2014

Breast Cancer Survivorship in African American Women

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Recommended Citation
Mollica, Michelle Arda, "Breast Cancer Survivorship in African American Women" (2014). *MUSC Theses and Dissertations*. 510.
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Breast Cancer Survivorship in African American Women

by

Michelle Arda Mollica

A dissertation submitted to the faculty of the Medical University of South Carolina in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Nursing

2014

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ACKNOWLEDGEMENTS

This journey to my dissertation would not be possible without the support of several individuals. Dr. Lynne Nemeth has been more than a mentor to me; she has been a role model and inspiration, and has pushed me to do things of which I never thought I was capable. She advocated for me and pushed through incredible barriers so that I would have the opportunities that I have had. Dr. Nemeth picked me up when I doubted my path, and worked with me when I created sometimes overambitious timelines for myself. She never questioned me, but instead challenged me to be a better researcher. I feel incredibly blessed to have worked with her and grown through her support and mentorship.

I would also like to thank my committee members: Dr. Martina Mueller, Dr. Susan Newman, and Dr. Katherine Sterba. Dr. Newman was so helpful with my community-based engagement, and important considerations and support with my navigation intervention. Dr. Mueller offered amazing insight with my many statistical questions and need for clarity in my manuscripts. Finally, Dr. Sterba has urged me to consider different viewpoints in survivorship research, and I have learned so much from her expertise.

I have been afforded many opportunities throughout this program, including prospects for grant funding as well as a postdoctoral fellowship. I would not have taken advantage of these opportunities without the urging of Dr. Nemeth, and two additional esteemed faculty members. For this I would like to thank Dr. Barbara Edlund, who when I walked into her office during Residency Week and had no idea of my research path, urged me to look closer at the oncology nursing role that I was in. I would not be on this path without her. I have also been lucky to have an advocate in Dr. Elaine Amella, who sent me every funding announcement and postdoctoral experience that I applied for, even when I was just starting the program and hadn't yet proved myself. I could really name every faculty member here, each of whom has challenged me to grow and become a better scientist. I thank each and every one of you.

My gratitude as well to Julie McCulloh Nair, who has been through this crazy journey with me from the start. She and I will always be bonded by this experience, and I cannot thank her enough for her support and laughter during stressful times. I also must thank Susan Flavin, Theresa Wyatt, Edith Crook, and Amy Szajna. It was a tough road, but we've all endured and achieved something amazing. I am so proud to know each and every one of these scientists.

Last, but certainly not least, I must thank my family. To my husband, Jason, who has never questioned my need to do work on a Friday night (or every night, for that matter), and who has supported me to the ends of the earth through this whole process, I thank you. I wouldn't be here without you, and your support and love are everything to me. Thank you to my mother and father, who have backed me throughout this process. To my children, Ellie and Tyler, you mean the world to me, and I hope that this degree shows that you can be anything that you want to be in life. The sky is truly the limit!

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ABSTRACT

With advances in screening, diagnostic capabilities, and treatments, the amount of breast cancer survivors continues to grow. African American (AA) breast cancer survivors (BCS) are a particularly vulnerable group, who experience persistent disparities in outcomes, information, and support post primary cancer treatment. Peer navigation (PN) in AA BCS could be one strategy to increase quality of life and follow-up care after treatment, though research on quality of life and PN in this population is limited.

This dissertation first examines factors contributing to quality of life in AA BCS, utilizing the Quality of Life Model Applied to Cancer Survivors. Next, the experiences of AA women who have completed treatment for breast cancer are examined through a qualitative grounded theory study. Finally, the PI developed a PN intervention, and evaluated the feasibility, acceptability, and targeted outcomes through a mixed methods proof of concept study. The information presented within this dissertation creates the foundation for future studies implementing the PN intervention to increase quality of life and following up care in African American women completing treatment for breast cancer.

INTRODUCTION

There is an increased need to address African American women's experiences as they complete treatment and enter the next phase of their cancer experience. Breast cancer is the most common cancer among African American (AA) women, and the survival rate is 78 percent, which is lower than other ethnic and racial groups in the US (American Cancer Society, 2013b). Due to advanced diagnostic capabilities and treatments, there are an estimated 2.9 million breast cancer survivors in the US (American Cancer Society, 2013a). As the number of survivors increases, identifying and addressing the physical and psychosocial complaints that affect those who have completed cancer treatment becomes increasingly critical.

Differences experienced by racial and ethnic minorities in cancer care persist, according to the National Health Disparities Report, 2010 (Agency for Healthcare Research and Quality, 2012). Such disparities include timeliness of delivery of treatment, culturally centered care appropriate for the population, and effectiveness of treatments. AA women are a particularly vulnerable population, who experience poorer functional health after cancer diagnosis, and have an increased risk of late diagnosis of second primary cancers, as well as recurrence (Miles, 2005; Wilder Smith et al., 2009) making survivorship research in this group especially important. As cancer survivors, AA women receive care after cancer treatment that is often characterized by disparities in services. Compared to non-Hispanic White women, AA cancer survivors are less likely to attend follow-up care after cancer treatment and receive information on emotional and physical concerns, as well as support services (Ademuyiwa et al., 2011; Gilligan et al., 2003). After treatment, AA women continue to report receiving less information about subsequent self-management, sequelae, peer support, and other social, material, and emotional resources than non-Hispanic White women (von Friederichs-Fitzwater & Denyse, 2012). Interventions targeting improved adherence to follow-up care may be beneficial; however, to date few interventions focused on improving post-treatment outcomes in AA survivors have been developed and tested.

