 703 participants exploring functional strain and emotional well-being by race/ethnicity. In this study, the researchers found that African American survivors tend to have better mental health, emotional well-being, and less fear of recurrence than their White American counterparts (Ashing-Giwa & Lim, 2010a). Bowen and colleagues found similar results in their 2007 study of 804 breast cancer survivors suggesting that the differences in mental and emotional functioning between African American breast cancer survivors and White American breast cancer survivors may be associated with the spirituality, social support, resiliency and post-traumatic growth present among African American survivors (Bowen et al., 2007). Although African American survivors fare better than their White counterparts on mental health and emotional well-being, they continue to be significantly worse than African American women without a cancer diagnosis in these areas as demonstrated in the study by Paskett and colleagues (2008).

Most of the research discussed above used QOL assessment instruments that had been validated with primarily White American samples and do not address the socio-cultural context within which African American women endure their breast cancer experience (Bigby & Holmes, 2005; Powe et al., 2007; Russell et al., 2008). The few studies that focus specifically on African American survivors show that the unique socio-cultural context within which these women experience, perceive, and respond to QOL challenges may help to explain their increased risk for QOL impairment (Fatone et al., 2007; Lopez et al., 2005; Powe et al., 2007). There are three social forces that drive and shape the socio-cultural context for African American survivors: stigmatizing beliefs about cancer, racial discrimination, and cultural beliefs about African American women (Lopez et al., 2005; Powe et al., 2007). Within the African American community, cancer is often thought of as something to be feared and that a cancer diagnosis would ultimately mean death. This fear often leads to the secrecy amongst those who have been diagnosed with cancer and helps to shape the stigmatizing beliefs about cancer within the African American community (Lopez et al., 2005). African American breast cancer survivors often report experiencing racial discrimination within a healthcare setting and in other settings at some point in their lives (Benjamins, 2012; Lopez et al., 2005; Quach et al., 2012). Quach and colleagues (2012), in a qualitative study of 60 breast cancer survivors that included nine African American women, found that African American survivors who do not report personal experiences of discrimination often report discrimination towards the African American community as a whole. These experiences may lead to the individual internalizing the discrimination leading to the belief that their experiences are result of their own perceived downfalls, such as having a low income, lacking an education, race, etc (Quach et al., 2012). There is the cultural belief within the African American community that the role of a woman is to care for others, particularly the children and elderly in her family. This belief places a particular burden on an African American woman who has been diagnosed with cancer because of the potential limitations her diagnosis may have on her ability to continue this role and to fulfill all of her perceived obligations (Lopez et al., 2005). Understanding the unique socio-cultural context for African American breast cancer survivors and the social forces that influence them is important in adequately addressing the QOL needs of these survivors.

2.3 Unique Needs of African American Survivors

Needs assessments of African American survivors highlight needs that are distinct from White American survivors in that they reflect the socioeconomic characteristics, cultural values and beliefs specific to African American women, in general. In an exploratory, qualitative research study conducted by Coggin and Shaw-Perry (2006) to assess the perceived needs of African American breast cancer survivors, the researchers categorized the needs of the study participants into five themes: (a) physical, (b) social, (c) psychological, (d) spiritual, and (e) financial needs. The QOL needs highlighted by survivors often reflected more than one of these themes and include seeking safe and accessible resources, becoming comfortable with the future, role adjustment, and serving the community as role models (Shaw & Coggin, 2008).

2.3.1 Seeking Safe, Accessible Resources

African American breast cancer survivors in a qualitative study conducted by Coggin and Shaw-Perry (2006) expressed the need for affordable, accessible, and culturally appropriate medical and support services, understanding of the unique life experiences of African American survivors by healthcare professionals, resources for family and self-care, as well as, contacts for information related to breast cancer symptoms and health-related issues. Similar results were found by Powe and colleagues (2007) in their systematic review of the literature related to African American cancer survivors, in general. Seeking safe, accessible resources among African American survivors requires that they put themselves at risk for stigmatization, discrimination, and/or rejection both within their own community and within society (Coggin & Shaw-Perry, 2006; Fatone et al., 2007). This is particularly important because of the mistrust of the healthcare system present in African American culture and the fatalistic view of cancer within the African American community (Corbie-Smith, Thomas, & St. George, 2002; Gamble, 1997; Lopez et al., 2005). Mistrust in the healthcare system among African American survivors may be caused by the survivors' real or perceived experiences of racism and/or racial discrimination at both the individual level and within the African American community as a whole. Hamilton and colleagues (2011), in a cross-sectional study of 449 African American cancer survivors exploring various coping profiles and the relationship with QOL, found that the experiences of real or perceived racism has an impact on QOL and health disparities among African American survivors regardless of the amount of time since the experience creating a mistrust in the healthcare system. This mistrust often leads African American survivors to seek informational support from other sources such as relatives and friends. Survivors typically use the information received from these sources to learn what to expect throughout the breast cancer experience, to validate information received from medical professionals, and as assistance in understanding information they have received from other sources (Hamilton & Sandelowski, 2004). This, along with the fatalistic view of breast cancer present within the African American community, may lead to delayed or avoided medical care and increased bodily pain. The fatalistic view of breast cancer, in particular, may limit the survivor's desire to disclose a breast cancer diagnosis even to family members, thereby, limiting the social support they have available and increasing their isolation (Hamilton et al., 2011).

2.3.2 Becoming Comfortable with the Future

Lopez and colleagues (2005) conducted a qualitative study exploring the QOL concerns of 13 African American breast cancer survivors in a rural county of North Carolina. The researchers in this study found that the need to become comfortable with the future is specifically related to the fear and uncertainty of cancer recurrence (Lopez et al., 2005). Uncertainty can be triggered at random by the development of new aches, pains, and other physical symptoms, hearing about someone else's cancer, information about breast cancer from the media and the internet, doctor's appointments, and mammograms (Gil et al., 2004). It decreases the survivor's sense of control over their lives and resourcefulness, and increases their emotional distress (Dirksen, 2000; Mast, 1998). Fear and uncertainty related to cancer recurrence affects the survivor's ability to form a cognitive structure for the cancer and may result in poor decision-making, poor psychosocial adjustments, and increased likelihood for post-traumatic stress like responses in their daily lives (Mishel, 1999). Emotional support has been identified as important to the improvement of African American survivors' comfort with their future (Hamilton & Sandelowski, 2004). Unlike their White American counterparts, however, having someone there to listen to their personal problems is not very important to these survivors. African American survivors have indicated that simply having people around who are available and willing to help, receiving encouraging words, participating in distracting activities, and having people there to monitor and protect them from negative individuals are most important to them for emotional and social support (Hamilton et al., 2010; Hamilton & Sandelowski, 2004; Russell et al., 2008). These findings have implications for African American breast cancer survivors who also serve as peer educators.

2.3.3 Role Adjustment

Role adjustment needs highlighted by survivors are associated with the long-term work and personal role limitations resulting from the cancer and the treatments endured. Ashing-Giwa and Lim (2010a) found that African American breast cancer survivors more often experience greater physical limitations and decreased work capabilities as a result of the enduring physical and psychosocial effects of the cancer and treatment. They also found that African American survivors are more likely to have dependents for which they are financially responsible. The limitations that these survivors experience as a result of their cancer may create both familial and work strain because of the survivor's inability to care for her dependents in the way she had prior to her cancer diagnosis (Ashing-Giwa & Lim, 2010a). This adjustment means the survivor must redefine herself within the context of the breast cancer experience. In other words, the survivor must understand the meaning of the cancer experience in terms of how it will affect them and redefine themselves and various roles they play in relation to the illness (Carpenter et al., 1999). Positive role adjustment among African American breast cancer survivors may result in the need/desire for them to serve as role models within the community (Lopez et al., 2005).

2.3.4 Serving as a Role Model

In addition to other findings, Lopez and colleagues (2005) also demonstrated that African American breast cancer survivors also desired to serve as role models for other African American women. As role models, these women aimed to help dispel the stigma within the African American community that "cancer equals death" by demonstrating that they have "survived" the disease and to inspire and encourage other African American women (Lopez et al., 2005). The need to serve as role models may be related the importance of faith and spirituality in traditional African American culture and to breast cancer survivors, in particular (Simon, Crowther, & Higgerson, 2007). Spiritual beliefs are extremely important to African American survivors and often influence the coping mechanisms used among this group and aid them in their adjustment to changes that occur as a result of the cancer (Lopez et al., 2005; Powe et al., 2007; Simon et al., 2007). In fact, as demonstrated by Bellizzi and colleagues (2010) in their cross-sectional study of 802 breast cancer survivors stratified by race, higher levels of spirituality or religiosity among African American survivors is associated with better functioning in the mental health domain of QOL. This suggests that spirituality may serve as a buffer to the mental health impact of the breast cancer experience.

African American breast cancer survivors often view their spirituality as the reason for their survival (Simon et al., 2007). The belief in the spiritual nature of their cancer experience leads the survivor to feel the need to find a way to “give back” and serve as role models or “witnesses” within their community (Fatone et al., 2007; Hamilton, Powe, Pollard, Lee, & Felton, 2007). “Witnessing” is a traditional African American spiritual/cultural belief in the need for individuals to tell the story or give testimony about their lived experiences (Fatone et al., 2007). African American survivors are increasingly serving as “witnesses” in various breast cancer peer outreach programs. Through these breast cancer peer outreach programs, African American breast cancer survivors often take on the role of peer educator or peer supporter in an effort to educate other African American women about breast cancer screening and prevention and to provide support for those who are currently going through the breast cancer experience (Boyd & Wilmoth, 2006; Natale-Pereira, Enard, Nevarez, & Jones, 2011; "Sisters

Network, Inc: A National African American Breast Cancer Survivorship Organization," 2009; Wells et al., 2011).

2.4 Peer Health Education Amongst African American Breast Cancer Survivors

2.4.1 Peer Education in General

Peer health education is defined as “the teaching or sharing of health information, values and behaviors by members of similar age or status groups” (Sciacca, 1987). Several terms have been applied to peer health education and they have often been used interchangeably. These terms include peer counseling, peer support, peer training, peer facilitation, and peer education (Green, 2001). For the purposes of this paper, peer health education will be referred to as peer education. Increasingly, peer education has been used in a variety of interventions across a range of both physical and mental health issues, including safe sex practices, chronic illnesses, such as diabetes, cancer, and heart disease, substance abuse and mental health recovery (Funnell, 2010; Green, 2001; Hunt, Grant, & Appel, 2011; Viswanath & Emmons, 2006). Peer education can occur in either a formal or informal setting and may take place on a one-on-one basis or within a group with one or more peer educators present (Funnell, 2010; Green, 2001). Regardless of the methodology used, interventions that include peer education aim to improve the health status, quality of life and health outcomes of a specific group and often have a positive impact on the target audience (Funnell, 2010; Green, 2001; Hunt et al., 2011). Data on the impact of peer education programs on the peer educator is limited. However, the data that does exist has varied with some study results suggesting a potentially negative impact of the peer educator role while other studies suggest potentially positive impacts of the role (Badura, Millard, Peluso, & Ortman, 2000; Dhlamini, Knight, van Rooyen, van Heerden, & Rotheram-Borus, 2012; Mahat, Ayres, & Scoloveno, 2013). The impact of peer education on the peer educator will be discussed in greater detail later in this chapter.

2.4.2 African American Survivors as Peer Educators

Efforts to eliminate breast cancer disparities between African American and White women have resulted in the development and implementation of several interventions targeted towards African American women that include African American breast cancer survivors as a providers of peer education or support (Boyd & Wilmoth, 2006; Braun et al., 2012; "Sisters Network, Inc: A National African American Breast Cancer Survivorship Organization," 2009; "The Witness Project: History," 2000). These survivors can provide peer education under a variety of titles, including: patient navigator, community health worker, lay health advisor/community health advisor, peer educator, and peer support person (Braun et al., 2012; Fiscella et al., 2012; Hilaire, 2011; Power & Hegarty, 2010). Survivors can participate in these roles on a volunteer basis, paid basis, or some combination of the two (Solomon, 2004). The duties of African American survivors who participate in these different roles vary according to their specific title; however, they all include peer education in some aspect. The training required for these roles can vary greatly and are often influenced by the individual role expectations. Those whose primary role is to provide support generally have less training, while those whose primary role is to provide education tend to have more training (Holt et al., 2011; Hunt & Grant, 2012; Hunt et al., 2011; Solomon, 2004). While the data specific to African American breast cancer survivors in these each roles is limited, there is data that focuses on these roles, in general, and in relation to specific physical and mental health issues such as mental health recovery and diabetes within the African American community. These studies, along with studies that have a cancer-specific focus, will be used to describe the roles in which African American breast cancer survivors may serve as peer educators.

Patient navigators and community health workers are often employees in formal healthcare settings and tend to have significantly more responsibilities than those in the other categories (Braun et al., 2012; Hunt et al., 2011; Raj, Ko, Battaglia, Chabner, & Moy, 2012). For example, in Braun and colleagues' (2012) descriptive study of five of the 25 Community Network Programs funded by the National Cancer Institute it was found that the tasks of patient navigators in these programs ranged from providing education and helping the patient to search for additional information to arranging transportation and addressing barriers to the patient receiving the appropriate care. African American breast cancer survivors are often hired for these roles in the Community Network Programs with the express purpose of improving the access to the appropriate healthcare amongst the population they represent (Braun et al., 2012; Raj et al., 2012). Significant training is also provided for individuals in these roles. The amount of training required for these roles can range from 2 hours to 6 months and is dependent on the amount of responsibility required in the role (Braun et al., 2012; Hunt & Grant, 2012; Raj et al., 2012).

An integrative review of the literature conducted by Hunt and colleagues (2011) describes the various roles and activities of lay health advisors/community health advisors in diabetes related interventions. These roles and activities can be classified into 4 categories: supporter, educator, advocate, and program facilitator (Hunt et al., 2011).

The supporter role generally involves promoting increased physical activity, sending motivational and inspirational messages, and assisting their target population with arranging physician appointments and transportation to appointments (Hunt & Grant, 2012; Hunt et al., 2011). The educator role can occur in formal or informal settings either one-to-one or within a group. The topics usually covered include healthy eating, physical activity, self-management of illnesses, medication review, and potential complications of illnesses and treatments. Advocators often serve as a link between those with the illness and available community resources. They often make referrals to clinics, alternative therapies, and other resources, as well as, promoting awareness of the illness with the community at large. Program facilitators often organize and facilitate meetings, outreach efforts, and support groups for those with an illness and their caregivers and families (Hunt et al., 2011).

A review by Solomon (2004) of peer educators/supporters in mental health recovery describes 6 different categories of peer support/peer education. These are self-help groups, internet support groups, peer-delivered services, peer-operated services, peer partnerships, and peer employees. Self-help groups and internet support groups tend to be voluntary and set up for the mutual benefit of all involved in the group. Internet support groups also provide a level of anonymity that may make it more appealing for some individuals (Solomon, 2004). Peer-delivered services and peer-operated services are often a part of a larger, formal organization. In peer-delivered services, persons with mental illnesses who have in the past or may currently be receiving treatment for that illness provides services for others with mental illnesses in an effort to help them in their recovery. Peer-operated services may include peer-delivered services but they can also include services provided from those without a diagnosed illness, albeit under the guidance and direction of those with a mental illness (Solomon, 2004). Peer partnerships refer to freestanding peer-operated services and peer-delivered services that partner with a formal organization or others without a diagnosed illness therefore sharing control of the services provided. Peer employees, similar to patient navigators and community health workers, are often hired to improve access to the appropriate care and treatment amongst those in their peer group (Solomon, 2004)

Peer outreach programs that incorporate African American breast cancer survivors as peer educators/supporters, regardless of the specific role title, have the potential to meet some of the unique QOL needs of African American survivors in ways that are relevant to the socio-cultural context within which these women experience their cancer (Hamilton et al., 2011; Lythcott et al., 2003; Moore, 2001). Specifically, as the use of “witnessing” through the illness narrative, health education , and social support provided through the exposure to other African American survivors generally found in these interventions may directly influence the QOL of the survivor (Boyd & Wilmoth, 2006; Braun et al., 2012; Raj et al., 2012; "Sisters Network, Inc: A National African American Breast Cancer Survivorship Organization," 2009; "The Witness Project: History," 2000). These interventions may or may not have a spiritual foundation.

The Witness Project® (WP), for example, is deeply grounded in the spiritual roots of African American women and incorporates the African American spiritual tradition of “witnessing.” In this program, survivors work closely with a lay health advisor who teaches about breast cancer screening and prevention methods. The survivors serve as “witnesses” who tell the story, or the illness narrative, of their breast cancer experience to their peers in an effort to promote screening and early detection amongst their peers (Boyd & Wilmoth, 2006; "Research-tested Intervention Programs: The Witness Project," 2013; "The Witness Project: History," 2000). Other programs, such as the Gift for Life Block Walk of the Sister Network, Inc., aim to increase breast health knowledge and awareness within the African American community by incorporating survivors as role models who go door-to-door and to share the stories of their cancer experience and encourage positive health practices ("Sisters Network, Inc: A National African American Breast Cancer Survivorship Organization," 2009).

2.5 Use of Illness Narratives in Peer Education Programs

With witnessing, there is the assumption that the witness has a responsibility for telling what happened. Illness narratives are, in a sense, a testimony to the lived experiences of the storyteller (Frank, 1995). In addition, the exposure to other survivors and their illness narratives may increase survivors' social support network and provide trustworthy sources for information related to the breast cancer experience (Hamilton & Sandelowski, 2004; Kent et al., 2012). The use of illness narratives in peer outreach programs can affect the peer educator in several ways. It has been suggested that stories and narratives can enable the cancer survivors to fully explore the impact and meaning of the cancer experience (Anderson & Geist Martin, 2003; Coreil, Corvin, Nupp, Dyer, & Noble, 2012). As the narrative is formed, the storyteller highlights unique attributes of the experience and forms the meaning and understanding of the experience in light of the individuals previous life experiences. The development of the meaning of the experience requires reflection on all aspects of the experience. This reflective nature suggests that narratives allow the narrator to be "endowed with power and control" (Carlick & Biley, 2004; Coreil et al., 2012; Frank, 1995). The development of meaning and understanding of the breast cancer experience can be particularly helpful for African American breast cancer survivors who express the need to become comfortable with the future as demonstrated by Lopez and colleagues (2005). Illness narratives also allow the narrator to reclaim their voice, which may be suppressed by the social and professional environment related to cancer (Coreil et al., 2012; Mathieson & Stam, 1995).

Illness narratives can either positively or negatively affect the cancer survivor. For some survivors the telling of the story repeatedly may increase stress and anxiety related to the illness. For others, telling their stories empowers them and gives them a sense of control by understanding themselves and their relationships (Anderson & Geist Martin, 2003). Illness narratives also promote emotional coping by objectifying the experience and creating room for distancing to occur (Carlick & Biley, 2004; Hamilton et al., 2011). Distancing is an important component of emotion-focused coping that will allow the cancer survivor to negotiate the changes in identity related to the cancer experience (Carlick & Biley, 2004; Frank, 1995).

2.6 Effect of Peer Education on the Peer Educator

2.6.1 Quality of Life

There are no published data available on the experiences of African American breast cancer survivors who are also peer educators in programs such as WP or how these experiences may influence the peer educator’s QOL. Data on peer educators in other disciplines are also limited; however, data that are available suggest how peer education affects African American breast cancer survivors/peer educators. For instance, increasingly, peer education/support is used among persons with serious mental illnesses as an aid in mental health recovery. Research in this area show that peer education/support is beneficial, not only to the person receiving support, but also to the peer educator (Bracke et al., 2008; Davidson et al., 2006; Mowbray et al., 1996; Solomon, 2004). Peer educators report that they personally benefit from the roles that they play in areas such as self-confidence, communication skills and personal growth (Mowbray et al., 1996; Solomon, 2004). They also report decreases in hospitalization and increased likelihood of help-seeking (Solomon, 2004). Studies focusing on peer education related to HIV/AIDS testing and prevention demonstrate that the peer educator gains self-confidence from participation in the role, as well as, increased knowledge about HIV/AIDS and increased self-efficacy (Dhlamini et al., 2012; Mahat et al., 2013).

These studies also show that, while for some repeatedly telling the story of their experiences may cause pain and emotional distress, the peer educators in these HIV/AIDS interventions often find telling their story to be therapeutic and empowering (Dhlamini et al., 2012) The balance of receiving and providing peer education positively influences an individual’s subjective well-being. In particular, providing support increases an individual’s self-efficacy beliefs and self-esteem (Bracke et al., 2008). This is important because higher self-efficacy beliefs positively influence the emotional and psychological well-being of an individual (Bandura, 1997). High self-efficacy beliefs also positively influence an individual’s health behaviors and healthcare utilization resulting in more positive health-related QOL outcomes (Bandura, 1986; Ley et al., 2002). Hamilton and colleagues (2011) conducted a cross-sectional research study that included 449 older African American cancer survivors recruited from outpatient oncology clinics. The purpose of this research study was to determine if there were clusters of coping profiles among African American cancer survivors and to determine the impact of these unique coping styles on the QOL of the survivors. The study findings suggest that serving in the peer educator role may influence the QOL of African American breast cancer survivor in a way similar to that found in mental illness peer educators (Hamilton et al., 2011). Some African American cancer survivors share their own cancer experience with others, in either a formal or an informal setting, as a way of coping with the illness and its lasting effects. They often do this with the intent of educating those within their community and encouraging them to seek screening or treatment. Survivors who use this method often have better QOL and more positive health behaviors than survivors who do not (Hamilton et al., 2011).

2.6.2 Health Behaviors

Research on peer education in health-related areas has produced mixed results on the effect the peer education programs have on the health knowledge and behaviors of the peer educator. Studies of sexually transmitted disease (STD) prevention programs on college campuses demonstrate that, while there is an increase in knowledge about STD prevention and in intentions for safer sex practices, there was little change in the actual behaviors of the peer educators in the program (Tyden et al., 1998). A study of 30 undergraduate peer health educators, however, demonstrated that being a peer educator had a positive impact on the peer educators motivation for personal behavior change, as well as on their health knowledge (Badura et al., 2000). Positive results were also found in a diabetes telephone peer support program. Participants in this program reported an increase in their self-efficacy and indicated that they were able to find meaning and positive reinforcement for their own self-care through supporting others in their efforts to manage their diabetes (Heisler & Piette, 2005). Few studies have focused specifically on African American peer educators. Studies that do focus on this group are generally related to HIV/AIDS peer education programs (Bazargan et al., 2000; Downing et al., 1999). An evaluation of one such program by Downing and colleagues (1999) demonstrated a positive effect of being a peer educator. Peer educators in the Perinatal HIV Reduction Education Demonstration Activities (PHREDA) project in San Francisco expressed a sense of purpose as a result of participation in the program. They also reported benefits such as personal empowerment, pride, and increases in communication skills and in knowledge about HIV/AIDS. These benefits are attributed to the peer educator training and the responsibilities of the peer educators within their communities. The influence of being a peer educator on HIV/AIDS risk behaviors, however, was not explored in this study (Downing et al., 1999). Studies that have explored this phenomenon have demonstrated that the increase in knowledge among African American peer educators in a college level HIV/AIDS prevention program did not necessarily result in an increase in safer sex practices (Bazargan et al., 2000). The findings of research in this area demonstrate that peer education may have a positive or, at the very least, no effect on the peer educators behaviors and QOL. Programs that incorporate African American survivors as peer educators or supporters may be particularly effective because of the incorporation of witnessing through the illness narratives, social support through exposure to other survivors, and health knowledge through the health education component of these programs. These program components are relevant to the unique socio-cultural context within which African American breast cancer survivors live and, therefore, may help to increase the survivors’ QOL (Fatone et al., 2007; Lopez et al., 2005; Powe et al., 2007).

2.7 Research Questions

While there are no data available on the effects of being a peer educator among African American breast cancer survivors, the previous research reviewed on the effects of participating as a peer educator in mental health and other health-related programs have demonstrated mixed results ranging from a positive effect to no effect. Taken together, however, these studies highlight the potential for participation in peer educator roles to have a positive effect on the QOL of African American breast cancer survivors (Coggin & Shaw-Perry, 2006; Lopez et al., 2005). Program components, such as health education, the sharing of survivor stories, and exposure to other survivors are common to peer education/support programs that incorporate these survivors (Boyd & Wilmoth, 2006; "Sisters Network, Inc: A National African American Breast Cancer Survivorship Organization," 2009; "The Witness Project: History," 2000). These components reflect cultural themes that have been identified as important to African American breast cancer survivors and increase the potential for participation in these roles to meet the QOL needs of survivors (Fatone et al., 2007; Lopez et al., 2005; Powe et al., 2007).

The significance of this study is to understand the potential benefits and/or risks of being a peer educator and the impact of being a peer educator on the health behaviors, healthcare utilization, and QOL needs of African American survivors. In addition, exploring the experiences of these peer educators may also aid in informing health policies and in the recruitment and retention of survivors by allowing the motivations and expectations of peer educators and how these may change over time to be examined.

The two primary objectives of this study are to (a) describe the experiences of African American breast cancer survivors serving as peer educators in Breast Cancer Outreach Programs and any potential benefits or risks associated with being a peer educator and (b) to explore the ways in which speaking about their breast cancer experience influences the self-efficacy, health behaviors and healthcare utilization, and ultimately QOL needs of survivors. Two research questions (along with a three sub-questions) have been developed. These are:

1. What are the experiences of African American breast cancer survivors serving as peer educators in Breast Cancer Outreach Programs?
    a. What were their initial motivations and expectations for becoming a peer educator?
    b. How have these motivations and expectations changed or stayed the same in light of their experiences as peer educators?
    c. What positive or negative impact has being a peer educator had on the quality of life needs of peer educators who are also survivors?
2. How has being a peer educator influenced the health behaviors and healthcare utilization of African American breast cancer survivors?

CHAPTER 3: METHODOLOGY

There is insufficient data on the experiences and effects of the peer educator role on the African American breast cancer survivor who is also a peer educator. This study on the effects of being a peer educator on African American women who are breast cancer survivors can contribute to a better understanding of the experiences of survivors who currently participate in the role. The purpose of this study is to explore the experiences of these women, as well as, the effect of the peer education/support program on the peer educators' QOL, health behaviors and healthcare utilization.

This chapter addresses the methodology employed including: qualitative research design, sample, assessment measures, data collection, data analysis, steps taken to ensure trustworthiness and rigor, and the protection of human subjects. The research study is based on two research questions examining the experiences of African American breast cancer survivors who currently serve as peer educators in breast cancer outreach programs. The first question is: What are the processes of African American breast cancer survivors serving as peer educators in breast cancer outreach programs? The second research question is: How has being a peer educator influenced the health behaviors and healthcare utilization of African American breast cancer survivors?

3.1 Study Design

This study incorporates a qualitative research, grounded theory design with one quality of life assessment tool and a demographic survey used to describe participants' demographic characteristics and QOL functioning. A qualitative research design, specifically a grounded theory design, was chosen primarily because there is little data about the experiences of African American breast cancer survivors who also serve as peer educators. In addition, a qualitative research design allows for the complexity of the peer educator experience and its influence on the health behaviors, healthcare utilization, and QOL needs of survivors to be examined from the perspective of the peer educator herself. This information is important in informing future health services research with this population as it will highlight social factors, personal behaviors, and program structures and processes that influence African American breast cancer survivors to initiate and continue participation in the peer educator role. These results can then be used to suggest factors that should be explored in more depth and provide direction for future research with this population. Using a qualitative research methodology, the experiences of participants will emerge through the data allowing the researcher to discover meanings that are formed in and through the participants' breast cancer and peer educator experiences, as well as, the processes and concepts involved in participants becoming and remaining peer educators (Corbin & Strauss, 2008).

The grounded theory design allows individual participants, in a one-to-one setting with the researcher, to describe their own process of witnessing as a peer educator. The participants' stories provide the foundation for the development of a conceptual model of the phenomenon grounded in the participants' experiences (Ononeze, Murphy, MacFarlane, Byrne, & Bradley, 2008; Starks & Brown Trinidad, 2007). Grounded theory was chosen for this study over other qualitative methods because it specifically emphasizes the development of theory through the continuous interplay between the data analysis and data collection process (Strauss & Corbin, 1994). This methodology allowed for the development of theory through constant comparison, systematic asking of general and concept related questions, theoretical sampling, systematic coding procedures and guidelines for attaining conceptual density and data saturation (Strauss & Corbin, 1994). In this study, each participant explained their experiences as a peer educator, the way it influences their health behaviors and healthcare utilization as well as the negative and/or positive impact of participation on their QOL needs according to their own ideals and beliefs. The multiple iterations involved in grounded theory allowed for the interview guides to be adjusted for further exploration of themes that are found in the data with the goal of developing a framework for the phenomenon (Starks & Brown Trinidad, 2007). Quantitative methods were employed to provide descriptive statistics of the participants' demographic characteristics and the quality of life.

3.2 Sample

Eligibility criteria for inclusion in the study included being an English speaking, African American woman over the age of 18 with a diagnosis of breast cancer who has completed her primary cancer treatment, including surgical procedures, radiation therapy, and adjuvant chemotherapy at least 3 months prior to enrollment in the study. The timeline for completion of treatment was changed from 6 months to 3 months after a period of a year and a half without any eligible participants due to the requirements for treatment completion. Those who were currently undergoing adjuvant hormone therapy, such as tamoxifen, were also included. Participants must have also been involved with a breast cancer outreach program as a peer educator or peer supporter at the time of enrollment in the study. Exclusion criteria included being less than 3 months out from the completion of their primary breast cancer treatment and not currently serving as a peer educator or peer supporter at the time of study enrollment.

3.3 Assessment Measures

Both qualitative and quantitative measures were used in this study. Each participant completed two questionnaires, (1) the demographic questionnaire and (2) the Quality of Life of Adult Cancer Survivors (QLACS) scale (See Appendix C for Questionnaires). These questionnaires were used to provide a description of the study sample. Variables in the demographic form include age, education, marital status, income, race/ethnicity, religious affiliation, self-rated health, breast cancer recurrence, cancer type and stage at diagnosis, breast cancer screening methods utilization, physician visits and participation in peer outreach programs.

The second questionnaire administered was the Quality of Life of Adult Cancer Survivors (QLACS) scale. The QLACS was selected over several other cancer-related QOL instruments because of the applicability to long-term cancer survivors, the broad range of QOL domains that are assessed in the instrument and its use with both older and younger populations (Pearce, Sanson-Fisher, & Campbell, 2008). The domains measured in the subscales of the QLACS include items related to QOL needs. Because of this, the subscales on the QLACS may indicate domains where there are significant QOL needs.

The 47 item QLACS measures 12 different domains in 13 subscales: negative feelings (4 items), positive feelings (4 items), cognitive problems (4 items), sexual interests (2 items), sexual function (2 items), pain (4 items), fatigue (4 items), social avoidance (4 items), appearance concerns (4 items), financial problems (4 items), distress from recurrence (4 items), distress from family (3 items), and benefits of cancer (4 items). These 12 domains are divided into two categories, cancer-specific and generic.

The possible scores on the total QLACS scale range from 47 to 329. Scores in the cancer-specific category can range from 19 to 133. While scores in the generic category can range from 28 to 196, scores are determined by the sum of the answer responses to each question within each domain. Higher scores on the total scale and each of the categories and individual domains indicate lower QOL functioning. The scale has moderate internal consistency and validity with Cronbach’s alpha for each domain ranging from .72 to .91. The scale also has good validity with correlations to criterion measures ranging from .61 to .84, with the exception of the financial problems domain (.57) (Pearce et al., 2008). Table 3.1 describes the possible range scores and the Cronbach’s alpha for each domain in the QLACS scale.

Table 3.1: QLACS possible score range and Cronbach's alpha for each domain

	Possible Score Range	Cronbach's Alpha
Generic Category		
Negative Feelings	4 – 13	0.78
Positive Feelings	4 – 28	0.82
Cognitive Problems	4 – 28	0.75
Pain	4 – 28	0.89
Sexual Interest	2 – 14	0.89
Energy/Fatigue	4 – 28	0.84
Sexual Function	2 – 14	0.89
Social Avoidance	4 – 28	0.86
Total Generic Category Score	28-196	0.91
Cancer-Specific Category		
Financial Problems	4 – 28	0.82
Benefits	4 – 28	0.82
Distress-Family	3 – 21	0.88
Appearance	4 – 28	0.83
Distress-Recurrence	4 – 28	0.85
Total Cancer-Specific Category Score	19 – 133	0.89

Turning to the qualitative measures, participants were given the choice of either participating in one-to-one interviews or focus groups exploring social support, health knowledge, anxiety and emotional distress, the burden of the peer educator role, the tradition of witnessing, as well as health behaviors and healthcare utilization. All participants selected the one-to-one interview. A minimum of one interview was conducted with each participant using a semi-structured interview guide that was updated following each participant interview (See Appendix C for Semi-Structured Interview Guide). The Semi-Structured Interview Guide included open-ended questions that solicited the participants own experiences and allowed them to elaborate and provide examples of their own thoughts and ideas. Prompts were included in the interview guide to elicit more details from the participants.

Each one-to-one interview lasted approximately 60 to 90 minutes. The researcher, an African American female, conducted each interview at a location chosen by the participant. Due to financial constraints, the interviews were audiotaped and transcribed verbatim by the researcher. Participants were given pseudonyms during the transcription process. These pseudonyms were used in the discussion of the research findings. After each interview, the data were analyzed and the semi-structured interview guide was updated in accordance with the themes that emerged from the previous interviews.

A reflexive journal was used to document each step of the research process and was included as a part of the study data. This journal created transparency in the research process by creating a space to document each step of the research process, as well as, the rationale behind each step throughout the research study. The reflexive journal also allowed for critical self-reflection by the researcher that helped her to identify where her own individual perspective may be coming into play and how this effects the data analysis and research findings (Smith, 2007). Participants received a summary of the study findings and were asked to validate the findings either by mail, telephone, or email.

Participants that did not respond to the summary within three weeks were contacted by the researcher via telephone to ensure they received the summary and to discuss any comments or questions. The information received from the participants' review of the findings was used to refine the final research findings.

3.4 Data Collection

Participant recruitment occurred from August 10, 2009 to August 7, 2012. Several recruitment methods were used (See Table 3.2). The assistance of a key gatekeeper to the African American community in a large metropolitan area in North Carolina was solicited to help in identifying the initial participants. Flyers were posted on the campus of the University of North Carolina at Charlotte, as well as~~,~~ at various locations throughout the African American community in the Charlotte-Mecklenburg area (i.e., churches, libraries, community centers and hair salons). Flyers were also mailed to numerous African American churches and Sororities. Print ads were placed in the University of North Carolina at Charlotte Faculty Newsletter (See Appendix B for Flyer and Print Ad).

In addition to these methods, brief presentations about African American women and breast cancer (including a handout of PowerPoint slides, See Appendix B), the research study and the recruitment/participation process were given at various organization and public meetings throughout the Charlotte-Mecklenburg area, including: the House of David Women's fellowship, Unity Fellowship Church Charlotte Health and Wellness Ministry Health Fair, and the Advenir at Casa Bella Health Fair. A mass recruitment email specifically targeted toward African American women at UNC Charlotte was also utilized. Each participant recruited through these methods was asked to suggest other potential participants and venues for potential recruitment (i.e., snowball sampling). Permission to use the participant as a reference was obtained prior to contacting the potential participant.

Throughout the duration of this study, the researcher received a total of 35 responses from women interested in learning more about the study. Of these 35 women, only 15 (43%) were eligible for the study at the time of their response. Most often women were not eligible because they were too close to the end of their treatment date, 7 (20%) women stated that they did not view themselves as peer educators although they participated in the groups. Of those women that were eligible for the study, 10 (67%) declined to participate after hearing the requirements of the study. The final three participants in this study were referred to the researcher by other study participants. The researcher used the referring participant as a reference when contacting the new potential participant. These efforts resulted in a total of 8 study participants.

Table 3.2: Recruitment efforts table

Method	Dates	Number Interested	Number of Participants Recruited
Flyers	September 2009 – July 2012	18	2
Print Ads	September 2009 – July 2012	4	0
Targeted Email	January 2011, September 2011	3	0
Recruitment Presentations	April 2011 – February 2012	7	3
Snowball Sampling	August 2011 – April 2012	3	3

The use of several different recruitment strategies was necessary to make up for the difficulties experienced during the first 2 years of recruitment. Initially, there was a significant response to the posted flyers; however, a significant amount of those women were not eligible for the study (*n*=15). This trend was followed by a period of no response (i.e., 6 months). Through discussions with the dissertation committee chairs and other committee members, the additional recruitment methods were developed and a sufficient number of participants were recruited in order to achieve data saturation. Eligibility requirements for time since the completion of primary treatment was also changed from 6 months to 3 months to increase the number of women who may be eligible to enroll in the study.

Purposive sampling was used to allow for the selection of participants that were particularly informative about the experiences of African American breast cancer survivors who are also peer educators because of their own lived experiences. This method allowed for enhanced understanding of the experiences of African American breast cancer survivors who serve as peer educators. All participants were screened via a brief telephone interview (See Appendix B for Screening Script) conducted by the researcher to ensure they met eligibility criteria (Devers & Frankel, 2000).

After eligibility for the study was determined and the individual agreed to participate in the study, a time and location for the initial visit and interview with the researcher was selected by the participant. At this first meeting, the participant completed the demographic questionnaire prior to the beginning of the interview. The one-to-one interview was then conducted and recorded by the researcher. Following the interview, each participant was given a copy of the QLACS scale to be completed at their convenience. The researcher picked up the scale during a second visit with the participant, within a 3 week time frame.

Data collection for the study continued until the point of data saturation which was achieved with 8 participants. Saturation was reached when no new themes emerged from the data and a cohesive conceptual framework was able to be developed (Onwuegbuzie & Leech, 2007; Strauss & Corbin, 1998). Criteria for data saturation will be discussed further later in this chapter. After data saturation had been reached, each participant was sent a summary of the study findings for them to review and respond to any discrepancies they found. Those who did not respond to the summary within 3 weeks were contacted by the researcher to ensure that they had received the summary and to discuss any discrepancies they may have found. Participants were not incentivized but did receive hand written thank you notes.

3.5 Data Analysis

3.5.1 Quantitative Data Analysis

Descriptive statistics (i.e., frequencies and percentages) provided a description of the study sample. Each QLACS subscale is scored by summing the score on each item in the subscale. Higher scores on the subscales imply poorer QOL functioning for that subscale. For data analysis purposes, the results of the QLACS were transformed into categorical variables (i.e., Low, Mid-Range, and High QOL scores) to provide a description of the study participants' QOL functioning based on an accepted instrument for assessing QOL in adult cancer survivors.

3.4.2 Qualitative Data Analysis

A grounded theory methodology involving multiple iterations of the data analysis was performed with the transcribed interview in multiple phases (Strauss & Corbin, 1998). The researcher performed all analyses and coding of concepts and themes found in the transcripts after each interview using Atlas, ti. Atlas, ti is software program often used in qualitative research. This program allows the researcher to systematically analyze qualitative data and to create codes, annotations, and memos that will assist in the data analysis process ("Atlas. ti 5.0," 2004).

3.4.2.1 Phase One

In the first phase of the data analysis, concepts and themes that emerged from the interview data were identified and coded line-by-line using in vivo codes, or terms specifically referred to by the participants when discussing their personal experiences, beliefs, and behaviors. These codes were used as "tags or labels for assigning units of meaning to the descriptive or inferential information compiled during the study" (pg. 56) (Miles & Huberman, 1994). While coding, memos were written for each code to provide a bridge between the concreteness of the data and theoretical thinking (Neuman, 2000). Each memo contained notes and thoughts on each code, as well as, questions related to the code to elicit further analysis (See Appendix L for a sample memo). These preliminary concepts and themes were used to update the semi-structured interview guide to more appropriately address these concepts and themes prior to the next participant interview (Strauss & Corbin, 1998). After the researcher transcribed the next participant interview, the data analysis was performed again using the same methods as the initial data analysis phase.

3.4.2.2 Phase Two

The second phase of the data analysis involved axial coding or organizing codes in a manner that allows for the identification of key concepts in the data (Corbin & Strauss, 2008). Of particular interest in this phase were any causes, consequences, and categories of themes that could be clustered together. The concepts and themes were sorted through and grouped into manageable categories and sub-categories allowing a web of connectedness between categories to be revealed (Neuman, 2000). For example, when reviewing transcripts of breast cancer survivors who are also peer educators, a recurring theme might be spiritual beliefs (i.e., a belief in God). All parts of the participant interviews that are related to this theme are relegated to this category. Through constant comparison of individual concepts/themes, as well as, within and between categories and sub-categories, relationships between the categories and sub-categories were determined.

3.4.2.3 Phase Three

The relationships between categories and sub-categories provided the basis for the third phase of the data analysis, the development of the broad processes and central process involved in becoming and remaining a peer educator for participants in this study. This was accomplished using selective coding to establish relationships between categories and sub-categories and to identify the central process involved in the participants' experiences (Corbin & Strauss, 2008). By looking for patterns, ideas, and events that occur regularly across interview transcripts, the broad processes and central process were refined and questions and gaps in the data emerged (Neuman, 2000). Revisions to subsequent semi-structured interview guides reflected the concepts/themes and gaps that emerged through the on-going data analysis (Corbin & Strauss, 2008). This process was repeated with each participant interview. Each phase of the analyses included an analysis of each interview transcript obtained up to that point.

These steps were repeated with each interview until there was data saturation, or no new concepts, categories, or relationships emerged from the data. The point of data saturation was determined to be reached when the results of the data analysis confirmed what had already been found in previous phases of the data analysis but did not add any new information or provide any refinement for the resulting broad processes and central process (Onwuegbuzie & Leech, 2007). Other criteria used to determine data saturation included ensuring that the data appeared internally and externally consistent, and ensuring that the resulting categories, broad processes and central process maintain credibility when viewed by the participants who provided the information (Guba, 1978).

3.5 Trustworthiness and Rigor

Because the researcher serves as a research instrument in qualitative research, her own beliefs, biases, and preconceived ideas have the potential to influence the data analysis (Lincoln & Guba, 1985). In order to maintain trustworthiness and rigor in the study, several methods were used. First, the grounded theory methodology used in this study mandates that the researcher strive toward the verification of the resulting theories/processes through statements of relationships between concepts given by participants during the study (Strauss & Corbin, 1994). The constant comparative nature of the grounded theory design also added rigor to the study by ensuring that the model evolved with the data (Strauss & Corbin, 1998). During the interview and data analysis process, the assistance of a dissertation committee member who specializes in qualitative research was solicited to ensure the credibility of the analysis results. To do this, the committee member analyzed several de-identified interview transcripts for comparison with the results of the analysis done by the researcher (Lincoln &Guba 1985). .

Both the participant and the researcher are stakeholders in a research project of this caliber. Because of this, they both have their own perspectives and agendas in the research process which can result in different ways of viewing and shaping the data (Sandelowski, 1993). Grounded theory methodology requires that the resulting concepts and process be grounded in the participants own experiences; therefore, it is important that the researcher’s interpretation of the data is comparable to the participants own experiences (Corbin & Strauss, 2008). This was accomplished in this study through member checks. A summary of the study findings and a stamped, return addressed envelope were provided to each participant at the completion of the data analysis. These member checks improved accuracy, credibility, and validity by checking the feedback from participants against the study results (Sandelowski, 1993; Yanow & Schwartz-Shea, 2006). Participants were asked to validate the findings in the summary and to respond to any discrepancies they found or any issues they may have had with the results. The research findings were refined using participant responses (Strauss & Corbin, 1998).

Lastly, as discussed earlier in this chapter, a reflexive journal that documented each step of the research process and allowed the researcher to acknowledge her own beliefs, biases, and preconceived ideas and to understand how they influenced the data analysis was kept (Morrow, 2005). (See appendix m for a sample entry from the reflexive journal).

3.6 Protection of Human Subjects

Initial Institutional Review Board approval was obtained through the University of North Carolina at Charlotte Office of Research Services in August 2009. Yearly renewals were filed. A new, continuing application was filed and approved on August 10, 2012. No personal identifiers were kept in connection to the data obtained. Each informant was given a pseudonym that will be used on each transcription and in any subsequent reports of the data.

Each participant signed an informed consent form prior to participating in the study (See Appendix D for Informed Consent Form). A copy of the signed Informed Consent form is maintained in a separate file from the rest of the research study data. At the beginning of each interview, the researcher reviewed the consent form and explained that participation is voluntary, allowing participants the opportunity to decline to participate any further at that time. Efforts were made to provide referrals to appropriate sources of care for those participants who have additional problems identified through the one-to-one interview and for those who requested additional help. Referrals included local community resources and peer support groups, as well as national breast cancer support hotlines.

3.7 Summary

This study incorporates a qualitative research design and includes quantitative methods for descriptive purposes. A grounded theory design was utilized to allow each participant to describe their own experiences as a peer educator and lead to the development of a conceptual framework of the phenomenon. Each participant completed a semi-structured interview exploring their social support, health knowledge, emotional distress, burden of the peer educator role, and the spiritual/cultural tradition of witnessing. The Quality of Life of Adult Cancer Survivors scale was used to provide a description of the survivors' QOL functioning. Demographic data were collected to provide a description of the sample. Participants included African American women with breast cancer, aged 18 years and older, that have completed their primary treatment and adjuvant chemotherapy at least 3 months prior to enrollment in the study. Participants must have also be involved in a breast cancer outreach program as a peer educator at the time of their enrollment in the study. The findings of this study and a detailed description of the sample are discussed in chapter four.

CHAPTER 4: RESEARCH FINDINGS

Chapter four begins with a presentation of the research sample demographic characteristics and QLACS scores. Next, the research questions will be addressed through the presentation of the qualitative findings, beginning with an overview of participant interviews. Then, the codes, organized by themes that emerged during the interviews are shared. Finally, a description of the broad processes and central process involved and the relationships of the various concepts to that process are presented. The research questions that will be addressed in this chapter are:

1. What are the experiences of African American breast cancer survivors serving as peer educators in Breast Cancer Outreach Programs?
   a. What were their initial motivations and expectations for becoming a peer educator?
   b. How have these motivations and expectations changed or stayed the same in light of their experiences as peer educators?
   c. What positive or negative impact has being a peer educator had on the quality of life needs of peer educators who are also survivors?
2. How has being a peer educator influenced the health behaviors and healthcare utilization of African American breast cancer survivors?

4.1 Description of Study Participants

4.1.1 Sample Demographics

The study participants were selected as a purposive sample because they were conveniently available, met the eligibility requirements, and the researcher wanted to examine a particular group in-depth, African American breast cancer survivors who are also peer educators. A total of 8 volunteers, from 3 different peer support/education programs in the Charlotte, NC area, participated in this study. Table 4.1 gives a detailed description of sample and demographic characteristics. The mean participant age was 49.5 years. Of the 8 participants, 5 participants (62.5%) were divorced, 2 (25%) were married, and 1 (12.5%) was single. Seven of the 8 participants in this study had at least a college degree and all participants had health insurance. The length of time since their original breast cancer diagnosis ranged from 2 to 9 years for these participants, with a mean of 6 years. Three participants were originally diagnosed at stage II breast cancer, 3 at stage III, and 2 participants were diagnosed with stage IV breast cancer. Only 3 participants had experienced a recurrence of their breast cancer. Half of the participants (n=4; 50%) rated their over-all health as very good, while the other half rated their overall health as good. All participants performed monthly self-breast exams and stated that they regularly visited their physician. Four participants described their religious affiliation as Baptist, 3 as Christian, and 1 as Church of Christ.

The length of time participants had served in peer outreach programs ranged from 2 to 48 months with the mean being 22.25 months (SD=14.2). All participants served in faith-based peer outreach programs. Although each of these programs was associated with a specific church, only 5 of the 8 women were members of the particular church with which their program was associated. Overall, the programs participants served in were very similar, in that they were all faith-based and used spiritual principles to reinforce positive health behaviors. Each of these programs also provided support for other women with breast cancer and education for women in general about breast health and screening. One of the programs also included support for women with other forms of cancer. All three programs included a strong health education component and provided information on holistic health practices in addition to having health professionals as resources for members.