Cancer Survivorship: Definition

Cancer survivor is a concept that appears frequently in the literature with varied definitions. The National Coalition of Cancer Survivors proposes that from the time of diagnosis and for the balance of life, a person diagnosed with cancer is a survivor (National Coalition for Cancer Survivorship, 2011). Feuerstein defends, however, that the term extends from the completion of primary treatment up to end-of-life care (2007). For the purpose of this study, where the aim is to determine the experience transitioning from cancer patient to survivor (the "re-entry phase" (Stanton et al., 2005)), a cancer survivor will be operationally defined as a breast cancer patient who has completed primary cancer treatment (i.e., any combination of surgery, radiation, and/or chemotherapy). It is important to note that daily endocrine therapy is often taken for up to five years after completion of primary breast cancer treatment. In this study, a patient that takes daily endocrine therapy post primary treatment is still considered a survivor (Feuerstein, 2007).

The transition from cancer patient to cancer survivor may be a particularly important point in recovery (Institute of Medicine, 2005), and the quality of the care transition experience immediately after treatment could affect the level of stress experienced. Survivors often find themselves unprepared and fearful about the loss of medical monitoring, risk of cancer recurrence, and potential changes in social support from healthcare providers and caregivers (Hamilton, Powe, Pallard, Lee, & Felton, 2007). Moreover, many AA survivors carry the psychological burden of needing to appear strong based on cultural and contextual factors, deemed the "Superwoman" role (Woods-Giscombe, 2010).

Patient Navigation and Peer Navigation

Navigation is a concept that encompasses many different roles and functions (Robinson-White, Conroy, Slavish, & Rosenzweig, 2010). It has become prevalent in cancer care, originally in response to disparities in late diagnosis in AAs, and was aimed at removing barriers and increasing access to care, early detection, and simpler delivery of information (Freeman & Rodriguez, 2011; Natale-Pereira, Enard, Nevarez, & Jones, 2011). Navigators include nurses, trained lay persons, or other medical staff (Winstead, 2012), who coordinate care and provide support to those in need. Although activities vary for navigators, they have historically included attending diagnosis and treatment planning meetings, and corresponding regularly with patients. Little research has been conducted on patient navigation in the context of post treatment care transitions. One novel application may be engaging breast cancer survivors as peer navigators for patients who are approaching the end of treatment. Increasing attention has been placed on breast cancer survivors as an important group for support and motivation (McQueen & Kreuter, 2010), as women report that they most want to speak with someone who has the same cancer and lived through a similar crisis of treatment (Giese-Davis et al., 2006). Results indicate that survivor stories could be effective messages (Kreuter et al., 2008) where cancer survivors can play a vital role as messengers of hope and information, and as advocates for prevention and continued screening. Their role as peer navigators for breast cancer survivors, however, requires investigation. Support groups provide information; however groups specific to AA women are rare, and those with all races and ethnicities may fail to address individualized needs. Peer navigation (PN) utilizes trained breast cancer survivors as navigators into survivorship, and is currently being preliminarily explored for improving usage of survivorship care plans (SCP), though no results have yet been published. This research is significant because it provides a foundation for intervention research for AA women entering breast cancer survivorship.

Theoretical Framework

This dissertation work utilized the Quality Of Life (QOL) Model Applied to Cancer Survivors (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995) as its primary theoretical framework (Figure 1). This model incorporates four domains influencing QOL: physical well-being and symptoms, social well-being, psychological well-being, and spiritual/existential well-being. Ferrell and colleagues (1991) created and validated the model through studies of bone marrow transplant survivors and breast cancer survivors (BCS). Physical well-being includes intermediate and late effects associated with all cancer treatments. Psychological well-being includes emotional issues, anxiety, and mental distress post treatment. Social well-being considers the financial implications of going through treatment, availability of follow-up care, and the evolution of roles and relationships after cancer treatment. Finally, spiritual well-being includes religiosity, power, and self-transcendence. All four domains have a specific and important effect on the QOL of the cancer survivor. To truly address QOL in AA breast cancer survivors, one must consider all domains in concert.

Innovation

This research applies a peer navigation model that focuses on the transition period known as survivorship, after treatment cessation. Most prior research addresses the use of patient navigators during the treatment phase; however there is a need to expand the current model to provide social support and navigation after treatment and into the survivorship phase (Pollak et al., 2005). Little research is available on whether AA survivors who have completed breast cancer treatment can be effective as peer navigators (PN) beyond the treatment phase and into survivorship. The Survivorship Working Group (SWG), consisting of 8 national leaders in cancer survivorship and patient navigation, was created to identify optimal outcomes of survivorship navigation (Pratt-Chapman, Simon, Patterson, Risendal, & Patierno, 2011). After literature review and roundtable discussion, the SWG identified certain clinical outcomes as measures to evaluate navigation efficacy, including symptom management, physical functioning, and mental health of cancer survivors. Healthcare utilization outcomes such as access to care, adherence to clinical follow-up recommendations, timely utilization of survivorship care, and continuity of care, were also deemed important measures to evaluate effectiveness of navigation. It is important to note that the SWG included trained patient navigators, and did not address peer navigation, specific ethnic/minority or cultural considerations, or the specific needs of AA women in their report. This dissertation research applies navigation in a novel way, using AA breast cancer survivors as PNs for BCS entering survivorship. The outcomes of the SWG were adapted based on Ferrell's QOL Model Adapted for Cancer Survivors (Ferrell, et al., 1995) and findings from an integrative review of factors contributing to QOL in AA breast cancer survivors.

Specific Aims

This dissertation consists of three manuscripts; (1) an integrative review of factors contributing to quality of life in African American breast cancer survivors, (2) a qualitative study exploring the experiences of African American breast cancer survivors as they transition from patient to survivor, and (3) an analysis of the feasibility of a peer navigation intervention that pairs African American breast cancer survivors with African American women completing treatment for breast cancer. This dissertation research examines quality of life in African

American breast cancer survivors, and assesses the feasibility of an intervention aimed at improving quality of life.

Aim 1: To synthesize factors contributing to quality of life in African American (AA) breast cancer survivorship utilizing the Ferrell et al. (1995) Model.