Table 4.1: Sample demographic characteristics

Age:	
Range (years)	32 - 66
Mean (SD)	49.5 (12.2)
Median (years)	49
Marital Status:	
Married	2 (25.0%)
Divorced	5 (62.5%)
Single	1 (12.5%)
Education Level:	
Some College	1 (12.5%)
College Graduate	3 (37.5%)
Post-Graduate Degree	4 (50.0%)
Insured	
Yes	8 (100%)
No	0 (0%)
Time Since Original Diagnosis	
Range (years)	2 – 9
Mean (SD)	6.0 (2.5)
Median (years)	5.5
Stage of Cancer at Diagnosis	
Stage I	0 (0%)
Stage II	3 (37.5%)
Stage III	3 (37.5%)
Stage IV	2 (25.0%)
Recurrence	
Yes	3 (37.5%)
No	5 (62.5%)
Self-Rated Health	
Excellent	0 (0%)
Very Good	4 (50.0%)
Good	4 (50.0%)
Monthly Self-Breast Exams	
Yes	8 (100%)
Regular Physician Visits	
Yes	8 (100%)
Religious Affiliation	
Baptist	4 (50.0%)
Christian	3 (37.5%)
Church of Christ	1 (12.5%)
Length of Time in Peer Outreach Program	
Range (months)	2 - 48
Mean (SD)	22.25 (14.2)
Median (months)	25

4.1.2 QLACS Scores

Table 4.2 presents the participant scores on the total Quality of Life for Adult Cancer Survivors (QLACS), as well as, the scores of each individual category and domain. Higher scores on the QLACS domains indicated lower QOL functioning, while, lower scores indicate higher QOL functioning. Individual participant scores will be discussed later in this chapter. Participants' scores on the *Generic* category ranged from 66 to 85 with a mean of 71.75. Participant scores on the individual domains within the Generic category indicated that, overall, participants had high QOL functioning within these domains. The mean participant scores for these individuals' domains were 7.63 for the Negative Feelings domain, 26.13 for the Positive Feelings domain, 7.38 for the Cognitive Problems domain, 7.13 for the Pain domain, 2.88 for the Sexual Interest domain, 12.50 for the Energy/Fatigue domain, 2.25 for the Sexual Function domain, and 5.88 for the Social Avoidance domain.

Participants' scores on the *Cancer-Specific* category ranged from 58 to 62 with a mean of 60.13. Scores for the individual domains within this category indicated that, overall, participants had some QOL impairment within these domains. The mean participant scores on the individual domains were 6.50 for the Financial Problems domain, 23.13 for the Benefits domain, 6.88 for the Distress-Family domain, 13.63 for the Appearance domain, and 10.00 for the Distress-Recurrence domain.

Table 4.2 Quality of Life in Adult Cancer Survivors Survey scores

	Score Range	Mean (SD)
Generic Category		
Negative Feelings	5 – 13	7.63 (2.56)
Positive Feelings	24 – 28	26.13 (1.25)
Cognitive Problems	6 – 9	7.38 (1.06)
Pain	5 – 10	7.13 (1.64)
Sexual Interest	2 – 4	2.88 (0.99)
Energy/Fatigue	10 – 14	12.5 (1.31)
Sexual Function	2 – 3	2.25 (0.46)
Social Avoidance	4 – 9	5.88 (1.96)
Total Generic Category Score (Total Possible Range: 28 – 196)	66 – 85	71.75 (5.82)
Cancer-Specific Category		
Financial Problems	4 – 11	6.50 (2.45)
Benefits	18 – 26	23.13 (2.53)
Distress-Family	4 – 9	6.88 (1.89)
Appearance	10 – 17	13.63 (2.88)
Distress-Recurrence	8 – 11	10.00 (1.07)
Total Cancer-Specific Category Score (Total Possible Range: 19 – 133)	58 – 62	60.13 (1.46)
Total QLACS Score (Total Possible Range: 47 – 329)	126 – 147	131.88 (6.73)

Transforming the total QLACS, Generic category, and Cancer-Specific category scores into categorical variables allowed for the participants QOL status at the time of survey completion to be assessed. This was done by taking the total possible score range for the Cancer-Specific category, Generic category, and total QLACS score and dividing each score range by 3. This created 3 categories of scores, High QOL Functioning, Mid-range QOL Functioning, and Low QOL Functioning. Table 4.3 gives the transformed QLACS and category scores and the frequency of the participant scores for each. When the scores were transformed into categorical variables, it was found that 7 participants (87.5%) scored in the High QOL Functioning range for the Generic category and only 1 participant (12.5%) scored in the Mid-range QOL Functioning range. All 8 participants scored in the Mid-range QOL Functioning range for the Cancer-Specific category, although their scores were relatively close to the high QOL Functioning range. And, 7 participants (87.5%) scored in the High QOL Functioning range and 1 participant (12.5%) scored in the Mid-range QOL Functioning range on the total QLACS. These scores indicate that overall participants had high QOL functioning and that many of their QOL needs, such as financial needs, emotional support, and sexual function,are being met within the Generic category. Scores within the Cancer-Specific category, however, indicate that participants may have more QOL needs that are not being met within these specific domains in comparison to the domains within the Generic category.

Table 4.3 QLACS scores transformed into categorical variables to assess participant QOL status

	Frequency (n=8)
Generic Category (score range)	
High QOL Functioning (28 to 84)	7 (87.5%)
Mid-range QOL Functioning (85 to 140)	1 (12.5%)
Low QOL Functioning(141 to 196)	0
Cancer-Specific Category (score range)	
High QOL Functioning (19 to 57)	0
Mid-range QOL Functioning (58 to 95)	8 (100%)
Low QOL Functioning(96 to 133)	0
Total QLACS (score range)	
High QOL Functioning (47 to 141)	7 (87.5%)
Mid-range QOL Functioning (142 to 235)	1 (12.5%)
Low QOL Functioning (236 to 329)	0

4.2 Qualitative Findings

4.2.1 Use of the Reflexive Journal

The reflexive journal was used to document several types of entries. These entries include reflections on my upbringing and similarities to participants, critiques of participant interviews, observations and thoughts during and after interviews, thoughts and ideas about the data collection and data analysis process. After reviewing the reflexive journal, several themes and incidents were found to be significant to the conduct and analysis of this study and influential to my interpretation of the data. In this section, I will discuss the important themes found in the reflexive journal and a few key incidents that were influential to the data collection process and interpretation.

Several entries in the reflexive journal included the discussion of recruitment challenges and the brainstorming of ideas that could help improve participant recruitment. In these entries, discussions with members of the dissertation committee regarding the recruitment challenges that existed during the data collection phase of this study. While, these discussions had little to do with the data analysis, they did influence the data collection process and influence changes in the study procedures that resulted in more participants enrolling in the study.

Among the first types of entries in the journal that was influential to the data analysis were the documentations of my own personal beliefs, biases and assumptions. As an African American woman, raised in a culturally traditional African American household, I assumed that I would share some common background with the participants in this study, particularly as it relates to spiritual/cultural beliefs and values. I have also had some family members who have been diagnosed with various forms of cancer in the past. Initially, I viewed myself as an outsider to this group because I had not had my own personal experience with a breast cancer diagnosis. However, while conducting this study, I discovered that despite not having a personal experience with breast cancer, I was more of an insider because of our shared common background and my understanding of traditional African American spiritual/cultural beliefs. Study participants indicated that they also viewed me as an insider when they would refer to aspects of traditional cultural beliefs and practices in the African American community using terms such as “we” and "us" in a way that was inclusive of me as a part of their group. This shared background between me and the participants allowed me to build a rapport with the participants quickly and helped them to be comfortable and at ease speaking with me. While, our shared background may have helped to build rapport with the study participants, I had to be intentional about asking questions that generated an original and spontaneous response from the participants and did not lead them to a specific response based on my own beliefs.

Our shared background also influenced the data analysis and my interpretation of the data because of my familiarity with African American culture and spiritual traditions. During the data analysis phases, the codes and themes that referred those values and beliefs often stood out to me and where among the first codes and themes that was highlighted during the data analysis. For example, based on my own personal beliefs, I expected participants who were similar to me to believe that a part of spiritual growth and as a demonstration of gratitude to God for making it through difficult situations is to provide "testimony" to others about their experiences. During the data analysis, I found myself looking for participant statements that directly stated or eluded to that very belief.

Because I found myself to have an insider perspective, it was important to me to solicit the assistance of one of my committee members in the review and discussion of the data collection and interpretation of the data. These discussions were also documented in the reflexive journal. Discussions with this committee member helped me to focus my interpretation of the data and to brainstorm, on what the codes and categories that were found during the data analysis meant and how they came together to tell the whole story. This helped to ensure that my interpretation of the data was not solely based on my own personal beliefs but that it was also grounded in the data received from the participants.

4.2.2 Overview of Participant Interviews

Participant interviews lasted for 45 minutes to 1.25 hours, with the average interview time being 1 hour. Interviews were conducted at the participants' location of choice. Two interviews were conducted on the UNC Charlotte campus, 3 were conducted at local coffee shops, and 3 were conducted in the participant's home. Before beginning the interview, informed consent was obtained from all participants and they were informed that they did not have to answer any questions with which they were not comfortable and could stop the interview at any time. Participants were informed that a referral to a counselor or other resources were available should they need it. Each interview was audiotaped and transcribed by the researcher. During transcription, participants were given pseudonyms that will be used in the discussion of the research findings. Both during and immediately following each interview, notations were made in the reflexive journal to document the affect of the participants, their body language, verbal and non-verbal communication, and the environment during the interview. All participants completed the interview and freely answered all questions. Overall, each participant appeared to be relaxed and comfortable during the interview and showed no overt signs of emotional distress when responding to any questions.

Interviews were conducted using a semi-structured interview guide (See Appendix C). Interview questions on the initial semi-structure interview guide were developed using Bandura's theory of self-efficacy. For example, Bandura's theory suggests that self-efficacy is strengthened through exposure to peer models, therefore several questions on the initial interview guide asked the participants about their exposure to other breast cancer survivors and how that exposure influenced their abilities to manage their own health and their belief in themselves. Open-ended questions were used during the interviews to elicit the most information from participants using their own words and thoughts. Prompts were included in the interview guide to educe more information from participants. Interview questions included: How have you personally benefited from these programs (Prompt: Can you provide examples of this?, Can you describe any spiritual connection you see in the work that you do in these program?, and What emotional impact does telling the story of your breast cancer experience have on you?)

As discussed in chapter 3, several methods were employed to ensure the trustworthiness of the data and maintain rigor during the data collection and data analysis process. These include constant comparison of the data, reviewing data analysis with a dissertation committee member, and member checks. The reflexive journal was also used to document each step of the research process, including field notes of researcher observations both during and after the interview.

4.2.3 Description of Participants

Gladys. Gladys was a 60 year old, divorced, African American female with a post-graduate degree. She has been a peer educator for 18 months. She was originally diagnosed in November of 2000 with stage 2 breast cancer. She experienced a recurrence of her breast cancer in 2007. Gladys chose to have her interview conducted in a meeting room at a local library. During the interview, she appeared relaxed and seemed eager to participate. She was very excited about the opportunity to tell her story and to help in research that may help others in her situation. On the QLACS, Gladys scored in the high range of QOL functioning for the generic category. She scored in the mid-range of QOL functioning on the Cancer-specific category. She showed the most QOL impairment on the Appearance Domain of the Cancer-specific category.

Robin. Robin was a 45 year old, divorced, African American woman. She has a post graduate degree and, as of the time of her interview, had only been a peer educator for 2 months. Robin was originally diagnosed with stage 3 breast cancer in September of 2007. Robin chose to have her interview conducted in a group study room at the UNC Charlotte Atkins Library. Robin seemed to be relaxed and comfortable during the interview and she willingly provided details on her own cancer experience and her experiences as a peer educator. However, she was not as talkative as some of the other participants. This may be because of the limited amount of time she had served as a peer educator. Robin's QLACS scores indicated that, overall, she had high functioning QOL. She did score in the mid-range of QOL functioning for the Cancer-specific category. She had the most QOL impairment in the Energy domain of the Generic category, and in the Appearance, and Family distress domains of the Cancer-specific category.

Kim. Kim was a 35 year old, divorced woman with a post-graduate degree. She was originally diagnosed with stage 2 breast cancer in January of 2005. At the time of her interview, Kim had been a peer educator for nearly 4 years. Kim chose to have her interview conducted in her home. During the interview, she appeared comfortable and had no difficulty expressing herself. Kim's QLACS scores indicated that she had more QOL impairment than the other participants in this study. She scored in the mid-range for QOL functioning on both the Cancer-specific and Generic categories, although her scores were relatively close to the high-range scores. She showed the most impairment on the Negative Feelings, Energy, and Distress from Family domains.

Brenda. Brenda was a 32 year old, college educated, single woman who had been a peer educator for 12 months at the time of her interview. She was originally diagnosed with stage 4 breast cancer in February of 2009. Brenda chose to have her interview conducted in a private area of a local coffee shop. She seemed very excited to participate and was very talkative. Brenda was particularly talkative about her experiences related to what she felt was her purpose in life. Overall, Brenda's QLACS scores indicated that she had high QOL functioning. She did, however, show some impairment on the Energy and Appearance domains.

Karen. Karen was a 55 year old, married woman with a college degree. At the time of her interview, she had been a peer educator for 36 months. She was originally diagnosed with stage 4 breast cancer in November of 2008. Karen chose to have her interview conducted in her home. Karen was somewhat reserved initially during the interview. But, as the interview progressed she became more engaged and expressed herself more freely. Her QLACS scores indicated that, overall, she had high QOL functioning, although, she did show some QOL impairment on the Energy and Appearance domains.

Martha. Martha was 66 years old, divorced, and had been a peer educator for 24 months at the time of her interview. Although, she did not have a college degree she had taken some college courses. Martha was originally diagnosed in January of 2004 with stage 3 breast cancer and had experienced a recurrence in 2007. She chose to have her interview conducted in a private area of a local coffee shop. During the interview, she appeared relaxed and had no problem answering questions. Her QLACS scores indicated that overall she had high QOL functioning with some impairment in the Appearance domain.

Sheryl. Sheryl was 58 years old and married at the time of her interview. She has a college degree and had been a peer educator for 18 months. She was originally diagnosed with stage 2 breast cancer in February of 2003. She experienced a recurrence of her breast cancer in May of 2008. Sheryl's interview was conducted in a private room at a local library. She seemed very excited to be participating in a study focusing on what she believed was her "calling in life." Throughout the interview, Sheryl was very expressive and seemed eager to answer the interview questions. Overall, her QLACS scores indicated that she had high QOL functioning, although she did score in the upper mid-range on the Cancer-specific category.

Pam. Pam was a 48 year old, divorced woman with a post graduate degree at the time of her interview. She had been a peer educator for 20 months. She was originally diagnosed in May of 2004 with stage 3 breast cancer. Pam's interview was conducted in a group study room at the UNC Charlotte library. During the interview, Pam appeared comfortable and relaxed. She freely answered all questions. She was particularly expressive about the spiritual connection she see's in the work she does with the peer outreach program. Overall, her QLACS scores indicate that she had high QOL functioning. She did show some QOL impairment on the Appearance domain.

4.2.4 Themes and Codes

Participant interviews were used to help answer the 2 research questions (and sub-questions): (1) What are the experiences of African American breast cancer survivors serving as peer educators in breast cancer outreach programs? (a. What were their initial motivations and expectations for becoming a peer educator? b. How have these motivations and expectations changed or stayed the same in light of their experiences as peer educators? c. What positive or negative impact has being a peer educator had on the quality of life needs of peer educators who are also survivors?) And, (2) how has being a peer educator influenced the health behaviors and healthcare utilization of African American breast cancer survivors? This was accomplished by first analyzing interview data to develop a list of codes and themes that describe the participants' backgrounds, cancer experiences prior to serving as a peer educator, experiences while serving as a peer educator, as well as, their health behaviors and healthcare utilization prior to and after serving as peer educators. The themes and codes that emerged from the interview data during the first phase of the data analysis were then used in the analysis and development of the broad processes involved in the participants' experiences and the health behavior and healthcare utilization outcomes related to those experiences.

Grounded theory methodology involving multiple iterations of the data analysis was used to develop a list of codes grounded in the data during the first phase of the analysis (Corbin & Strauss, 2008). In this phase, concepts and themes that emerged in the transcript data were identified and coded using terms specifically referred to by participants (in vivo codes). In the next phase of the analysis, the codes that emerged during the first phase were grouped into categories and subcategories of themes through axial coding by inductively and deductively determining the conditions, actions, interactions, and consequences that influences the way each code is related to the other (Corbin & Strauss, 2008). A total of 100 codes were classified into 4 themes and 16 sub-themes. Table 4.4 outlines the structure of the data as it emerged during data analysis. All themes, sub-themes, and codes are contained in this table. The four themes that emerged during the data analysis include: (1) Survivor Background, (2) the Decision to Participate in a Peer Educator Role, (3) Program Components, and (4) the Decision to continue in the Peer Educator Role. These themes and their respective codes reflect the participants experiences as peer educators, as well as, the factors that motivate them to participate in the peer educator role.

Table 4.4: Categorization of codes emerging from participant interviews by theme

Theme	Code
<u>Survivor Background</u>	

Table 4.4: Categorization of codes emerging from participant interviews by theme

Theme	Code
Spiritual/Cultural Beliefs and Traditions	· Believing in a higher purpose for experiences in life
	· Finding peace through a relationship with God
	· Finding strength through a relationship with God
	· Relying on God to be in control
	· Using spirituality as a positive coping mechanism
Cancer Experience	· Being concerned about what others would think
	· Being depressed as a result of medication
	· Cancer diagnosis creating positive changes in daily life
	· Cancer experience is humbling
	· Cancer experience resulting in spiritual growth
	· Cutting back on activities after diagnosis
	· Experiencing negative reactions from discussing cancer with others
	· Having a minimal physical impact of cancer
	· Having a positive prognosis helps to remain positive during experience
	· Having limited ability to perform daily life roles
	· Initially feeling stigmatized by society
	· Initially having a fatalistic view of cancer
	· Initially having difficulty talking about cancer diagnosis
	· Not having depression from diagnosis or treatment
	· Not letting family know the truth of what you are feeling
Life Changes Due to Breast Cancer	· Being more open to a variety of activities
	· Believing that God called you to comfort and support others
	· Believing there is a spiritual purpose of cancer related to the good of others

Table 4.4: Categorization of codes emerging from participant interviews by theme

Theme	Code
	· Considering self as role-model, advocate, or witness · Constructing a new identity · Engaging in informal one-on-one outreach · Finding my voice · Having a fear of recurrence · Knowing other women with cancer helps to view self as a survivor · Needing to engage in fun activities · Repeatedly telling the story of experience makes it easier to share · Telling the story of experience to help others
Health Behaviors Before and After Diagnosis	· Believing more can be done to manage health before diagnosis · Believing physician advice as an important influence to physical activity · Diagnosis resulting in change in behavior related to seeking healthcare · Having confidence in abilities to manage health after diagnosis · Routinely visiting physicians prior to diagnosis · Utilizing holistic health practices after diagnosis
Factors Important to QOL	· Financial Stability · Health · Helping others · Peace · Sharing Information with others · Social Support · Spirituality
<u>Motivation to Participate in Role</u>	
Past Experiences of Receiving Support	· Paying back support received during own cancer experience · Receiving support through formal support groups in the past

Table 4.4: Categorization of codes emerging from participant interviews by theme

Theme	Code
Serving a Higher Purpose	· Being grateful to God for own experiences · Being influenced by religious leadership to participate · Believing that making a difference is possible through giving love to others · Believing that purpose is to help others · Expecting to give support to others through program · Finding my Voice · Placing others needs as a priority · Viewing outreach as being obedient to God · Wanting to encourage other women to be screened for breast cancer
Expectations of Personal Benefit	· Expecting to develop friendships · Expecting to receive resources · Expecting to receive support · Having no expectations so as not to be disappointed
<u>Program Characteristics/Structure</u>	
Educational/Informational Resources	· Having professional resources available · Providing educational resources · Providing information to help in discussions with physicians · Reinforcing self-breast exams and mammograms · Sharing general health information · Sharing holistic health information
Exposure to Other Survivors	· Communicating honestly and openly · Having other survivors provides support from those who understand the experience · Hearing of others' deaths

Table 4.4: Categorization of codes emerging from participant interviews by theme

Theme	Code
	· Hearing stories of others who are currently going through treatment or just diagnosed · Hearing success stories · Minimizing burden by creating a family type feel in the group · Receiving encouragement from others · Sharing responsibilities among several survivors
Spiritual Foundation	· Having a faith-based foundation · Reinforcing spiritual beliefs
Diversity in Group Activities	· Discussing topics not specifically related to breast cancer · Having group activities outside of regular meetings
<u>Motivation to Continue Role</u>	
The Role as a Source of Joy	· Enjoying participating in the program · Feeling no burden from the role because of the joy · Feeling joy from helping others feel better · Wanting to increase outreach to more women
Positive Effects of Participation On Survivor	· Benefiting from relationship with other survivors · Peer support role is a humbling experience · Gaining peace through participation · Participating in group helps to have positive outlook on life · Improving health behavior and physical activity · Increasing social network and social support · Increasing breast health knowledge · Finding voice through group participation · Finding a safe place to tell story of cancer experience to others

Table 4.4: Categorization of codes emerging from participant interviews by theme

Theme	Code
Coping with Potentially Negative Effects of Participation	· Finding positives in hearing of women that did not survive · Group participation helping to cope with fear of recurrence · Training for the role
Motivations to Discontinue Peer Educator Roles	· Emotional distress from hearing of the deaths of group members · Focus of the group changing to no longer be uplifting to participants · Having limited physical ability due to illness · Increasing fear of recurrence · Lack of training

4.2.4.1 Survivor Background Theme

The Survivor Background theme refers to the time in the participants' life before participating in the peer educator role. The survivor background is influential in the participant's desire/decision to participate in the peer educator role. Each code in this theme and its subsequent sub-themes is related to a specific point in the cancer timeline from before the breast cancer diagnosis to after the completion of treatment.

4.2.4.1.1 Spiritual/Cultural Beliefs and Traditions

The Spiritual/Cultural Beliefs and Traditions sub-theme refers to beliefs and traditions adhered to before and after their cancer diagnosis. Spirituality was found to be an important coping mechanism to all participants in this study. As Karen stated, "…my spirituality, where I am spiritually, it helps me get through hard times. I pray a lot, read the bible a lot, and believe God will always make a way and prepare me to handle anything." Through their spirituality and having a relationship with God, these women were able to rely on God to be in control of the circumstances in their lives, allowing them to find peace and strength in their daily lives through their relationship with God. Martha summarized this best by stating "everyday through my relationship with him, God renews my strength and gives me peace to endure because God has it all in control. I was taught that a very long time ago and I still believe it to be true." These women also believed that there was a higher purpose for their experiences in life and that this higher purpose was ordained by God. As Brenda stated, "I believe that everything we go through in life we should take that and impact someone else…So, yea definitely I got that belief from my religious background, my spiritual background."

4.2.4.1.2 Cancer Experience

There are three aspects of the Cancer Experience theme that are important to the women in this study. First, there is the direct impact of the diagnosis and treatment on their activities of daily living and physical, emotional, and mental abilities. Next, there were the internal emotions related to the cancer diagnosis itself and their view of their position in the community and their own family because of the diagnosis. And, finally, the impact of the effects of the diagnosis, treatment, and their internal emotions on their openness with others about their experience is an important aspect of the Cancer Experience theme.

Seven women experienced a limited ability to perform daily life roles and had to cut back on activities as a result of their cancer diagnosis and treatment. As Karen stated, "I couldn't do the things I did before once I started treatment. It really drained me and I found myself asking for help with the most simple things sometimes. I think that was the hardest part of the experience." Gladys described the physical limitations caused by her cancer treatment by saying “I was no longer the strong superwoman, you know, the working spouse, the mom who did everything…I just didn’t have the stamina for that. And, it was very hard for me emotionally to have to be able to sit back and not be able, you know, wash one load of clothes and it took me all day to do that.” Only Sheryl indicated that her cancer diagnosis had minimal physical impact when she said “you know, the physical part of my diagnosis and treatment was not as bad as I thought would be. I was able to still do many of the things I could before. I mean I was tired a little but I still did activities.” Five of the eight participants experienced depression as a result of the cancer medication. The depression experienced as a result of the cancer medication is important because, as Karen stated, “being depressed makes it difficult to cope and deal with all the emotions that come up when you are diagnosed and have to go through horrible treatments.”

When participants were first diagnosed with breast cancer, they all had some form of negative reaction mentally and emotionally to the news. All participants initially had a fatalistic view of their cancer. Robin, for example, stated that “It was a lot of different things that I went through just because it was cancer. Thinking about death. What’s going to happen with my kids? Who should they stay with? How do I want them to be raised? What do I want them to remember about me?” Brenda stated “You hear cancer, you think death. So, I had to overcome that hurdle of thinking I am going to die.” Participants also initially felt stigmatized by society and were concerned about what others would think because of the perceived view of women with breast cancer. Martha described this feeling by saying “…it was almost like what are people going to think? I felt like people would put me in the ‘she is going to die’ box and look at me differently or as if I’m someone to be pitied. I felt that way for a little while, at first." Gladys stated that "in a way, I felt damaged or something. You know, like 'ohhh she has cancer.' And, I think it's society's way of making you feel that way sometimes. You know there's still people that think you can catch it." Those participants who were given a more positive prognosis at the time of diagnosis were able to remain positive throughout their cancer experience despite their initial negative reactions. Kim provides a great example of this when she states "I, thank God, I had a good prognosis. I mean stage 2 breast cancer and my outlook looked good. So, I guess if maybe it was stage 4 or, you know, really terminal then maybe that would have changed my positive outlook after I got past the initial shock of the diagnosis."

Despite the initial negative reactions, participants revealed that over time their cancer experience resulted in positive changes in how they lived their lives. For some participants, like Gladys, it gave them the push they needed to "remove toxic relationships" from their lives and to "focus on things that are uplifting and positive." For others, the cancer experience was very humbling. As Kim stated, "if you can go through cancer, you can go through a whole lot of things. Yes ma'am, you can go through a whole lot of things. That's where I think the humility comes in and being able to give back." All participants indicated that their cancer experience resulted in spiritual growth. Robin demonstrated this when she said, "I think it strengthened my spiritual experience. And, I think it helped make my relationship with the Lord even closer." Pam stated that her experiences, "…caused me to go to God a lot more than I had in the past. I prayed more, read more, meditated more. I think I learned so much more about believing in God for myself because of this experience."

Because of the initial negative reactions of participants to their breast cancer diagnosis and their perception of others views of themselves, participants initially had a lot of difficulty in talking about their cancer experience. Some participants, such as Gladys and Sheryl, kept their diagnosis secret from all those that did not “need to know.” Gladys went as far as taking a leave of absence from work so that she could go through her cancer treatments without any of her co-workers or other people she encountered on her job knowing about her diagnosis. Only her immediate family was aware of her breast cancer until after she completed her treatment. She described this by saying “…I was so shocked that I had the diagnosis that I kept it a secret. I had very few people that I told, very few. And, I swore them to secrecy, you know. And, it was like it was. I had to struggle through that.” Those participants who were not as secretive about their diagnosis initially stated that experiencing negative reactions from discussing their breast cancer with others decreased their desire to share that information with anyone else for fear of receiving the same reaction, again. As Karen stated, “I had told a couple of people initially, other than my husband. It almost seemed like me telling them about my diagnosis was a personal attack on them and I could kind of feel them distancing themselves from me and my diagnosis. After that, I was a little worried about telling other people because I didn’t want to get that same reaction.” Participants were not only secretive about their diagnosis, they were also not fully open and honest with those family members that did know about their cancer with regards to the truth of what they were feeling both physically, mentally, and emotionally. Gladys described this best when she said “So, I felt I had to be strong for my husband at the time, you know, men can’t handle anything. They fall apart. And, I had to be strong for my kids. And, no matter how bad I felt, I couldn’t let on that I was feeling that bad. I would just say ‘oh, you know mommies a little tired.’ You know, this kind of thing but feeling terrible.”

4.2.4.1.3 Life Changes Due to Cancer

Participants in this study highlighted several life changes due to their breast cancer that occurred after the completion of their treatment. First, these women were more open to a variety of activities and that they actually had a need to engage in activities that were simply fun to do. As Pam stated, “I just wanted to live. I wanted to travel, meet people, do things I had never done and have a lot of fun doing it.” Karen described this by saying “I wanted to live my life with no regrets. You know, try all the things I was afraid to before. It’s something about facing cancer that makes you want to just get up and do.”

All participants believed that knowing other women with breast cancer helped them to view themselves as survivors. Brenda described this by saying, “when I met other women with the same diagnosis and I really realized how many women don’t make it. I felt so blessed that I had survived. I am a survivor.” Viewing themselves as a survivor encouraged the participants in this study to tell the story of their experiences in an effort to help others to either be screened for breast cancer or to become survivors, as well. Robin highlighted this best when she said “when I realized that I, with God’s help, I had beat this thing, I wanted to help as many women as I could to beat this, as well. And, it starts with early detection. I survived with stage 3 breast cancer. If we can get women to get screened so that it’s caught at an earlier stage, that increases the chances of more women surviving.” Through telling their story, these participants found that repeatedly telling the story of their experience made it easier and actually increased the participants desire to share with family and friends. Robin stated “The first few times it was difficult. It was difficult because it was cancer, the word cancer, it’s like people think ‘oh my God, death’…but after the first few times it’s not difficult at all and I started to enjoy telling my story.” Some women believed that telling their story repeatedly also helped them to construct a new identity and find their voice. For example, Sheryl mentioned that the changes she went through because of the chemotherapy caused her fear in telling her story initially because she had to “first acknowledge and accept the changes within herself.” Telling her story allowed her to put her experience in perspective, understanding the changes she went through and what they meant for her now. Other women suggested that, while they began constructing a new identity during and after completion of treatment, their new identity was not fully constructed, nor, did they fully “find their voice” until after participation in the formal peer outreach group. For Karen, “it wasn’t until after I joined the outreach group that I really felt like I had a voice, that I had something to say that could help a lot of people. And, I have been using that voice ever since.

As a result of the cancer experience, all women believed that there was a spiritual purpose for their breast cancer related to the good of others. Even if they did not see a spiritual purpose for their cancer experience when they were first diagnosed, at some point during their experience, they began to feel as if there was a purpose for their cancer. Gladys provided a great example of this when she said “The first time I got the diagnosis, it just threw me for a loop. You know, but then when I saw where the Lord was taking me through that journey I was like wow. It was almost a privilege. Because, then I could connect with people who were hurting.” Brenda stated that this spiritual purpose “has helped to share my experiences with others because this cancer was not about me but about how I can help others through my own experiences." Most of the women in this study believed that God called them to comfort and support others and they often engaged in informal one-on-one outreach prior to participating in a formal outreach group. For example, Gladys said, "you know, the Lord calls us to comfort others and to show love...I needed to because when you think about it, there are some women who are diagnosed with it…sitting at home thinking they're the only one's that's going through, that's feeling this way. That is who I am meant to help." One additional change that occurred in the life of these women after their completion of treatment is having the fear of recurrence. Martha described her fear of recurrence by stating "I think about cancer everyday of my life….You think about it every day you wake up. So, yea, I think about recurrence." Pam stated that she thinks about the possibility of recurrence "at least twice a day, everyday. It's something that never goes away because you know it can always come back."

4.2.4.1.4 Health Behaviors Before and After Diagnosis

Prior to their breast cancer diagnosis, most women believed that they could have been doing more to manage their health, although, they all had regular physician visits prior to their diagnosis. As Martha stated, "you know, I took care of myself before I was diagnosed but even then I knew that I probably should have done more and been more pro-active about some things." After their diagnosis and treatment, they felt more confident in their abilities to manage their own health. With the health information she learned while going through her treatment, Brenda stated that "when I'm on a roll, I'm really on a roll. I am definitely on a roll with taking care of myself. It is good to have peer support but I also realize to that this is my journey. And, that if I want to make it happen I have to take care of myself." These women also revealed that their cancer experience resulted in a change in behavior related to seeking healthcare. For example, Karen was "more proactive in getting help now. If I feel something is wrong, I get it checked out right away. I don't wait like I used to in the past." They utilized holistic health practices as well as traditional health practices in an effort to manage their own health. Robin was particularly interested in holistic health practices. As she stated, "I look more at holistic doctors now than I do regular doctors I would say. Because, it just seems like this is a medication type of society and I really would rather know a more natural way than taking a bunch of meds. And, I don't know if that is from me being on different meds at one time. But, I went natural with the hair. I don't even put dye in my hair anymore. I use what is called henna. The more natural that I can go in every aspect even with lotions, soaps, detergents. I am definitely more self-conscious." These women also indicated that after their diagnosis physician advice was an important influence on their physical activity. As Gladys stated, "I really took the doctor's advice when he said I needed to exercise more. I have been physically active ever since."

4.2.4.1.5 Factor Important to QOL

The women in this study highlighted several factors that are important to their QOL in light of their cancer diagnosis and the changes experienced as a result of it. All women believed that financial stability, health, peace, spirituality, and helping others are important factors to their own self-rated QOL. For Gladys, of these factors, peace and spirituality were the most important. She describes this by saying "Peace. That's number 1. If you got peace, that is the quality of life. You know, I mean, that because you are only going to have peace if you have that real honest relationship with the Lord. Because, then if you do have that relationship, he will tell you and he will show you things and people that don’t need to be in your life and drama’s that do not need to be in your life. And, then he will turn around and give you the strength to be able to put that distance. Put them in their appropriate place.″ While, Martha thought peace was an important factor, she also mentioned that “good health and financial stability is also important to me.” Robin indicated that helping others is an important QOL factor for her. As she stated, “…helping others to me, it helps my quality of life.” About half of the participants revealed that social support and sharing specific breast cancer knowledge and screening information with other women is important to QOL. Brenda described this by saying “you know, having good people around me who believe in the same things and helping them by sharing the information and knowledge I have is really important to me and I think my quality of life.”

4.2.4.2 Motivation to Participate in the Peer Educator Role Theme

The motivation to participate in the peer educator role begins with participants making their cancer experience public. For some participants, this occurred after finding their voice and telling the full story of their cancer experience to others. For other participants, making their cancer experience public helped them in the process of finding their voice and becoming comfortable in telling their story. The motivation for participants in this study can be classified into 4 sub-themes: (1) past experiences of receiving support, (2) serving a higher purpose, (3) spiritual/religious motivation and (4) expectations of personal benefits.

4.2.4.2.1 Past Experiences of Receiving Support

All women in this study had received support in informal ways from others during their cancer experience. Several of them suggested that they were so grateful for the support they had received from others that they felt the need to “pay that back” by giving support to other women with cancer. Gladys demonstrated this by stating that her participation as a peer educator provides a “great opportunity to pay back some of the support that I received when I was going through cancer.” Kim stated that the support she received from her church family influenced her desire to give support to other women. As she said, “I had the mothers of the church pray for me. Prayed over me. And, really go into battle. I mean I never saw women really get together and pray like they prayed and that increased my strength. People in my church just started coming in. I was hardly ever alone. I want to do that for other women because that meant so much to me.” Two women, who received support in the past through formal peer support groups, indicated that the support they received in those programs was motivation to participate in the peer educator role in their current programs. As Robin stated, “the group I was in in Atlanta gave me so much hope while I was going through treatment. If it had not been for them, I think things would have been a lot more difficult for me, especially emotionally. And, I know there are a lot of other women with cancer that need that type of support.” Pam’s experience in a support group while she was undergoing treatment influenced her to provide “support for other women the same way the women in that group supported me.”

4.2.4.2.2 Serving a Higher Purpose

All women expressed that they placed others needs as a priority in their life and they believe that their purpose is to help others. A good example of this is Gladys, who stated “I guess, knowing my spiritual gifts, one of them is service. It just, I can be tired as all get out. And, if there is someone hurting it’s almost like there is this extra strength that God gives me to be able to put them first.” Robin stated that going through her cancer experience allowed her to “really reflect on myself and what I could do even more to help other people.” Because of this, participants believed they were serving a higher purpose by participating in the peer educator role. Brenda describes this by saying “I feel like I am serving my purpose as a result of being a breast cancer survivor. I definitely feel that, like I said, it wasn’t just for me to go through it just to go through it. I feel like there is more for me to do actually.”According to Gladys, this higher purpose for participants essentially revolved around “giving love and support, encouragement, and a sense of humor to make a difference.” Several participants viewed their outreach work as being obedient to God. Gladys explained this best when she stated:

> For example, being obedient to God when he places something on your heart is a large part of ministry. And, last year for some reason, the Lord placed on my heart to send everyone in the group just a card, an encouragement card. And in the card, I had written “be encouraged and encourage others.” And, I just thought “well, I’m just being obedient and letting everyone know that I’m thinking of them.” I had no idea until the next meeting and I’m still meeting people that say “oh, you’re _____ ________.” I had no idea. I had no way to know that it did make a difference to those people.

Several women also expressed that their religious leadership encouraged them to participate in these programs. For example, Pam first became interested in her church-based cancer peer support group after her pastor approached her about ministering about her cancer experience to others. As she stated, “He came to me one Sunday after service and said ‘you have a story to tell that can help a lot of women. I believe this may be your ministry.’ I had already felt that way but that was the confirmation I needed to really do the work.” For Gladys, the encouragement to participate came from one of the ministers in her church. She described this by saying “I was already doing outreach and I felt that I was being very effective in that. But, then when Minister Michelle asked me and another survivor would we help her get this off the ground I was not going to say no. And, that’s my answer.” For some participants, the motivation for participating in peer outreach programs comes from the participant “finding her voice” and wanting it to be heard by others. For example, Kim believed that through participating in her church’s outreach program, she would be able to “give cancer support a voice” in her church. Because she had been able to find her voice prior to participating in the program through informal one-to-one outreach, she felt comfortable being “able to just go in and zone in on exactly what it is that they’re going through or what phase they are at.”

4.2.4.2.3 Expectations of Personal Benefit

Seven of the eight women had several expectations of personal benefit from participating in the peer outreach programs. These expectations included developing friendships with other survivors, receiving support, providing support to others, and receiving informational resources. As Robin said, “I expected to get support and to support others. And, just a group of people we could hang out. Like we went to dinner. So, just support and friendship.” Sheryl described her expectations by saying “I knew that I would get specific resources about cancer, preventive resources, and the different networking facilities and avenues that I could take advantage of…and also just the encouragement and love from others who were impacted by the disease.” Kim’s only expectation was to provide support to others. She described this by saying “I just wanted to give that support. That’s the only thing I really have any expectations about. I just wanted to help wherever I could and whatever that meant.” Gladys was different from other participants in this study in that she did not “want to set herself up for disappointment” and therefore, did not have any expectations for her participation.

4.2.4.3 Program Components Theme

Each component of the peer outreach program effected participants and provided either a benefit or drawback to participation in the peer educator role. The way in which the program components impacted the participants influenced their decision to continue or discontinue the peer educator role. The program components’ theme can be broken down into four sub-themes. These include: (1) educational and informational resources, (2) exposure to other survivors, (3) spiritual foundation, and (4) diversity in group activities.

4.2.4.3.1 Educational and Informational Resources

All of the peer outreach programs in which participants were involved incorporated an educational component. The educational components of these programs included sharing holistic health information, such as mediation and prayer, and general breast health information. Several of the participants expressed that they were most interested in the holistic health information provided in the programs. Kim, for example, stated that “I look more to holistic doctors now than I do regular doctors, I would say. Because, it just seems like this is a medication type of society and I really would rather know a more natural way than taking a bunch of meds.” Karen particularly enjoyed learning about holistic health practices in her peer outreach program. As she stated, “I have learned so many things about more natural ways to take care of myself through this group…I’m doing things I never even thought of before to stay healthy like getting massages, meditating. I’m even starting to get into yoga because one of the ladies in our group told us how helpful it has been for her physically and mentally so I said why not give it a try.”

These women also felt it was beneficial for the programs to provide information to help in discussions with physicians, reinforcement of self-breast exams and mammograms through the program, and having a professional resource as a part of the group. Sheryl described this by saying “it’s one thing to encourage someone and provide support like emotional support but if you don’t have something tangible to provide someone then thank you but what should I do…You need to provide some resources and tools so that somebody can believe that it’s going to be okay.” As Robin stated, “I keep hearing, you know, make sure you’re doing your breast exam. Make sure you’re getting your mammograms. Talk to your doctor. Make sure you stay on top of things if anything changes. So, yeah. Even though I was that way before, it’s good to hear it.” All three peer outreach programs had health professionals that served as resources for the group. Pam’s outreach group had been started by a nurse. For her, this provided “a great resource for information. Anything we have questions about, we can go to her.” For Brenda, having a physician available at some of the outreach program meetings gave her a chance to “ask questions and learn more about things I need to be aware of and pay attention to.” Kim’s chiropractor served as a resource for her group. She even invited group members to visit her chiropractor with her. As she stated, “The chiropractor that I go to is holistic and he’s a Christian based chiropractor. We talk about different types of things. So, I invited the group to come with me to chat with the doc. Just different educational stuff, exercises that he shows us that are eye-openers of what we can do to help ourselves.”

Through the educational components in these programs, participants have learned new ways of managing their health and healthy behaviors. Martha was particularly enthusiastic about the information she has learned through her program participation. In her interview, she stated “I love the educational materials and talks we have. They have been really eye opening on new ways to take care of yourself and make sure you stay healthy.”

4.2.4.3.2 Exposure to Other Survivors

Exposure to other survivors was very important to the women in this study. For Pam, “relationships is what it boils down to with any kind of support. You have to establish that bond.” Exposure to other survivors allowed the women to receive emotional support from other women who understand the experience firsthand. Robin described the exposure to other survivors as being particularly helpful when she said “It helps a lot. My family was great and my friends were great. But, again, just knowing somebody that has gone through it, know how you feel and stuff, makes a big difference.” Through this exposure participants’ were able to receive encouragement from others who understood their situations, communicate openly and honestly in a forum of individuals who understood the experience, and hear success stories from other survivors that served as encouragement. This was best described by Gladys when she said:

> Your family can love you and your friends can love you…but there is this little extra peace that comes with talking to someone who's been through it. There's like that connection and so there are things that you can't even tell your family that you can tell someone who has been through cancer because they understand the language. They understand the emotions. And, they know that even one day when we say "oh , I just, Lord just take me," we don't really mean it. But, if you said that to your family member, oh my gosh, they would be calling everybody. We got to have a family get together, everybody, you know. Freaking out and stuff."

Sheryl was particularly appreciative of the "encouragement and support from others impacted by cancer." For Robin, "…hearing other people's stories and their success stories and even the stories that somebody passed from it, still their stories it helps a lot for me to continue to feel positive and not to sweat the small stuff." Participants also expressed how sharing their experiences with other survivors make it easier for them to share with their family and the rest of their community. Robin, for example, stated "I think it gives me more confidence in sharing my experience. By sharing my experience with people like this group, it gives me more, maybe, courage and being comfortable sharing my story to help other people." Having other survivors in the group was also found to be beneficial for participants in this study because having other survivors allowed for the minimization of burden of the role by creating a family type feel within the group. This family type feel allowed for responsibilities to be shared among several survivors so that no one survivor is overwhelmed. As Karen stated, "we have a pretty good size group so we can share responsibilities. I think it helps because when one person can’t help, there is someone else that can. That may be why I never feel burdened or overwhelmed. We work as a family to help each other which makes it a lot easier.”

Exposure to other survivors also has the potential to negatively impact the participant. Four of the women in this study highlighted the fact that hearing of the death of a group member or another person with cancer, as well as, hearing about someone who was just diagnosed or currently undergoing treatment triggered a fear of recurrence and emotional distress. Martha and Kim provided great examples of this. As Martha stated, “when you hear about somebody dying or somebody being diagnosed with cancer it makes you think about your own mortality. You know, I think about my own cancer coming back because that’s always a possibility. And, it’s hard to watch someone you have come to care about go through that, very hard.” Kim described how hearing of women who have died from breast cancer or have just recently been diagnosed affected her by stating “When I see the people that we have spent time with, when I see death coming…You want them to live. You know, you want them to. Because you survived, you want them to survive. You want to be that catalyst for hope. But, it doesn’t always work that way. And, that can be hard to deal with.”

4.2.4.3.3 Spiritual Foundation

All women expressed the importance of the spiritual foundation as a part of the peer outreach program. Six of the women indicated that the faith-based foundation of the program was very important in their decision to participate and continue participating. Karen described this by saying, “the spiritual foundation that there is in the group has been a tremendous help for me. I don’t think the program would have impacted me as much if there wasn't a spiritual base. That's what's most important." Martha stated that she choose her peer outreach group specifically because it was a "faith-based group. I was looking for a group that I could connect with spiritually, as well." For Kim, the faith-based component in her outreach program provided her with a sense of support that she had not previously received. She expressed this by stating "Faith-based has been really good…I haven't seen people who will go in and just start praying for you. I have seen people who have said 'I'm going to pray for you.' But, I haven't seen people who say 'okay, let's get together and let's do it right then and there.' And, because it's an issue that you have, you walk away being prayed for."

The reinforcement of spiritual beliefs was important because it kept the program in line with the women's own spiritual/cultural beliefs and traditions. Six of the eight women expressed that their participation in the peer outreach programs and the duties they performed aligned perfectly with the spiritual/religious activities and beliefs they already engaged in. As Pam stated, she chose to participate in her peer outreach program specifically because "it was a faith-based group that lined up with my own beliefs. I knew that I could get what I needed from the group because of that." In particular, telling the story of their cancer experience in the peer outreach program is a reflection of the spiritual/cultural tradition of giving "testimony" in the African American community. Because of the spiritual beliefs that these women had, it was important for them to give the testimony of their experience to as many as they could. Brenda and Gladys even used the term "testimony" to describe part of their work in the outreach programs. Brenda stated that "some of the things we do in the group, especially the prayer and giving our testimonies were things that I have done throughout my life. So, it was kind of a natural transition for me joining the group." While, Gladys stated, "And, I gave that testimony, I don't know how many, a thousand times. Because, it was like he revealed himself to me in a very personal way and my life hasn't been the same since then."

4.2.4.3.4 Diversity in Group Activities

Half of the women in this study mentioned diversity in group activities as being an important aspect of their outreach program. These four women indicated that discussing topics that are not specifically related to cancer and having activities outside of regular meetings was important in keeping them engaged in the programs, as well as, in keeping other women motivated to attend the program meetings. Robin particularly enjoyed the range of topics they would discuss in the group and at various events the group held. She "really enjoyed when we went to dinner we just talked about any and everything. About basketball, because some of us are basketball fans and the playoffs are going on….And, then we talked about this one lady was still going through treatment so we were talking about the effects and how it was making her feel and how it affected us. We talk about a lot of different things." Gladys described the need for diversity in activities as "sometimes you need to change up. You know, yes, there is the focus on the support and the prayer and the sharing and the gut wrenching feelings and emotions and all that. But, if that's all we are known for, you know, when you first think of the CROSS meeting you think 'oh everybody's always crying and praying and everything.' We are vibrant women." While, Pam believed that programs that constantly focus only on cancer related topics are actually be discouraging and tend to keep people in a "negative emotional space."

4.2.4.4 Motivation to Continue in the Peer Educator Role Theme

The motivation for women to continue in the peer educator role is related to the effects of the program components and the individual survivor characteristics and background. This theme can be broken down to four sub-themes, including: (1) the role as a source of joy, (2) positive effects of participation on the survivor. (3) coping with potentially negative effects of participation, and (4) motivation to discontinue peer educator role. Due to the limitations in the sampling frame for this study (See Chapter 5 for detailed explanation), it was not possible to adequately address the factors that are involved in discontinuing the peer educator role because the researcher did not have access to this group. However, participants were asked about the potentially negative effects of participation and what they think would motivate them to discontinue participation.

4.2.4.4.1 The Role as a Source of Joy

All participants in this study indicated that they enjoyed participating in their respective outreach programs, overall. As Robin described this best when she stated, “We are there. We support one another. We have fun. We talk about different topics. So, right now, I’m pleased.” Participants also expressed that they simply enjoyed helping other people as a part of their work in the programs. Gladys enjoyed her work in the program so much she stated “You know, in a way it’s almost selfish because I get so much joy from helping and making others feel better.” The joy these women felt from helping others in the programs often led participants to express the need and desire to increase outreach to more women. Karen described this by saying “it feels so good helping the women in the group that I want to reach out to a lot more women. There are a lot of women that go through this and need that support.” Several women, such as Brenda, stated that they felt no burden from the role they play because they enjoy what they do so much. When asked about any burden she may have felt from the participating in the peer educator role, Brenda stated “No, I have not felt any burden. It has been a privilege, a joy to do this work.”