The first manuscript is a comprehensive integrative literature review of factors contributing to quality of life in AA BCS (Mollica, Nemeth, Newman & Mueller, 2014). It specifically answers the research question: *Which factors are utilized in studies of quality of life in African American breast cancer survivorship?* The quality of life of AA BCS is poorer than that of non-Hispanic White BCS. It is necessary to address factors related to poor quality of life of AA women entering survivorship. Studies were included that explored some aspect of QOL in AA breast cancer survivors. A total of 19 articles met the relevance criteria. The review showed a lack of research exploring factors affecting spiritual and physical well-being domains, demonstrating a need for future research. In addition, the lack of community based studies signals a need for community engagement in the research process, starting with the spiritual community. Researchers must focus on factors from a multi-domain perspective to truly understand the varied dimensions influencing QOL of AA BCS.

Aim 2: Describe the experience and coping sources of African American women as they complete treatment for breast cancer and transition into survivorship.

The second manuscript is a qualitative study exploring the transition of African American women from breast cancer patient to survivor (Mollica & Nemeth, 2014). The principal investigator (PI) completed a mentored research study (with Dr. Lynne Nemeth), titled:

Transition from Patient to Survivor in AA Breast Cancer Survivors (Study ID # Pro00016967), to answer the question: What is the experience of the transition from cancer patient to survivor in AA breast cancer patients? This interpretive, descriptive qualitative study characterized the stressors, resources, and coping mechanisms after treatment specific to this population, and provided formative data for the current study proposal. The PI obtained IRB approval, recruited participants, conducted qualitative interviews (N = 15) and performed qualitative analysis using NVivo 10.0 software (QSR International, Pty, Doncaster, Australia).

Aim 3: To explore the feasibility and acceptability of a peer navigation breast cancer survivorship intervention, including navigator recruitment and training, participant recruitment, and outcome data collection and further refine the intervention protocol for future iterations, including intervention dosage and fidelity as well as monitoring and measurement of targeted outcomes.

Building on the first two dissertation aims, this mixed methods, proof of concept study (Study ID #Pro00028258) employed a convergent parallel approach design to develop and test the feasibility of a survivorship peer navigation program for AA BCS and its potential effects on selected outcomes. Specifically, this study addressed the development of an intervention using community-based AA breast cancer survivors as Peer Navigators to provide transitioning BCS with social support and resources, with the long-term goal of reducing social isolation and improving adherence to evidence-based follow up with primary care appointments, quality of life, preparedness for recovery, and perspectives of support from God. This study evaluates the training, intervention implementation and measurement protocols, examines feasibility and acceptability of the proposed intervention, and investigates whether changes in scores are favorable. This study includes an exploratory trial of the AA BCS Peer Navigator intervention through a small, 2-month, “proof of concept” trial (BCS n=4).

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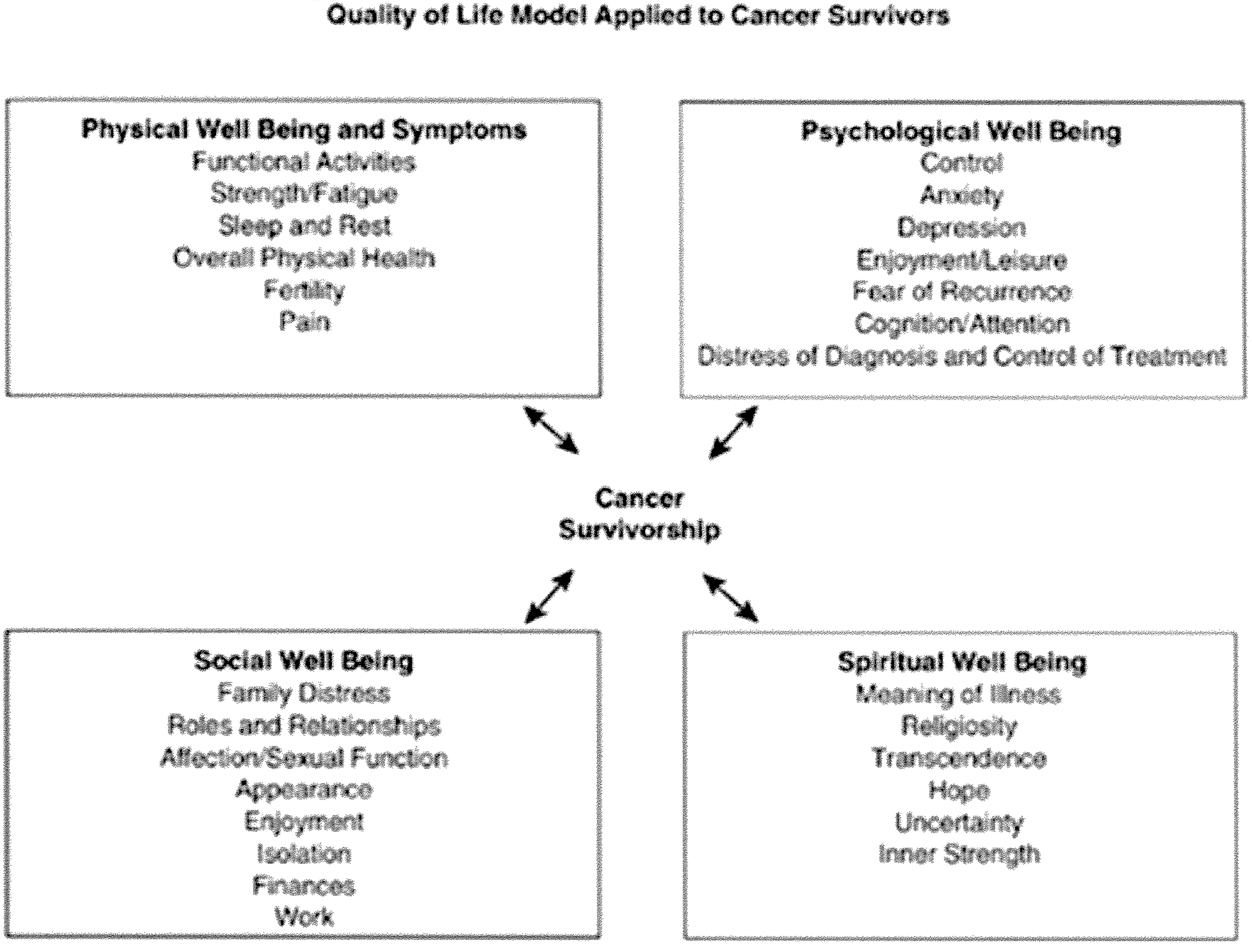
Figure 1. QOL Model Applied to Cancer Survivors