4.2.4.4.2 Positive Effects of Participation on Survivor

One of the positive effects these women received through participation in the program was “Finding My Voice.” For example, Brenda expressed how initially her participation in the program was because she felt like she had to do it but over time it became something she wanted to do. As she stated, “I think I’ve switched from doing this because I thought I had to it because I was a survivor and I was so grateful. You know, I’ve got to do this. I’ve got to do this. And, now I want to do this. I want to communicate. I want to share my story with others.” Through the program she was able to “find my voice” and now she “wants to communicate” and share her story with others. For all participants, telling the story of their cancer experience in a safe space within the program had a positive effect on their ability to be open with others outside of the group about their cancer experience. As Gladys stated, “yes it does make it easier. Because, now I can. I’m just not a survivor, I’m a victor. I been through the battle and I survived. And, when I think about what it could have been and what it is, I can’t help but be grateful. So, it does make it easier.” This aided the women in constructing their new identity and in having a more positive outlook on life. Brenda provided a great example of this when she stated “people identified me by my hair. And, then my body changed. I gained so much weight. My skin changed significantly. And, of course, lost all my hair. So, I mean it was out there. So, when I started to really start communicating and sharing my story with people, it was scary at first. So, I almost had to find a new identity almost."

Other positive effects of participation in these programs for these women include benefitting from the relationships built with others within the program by increasing their social support network. For example, Brenda stated that "I've met some great people through the group. And, it's always good to see them at church…Even, if I don't get to see them on a regular basis." Gladys described this by saying "I think just that, the relationships. The interpersonal relationships. And, also that there are so many talented young women in our church, like yourself, our ministry is benefitting from their talents and their energy and their youth. It has definitely increased the support network I have." Other participants mentioned that even just the fellowship with other survivors is beneficial. Kim believed "the fellowship is what is important, us actually coming together." All women also experienced increases in their breast health knowledge and improved their health behaviors and physical activity levels through the information provided in the programs. Brenda stated that since participation in the group her knowledge of breast cancer and breast health "has increased tremendously. I am much more aware of some things now then I was even after I finished my treatment." Sheryl stated that "Eating vegetables and fruits. You know, staying away from fatty foods and sugars and things like that. I look at all labels now… And, then also physical activities. Because, I've always been in good physical health. And, as a result I wasn't all that consistent with working out…But, now I make sure I go consistently." These women also expressed that they were able to gain peace through their participation in the programs because of the faith-based foundation. Gladys described this best when she said "from the group there is already peace because I know that if there is another diagnosis, I know that peace is going to be there because that’s going to be the group that I can come and I can cry and say, you know, I used to be strong but today I’m a little weak. You know, I need prayer, I need this. I need whatever.” Some participants indicated that they were humbled by the role they played in the programs. For Kim, “It humbled me. I think that I’ve been humbled by a lot of the things that different people in the group go through and I’m more grateful for my own experiences.”

4.3.4.4.3 Coping with Potentially Negative Effects of Participation

Participants identified several factors that were important in coping with the potentially negative effects of participation. All women in the study identified training for the role as being important for coping with the potentially negative effects of participation, such as emotional distress from hearing about another woman’s cancer recurrence or death. For Kim, in particular, the counseling and hospice training provided in her group was helpful in “recognizing the signs and symptoms of death and actually taking us through that process…it helped me to recognize some things and it kept me in the emotional balance versus being just uncontrollable.” Karen stated that the training provided in her group “helps me to know how to kind of deal with hearing stories of women who are not doing well or that we know have died from this. You know, we are dealing with a situation now with one of our members and it doesn’t look good for her and it does affect me because she is a part of our group, our family but I think learning how to deal with situations like that before hand makes it a little easier.” One woman described how she was able to see a positive effect of hearing of people that did not survive their cancer. Robin believed “we need to hear that because that will help us to raise more money to put on events and to keep talking about it so that people can be aware so that a cure can be found and research can be done. So, it has a negative effect but also you can use that negative for positive things."

These women also expressed that, while participation did not necessarily reduce the fear of recurrence and may even reinforce the possibility of a recurrence, participation did help the participants to cope with that fear through the faith-based foundation. For Brenda, "It's interesting. Yes, it definitely helps me cope with it because the group is spiritually based. But, as I see, like there are several people in the group now that have had a recurrence. So, that kind of like, you know, it's like 'oh, God,' you know. It does… So, I mean yes it helps me deal with it. But, on the flipside it also re-highlights the fact that people can have a recurrence." Kim quoted a scripture that is used often in her outreach program to help their members cope with the fear of recurrence when describing how she has learned to cope with fear of recurrence through her group. She stated "I go with the scripture we use a lot in the group 'God has not given us the fear' I go with that. And, I think that some of it is a natural fear. I know that if some changes have to be made I have to do them…I'm better at it now than I ever was before."

4.2.4.4.4 Motivation to Discontinue Peer Educator Role

As stated above, due to the limitations in the sampling frame for this study (See Chapter 5 for detailed explanation), it was not possible to adequately address the factors that are involved in discontinuing the peer educator role because the researcher did not have access to this group. However, participants were asked about what they think would motivate them to discontinue participation. These women highlighted five factors that could possibly motivate them to discontinue the peer educator role. The first of these factors is having a limited physical ability to perform her duties because of illness. As

Sheryl stated, "… the one thing that would really get in the way of me doing this work would be if I just couldn't physically do it because I was sick or something like that." Other women suggested that changing the focus of the programs to no longer be uplifting to participants would influence them to stop participating. Martha described this by saying "The most important part of the group is the focusing on uplifting and encouraging women. If that was to change, I don't think I would still be a part of the group. For me, that would go against why I believe in the group in the first place." Several women believed that having a lack of proper training for the role could also potentially motivate them to leave the program. As Kim stated, a lack of proper training "can be disastrous because you will be dealing more with your issues than the person's issues." Not having the proper training could lead to being overwhelmed by the emotional distress caused from hearing about a group member dying and increasing fear of recurrence. For Robin, "whether we are talking about somebody that just went through it or somebody that was just diagnosed or whatever, that would probably be the negative that I can see. Focusing on it. And, then sometimes I guess it could make you feel anxious and emotional. Just like I said, somebody was diagnosed with liver cancer. It makes you think 'could that be me the next time I go to the doctor?' It can be very difficult."

4.2.5 Broad Process of African American Breast Cancer Survivors Serving as Peer Educators

Each of the themes discussed above played a role in the processes involved in the women's experiences as peer educators. The themes and codes that emerged during the first phase of the data analysis were used in the analysis and development of the broad and central processes involved in the participants’ experiences and the health behavior and healthcare utilization outcomes related to those experiences. Selective coding was used to establish relationships between categories and sub-categories and to identify the central process involved in the participants’ experiences. This phase of the data analysis provided a more detailed answer for the first research question: What are the experiences of African American breast cancer survivors serving as peer educators in Breast Cancer Outreach Programs? (a) What were their initial motivations and expectations for becoming a peer educator? (b) How have these motivations and expectations changed or stayed the same in light of their experiences as peer educators? (c) What positive or negative impact has being a peer educator had on the quality of life needs of peer educators? Figure 4.1 presents a diagram of the previously discussed themes and how they are related across time to form the broad process involved in serving as a peer educator.

The Survivor background theme, which includes spiritual/cultural beliefs and traditions, health behaviors before and after the cancer diagnosis, the cancer experience, life changes as a result of cancer, and QOL needs, helped to motivate the women to choose to participation in peer outreach programs. The spiritual growth gained through the cancer experience, the construction of a new identity, and beginning the process of “Finding My Voice” were the most important aspects of their backgrounds that motivated them to participate in peer outreach. The motivation for women to accept this role came in the form of wanting to payback the support the participant had received during her cancer experience, desiring to serve a higher purpose, and expectations of not only supporting and encouraging those they are serving but of receiving support and encouragement from those they are serving and other survivors in the program.

As these women served in the peer educator role, they experienced both positive and negative effects from their role in the programs. The positive effects of their role included simply enjoying being able to help someone else, receiving encouragement and support from the other women in the group, reinforcement of their spiritual beliefs, being able to tell their story in a safe environment and finding their voice as a result of that. The women in this study also gained valuable health information, learned of holistic health practices, and had access to health professionals to assist in the management of their own health. Some of the negative affects of the peer educator role for women in this study were experiencing emotional distress and fear of recurrence from hearing of another woman being diagnosed with or dying from cancer. These women were able to positively cope with the negative effects they experienced through training and having a spiritual focus and continued to be motivated to participate in peer outreach. Although, they did not experience any negative effects that were strong enough to make them discontinue their participation, they did express some things that would make them consider no longer participating. These include having a lack of training that leads to overwhelming emotional stress from the deaths and sickness of program members and increased fear of recurrence, having limited physical ability, and the programs straying from its original focus

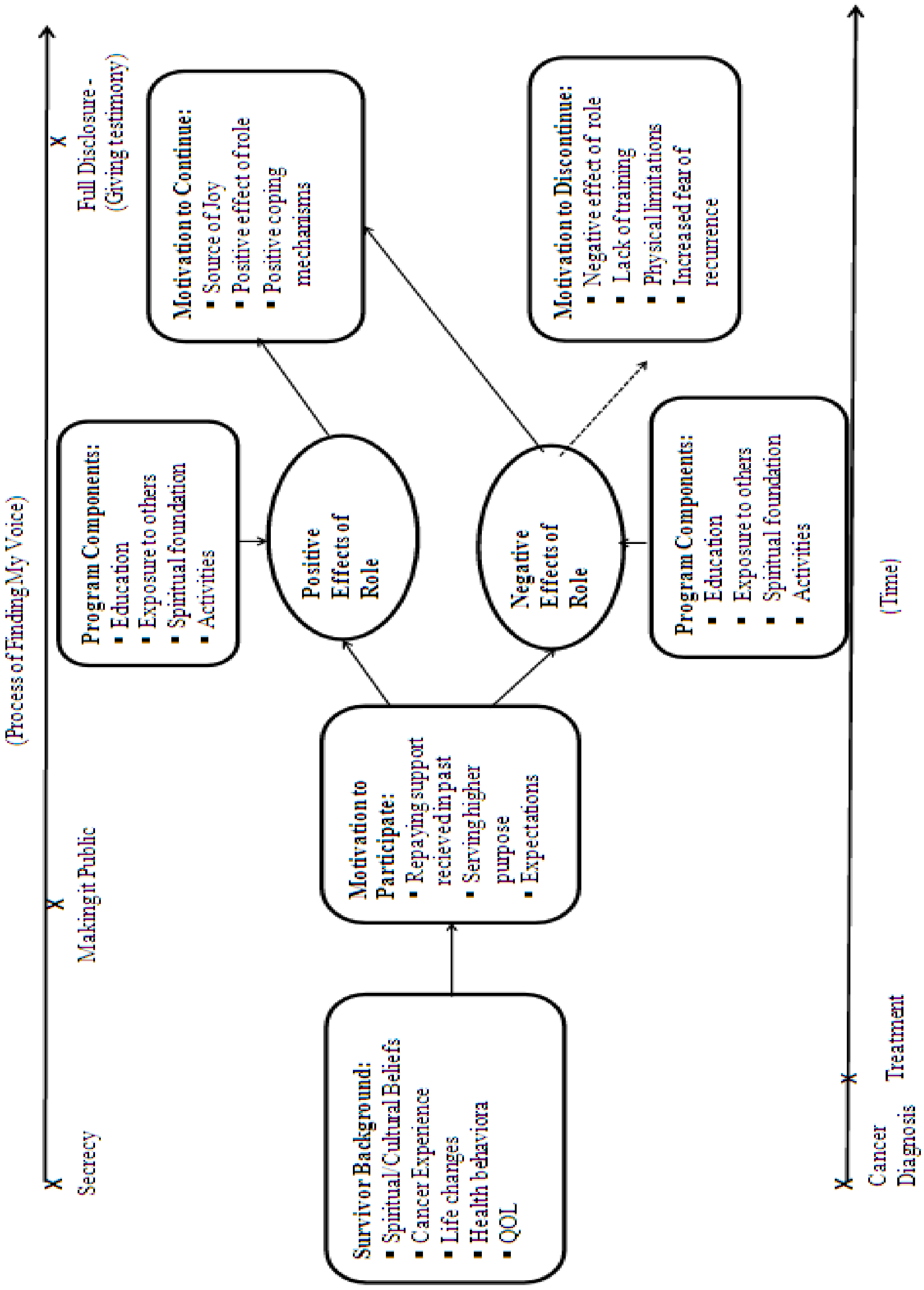

Figure 4.1 Broad process involved for study participants

4.2.6 Central Process of Finding My Voice

Further analysis of the broad process that emerged from the data, revealed a central process that is particularly influential in these women choosing to become a peer educator and continuing in that role at each stage of the broad process. The central process involved is the process of "Finding My Voice." Figure 4.2 presents a conceptual map of the central process across the same timeline in which the broad process occurs. The process of finding my voice moved from a state of secrecy at the time of diagnosis because of shame, stigma, or reactions from others, to making their diagnosis public during treatment or just after completion of treatment. For some women, their diagnosis was made public because they were unable to hide their diagnosis. For example, Kim " got sick all the time. They couldn't find what medications worked right. What didn't work right. I was on 17 different meds at one time just trying to find something. And, I really think that the meds were making me more sick than anything else. So I really couldn't hide it from people." For others, they made their diagnosis public because they no longer felt ashamed and had started believing in a higher purpose for their cancer. As Sheryl stated, "once I became okay with what I was going through, I was able to tell other people without feeling ashamed." Once the diagnosis had been made public participants continued through the process of finding their voice by giving "testimony" (i.e., full disclosure of cancer experience). For some women, this was not achieved until after choosing to participate in a peer outreach group and they experienced this as a benefit from participating as a peer educator. For Karen "…the first time I really fully opened up about what I went through was in the group. There was a comfortable feeling there." Other women were able to find their voice prior to their participation and it motivated them become a peer educator and helps them maintain that motivation to reach out to others. Gladys described this by saying "I was already doing outreach and I felt that I was being very effective in that. But, then when Minister asked me and another survivor would we help her get this off the ground I was not going to say no."

Finding one's voice for women in this study was influenced by several factors. These included needing time to move past the initial stigma and shame felt because of the diagnosis and needing non-judgmental support from those around them. There were also two important processes that emerged in the data that influenced the participant's ability to find their voice: spiritual growth and constructing a new identity in light of her cancer experience.

4.2.6.1 Constructing a New Identity

Constructing a new identity for these women came through the cancer experience itself. This new identity was developed through the treatment process and even thereafter. It was partially constructed through the woman going through the process of Finding My Voice and moving from Secrecy to Making her Diagnosis Public. The more a participant told the story of her cancer experience, the more her new identity was constructed and the closer she was to finding her voice. For several participants, the construction of their new identity was not completed until after they began participating in the peer outreach program. For example, Pam expressed that she did not realize how much she would enjoy participating until after she joined. It was through her participation that she realized how much joy she received from helping others. Because of the enthusiasm she had she became involved with her peer outreach program at a level that she did "more than I think. Because I have really become an advocate for women with cancer since I joined. I don’t know, I guess it doesn’t feel like that much because I enjoy it so much.”

A new identity was also constructed through spirituality for the women in this study. All women mentioned a spiritual growth that occurred as a direct result of their cancer experience and their experiences in the peer outreach programs. Spiritual growth led the participants to feel their life had a higher purpose and that was the reason for their cancer experience. This spiritual growth further influenced the construction of a new identity these women. Brenda felt “like I am serving my purpose as a result of being a breast cancer survivor. I definitely feel that, like I said, it wasn’t just for me to go through it just to go through it. I feel like there is more for me to do actually.” Because of this higher purpose, they viewed themselves differently than they did before and were more open to taking on roles they may not have taken on in the past.

4.2.6.2 Spiritual Growth

All women could be described as being spiritual and believing they had a connection to God prior to their diagnosis. For some women, when they were first told of their diagnosis, their spirituality tended to weaken a bit. For example, Martha stated, “I feel like I didn’t deserve this. I was wondering what I did to deserve it.” However, over time the spirituality of all participants strengthened. This was particularly true between the treatment and post-treatment stage. Gladys provided a great example of an experience she had while undergoing treatment that really strengthened her spiritually and brought her closer to God:

> No matter how bad it was I could not believe in those eight months I grew so much more as a Christian that I had in any space of time in my life it was just and I just sat back and God just worked miracles… I had this one experience and I want to tell you about that because it was then that it just

> put me on a different level in my walk. It was 2 weeks before my last chemo treatment. And, you know, I just didn't want to have it. I just didn't feel I could make it. And, for a solid week, I kept praying and I told the Lord, "I can't make it. I don't want to take this last treatment. I can't do it. I cannot make it. I just can't." Those were my words, "Lord I just can't make it." For a week, I cried and prayed. Didn't let my husband at that time know that I was doing that. So, this particular Monday, it was two weeks before my treatment date. And, the first week I was crying and carrying on. So, that Monday, the week before my treatment I had to go to the Presbyterian Hospital – Matthews to get my shots for my blood count and everything. So, I was driving and I got into the intersect left hand turn at 51 and Idlewild. And, you know, you see those custom made plates. And, I always try to read them out loud, you know. So, I saw this custom made plate and I was sitting there looking at because it was the red light, that car, and I was the second car. I read that license plate out loud and it read "I can make it." No, "You can make it. " And, I said that out loud. I said "oh my gosh. What are the odds that particular morning, at that particular time, that that particular car with those tags would be in front of me? What are the odds that the light would turn red, that I would be sitting?".…And, that following Monday, I went in for my last treatment and I made it.

Spiritual growth through the cancer experience helped these survivors to construct a new identity and find their voice. These women often felt that they were being prepared for something bigger than anything they had done before. Brenda "felt like God was preparing me for something. And, nobody can really understand that unless it's you." These women believed that their survival was meant so that they could give testimony. This spiritual growth helped provide a platform/meaning of the experience so they could construct a new identity and find their voice. Spiritual growth also gave them a sense of being "okay" even with the possibility of recurrence and death. In particular, spiritual growth is influential in how despite the negative effects of the program on the participant; they still chose to continue participating in the peer educator role.

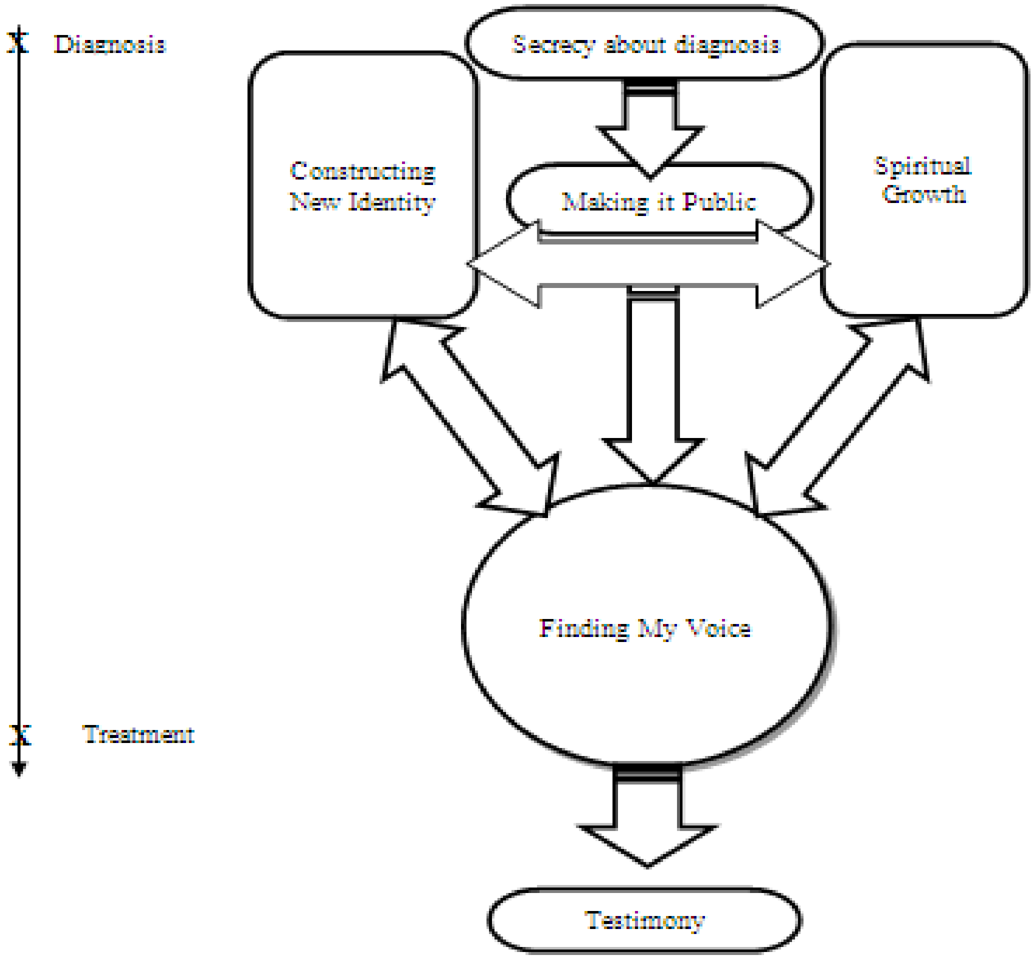

Figure 4.2: Central process: Finding my voice

4.3 Member Checks

Member checks were used in this study to ensure that my interpretation of the data was in line with the study participant's own personal beliefs and thoughts. After completion of the final phase of the data analysis, a summary of the findings were mailed to each of the women in this study. They were asked to provide any feedback or comments they may have on the study findings. Five of the eight women in the study responded to the member checks within three weeks. I personally contacted the three women that did not respond within three weeks to receive their feedback and comments.

All of the women were in agreement with the study findings and did not have any suggestions for changes that should be made to the final results. Brenda felt that the findings were “right on point.” And, Kim believed that the findings provided a “great description of my experiences and the experiences of other survivors in peer educator roles.” One woman, in particular, was very pleased with the results of the study and felt as if the findings in the study would be helpful for the additional recruitment of peer educators in her own program. In Martha’s response to the findings summary she stated, “I think you are on to something. I am really glad you did this study because it put my own experiences in front of me in a way that I can see some things that can be done in my own group to recruit more survivors and keep the program going strong.”

4.4 Summary

Overall, the women in this study were educated, African American women with self-described good or very good health and mid to high-range QOL scores. Each woman stated that she performed regular breast cancer screenings and visited their physician regularly. The amount of time since their breast cancer diagnosis varied among participants; ranging from two to nine years. The amount time of participation as a peer educator in the specific peer outreach program at the time of their enrollment in the study ranged from two months to four years.

Themes and codes that emerged from the interview data revealed a broad process involved in the women’s decisions to serve as a peer educator and to continue the role. This broad process involved the survivor’s background, their motivation to participate, the program components and its effect on the survivor, and their motivation to continue in the role. Throughout this broad process, there is one process/concept that is central to each aspect of the broad process. The central process found to be involved for participants serving as peer educators was “Finding My Voice.” This process moved the survivor from being secretive about their diagnosis to making it public. And, through spiritual growth and constructing a new identity in light of their cancer experience, survivors were able to find their voice. For some participants this happened prior to participating in the program and was simply improved by their participation. For others, finding their voice came as a result of their participation and telling their story repeatedly within the peer outreach environment. In Chapter Five, qualitative and quantitative findings will be analyzed in light of the current state of the literature. Study limitations and future implications for health services research policy, practice, and research will also be discussed in Chapter Five.

CHAPTER 5: DISCUSSION

5.1 Discussion

Prior to this research study, there was insufficient data on the experiences of African American breast cancer survivors who also serve as peer educators in breast cancer outreach programs. This study was undertaken to achieve two objectives. The first objective was to describe the experiences of African American breast cancer survivors who also serve as peer educators in breast cancer outreach programs and to explore the potential risks and/or benefits associated with participation in this role. Secondly, the researcher wanted to explore the ways in which participation in this role influenced the survivor's health behaviors, healthcare utilization, and ultimately, QOL needs of survivors. The study sample included eight African American women from three different breast cancer outreach programs in the Charlotte, NC area. The average participant age was 49.5 years and all participants had at least some college education. Each participant in this study had been diagnosed with breast cancer between two and nine years prior to enrolling in the study. The amount of time the participants had served as a peer educator ranged from 2 months to 4 years. All participants said that they routinely performed self-breast exams and regularly visited their physician. They also all self-rated their health as good or very good. Overall, QLACS scores for participants showed that they had high QOL functioning.

A Grounded Theory approach was used to collect qualitative data in order to answer the two research questions and sub-questions: (1) What are the experiences of

African American breast cancer survivors serving as peer educators in Breast Cancer Outreach Programs? (a) What were their initial motivations and expectations for becoming a peer educator? (b) How have these motivations and expectations changed or stayed the same in light of their experiences as peer educators? And, (c) What positive or negative impact has being a peer educator had on the quality of life needs of peer educators who are also survivors? (2) How has being a peer educator influenced the health behaviors and healthcare utilization of African American breast cancer survivors?

5.1.2 Qualitative Findings

Overall, women in this study had positive experiences related to their participation as peer educators in breast cancer outreach programs. As detailed in Chapter Four, there were four themes that emerged during the qualitative data analysis. These themes include (1) the survivor background, (2) the decision to participate in the peer educator role, (3) program components, and (4) the decision to continue in the peer educator role. These themes reflect the women's experiences as peer educators, as well as, the factors that motivate them to initiate and continue participation in the peer educator role, and led to the women finding their voice.

5.1.2.1 Survivor Background

The survivor background, which includes spiritual/cultural beliefs, the types of activities involved in prior to their breast cancer diagnosis, health behaviors and healthcare utilization before, during, and after cancer treatment, along with the cancer experience and the life changes resulting from that experience, provided the foundation for participants' decisions to participate in the peer educator role. This is particularly true as it relates to the survivors spirituality prior to participation in the peer educator role. In this study, all survivors expressed that their spirituality was important to them prior to their cancer diagnosis and became even more important as a coping mechanism while they were enduring their cancer experience. The women expressed their belief in a higher purpose for their cancer experience and described a growth in their spirituality and belief in God. For most of the women, the purpose of their cancer experience was for them to help others. This finding is consistent with prior research on African American breast cancer survivors that showed spiritual beliefs as being extremely important to African American survivors and often influenced the coping mechanisms used among this group and aid them in their adjustment to changes that occur as a result of the cancer (Holt et al., 2011; Lopez et al., 2005; Powe et al., 2007; Simon et al., 2007; Umezawa et al., 2012). Likewise, the study findings confirmed results from prior research studies that suggested the belief in the spiritual nature of their cancer experience leads the survivor to feel the need to find a way to “give back” and serve as role models or “witnesses” within their community (Fatone et al., 2007; Hamilton et al., 2007). For most women in the study, the need to “give back” was their main motivation for participation in the peer educator role.

In addition to spiritual beliefs, study participants showed similarities to participants in other research studies when they expressed that after being diagnosed with cancer and starting treatment, they experienced limited activities of daily living and impaired physical, emotional, and mental abilities (Bowen et al., 2007; Giedzinska et al., 2004; Paskett et al., 2008; Russell et al., 2008; Schootman, Deshpande, Pruitt, Aft, & Jeffe, 2010). These women also expressed initially having negative internal emotions related to the cancer diagnosis itself and their view of their position in the community and their own family because of the diagnosis. For these women, as suggested in prior research, through the use of various coping mechanisms over time they began to experience more positive emotions related to their cancer experience and its impact on their lives (Ashing-Giwa & Lim, 2010a; Bowen et al., 2007).

Similar to participants in other studies, women in this study expressed that they did not actively seek healthcare services, health information or exercise regularly prior to their cancer diagnosis and, for some, after their diagnosis (Rust & Davis, 2011; Smith et al., 2009). However, contrary to previous research, they stated that their health behaviors and healthcare utilization improved as a result of the emphasis placed on positive health behaviors and the information provided through the peer outreach programs.

The women in this study also highlighted factors that are important to their QOL in light of their cancer diagnosis and the changes experienced as a result of it. All women indicated that financial stability, health, peace, spirituality, and helping others are important factors to their own self-rated QOL. Of these factors, helping others and spirituality are of particular relevance to the purposes of this research study and confirms the findings of previous research related to the QOL needs of African American breast cancer survivors (Bellizzi et al., 2010; Fatone et al., 2007; Lopez et al., 2005).

5.1.2.2 Motivation to Participate in the Peer Educator Role

For the women in this study, motivation to participate in the peer educator role began with the participant making their diagnosis public. Prior to making their diagnosis public, they often would keep it a secret and tell only those that needed to know or those they could not hide it from. These results may reflect the findings in prior research that suggest African American breast cancer survivors tend to have a more fatalistic view of breast cancer and may not disclose their diagnosis to avoid stigmatization, discrimination, and/or rejection both within their own community and within society, in general (Coggin & Shaw-Perry, 2006; Hamilton et al., 2011).

Other factors that were found to influence participants' motivation to participate in the peer educator role include receiving support from others during their breast cancer experience, believing that they are serving a higher purpose by helping others and having expectations of personally benefitting from participation in that role. These factors may reflect the women's spiritual beliefs. As demonstrated in prior research, African American survivors often find a spiritual purpose for their breast cancer experience (Fatone et al., 2007; Hamilton et al., 2007). Because of the perceived spiritual purpose for their cancer and the support they received during their own experience, participants felt it was necessary to "give back" to others and bear witness to their own lived experiences and use their testimony to help other women (Fatone et al., 2007). They also viewed participating in the peer educator role as a way to meet some of the QOL needs that have been expressed by African American cancer survivors both in the present study and in prior research. The personal benefits they were able to gain from participating in a peer outreach program with other survivors reflects their expressed need to receive emotional and social support by simply having people around that are available and willing to help, receiving encouraging words, and participating in distracting activities (Hamilton & Sandelowski, 2004; Russell et al., 2008). Women in this study expressed that they personally benefited from participation in the peer educator role through the development of friendships with other survivors, receiving support, providing support to others, and receiving informational resources.

5.1.2.3 Program Components

The program components that were the most influential on the study participants included: (1) Educational and Informational Resources, (2) Exposure to other survivors, (3) Spiritual Foundation, and (4) Diversity in group activities. Each of these components is reflected as an area of expressed need by African American cancer survivors in previous research. Rust and Davis (2011) found that African American breast cancer survivors often did not have access to adequate or correct health information and as a result did not adhere to recommended medication guidelines. Women in this study expressed that providing health information and educational resources through the outreach program helped participants in this study to improve their health behaviors and also reinforced appropriate healthcare utilization and informed survivors of alternative health services providers, such as a chiropractor and nutritionist, of which they may not have otherwise been aware. The diversity in group activities provided participants with activities that were a distraction from the difficulties of coping with breast cancer and its treatment effect (Russell et al., 2008). The spiritual foundation of each outreach program played an important role in meeting the needs of the African American breast cancer survivors/peer educators as previous research has shown that spirituality is very important within African American community, in general, and especially important for African American breast cancer survivors who use spirituality as a coping mechanism (Gall, Charbonneau, & Florack, 2011; Holt et al., 2009; Leak, Hu, & King, 2008; Matthews et al., 2012; Stewart, 2011). The exposure to other breast cancer survivors allowed the women in this study to openly express their cancer experience and discuss their feelings in a safe environment with other women that understood what they were going through. Having a safe environment within which to express themselves created the opportunity for another need expressed in prior research to be met, the need to become comfortable with the future (Hamilton & Sandelowski, 2004; Lopez et al., 2005; Russell et al., 2008)

5.1.2.4 The Decision to Continue in the Peer Educator Role

The motivation to continue in the peer educator role for study participants was related to the effects of the program components and the individual survivor characteristics and background. They expressed that participating in the peer educator role and placing others' needs as a priority, for them, was a source of joy and that they personally benefitted by feeling good about themselves and their work, as well as, increasing their own social support system and health knowledge. The benefits that were gained through participation in the peer educator role also demonstrate the potential for participation in this role to meet some of the previously discussed QOL needs of African American breast cancer survivors for adequate and correct health information and the need to help other women and tell the story of their breast cancer experiences (Hamilton et al., 2010; Kent et al., 2012; Mosher et al., 2010; Rust & Davis, 2011).

Women in this study also highlighted several factors that help them to mediate the potentially negative effects of the peer educator role. For example, they stated that sharing responsibilities with other survivors in the group helped to prevent burn-out and decreased the potential burden of the role. Appropriate training to help them deal with hearing about other group members worsening conditions or death was also highlighted as a way to mediate the potentially negative effects of the peer educator role. Employing these methods in the peer outreach program helped the potentially damaging effects that can occur from having a fear of cancer recurrence triggered during group meetings or while working with members one-on-one (Bowen et al., 2007; Gill et al., 2004; Taylor et al., 2012).

5.1.3 Central Process of “Finding My Voice”

For the women in this study, there is a broad process that emerged in the data and reflected how these African American breast cancer survivors decided to become a peer educator and chose to continue a peer educator role over time. The survivor background, which includes spiritual/cultural beliefs and the type of activities they were involved in prior to their breast cancer diagnosis, along with the cancer experience and the impact of that experience on their own lives helped them to become motivated to serve as a peer educator. The individual program characteristics and structure has the potential to positively or negatively affect the survivor and can influence their decision to continue or discontinue participating in that role. However, they found ways to mediate the potentially negative effects of the peer educator role. Throughout this broad process, there is a central process that occurs and is particularly influential at each stage of the broad process.

As previously discussed in chapter 4, the central process involved in study participants becoming and remaining a peer educator is the process of “Finding My Voice.” The process of finding their voice tends to move from a state of secrecy because of shame, stigma, or the reactions of others, to making their diagnosis public. These women often first made their diagnosis public (i.e., meaning they told those that absolutely did not have to know) either during or post treatment. For some, this was because they were unable to hide their diagnosis. For others, they made their diagnosis public because they no longer felt ashamed and had started believing in a higher purpose for their cancer. Once the diagnosis is made public, survivors were then able to, over time, find their voice and go into details about their experiences as a way to help others. They often began doing this in more informal settings initially and then more formal settings. Some women expressed that they did not fully find their voice until after participating as a peer educator and realizing that they had a story to tell that could really impact the lives of other women. Other women felt that they had found their voice before participating formally in the peer educator role. While there are no data specifically related to African American breast cancer survivors who serve as peer educators "finding their voice," the central process that emerged in the data analysis of this are in line with research of cancer survivors and their caregivers finding their voice over time through the cancer experience and beyond (Carroll, 2005; Chung & Hwang, 2012; Nelson, 2011; Ridner, Bonner, Deng, & Sinclair, 2012; J. N. Wells, Cagle, Bradley, & Barnes, 2008). For example, Ridner and colleagues(2012) conducted a study exploring perceptions and feelings related to lymphedema in breast cancer survivors. The results of that study demonstrated that although the breast cancer survivors were initially ashamed of their lymphedema, yearned for their life to return to normal, and sought out uplifting resources, communicating the feelings they were having and discussing their experiences with other people helped them to find solace, encouragement, and hope. Through finding their voice and expressing their feelings and experiences to others, the participants in that study were able to improve their QOL even if they could not return to "normal" as they so desired (Ridner et al., 2012).

Several factors influenced the women’s ability to find their voice. Spirituality was found to be very important in the sample because the women felt they were here for a reason and that reason was to help others. This was influenced by their spirituality prior to their cancer diagnosis. As a result of their cancer diagnosis, these women had to construct a new identity. If you have grown to believe you have a higher purpose and you have traditional African American cultural/spiritual beliefs, that purpose requires you to provide testimony to any and all that need to hear it. In addition to constructing a new identity and spiritual growth, they also needed time to move past the initial stigma and shame the felt because of their diagnosis. Non-judgmental support from those around the survivors also assisted them in finding their voice. It is possible that a barrier to an individual finding their voice would be negative reactions from people when they tell their story. However, this is a difficult question to answer as most women in this study have not really experienced in bad reactions to their story.

5.1.3.1 Constructing a New Identity

Constructing a new identity comes through the cancer experience itself. This new identity is developed through the treatment process and even after. It is partially constructed through the individual finding their voice and telling the story of their cancer experience. This new identity is also constructed through spirituality. All participants in the study mentioned a spiritual growth that occurred as a direct result of the cancer experience. This growth often came during the treatment process and even thereafter. Spiritual growth led the participants to feel their life had a higher purpose and that that was the reason for their cancer experience. Because of this “higher purpose” they viewed themselves differently than they did before the cancer. Prior research has shown that the illness narratives told by cancer survivors reflect their construction of a new identity as an individual who has survived cancer. Over time, as the survivor tells the story of their cancer experience, meanings and understandings of the experience are developed that allow the cancer survivor to re-define themselves according to these new meanings and understandings (Coreil et al., 2012; Glidewell, 2008; Mathieson & Stam, 1995; Vanderford, Jenks, & Sharf, 1997). For African American cancer survivors, in particular, this new identity is often constructed alongside and influenced by the individual's spiritual growth (Coreil et al., 2012; Levine, Aviv, Yoo, Ewing, & Au, 2009; Umezawa et al., 2012)

5.1.3.2 Spiritual Growth

All women in this study could be described as being spiritual and believing they had a connection to God prior to their diagnosis. For some women, when they were first told of their diagnosis, their spirituality tended to weaken a bit. However, over time the spirituality of all in the sample tended to be strengthened. This was particularly true between the treatment and post-treatment stage. They often discussed specific events or experiences they felt directly increased their spirituality and caused them to feel God was by their side.

Spiritual growth through the cancer experience helped these survivors develop a new identity and find their voice. They often felt that they were being prepared for something bigger than anything they had done before and they believed their survival was meant so that they could give testimony and tell their story to other women with whom they had contact. This spiritual growth helped provide a platform/meaning of the experience so they could construct a new identity and find their voice. This growth also gave them a sense of being “okay” even with the possibility of death. Spiritual growth, in particular, is influential in how, despite the negative effects of the program on the survivor, they may choose to continue participating in that role. Participants believed that the work they were doing was ordained by God and because of this he gave them the strength that they needed to endure any potential negative impact. The importance of spirituality and spiritual growth among participants in this study is consistent with prior research discussed in Chapter Two that highlights the importance of spirituality within the African American community, in general, and among African American cancer survivors specifically (Holt et al., 2011; Potts, 1996; Stewart, 2011; Umezawa et al., 2012; Wenzel et al., 2012)

5.2 Comparison of Study Findings to Bandura’s Theory of Self-Efficacy

Bandura’s theory of self-efficacy was used to guide the development of this research study. According to Bandura (1986), self-efficacy beliefs are created through personal and vicarious experiences, social persuasion, and somatic and emotional states. Self-efficacy beliefs can be influenced by an individual’s behavioral, cognitive, affective, and personal and situational environment. Higher self-efficacy beliefs have been shown to be positively associated with increases in QOL and self-esteem and the adoption and maintenance of positive health behaviors, such as increased physical activity, better eating habits, social and familial role adjustments, and improved access to health services (Bracke et al., 2008; Ley et al., 2002; Mosher et al., 2010). Self-efficacy beliefs can be strengthened through encouragement, informative feedback, and exposure to the peer-models and their personal stories (Bandura, 1997).

While the women in this study did not specifically mention self-efficacy, the characteristics and structure of the programs discussed by women in this study and highlighted in the broad process of becoming and continuing in the role of a peer educator include components that were found to be important in strengthening self-efficacy (Bandura, 1997). These include social support through exposure to other survivors, a health education component, and informative feedback and encouragement provided by other program participants. These women indicated that their participation in the peer educator role in these programs positively influenced their QOL, self-esteem, and health behaviors. Specifically, they indicated that their participation in the role resulted in having a more positive outlook on life, making appropriate social and familial role adjustments, experiencing increased knowledge of breast health and ways to manage their health, and improving health behaviors, such as eating healthier and increasing physical activity. They also suggested that their participation helped them to find their voice and be able to more freely discuss their cancer experience. The increase in self-efficacy that these women experienced helped them to be able to cope with the potentially negative effects of participation in the peer educator role and influenced their desire to continue participating in the role.

The central process of “Finding my voice” may be synonymous with an increase in self-efficacy amongst the women in this study because of the concepts involved in completing this process (Bandura, 1997). Overtime, these women were able to move from a place of secrecy about their diagnosis to a place where they were completely open about their diagnosis and freely told the story of their cancer experiences in an effort to help other women. The process of finding their voice required these women to construct a new identity and experience a spiritual growth. For women in this study, this often meant building their self-confidence and seeing their value to the African American community, in general, in light of their cancer experiences. The spiritual growth these women experienced helped them to find purpose in telling their stories, as well as, helping them to increase their self-esteem and belief in their own abilities. The more the women in this study believed in their ability to manage their own health and, in turn, be an advocate and role model to other women in the African American community the closer they came to finding their voice and using that voice within the community. The belief in their ability to help others as a result of their own experiences by using their voice suggests an increase in their personal self-efficacy beliefs (Bandura, 1997).

5.3 Study Strengths and Limitations

This research study had several strengths. First, the use of a grounded theory design allowed the data and the themes and processes that emerged from the data to be grounded in and reflective of the participant's own experiences. The constant comparative nature of the grounded theory analysis added rigor to the study by ensuring that the model evolved with the data (Corbin & Strauss, 2008). A reflexive journal, documenting each step of the research process, was maintained by the researcher to create transparency in the research process (Morrow, 2005). And member checks were used to ensure that study findings were consistent with the participants' experiences. Member checks were conducted by mailing a summary of the study findings to each participant and requesting that they respond to any discrepancies they may have found (Strauss & Corbin, 1998; Yanow & Schwartz-Shea, 2006).

Unmistakably, caution should be taken in applying the findings of this research study. Purposive sampling was used in this study to allow for the selection of participants who were particularly informative about the experiences of African American breast cancer survivors who serve as peer educators because of their own lived experiences. This method allowed for enhanced understanding of the experiences of African American breast cancer survivors who serve as peer educators. Study participants were also well-educated overall and grounded in spirituality a priori. While sampling frame is narrow and the study participants were very similar, the findings of this study are transferable to other groups and provide suggestions for the experiences of peer educators in other health areas such as diabetes, heart disease, and mental health illnesses. Findings from this study may be useful in the development and analysis of future studies in a variety disciplines that incorporate peer educators.

Difficulties in the recruitment of study participants created limitations in this study. Recruitment of participants lasted from August 10, 2009 to August 7, 2012. As this is a population with historically low participation rates in research studies, several recruitment methods were employed (e.g., flyers, print ads, targeted emails, recruitment presentations, and snowball sampling). However, even with the use of several different recruitment methods, there were difficulties in obtaining participants resulting in changes in the timeline for completion of treatment. The timeline was changed from 6 months to 3 months after a period of a year and a half without any eligible participants due to the requirements for treatment completion.

Another limitation to this study is the exclusion of a comparison group of African American breast cancer survivors who did not want to serve as a peer educator or who at one point in time were peer educators but had since decided to discontinue that role. The inclusion of a comparison group would add to the rigor of the study by allowing the differences between those who currently participate and those who participated in the past or have never participated to be explored. A comparison group was excluded, however, because of budget concerns and the length of time necessary for the study being unreasonable for the purposes of this project. The constant comparative nature of the grounded theory analysis will help reduce any bias related to this limitation.

5.4 Implications for Future Research

Findings in this study have significant implications for health services research, policy, and practice. This is particularly true because breast cancer survivors who are also peer educators can be considered adjunct lay service providers to other women with breast cancer across each stage of the breast cancer continuum. Breast cancer survivors who are peer educators may provide education and promotion of cancer prevention and screening amongst women prior to a cancer diagnosis, patient navigation and guidance at the time of diagnosis and during treatment, and support for survivors after the completion of their cancer treatment. The results of this study extends the current knowledge base in the field of peer education among African American breast cancer survivors and provides a foundation for further study of survivors who serve as peer educators. Study findings highlighted social factors, personal behaviors, and program structures and processes that influence African American breast cancer survivors to initiate and continue participation in the peer educator role.

These results can then be used to inform the development, evaluation, and improvement of interventions that focus on breast cancer-related peer education and incorporate survivors as a part of the intervention. They can also be used to inform health policies that aim to improve the quality of survivorship of African American breast cancer survivors, including policies that incorporate peer education/peer support as complementary to traditional healthcare services. Findings in this study show that peer education may have a positive impact on those that provide the peer education, as well as, those on the receiving end. This suggests that funding for interventions that utilize peer educators could be a good, cost-effective investment into the improvement of breast cancer-related outcomes because peer educators often participate on a volunteer basis and their participation in these roles can be beneficial for all involved.

This study provided valuable information and insight into the experiences of African American breast cancer survivors who serve as peer educators but it also spurred several other questions that need to be answered. Several potential benefits and some risks of participation in a peer educator role for African American breast cancer survivors were highlighted in this study, including increased social support and increased fear of recurrence. Further research is needed to assess the transferability of these findings to other African American women who are breast cancer survivors and peer educators but do not have background similar to the participants in this study, such as individuals with a lower educational level, lower income, and a less spiritual background. Future research should also explore the differences between African American breast cancer survivors who choose to continue in the peer educator role, those who at one point in time served as a peer educator but no longer serve in that capacity, and survivors who do not want to participate in the peer educator role at all. There is also the need to explore other non-faith-based peer outreach programs that incorporate African American breast cancer survivors as peer educators to determine if non-faith based programs will have a similar impact on the African American breast cancer survivor/peer educator.

In addition, research is needed to explore the central process of Finding My Voice and the factors that are involved. The results of this study demonstrate that finding her voice had a positive impact on the women in this study. Further exploration of the specific concepts and processes involved in Finding My Voice will be useful in the understanding of how women are able to move from a state of secrecy about their diagnosis to being open an willing to share their story with others. This will be useful in discovering ways to help other women who have been diagnosed with breast cancer with finding their own voice and, therefore, improving the QOL of African American breast cancer survivors, in general.

5.5 Conclusions

Prior to this study, there was insufficient data available on the experiences of African American breast cancer survivors who serve as peer educators in breast cancer outreach programs. This is despite the fact that African American breast cancer survivors are increasingly being incorporated into breast cancer outreach programs as peer educators. Exploring the experiences of the African American survivor/peer educator, how they perceive the benefits and/or risks, and the impact of the peer educator role on the QOL needs, health behaviors and healthcare utilization of the survivor is an important first step in understanding how being a peer educator may influence the survivors psychosocial and health status constructs.

This study demonstrates that participation in certain spiritually-based peer outreach programs as a peer educator has the potential to positively impact the African

American breast cancer survivor in several ways. The broad process that was revealed in the data analysis shows that the survivor’s background, including their spiritual/cultural beliefs, cancer experience and life changes as a result of that experience, QOL needs and health behavior, all influence the survivors’ motivation to participate as a peer educator. Among this sample, the motivation to participate in the peer educator role consisted of repaying support that was received during their own cancer experience, serving a higher purpose by being obedient to God, and having expectations of helping others, as well as, expectations of personal benefit such as increased health knowledge and social support. As all three of the peer outreach programs in which study participants belonged were faith-based, each program had a strong spiritual foundation that seemed to benefit study participants. Other program components such as health education, exposure to other survivors and diverse activities were also shown to positively impact participants in this study. While there was the potential for some negative consequences, such as negative emotions and fear of recurrence being triggered by hearing of a group members’ condition worsening or dying, participants expressed positive coping mechanisms, including the use of prayer and grief and hospice training received in the programs, to help mediate the potential negative effect of the peer educator role making it possible for the participant to continue in that capacity.

Further analysis of the qualitative data in this study revealed that there was a central process that is particularly important in African American breast cancer survivors choosing to become and remaining a peer educator. This central process is the process of Finding My Voice. This process occurs over time and begins when the survivor moves from a place of secrecy about her cancer diagnosis and begins to make her diagnosis public. Some participants completed the process of finding her voice prior to participation in the peer outreach group. Whereas others did not fully find their voice until after joining the peer outreach group, although they did make steps in that direction prior to joining the group by making their diagnosis public. Study results revealed that spiritual growth and constructing a new identity are both important factors in the process of Finding My Voice. Further research in this area will not only be beneficial to African American breast cancer survivors who serve as peer educators but also to African American cancer survivors, in general, as there is much that can be learned from the factors and processes that are positively influencing the QOL, health behaviors, and healthcare utilization of the participants in this study.