MANUSCRIPT I – COMPREHENSIVE REVIEW

This paper was accepted for publication in *Cancer Nursing* (reprinted with permission). Mollica, M., Nemeth, L.S., Newman, S., Mueller, M. (2014). Quality of life in African American breast cancer survivors: An integrative literature review. DOI: 10.1097/NCC.0000000000000160

Abstract

Background. The quality of life (QOL) of African American (AA) breast cancer survivors (BCS) is poorer than that of non-Hispanic White breast cancer survivors. It is necessary to address factors related to poor quality of life of AA women entering survivorship. Research addressing QOL in AA breast cancer survivors is inconsistent in measurements and methods.

Objective. To synthesize factors contributing to quality of life in AA breast cancer survivorship utilizing the Ferrell et al. (1995) Model; Research question: Which factors are used in studies of quality of life in African American breast cancer survivorship?

Review methods. This integrative literature review included studies exploring some aspect of QOL in AA BCS. Studies were excluded that validated psychometric measures, did not report QOL, or did not explore AAs and/or breast cancer survivors as a separate group within the study.

Results: The search strategy yielded 240 references; 38 were retrieved, read, and rated for relevance and research quality. A set of 19 articles met relevance criteria.

Conclusion: The review showed a lack of research exploring factors affecting spiritual and physical well-being domains, demonstrating a need for future research. In addition, the lack of community based studies signals a need for community engagement in the research process, starting with spiritual leaders.

Implications: Researchers must focus on factors from a multi-domain perspective to truly understand the varied dimensions influencing QOL of AA BCS.

Introduction

Due to advanced diagnostic capabilities and treatments, there are an estimated 2.9 million breast cancer survivors (BCS) in the US (American Cancer Society, 2013a). Breast cancer is the most common cancer among African American (AA) women, with a five-year survival rate of 78%, which is lower than that of other ethnic and racial groups (American Cancer Society, 2013b). Despite the fact that there are fewer AA survivors than non-Hispanic white survivors, there are almost 750,000 AA BCS in the U.S. (American Cancer Society, 2013c). As numbers of survivors increase, addressing the physical and psychosocial issues affecting those who have completed cancer treatment is important to improve quality of life (QOL). Investigators currently use varied and inconsistent methodologies for identifying factors that affect survivor QOL (Powe, Hamilton, & Hancock, 2007).

Regardless of methodological variance in determining the factors contributing to QOL in cancer survivors, clinical consensus exists that QOL for AA BCS is typically lower than for other racial/ethnic groups in the US (American Cancer Society, 2013b). As BCS, AA women report differences in follow-up care, resources, information, and support after treatment (von Friederichs-Fitzwater & Denyse, 2012). Racial and ethnic disparities persist including timeliness of delivery, culturally centered care, and effectiveness of treatments (Agency for Healthcare Research and Quality, 2012). AA women are particularly vulnerable, experiencing poorer functional health after cancer diagnosis and an increased risk of late diagnosis of second primary cancers, as well as recurrence (Miles, 2005; Wilder Smith et al., 2009). Survivorship disparities exist in access to follow-up care, information on emotional and physical concerns, as well as support services (Gilligan, et al., 2003).

Due to the continued disparities experienced by AA women after breast cancer treatment, examination of the literature for specific factors contributing to QOL studies of AA BCS is warranted to assess future research needs and properly address QOL issues. **The purpose of this integrative literature review is to synthesize factors contributing to QOL in AA breast cancer survivorship utilizing the Ferrell et al. (1995) QOL model.**

Previous QOL Reviews

Three known literature reviews have been completed that explored the QOL of either AA or BCS (Chopra & Kamal, 2012; Mols, Vingerhoets, Coeberg, & van de Poll-Franse, 2005; Powe, et al., 2007). Powe and colleagues (2007) completed a comprehensive literature review that examined the QOL of AA cancer survivors to explore their QOL experiences. All included studies were descriptive (qualitative or quantitative), and the conflicting results between each study made it difficult to appropriately describe the QOL of AA cancer survivors. It is important to note that this review was not specific to breast cancer.

An additional systematic review of QOL among long-term BCS aimed to identify the aspects of QOL affected in survivors (Mols, et al., 2005). Findings included studies revealing pervasive physical and psychological problems after treatment, however this review did not separate AA women into a separate category for specific analysis. Finally, Chopra and Kamal (2012) conducted a review to identify QOL instruments validated in long-term BCS and review studies that have used the QOL instruments in this population, utilizing the QOL Model of Ferrell and colleagues (1995). This review was limited to psychometrics of QOL instruments, rather than factors contributing to QOL; it was also not specific to AA.

To date, there is no known integrative review that explores factors contributing to quality of life in AA breast cancer survivors utilizing QOL Model Applied to Cancer Survivors as a framework (Ferrell, et al., 1995).

Survivorship Definition

Prior to discussing the outcome in studies of QOL in AA BCS, a clear definition of cancer survivor is needed. The National Coalition of Cancer Survivors (2011) proposes that from the time of diagnosis and for the balance of life, a person diagnosed with cancer is a survivor. Feuerstein argues, however, that the term is from the completion of primary treatment up to end-of-life care (2007). Research demonstrates a statistically significant difference in QOL (outcome measures and findings) between AA women post diagnosis, but still in active treatment, and AA women who have completed treatment (Russell, Von Ah, Giesler, Storniolo, & Haase, 2008). Primary treatment includes chemotherapy, surgery, radiation, and biotherapy. Daily endocrine therapy, which is utilized in many breast cancer patients, is often taken for up to five years after completion of primary treatment (American Cancer Society, 2013b). Per Feuerstein (2007), a patient that takes daily endocrine therapy post primary treatment is still considered a survivor. For the purpose of this integrative review, the operational definition of a cancer survivor is from completion of primary treatment to end-of-life. Thus, only studies of cancer survivors who have completed treatment are included in this analysis.

Theoretical Framework

This integrative review utilizes the QOL Model Applied to Cancer Survivors (Ferrell, et al., 1995), incorporating four distinct domains influencing QOL: physical well-being and symptoms, social well-being, psychological well-being, and spiritual/existential well-being.

Figure 1 depicts the QOL Model Applied to Cancer Survivors, where all four domains have a specific and important effect on the QOL of the cancer survivor. Ferrell and colleagues (1991) created and validated the model through studies of bone marrow transplant survivors and BCS. Physical well-being includes intermediate and late effects associated with all cancer treatments. Psychological well-being includes emotional issues, anxiety, and mental distress post treatment. Social well-being considers the financial implications of going through treatment, availability of follow-up care, and the evolution of roles and relationships after cancer treatment. Finally, spiritual well-being includes religiosity, power, and self-transcendence. To truly address QOL in AA breast cancer survivors, one must consider all domains in concert. By utilizing this framework in the present review, areas for improvement based on current lack of measured factors in respective domains will be identified.

The review

Design

The researcher chose an integrative literature review to identify and synthesize salient outcome measures utilized in selected prior studies. This rigorous review process enables analysis and synthesis of published qualitative and quantitative studies, as well as systematic reviews of a particular phenomenon (Whittemore & Knafl, 2005). By utilizing the step-by-step process of Whittemore & Knafl, nurse-scientists can outline the state of the science for a respective clinical issue and contribute to practice, policy, and future research.

Search Methods

The search strategy included literature from 2003- 2013 from PubMed, CINAHL, Cochrane, PsycInfo, and Googlescholar. In addition, Internet searches were conducted for epidemiological data, including the US census and the American Cancer Society. Journal hand searching, cross-searching, as well as a review of reference lists of pertinent articles yielded additional items for consideration. The following search terms were used in combination: quality of life, QOL, health-related quality of life (HRQOL), African Americans, breast cancer, cancer survivor, surviv*, outcome, spiritual domain, physical domain, psychological domain, and social domain. Inclusion criteria included studies (a) specific to an AA female population, or (b) included AAs as a separate group within the study, **and** were (c) specific to BCS after cessation of treatment, or (d) included breast cancer patients as a separate group. In addition, relevant articles explored some aspect of QOL based on Ferrell's (1995) theoretical framework, were peer reviewed articles published in English, and were either qualitative, quantitative descriptive, quantitative experimental, or systematic reviews. Studies were excluded if they only reported validation of psychometric measures, did not report QOL of AAs as a separate group within the study, considered cancer survivors who were post diagnosis but not post primary treatment, or were dissertations, book chapters, abstracts, or presentations.

Search Outcome

The search strategy yielded a total of 240 references, of which 13 were duplicates. All abstracts were reviewed for relevance, excluding 192 articles. Thirty-eight articles were retrieved for further analysis, read, and reviewed. All articles were assessed for inclusion and exclusion criteria, and re-rated for relevance. The final set contained 19 research studies. Figure 2 represents a flowchart for article selection.

Data Abstraction

Data were abstracted from each selected article based on the following considerations: purpose of study, design, data collection instruments, sample demographics, size, and analysis. Specific attention was given to the factors of QOL used, which are synthesized in the results section of this integrative review.

Quality Appraisal and Synthesis

Studies were divided into study design (qualitative, quantitative experimental, quantitative descriptive, mixed methods, and systematic review), and individually evaluated and appraised using appropriate tools for each study design. Qualitative studies were appraised with the Critical Appraisal Skills Program (CASP) Qualitative tool (National CASP Collaboration for Qualitative Methodologies, 2006). Descriptive quantitative studies were evaluated with the Strengthening the Reporting of Observational Studies (STROBE) tool (Gallo et al., 2011), and quantitative experimental studies assessed with the Consolidated Standards of Reporting Trials tool (CONSORT), which is appropriate for experimental trials (K. Schulz, Altman, & Moher, 2010). No study was excluded based on evaluation data, however the variance in meeting criteria was included as a variable and potential limitation because, per Whittemore & Knafl (2005) "reports of low relevance and rigor contribute less to the analytic process" (p.549). An expert researcher confirmed quality of selected studies, and concurred in deletion of excluded studies.

Results

The final set of relevant studies totaled 19, with pertinent details displayed in an evidence table (Table 1).

Overview of Studies

The set included 7 qualitative, 4 quantitative experimental, 6 quantitative descriptive, 1 mixed methods study, and 1 systematic review. Exploratory methods with thematic analysis were employed in 5 of the qualitative studies (Mosavel & Sanders, 2010; Rust & Davis, 2011; E. Schulz et al., 2008; Shaw & Coggin, 2008; Thompson, Littles, Jacob, & Coker, 2006), and the remaining 2 studies utilized grounded theory (Darby, Davis, Likes, & Bell, 2009; Royak-Schaler et al., 2008). All 4 quantitative experimental studies were randomized studies, although 2 specifically employed a 2 x 2 randomized block design (Germino et al., 2013; Gil et al., 2006), and 1 utilized a randomized, delayed control trial (Schover et al., 2006). All quantitative exploratory studies called their study design exploratory or descriptive (Ashing-Giwa & Lim, 2011; Brewster et al., 2007; Gil et al., 2004; Leak, Hu, & King, 2008; Shelby et al., 2008; Taylor et al., 2012). The mixed methods study was descriptive in both qualitative and quantitative arms (Lewis, Sheng, Rhodes, Jackson, & Schover, 2012).