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APPENDIX A: DEMOGRAPHIC DATA FORM

Participant ID ___________
Date___________

DEMOGRAPHIC DATA FORM

1. Age: __________

2. Marital Status:
   - ☐ Married
   - ☐ Divorced
   - ☐ Single
   - ☐ Widowed

3. Race/ethnicity: ____

4. Education:
   - ☐ Less than high school
   - ☐ High School graduate
   - ☐ Technical School
   - ☐ Some College
   - ☐ College graduate
   - ☐ Post-graduate

5. Insurance Status: ☐ Insured ☐ Uninsured

6. Religious Affiliation: ____________________________________

7. How would you rate your health?
   - ☐ Excellent
   - ☐ Very Good
   - ☐ Good
   - ☐ Fair
   - ☐ Poor

8. Date of Diagnosis: ☐☐-☐☐-☐☐☐☐
   mm dd yyyy

9. Stage of cancer at the time of diagnosis:
   - ☐ Stage 1
   - ☐ Stage 2
   - ☐ Stage 3
   - ☐ Stage 4

- 1 -

Participant ID ___________
Date___________

10. Has your breast cancer returned in the past 6 months? ☐ Yes ☐ No

11. Date of last mammogram: ☐☐-☐☐-☐☐☐☐
mm dd yyyy

12. How often do you perform self breast exams?

- ☐ Daily
- ☐ Weekly
- ☐ Monthly
- ☐ Yearly

13. Have you visited your doctor or nurse practitioner in the past 6 months?

☐ Yes ☐ No

14. Please list the name of the peer education or peer support groups in which you participate:

14a.____

14b.____

14c.____

14d.____

15. How long have you participated in each of these groups referenced in Q. 14?

15a.____

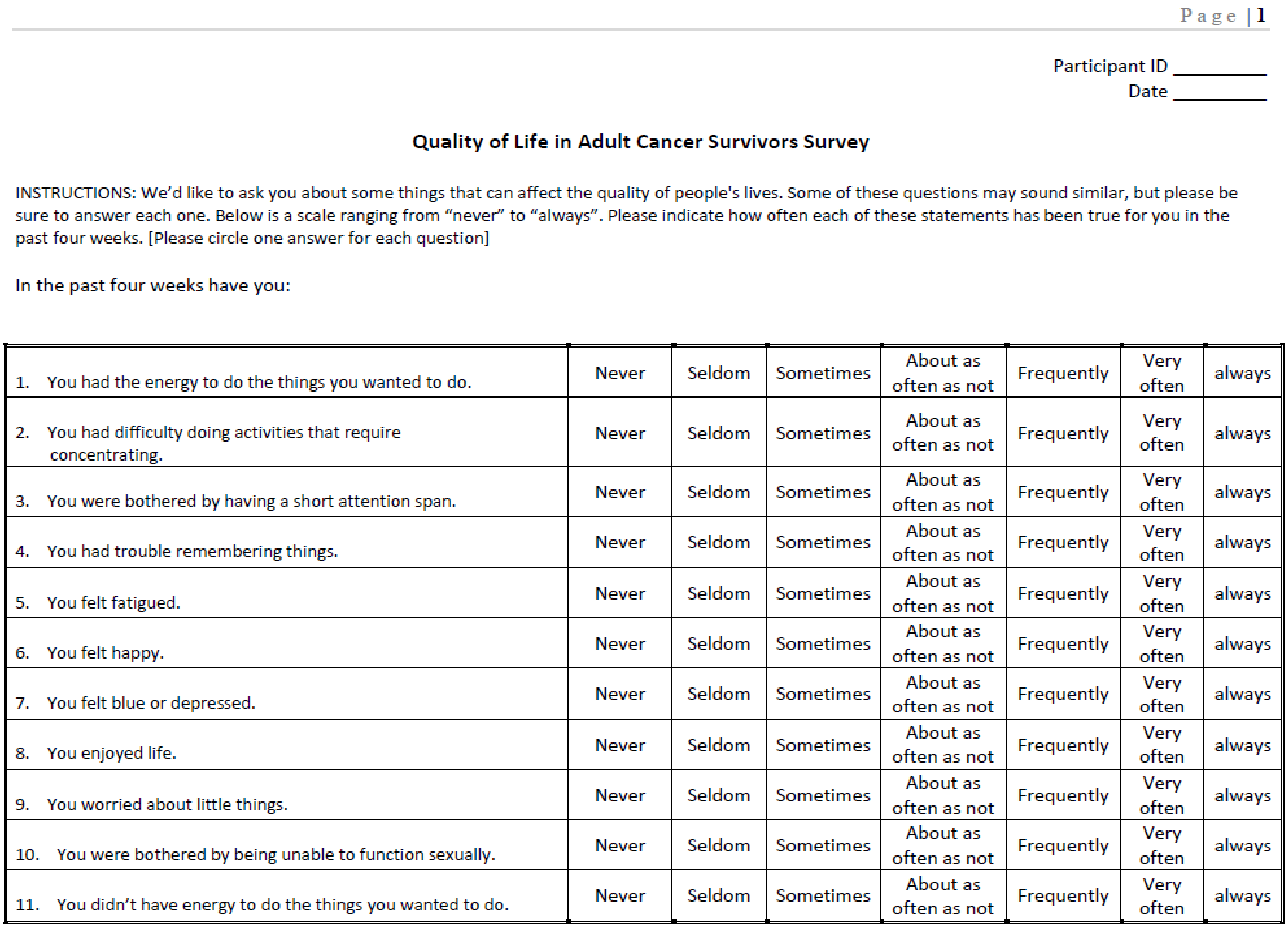
15b.____

15c.____

15d.____

Thank you for your time.

APPENDIX B: QLACS



Page | 1

Participant ID ________

Date ________

Quality of Life in Adult Cancer Survivors Survey

INSTRUCTIONS: We'd like to ask you about some things that can affect the quality of people's lives. Some of these questions may sound similar, but please be sure to answer each one. Below is a scale ranging from "never" to "always". Please indicate how often each of these statements has been true for you in the past four weeks. [Please circle one answer for each question]

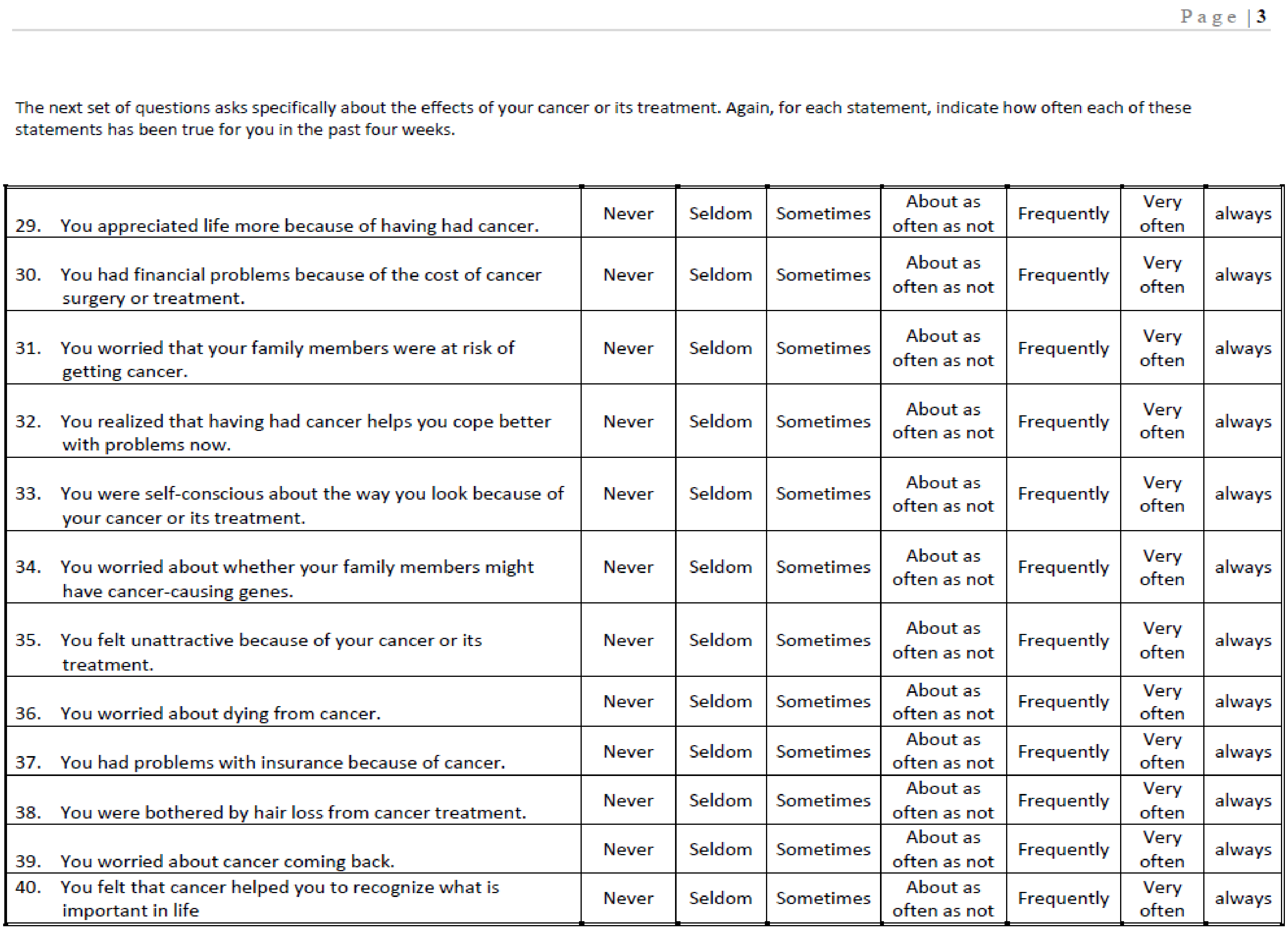
In the past four weeks have you:

1. You had the energy to do the things you wanted to do.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
2. You had difficulty doing activities that require concentrating.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
3. You were bothered by having a short attention span.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
4. You had trouble remembering things.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
5. You felt fatigued.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
6. You felt happy.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
7. You felt blue or depressed.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
8. You enjoyed life.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
9. You worried about little things.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
10. You were bothered by being unable to function sexually.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
11. You didn't have energy to do the things you wanted to do.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always

APPENDIX B: (Continued)

12.	You were dissatisfied with your sex life.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
13.	You were bothered by pain that kept you from doing the Things you wanted to do.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
14.	You felt tired a lot.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
15.	You were reluctant to start new relationships.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
16.	You lacked interest in sex.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
17.	Your mood was disrupted by pain or its treatment.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
18.	You avoided social gatherings.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
19.	You were bothered by mood swings.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
20.	You avoided your friends.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
21.	You had aches or pains.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
22.	You had a positive outlook on life.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
23.	You were bothered by forgetting what you started to do.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
24.	You felt anxious.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
25.	You were reluctant to meet new people.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
26.	You avoided sexual activity.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
27.	Pain or its treatment interfered with your social activities.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
28.	You were content with your life.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always

APPENDIX B: (Continued)



The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

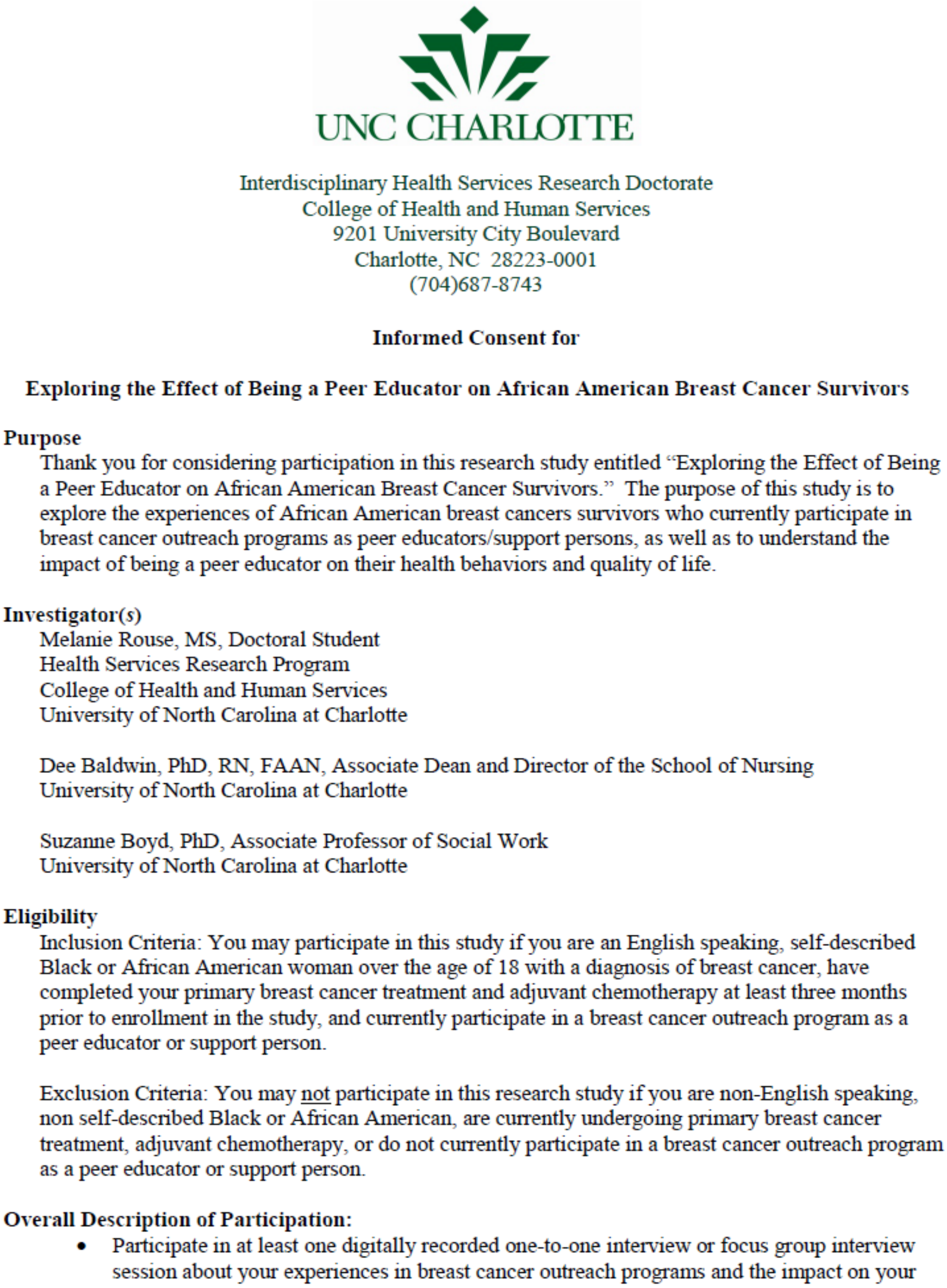
29. You appreciated life more because of having had cancer.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
30. You had financial problems because of the cost of cancer surgery or treatment.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
31. You worried that your family members were at risk of getting cancer.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
32. You realized that having had cancer helps you cope better with problems now.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
33. You were self-conscious about the way you look because of your cancer or its treatment.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
34. You worried about whether your family members might have cancer-causing genes.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
35. You felt unattractive because of your cancer or its treatment.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
36. You worried about dying from cancer.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
37. You had problems with insurance because of cancer.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
38. You were bothered by hair loss from cancer treatment.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
39. You worried about cancer coming back.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
40. You felt that cancer helped you to recognize what is important in life	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always

APPENDIX B: (Continued)

41. You felt better able to deal with stress because of having had cancer.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
42. You worried about whether your family members should have genetic tests for cancer.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
43. You had money problems that arose because you had cancer.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
44. You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
45. You had financial problems due to a loss of income as a result of cancer.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
46. Whenever you felt a pain, you worried that it might be cancer again.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always
47. You were preoccupied with concerns about cancer.	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	always

Thank you for your time!

APPENDIX C: INFORMED CONSENT



UNC CHARLOTTE

Interdisciplinary Health Services Research Doctorate
College of Health and Human Services
9201 University City Boulevard
Charlotte, NC 28223-0001
(704)687-8743

Informed Consent for

Exploring the Effect of Being a Peer Educator on African American Breast Cancer Survivors

Purpose

Thank you for considering participation in this research study entitled "Exploring the Effect of Being a Peer Educator on African American Breast Cancer Survivors." The purpose of this study is to explore the experiences of African American breast cancers survivors who currently participate in breast cancer outreach programs as peer educators/support persons, as well as to understand the impact of being a peer educator on their health behaviors and quality of life.

Investigator(*s*)

Melanie Rouse, MS, Doctoral Student
Health Services Research Program
College of Health and Human Services
University of North Carolina at Charlotte

Dee Baldwin, PhD, RN, FAAN, Associate Dean and Director of the School of Nursing
University of North Carolina at Charlotte

Suzanne Boyd, PhD, Associate Professor of Social Work
University of North Carolina at Charlotte

Eligibility

Inclusion Criteria: You may participate in this study if you are an English speaking, self-described Black or African American woman over the age of 18 with a diagnosis of breast cancer, have completed your primary breast cancer treatment and adjuvant chemotherapy at least three months prior to enrollment in the study, and currently participate in a breast cancer outreach program as a peer educator or support person.

Exclusion Criteria: You may not participate in this research study if you are non-English speaking, non self-described Black or African American, are currently undergoing primary breast cancer treatment, adjuvant chemotherapy, or do not currently participate in a breast cancer outreach program as a peer educator or support person.

Overall Description of Participation:

- Participate in at least one digitally recorded one-to-one interview or focus group interview session about your experiences in breast cancer outreach programs and the impact on your

health and quality of life. Participation in a second focus group may be requested.
- Complete a demographic and a quality of life questionnaire.
- Review and comment on a summary of the study findings.

Length of Participation:
- Each one-to-one interview will last approximately 60 to 90 minutes.
- Each focus group will last approximately 90 to 120 minutes
- The questionnaires will take approximately 20 to 25 minutes to complete.
- The review of the study findings will take approximately 15 to 20 minutes.

.

Risks and Benefits of Participation
- Because of the nature of this research study, there is a possibility for you to experience emotional distress. You will be advised that you do not have to answer any questions with which you are uncomfortable and you may decline to participate at anytime. You will also be given the option to participate in either a focus group interview or a one-to-one interview based on your own level of comfort expressing difficult ideas, beliefs, and experiences in these different settings. In addition, if you do experience emotional distress, there will be referrals provided for peer support and other community resources.
- There is the potential for you to benefit from discussing your experiences in a non-judgmental environment.

Volunteer Statement

You are a volunteer in this research study. The decision to participate in this study is completely up to you. If you decide to be in the study, you may stop at any time. You will not be treated any differently if you decide not to participate in the study or if you stop once you have started.

Confidentiality Statement

Any information about your participation, including your identity, is completely confidential. The following steps will be taken to ensure this confidentiality:
- Digitally recorded audio files will be transcribed and coded such that no personally identifying information is visible on them (i.e., via the use of an alias for all participants); they will be kept in a secure place (i.e., encrypted, password protected files on a secure network); and they will be heard or viewed only for research purposes by the investigator and her associates. Recordings and hardcopies of the data may be retained for possible future analysis. All hardcopies of the data will be secured in a locked filing cabinet in a locked office at UNC Charlotte. When analysis is complete, the files and hardcopy data will be erased or destroyed.

- The **records** of this study will be stored securely and kept private (i.e., via a locked filing cabinet in a locked office at UNC Charlotte). Authorized persons from The University of North Carolina at Charlotte and members of the Institutional Review Board have the legal right to review your research records and will protect the **confidentiality** of those records to the extent permitted by law. The final report and all ensuing publications will exclude any information that will make it possible to identify you as a participant.

Statement of Fair Treatment and Respect

UNC Charlotte wants to make sure that you are treated in a fair and respectful manner. Contact the university's Research Compliance Office (704-687-3309) if you have questions about how you are treated as a study participant. If you have any questions about the actual project or study, please contact Melanie Rouse (704-904-7122, mjrouse@uncc.edu) or Dr. Dee Baldwin (704-687-7953, dbaldwi5@uncc.edu).

Participant Consent
I have read the information in this consent form. I have had the chance to ask questions about this study, and those questions have been answered to my satisfaction. I am at least 18 years of age, and I agree to participate in this research project. I understand that I will receive a copy of this form after it has been signed by me and the principal investigator of this research study.

______________________________________ _______________________
Participant Name (PRINT) DATE

____
Participant Signature

______________________________________ _______________________
Investigator Signature DATE

APPENDIX D: SEMI-STRUCTURED INTERVIEW GUIDE

Interview Guide
Exploring Effect of Being a Peer Educator on African American Breast Cancer Survivors

Tell me how you got involved in the breast cancer outreach program.

[prompts] 1. Please describe the program you are involved in and what made you want to join.

2. How would you describe your role when you first became involved? How much time did you dedicate to the program?
   - a. Has your role changed since you first became involved? How so?
   - b. Can you describe any burden you may feel from your role in the program?
     - i. Can you provide an example of times when you did not feel that way?
3. Describe the typical activities that occur in the program.
4. How diverse would you say the program is in regards to the topics and activities they have?
   - a. Is there anything you would like to see discussed or any activities you would enjoy that you don’t have currently?
5. Do you feel that your support network has increased since your participation?
   - a. How have you benefitted from that?
     - i. Was there a time you didn’t feel that way?
   - b. Do you feel you need more support?
6. What impact do you feel you have on your peers, community, and society as a whole through your participation in these programs?
   - a. Do you see yourself as a role model, advocate, or a witness to the community?
7. Do you feel that your spiritual beliefs influenced your decision to participate in these programs? How so?
   - a. Can you describe any spiritual connection you see in the work that you do in these programs.
8. How have you personally benefited from participation in these programs?
   - a. Can you give me an example.
   - b. Was there a time when you did not feel this way.
9. Please describe any expectations you had when you joined the program?
   - a. Have these expectations changed during the time you have been a part of the program?

Please describe your cancer experience.

[prompts] 1. What impact did your cancer have on your day to day life before your participation in these programs?

   a. Describe the physical, psychological, and emotional effects your cancer and the treatment had on you.
   b. What were the positive and/or negative effects on your outlook on life?
   c. How has this changed since participation in these programs?
2. Can you describe any spiritual impact your cancer had on your life?
3. Prior to your participation in these programs, did you fear a recurrence of your breast cancer?
   a. Has this changed since your participation in these programs? How so?
4. Has your knowledge of breast cancer increased? How so?
5. Think about what quality of life means to you. What things do you consider important for your quality of life?
   a. How has participation in these programs influenced this?
6. What emotional impact does telling the story of your breast cancer experience have on you?
   a. When you first told you story, how did it make you feel (while telling the story and after)?
   b. After telling the story of your experience multiple times, was there a change in how you felt while telling your story and after?
      i. Can you tell about a time when you didn't feel that way?
      ii. What was different about that time?
   c. Explain any benefits or drawbacks from telling the story of your experience.

How have your health behaviors changed since participation in these programs?

[prompts]
1. Has participation in these programs increased your knowledge of how to manage breast cancer and the ways to prevent recurrence? In what ways?
2. How do you manage your breast health? Can you provide specific examples?
   a. How confident are you that you can do all things necessary to manage your breast health?
3. Describe any changes that you have made in your health behaviors since you have participated in these programs.
   a. Has your diet changed?
   b. Do you exercise more?
   c. How confident are you that you can perform these behaviors routinely?
   d. Can you give a specific example of information you have taken from the program and implemented in your own life?
4. Do you feel you are better able to manage your health and prevent recurrence because of these behavior changes?
   a. Can you tell me about a time you didn't feel that way?

How has your utilization of healthcare services changed since participation in these programs?

[prompts]
1. Prior to your participation in these programs, did you routinely visit your oncologist, nurse practitioner, or primary care doctor?
    a. Did you feel comfortable interacting with the doctors, nurses, and the healthcare system in general prior to participation?
    b. Has this changed since participating in these programs? How so?
2. Since participation in these programs, how confident are you that you can openly discuss with your physician any concerns or questions you may have?
3. Do you feel that participation in these programs has influenced your screening practices for breast cancer? How so?