Theoretical frameworks were only utilized in 5 of the 19 studies (Ashing-Giwa & Lim, 2011; Leak, et al., 2008; Russell, et al., 2008; Shaw & Coggin, 2008; Thompson, et al., 2006). The theoretical frameworks were: Health-Related Quality of Life Model (Dow, Ferrell, Haberman, & Eaton, 1999), Interaction Model of Client Health Behavior(Cox, 1982), Brenner's QOL proximal-distal continuum (Brenner, Curbow, & Legro, 1995), Anderson's (2012) Behavioral Model for Health Services Utilization, and Ferrell's QOL Model Applied to Cancer Survivors (Ferrell, et al., 1995).

Specific QOL factors utilized in each study were synthesized utilizing the domains of the theoretical framework (Ferrell, et al., 1995). Several studies utilized outcome measures in more than one domain, however only one study explored all four QOL domains (Shaw & Coggin, 2008). It is important to reiterate that the aim of this integrative review was to explore and synthesize the specific outcomes utilized in Shaw and Coggin's study. It is not the intention of this review to explore or report psychometrics of instruments, but rather to report the outcome variables in each study.

QOL Factors

Psychological well-being domain

Twelve studies from the final set explored psychological factors affecting QOL, making it the most highly represented QOL domain (Ashing-Giwa & Lim, 2011; Brewster, et al., 2007; Darby, et al., 2009; Germino, et al., 2013; Gil, et al., 2006; Gil, et al., 2004; Russell, et al., 2008; Schover et al., 2011; E. Schulz, et al., 2008; Shaw & Coggin, 2008; Shelby, et al., 2008; Taylor, et al., 2012). A relevant outcome utilized in three of the selected studies was the variable of uncertainty(Germino, et al., 2013; Gil, et al., 2006; Gil, et al., 2004), which includes uncertainty management, self-disclosure, cancer knowledge, problem solving, and sources of information, among other sub-variables.

Three studies included general emotional outcomes, perceived risk of recurrence, and temporal orientation(Ashing-Giwa & Lim, 2011; Brewster, et al., 2007; Germino, et al., 2013). Temporal orientation included attitudes about the past, present or future, and thus reflects how individuals give meaning to events or experiences, such as cancer (Brewster, et al., 2007). Psychological outcome variables also included self-reported psychological growth, affect, fear of recurrence, coping strategies, body image, and emotional distress.

Social well-being domain

Eight of the selected studies utilized social factors affecting QOL (Darby, et al., 2009; Gil, et al., 2006; Lewis, et al., 2012; Mosavel & Sanders, 2010; Royak-Schaler, et al., 2008;

Russell, et al., 2008; Rust & Davis, 2011; Shaw & Coggin, 2008; Thompson, et al., 2006). Social issues were divided into the sub-categories of communication with the health care team, need for support, and access to care. Patient-provider communication was explored in three studies, and included involvement in medical decision-making and patient-provider relationship (Gil, et al., 2006; Royak-Schaler, et al., 2008; Russell, et al., 2008). Need for support outcomes included social support, church community support, and informational needs (Lewis, et al., 2012; Mosavel & Sanders, 2010; Shaw & Coggin, 2008). Finally, access to care included financial burden, continued cancer care, services available, acquisition of medical information, barriers to access, health literacy, medication adherence, and participation in surveillance and follow-up care (Darby, et al., 2009; Mosavel & Sanders, 2010; Royak-Schaler, et al., 2008; Rust & Davis, 2011; Thompson, et al., 2006).

Physical well-being domain

More than one third of the studies (6) explored physical issues affecting the QOL of AA breast cancer survivors (Gil, et al., 2004; Leak, et al., 2008; Lewis, et al., 2012; Schover, et al., 2006; Schover, et al., 2011; Shaw & Coggin, 2008). Physical factors included physical symptom distress, self-reported physical symptoms after treatment, fertility, sexual function, self-reported menopausal symptoms, and general physical needs.

Spiritual well-being domain

Factors within the spiritual domain were among the least represented in the included studies (Leak, et al., 2008; Schover, et al., 2006; Schover, et al., 2011; E. Schulz, et al., 2008; Shaw & Coggin, 2008), with 5 studies exploring such variables. These spiritual outcome variables included beliefs, faith, having a relationship with God, seeking God's presence, spirituality, and spiritual well-being. Relationships with church community were categorized under the social well-being domain of the QOL model (Ferrell, et al., 1995). It is important to note that in Ferrell's QOL Model, support from the church community is found in the social well-being domain under the category of relationships, rather than the spiritual domain(Ferrell, et al., 1991).

Discussion

The following discussion highlights strengths and weaknesses of the current investigation that may influence future research. Although research shows that AA women experience poorer QOL than non-Hispanic white women after breast cancer treatment (American Cancer Society, 2013b), it [22]is difficult to make definitive statements about the QOL of AA BCS based on the analysis of the current study, nor was it the aim of this review. Table 2 provides the author's interpretation of priority factors for future research.

Psychological well-being domain

The psychological domain was the most highly represented QOL domain among the included studies. QOL studies have historically focused on emotional well-being as a cornerstone for a positive transition between cancer patient and cancer survivor (Powe, et al., 2007). While the domain was highly represented, none of the studies addressed important constructs within Ferrell's (1995) depicted model in Figure 1. Outcome variables that are noticeably missing from the studies include enjoyment/leisure, cognition/attention, and control of choices post treatment. The Survivorship Workgroup recognized that leisure and ability to control post treatment were extremely important aspects promoting an increased QOL (Pratt-Chapman, et al., 2011).

Social well-being domain

The reviewed studies covered many of the social factors included within Ferrell's QOL Model (1995). The financial burden of cancer treatment, however, was represented as an outcome in only one study (Darby, et al., 2009), in contrast to the extensive reported hardships related to low income in both physical and psychological domains (American Cancer Society, 2013b). In addition, the effect of breast cancer diagnosis and treatment on employment was noticeably absent. Darby and colleagues (2009) noted that very little is known about the long-term health-care costs associated with minority women who have completed treatment for breast cancer. Differences exist among ethnic/racial groups, with low-income women bearing a great portion of the financial burden. Future studies must explore the impact of cancer treatment and survivorship on employment and financial burden, to create interventions aimed at creating stability in the same.

Physical well-being domain

The domain of physical well-being was surprisingly under-represented among the studies included in this review. Among the physical constructs in Ferrell's QOL Model (Ferrell, et al., 1995), the studies did not include outcomes that explore strength, fatigue, sleep/rest, or pain. When considering the physical effects of cancer treatment, it is necessary to examine the type of treatment that the breast cancer patient has undergone. Studies have shown that chemotherapy treatments can have late and long-term effects, including fatigue, menopausal symptoms, neuropathy, "chemobrain," heart failure, liver problems, infertility, as well as osteoporosis (Burkett & Cleeland, 2007). Radiation therapy can cause many different skin sensitivities and irritations, and fatigue even after the completion of treatment. It is important to note that fatigue, pain, cognitive and affective dysfunction, sleep disturbance, and immobility have been shown to be greatly increased in the African American population, although causes of this disparity remain unknown (Burkett & Cleeland, 2007). This only further supports the need for enhanced research efforts exploring fatigue, pain and sleep issues in AA breast cancer survivors.

Spiritual well-being domain

As previously noted, the domain of spirituality was the most underrepresented among the studies of this review. There is a persistent need to assess spirituality and include it in interventions aimed at AA BCS (Hamilton, Crandell, Carter, & Lynn, 2010; Hamilton, et al., 2007). Among the spirituality constructs of the theoretical framework, none of the studies explored outcomes relating to meaning of illness in faith, uncertainty, or inner strength through God (Ferrell, et al., 1995). An AA cancer survivor's transition from patient to survivor is greatly affected by her or his relationship with God. AA cancer survivors cite their spirituality as a positive force in their healing, and research shows that many perceive their survival from cancer as a gift from God (Hamilton, et al., 2007). In their investigation of coping strategies, Lauver and colleagues (Lauver, Connolly-Nelson, & Vang, 2007) also found that female cancer survivors report "meaningful transformations and changes of a spiritual nature" (p.109), when transitioning from patient to survivor. Through future research centering on a survivor's inner strength and meaning of illness through faith, nurse scientists, organizations and communities can promote support groups that are spiritually based, and capitalize on AA spirituality and the often-resulting 'pay it forward' mentality (Lauver, et al., 2007).

Research and methodological issues

The majority of the included studies were quantitative, but it is important to note that qualitative work should be continued, to encourage a deep understanding of each outcome. In addition, according to the quality appraisal of the quantitative studies using CONSORT and

STROBE tools (Gallo, et al., 2011; K. Schulz, et al., 2010), there was great variance in quality. As previously stated, all studies meeting inclusion criteria were analyzed and included in this integrative review. Research studies that were of low quality and rigor, however, may contribute less to the review (Whittemore & Knafl, 2005).

There was a definite lack of community-based studies in this review, which, in the AA BCS population, provides an impetus for future research utilizing the principles of Community Based Participatory Research (CBPR) (Wallerstein & Duran, 2006). In addition, several QOL studies could have added greatly to the review, however they were excluded because the population was not specific to AA and/or to breast cancer. There was also great variance in operational definitions of the term 'cancer survivor'. Many included AA participants who were post diagnosis (National Coalition for Cancer Survivorship, 2011), but not necessarily post treatment. QOL experiences can differ greatly, however, between post diagnosis and post treatment cessation.

Research Implications

This integrative review revealed several potential areas for future research. Table 2 details final outcome measures found lacking within each QOL domain that are important for further research. Only one of the reviewed studies utilized outcomes from all four QOL domains (Shaw & Coggin, 2008), while the majority only focused on one or two domains. More emphasis on the multi-domain perspective of the Ferrell (1995) QOL framework is greatly needed in the development of interventions including all four domains, and might maximize effectiveness across the AA BCS population. In addition, the majority of included studies did not incorporate a theoretical framework, which signals a need for future research that can build on existing theory.

Clinically relevant findings of included studies also inform future research needs. Based on the review, it is evident that there is a persistent need to create interventions aimed at educating AA BCS on their risk for recurrence and the importance of medication adherence (Brewster, et al., 2007; Rust & Davis, 2011; Taylor, et al., 2012). Interventions should be appropriate both for cultural considerations and educational preparation (Rust & Davis, 2011).

There was a noticeable lack of studies both exploring the spiritual well-being domain and utilizing CBPR. CBPR centers on an integral partnership between community and researchers, in order to benefit both parties for collaborative efforts (Wallerstein & Duran, 2006). Members of the AA community, breast cancer survivorship support groups, spiritual leaders and congregations, healthcare providers, and researchers must all play an active, vested role in improving research and care for survivors after treatment. An understanding of the impact of this transition into survivorship for AA women could provide valuable data to support the development of future initiatives addressing existing disparities in cancer survivorship outcomes.

Peer navigation research

Peer navigation is an innovative application of previous navigation iterations, and utilizes trained BCS as navigators into survivorship, and can be utilized to address many of the deficits noted in this discussion. Future research of this intervention could include outcomes in all four domains of Ferrell's QOL Model (1995), most notably those that were absent among the included studies: strength, fatigue, sleep/rest, pain, control post treatment, employment concerns, inner strength and meaning of illness in faith. One cannot discount the social support provided by a peer navigator (Pratt-Chapman, et al., 2011). Cancer survivors can play a vital role as messengers of hope and information, and as advocates for prevention and continued screening, although their role as peer navigators for breast cancer requires investigation. Support groups provide information; however groups specific to AA women are rare, and those with all races and ethnicities may fail to address individualized needs.