Final Questions

1. What specific attributes of these programs do you feel have had the most influence on your life? How so?
2. Is there anything that you feel is lacking in the programs or needs to be improved?
3. Would you recommend that other breast cancer survivors participate in these programs? Why or why not?
4. Is there anything else you would like to add?

APPENDIX E: TARGETED RECRUITMENT EMAIL

Targeted Recruitment Email for "Exploring the effects of being a peer educator on African American breast cancer survivors":

SUBJECT: Participant Recruitment for an African American Breast Cancer Survivor Study

Hello,

I am Melanie Rouse, MSHP, a doctoral candidate in the Health Services Research program at the University of North Carolina at Charlotte. I am currently recruiting volunteers to take part in a research study on the experiences of African American breast cancer survivors who serve as peer educators/support persons.

Increasingly, African American breast cancer survivors are serving as peer educators or support persons in breast cancer outreach programs. However, there has been little to no research on the impact of participation in these roles on the survivor themselves. This research aims to describe the experiences of African American breast cancer survivors in these programs and any benefits and/or risks that are associated. It also aims to examine the ways in which exposure to other survivors, health education, and speaking about their experience influences their health behaviors, healthcare utilization, and quality of life (QOL).

Participants in this study will include African American women aged 18 years and older, with a diagnosis of breast cancer that have completed their primary treatment and adjuvant chemotherapy at least three months prior to enrollment in the study. In addition, participants must also be involved in a breast cancer outreach program as a peer educator.

Each participant will be asked to participate in either a 60 to 90 minute one-to-one interview or a 90 to 120 minute focus group interview where they will be asked to exploring their experiences as a peer educator/support person and it's impact on their QOL. Some partipants may be asked to complete a second focus group interview. Participants will also complete the Quality of Life of Adult Cancer Survivors questionnaire and a demographic survey. These two surveys will take approximately 20 to 25 minutes to complete.

This study has been approved by the UNC Charlotte Institutional Review Board.

For more information, I may be contacted at 704-904-7122 or mjrouse@uncc.edu. Please, feel free to pass this information along to any other interested parties. Thank you for your consideration.
Sincerely,
Melanie J. Rouse
Doctoral Candidate
Health Services Research

University of North Carolina at Charlotte
Email: mjrouse@uncc.edu
Phone: 704-904-7122

APPENDIX F: PRINT AD

Print Ad
Exploring the Effects of Being a Peer Educator on African American Breast Cancer Survivors

Melanie Rouse MS, doctoral student at the University of North Carolina at Charlotte, is conducting a study on the experiences of African American breast cancer survivors and the impact that their participation in breast cancer outreach programs may have on their health behaviors and quality of life needs. Self-described Black or African American women aged 18 and older who have completed their breast cancer treatment at least 3 months prior to enrollment in the research study, and have participated in breast cancer outreach programs, such as The Witness Program, are eligible for the study. The study will take approximately two and a half hours and involves the choice of participating in a one-to-one interview or a focus group interview, completing two sets of paper and pencil questions, and a review of the study findings. Some participants may be asked to participate in a second focus group that will take approximately two hours. If interested, please contact Melanie Rouse, MS at 704-904-7122, mjrouse@uncc.edu.

APPENDIX G: SCREENING SCRIPT

Screening/telephone Script “Exploring the effects of being a peer educator on African American breast cancer survivors”:

Thank you for calling to find out more about my research study. My name is Melanie Rouse and I am a doctoral student at the University of North Carolina at Charlotte. The purpose of this research study is to learn more about the experiences of African American breast cancer survivors and the impact that participation in breast cancer outreach programs, such as the Witness Project, may have on their health behaviors and quality of life.

As a part of this study, you will have the choice to participate in a 60 to 90 minute long one-to-one interview or a 90 to 120 minute focus group interview about your experiences after completing your breast cancer treatment. Both the one-to-one and focus group interviews will also include questions about your quality of life and health behaviors. Some participants will be asked to participate in a second two hour long focus group. The one-to-one interviews can be conducted at a location and time that you choose, while the location and time of the focus group interviews will be determined by me once the minimum number of focus group participants enroll in the study. In addition, I will be asking you to complete a 5 minute questionnaire about your background information, a 15 to 20 minute questionnaire about your quality of life after completing your breast cancer treatment, and a 15 to 20 minute review of the study findings.

(If No): Thank you very much for calling.

(If Yes): That's great. But, before enrolling in the study, we will need to make sure that you are eligible. I would like to ask you a few questions to determine if you are eligible. You do not have to answer any questions that you are uncomfortable with and everything that we discuss today will be strictly confidential and kept under lock and key. Do I have your permission to continue?

(If No): Okay. Thank you very much for calling.

(If Yes):

1. How did you hear about the study?

2. Do you describe yourself as Black or African American?

3. Are you aged 18 or older?

4. When were you diagnosed with cancer?

5. Have you completed your primary breast cancer treatment, including any surgical procedures, radiation therapy, and adjuvant chemotherapy? If so, when?

6. Have you participated in any breast cancer outreach programs, such as the Witness Project or the Sisters Network, since you have completed your treatment?

7. Have you served as a peer educator or peer support person in these programs?

If Eligible: It looks like you are eligible for the study. If you would like, we can set up your one-to-one interview now or I can place you on the list to participate in a focus-group interview. You can also give me your contact information and I will call you back to set up the interview at a later time. Or, you can call me back at a time convenient for you. (set up interview & obtain contact information)

It has been a pleasure to speak with you. Thank you very much for your time. I look forward to meeting with you

If Ineligible: I'm sorry but it appears that you are not eligible for this study. However, it was a pleasure speaking with you. Thank you for your time.

APPENDIX H: RECRUITMENT PRESENTATION SCRIPT

Recruitment Presentation Script “Exploring the effects of being a peer educator on African American breast cancer survivors”:

Hello. I am Melanie Rouse and I am a Doctoral Candidate in Health Services Research at UNC Charlotte. I am here today to speak with you a little about the study I am currently conducting entitled “Exploring the effects of being a peer educator on African American breast cancer survivors.”

There are two main objectives of this research. The first objective is to understand the potential benefits and/or risks of being a peer educator in a breast cancer outreach program on African American breast cancer survivors. Secondly, the impact of this role on the survivors’ quality of life needs and healthcare decisions related to early detection, disease prevention, and healthcare services utilization will be explored.

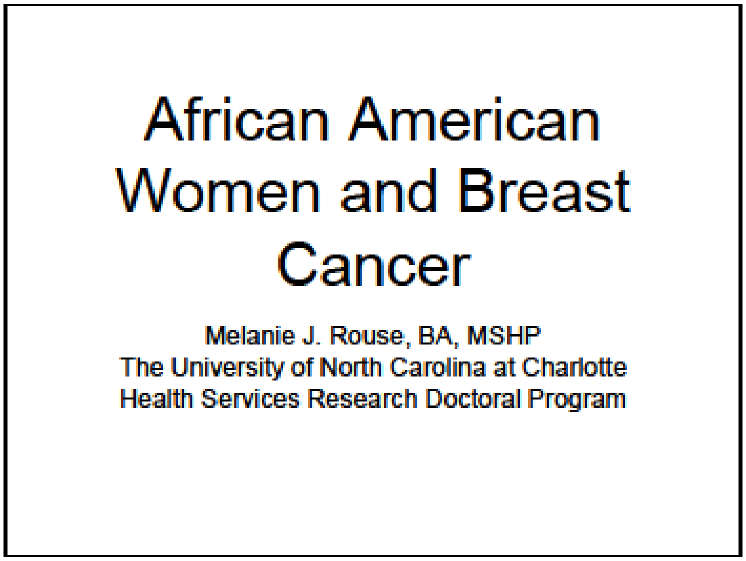
Participants in this study include African American women aged 18 years and older, with a diagnosis of breast cancer that have completed their primary treatment and adjuvant chemotherapy at least 6 months prior to enrollment in the study. In addition, participants must also be involved in a breast cancer outreach program as a peer educator.

Each participant will be asked to participate in a 60 to 90 minute interview where they will be asked to describe their experiences as a peer educator or peer support person, as well as discuss the way in which their exposure to other survivors, health education, and speaking about their experience influences their health behaviors, healthcare utilization, and quality of life. Participants will also be asked to complete a demographic data survey and the Quality of Life of Adult Cancer Survivors questionnaire. These two surveys will take approximately 20 to 25 minutes. Some participants may be asked to complete a second interview.

If you are at all interested in participating in this study, please let me know and I will provide you with my contact information. Also, please feel free to take a recruitment flyer and pass it along to anyone you feel may be interested.

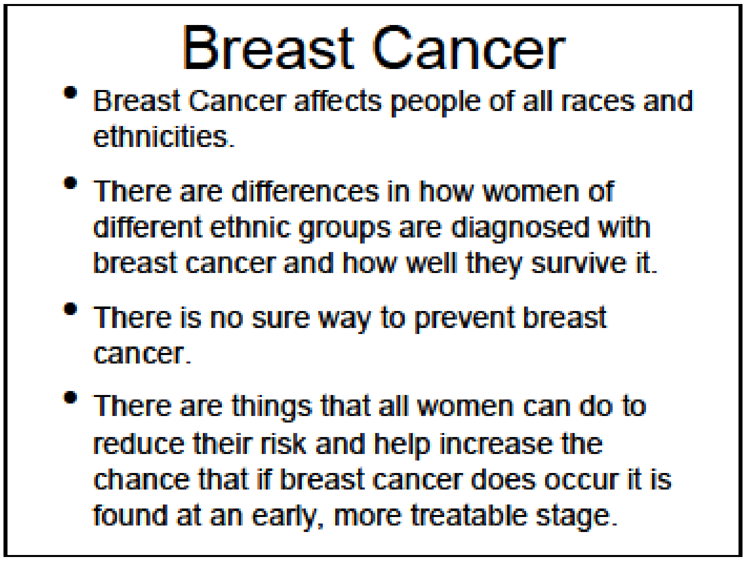
Thank you so much for your time.

APPENDIX I: RECRUITMENT PRESENTATION



African American Women and Breast Cancer

Melanie J. Rouse, BA, MSHP
The University of North Carolina at Charlotte
Health Services Research Doctoral Program



Breast Cancer

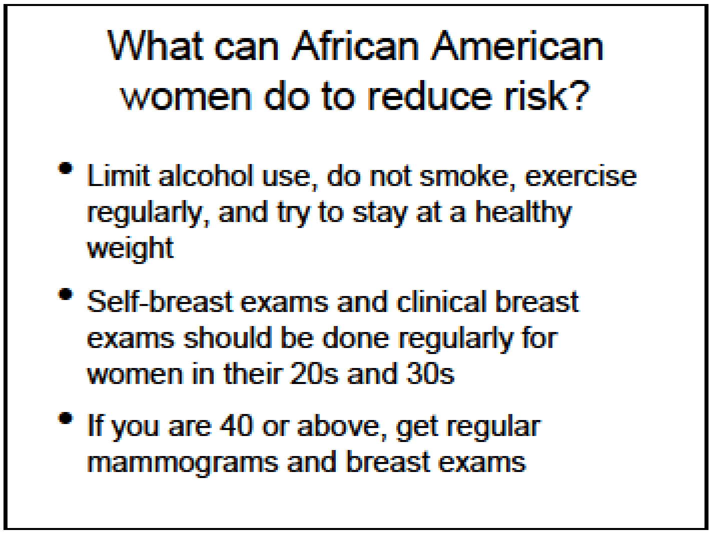
- Breast Cancer affects people of all races and ethnicities.
- There are differences in how women of different ethnic groups are diagnosed with breast cancer and how well they survive it.
- There is no sure way to prevent breast cancer.
- There are things that all women can do to reduce their risk and help increase the chance that if breast cancer does occur it is found at an early, more treatable stage.

Breast Cancer in African American Women

- It is the leading form of cancer and second leading cause of death in African American Women.[1]
- African American women are more likely than white women to get breast cancer between ages 24 and 40.[2]
- African American women are less likely than white women to get breast cancer after age 40.[2]
- African American women of all ages are more likely to die from breast cancer than any other group of women.[2]

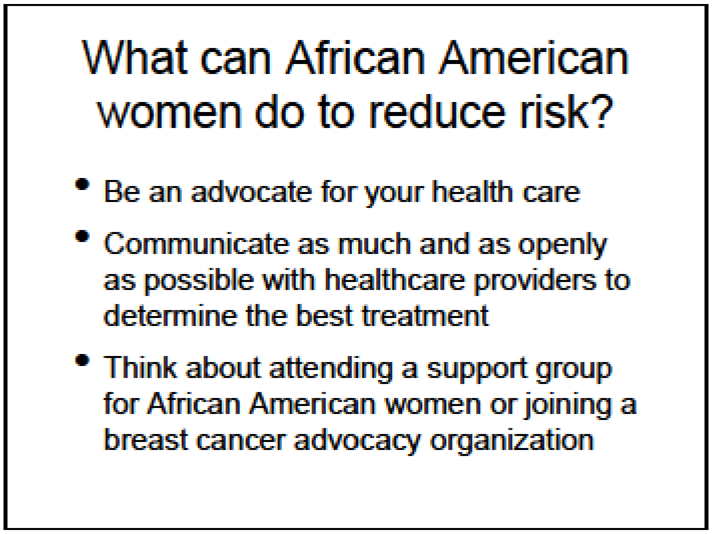
Why are African American women at greater risk?

- Late-stage diagnosis of breast cancer[1]
- Less use of mammograms and breast exams[1]
- Lack of health insurance, less access to medical care[1]
- Differences in breast cancer treatment[1]
- Presence of additional illnesses[1]
- Past history of discrimination and cultural issues[1]



What can African American women do to reduce risk?

- Limit alcohol use, do not smoke, exercise regularly, and try to stay at a healthy weight
- Self-breast exams and clinical breast exams should be done regularly for women in their 20s and 30s
- If you are 40 or above, get regular mammograms and breast exams

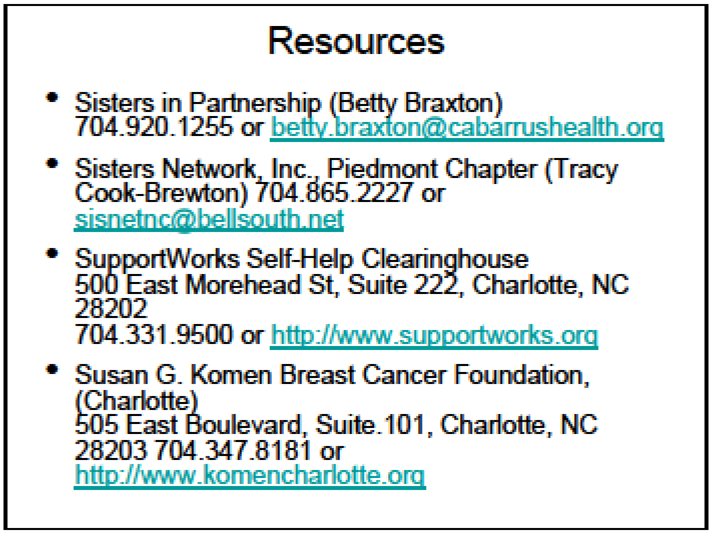


What can African American women do to reduce risk?

- Be an advocate for your health care
- Communicate as much and as openly as possible with healthcare providers to determine the best treatment
- Think about attending a support group for African American women or joining a breast cancer advocacy organization

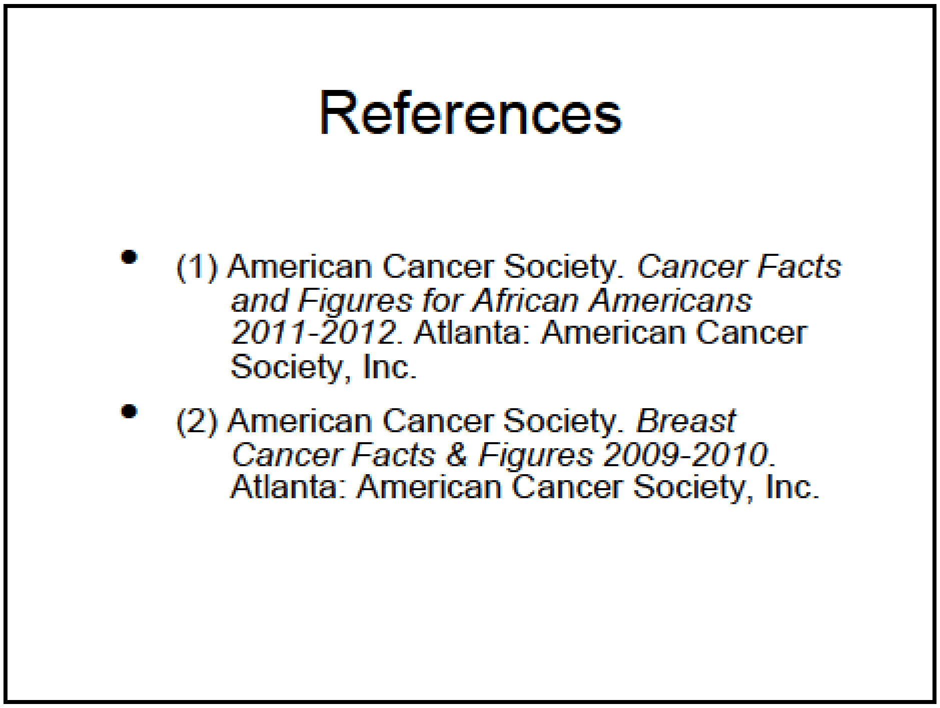
Resources

- African American Breast Cancer Alliance (AABCA) 612.825.3675 or http://aabcainc.org
- Black Women's Health Imperative 202.548.4000 or http://www.blackwomenshealth.org
- Breast Cancer Resource Directory of North Carolina
  Post Office Box 1188, Greenville, NC 27835
  800.514.4860 or http://www.bcresourcedirectory.org
- Buddy Kemp Caring House
  242 Colonial Avenue Charlotte, NC 28247
  704.384.5223 or
  http://www..novanthealth.org/buddykemp



Resources

- Sisters in Partnership (Betty Braxton) 704.920.1255 or betty.braxton@cabarrushealth.org
- Sisters Network, Inc., Piedmont Chapter (Tracy Cook-Brewton) 704.865.2227 or sisnetnc@bellsouth.net
- SupportWorks Self-Help Clearinghouse
  500 East Morehead St, Suite 222, Charlotte, NC 28202
  704.331.9500 or http://www.supportworks.org
- Susan G. Komen Breast Cancer Foundation, (Charlotte)
  505 East Boulevard, Suite.101, Charlotte, NC 28203 704.347.8181 or
  http://www.komencharlotte.org



References

- (1) American Cancer Society. *Cancer Facts and Figures for African Americans 2011-2012*. Atlanta: American Cancer Society, Inc.
- (2) American Cancer Society. *Breast Cancer Facts & Figures 2009-2010*. Atlanta: American Cancer Society, Inc.

APPENDIX J: COVER LETTER FOR FLYER DISTRIBUTION

UNC CHARLOTTE

Interdisciplinary Health Services Research Doctorate
College of Health and Human Services
9201 University City Boulevard
Charlotte, NC 28223-0001
(704)687-8743

[Date]

Dear XX:

My name is Melanie Rouse and I am a doctoral candidate in the Health Services Research program at the University of North Carolina at Charlotte. I am currently conducting a study entitled “Exploring the Effect of Being a Peer Educator on African American Breast Cancer Survivors” to fulfill the dissertation requirements of the program. The purpose of this study is to explore the experiences of female African American breast cancers survivors who currently participate in breast cancer outreach programs as peer educators or support persons, as well as to understand the impact of their participation on their health behaviors and their quality of life.

This study has been approved by the University of North Carolina at Charlotte’s Institutional Review Board. Currently, I am recruiting participants for the study. As part of my recruitment efforts, I am distributing flyers to various organizations throughout the Charlotte-Mecklenburg area. I have included a copy of the flyer in this mailing. I would greatly appreciate your passing this information along to the respective organization members of your organization.

If you have any questions, I can be contacted by email at mjrouse@uncc.edu or by phone at 704-904-7122. Thank you for your assistance with this endeavorconsideration.

Sincerely,
Melanie Rouse, MS
Doctoral Candidate
Health Services Research Doctoral Program
College of Health and Human Services
The University of North Carolina at Charlotte

APPENDIX K: RECRUITMENT FLYER

Are you a Black or African American breast cancer survivor aged 18 or older?

We are looking for women to participate in a research study on the experiences of African American breast cancer survivors who participate in breast cancer outreach programs.

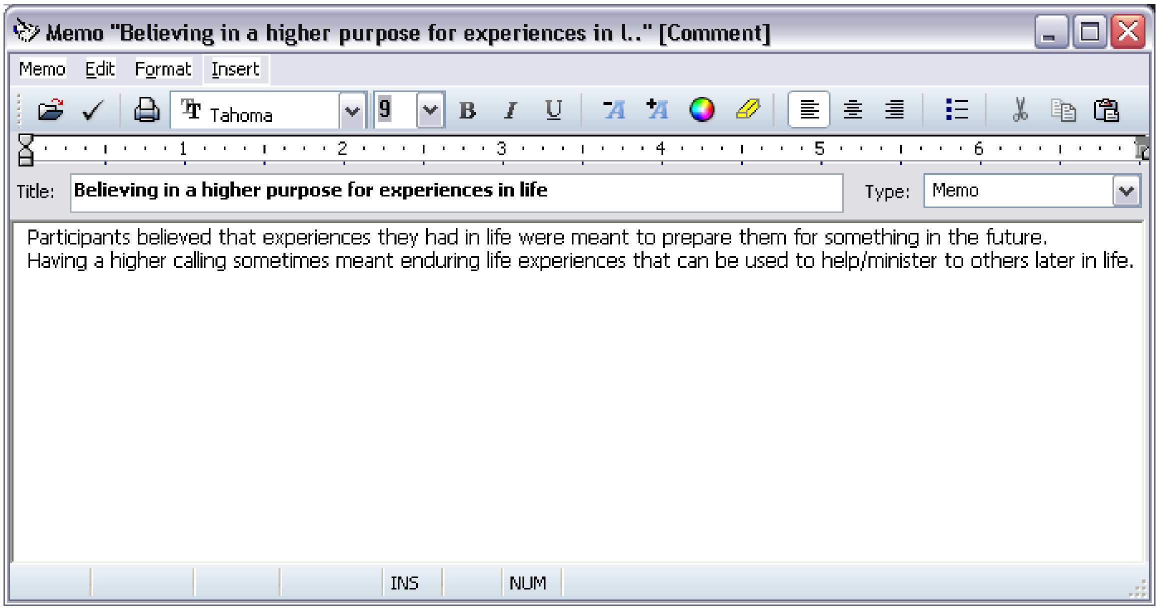
Participation includes a 20 to 25 minute survey, at least one 60 to 90 minute face-to-face interview, and a 15 to 20 minute review of the study results. Some participants will be asked to participate in a second 60 to 90 minute interview.

The survey and interviews can be scheduled at a time and location of your choice.

If interested, please contact Melanie Rouse at 704-904-7122 (mjrouse@uncc.edu)

This Research was approved by the UNC Charlotte Institutional Review Board on August 10, 2009 for a period of 1 year.

APPENDIX L: SAMPLE MEMO FROM DATA ANALYSIS



Title: **Believing in a higher purpose for experiences in life**

Type: Memo

Participants believed that experiences they had in life were meant to prepare them for something in the future.
Having a higher calling sometimes meant enduring life experiences that can be used to help/minister to others later in life.

APPENDIX M: SAMPLE ENTRY FROM REFLEXIVE JOURNAL

***This entry has been transcribed so that it is legible.

Entry Date: 8/1/11

Topic: Interview with participant 3 (Kim)

- Interview conducted at her home (participant’s choice)
- Relaxed/comfortable demeanor. Smiles when talking about helping others.
- Humbleness is an important quality for p.e.
- Also considers herself an advocate
- Spiritual purpose seen as a reason for participation in the role
- At times, it can be a burden.
- Can be emotional telling her story but that is okay because it is her life.
- Big focus on alternative medicine now (example: chiropractor)
- Interested in seeing more holistic doctors.
- Training is very important