Clinical Implications

Providers have an obligation to address QOL issues in African American women who have completed treatment for breast cancer. Studies in this review indicate that there are protective factors that contribute to QOL in this population and should be utilized when exploring interventions. Through identification of influencing factors in individual survivors, health care providers can develop strategies to deal with the emotional distress and negative complications of transition post treatment (Mollica & Newman, 2014).

To facilitate best practice in follow-up care for cancer survivors, the Institute of Medicine (IOM) advises that cancer survivors be provided with survivorship care plans (SCP)(Institute of Medicine, 2007), which are personalized treatment plans. SCPs include cancer treatment history, long-term and late effects of treatment received, surveillance for recurrence and new cancers, and resources to address QOL issues. Ashing-Giwa and colleagues(Ashing-Giwa et al., 2013) found that SCPs for AA BCS must include factors that constitute the underlying psychosocial, cultural, and behavioral risks for poor disease outcomes that are exacerbated in AA BCS. Providers should use the knowledge gained in this review to appropriate utilize SCPs to enhance follow-up care and QOL.

Limitations

Despite the rigor of the process, important work regarding QOL in AA BCS may not have been included in this research for several reasons. Based on exclusion and inclusion limitations, specified key word searches may have excluded pertinent studies that did not identify the exact terms. As a result of the sampling method, some research concerning QOL outcomes in AA BCS may have been missed. In addition, it was the not the purpose of this review to explore clinical issues or findings of studies, but rather to explore factors contributing to QOL. Limiting articles to those published in the English language could also have resulted in the exclusion of important work.

Conclusion

This integrative review synthesized specific outcomes utilized in QOL studies of AA BCS. Despite previous research in this area, there is a need for more research specific to AA women after treatment, especially in the areas highlighted. Future research from a multi-domain perspective and specifically spiritual well-being, and interventions that target culturally appropriate resources and support for AA BCS will help inform culturally tailored interventions and survivorship care plans that have the potential to improve QOL in this vulnerable population.

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Figure 1. QOL Model Applied to Cancer Survivors

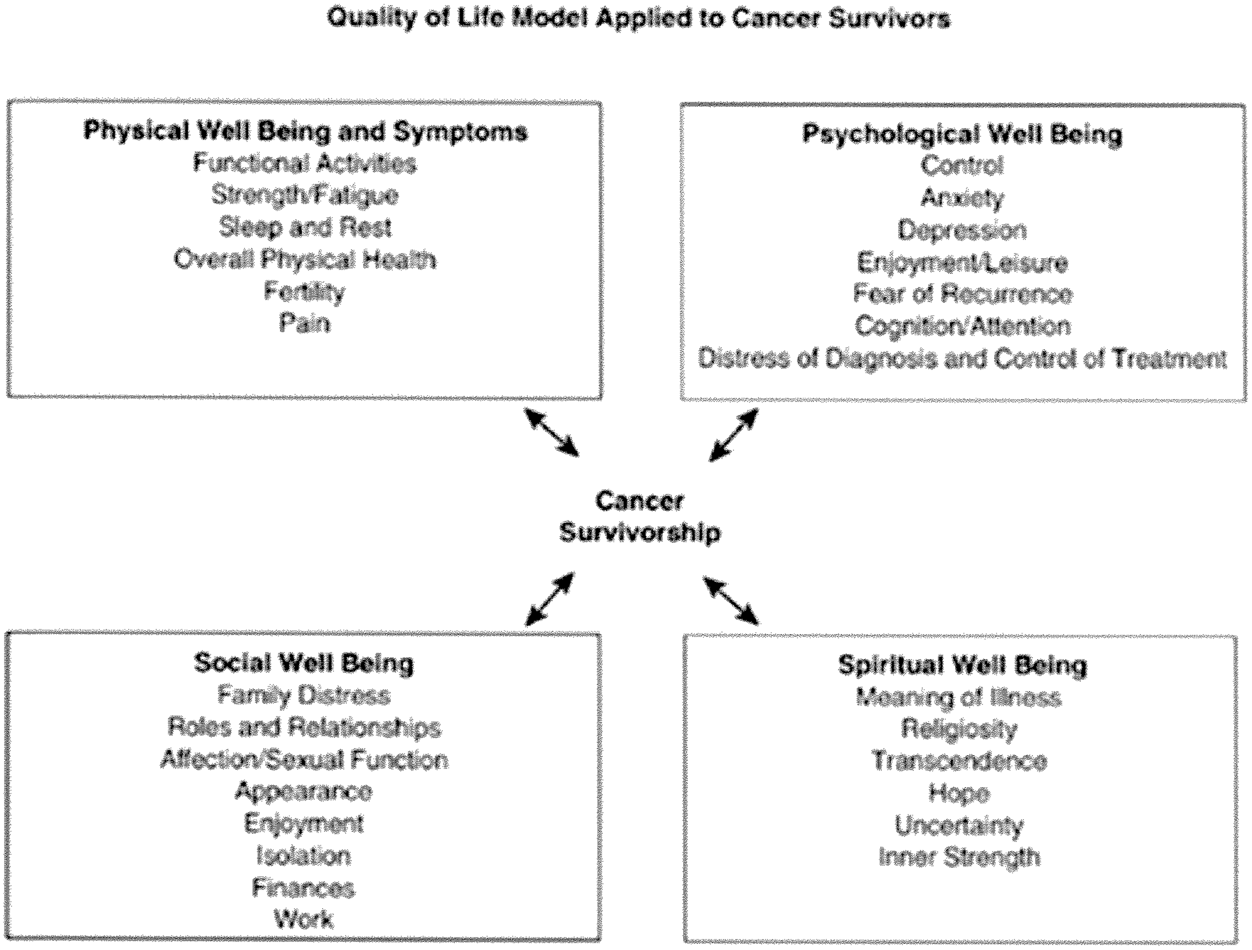

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Figure 2. Flowchart for article relevance assessment

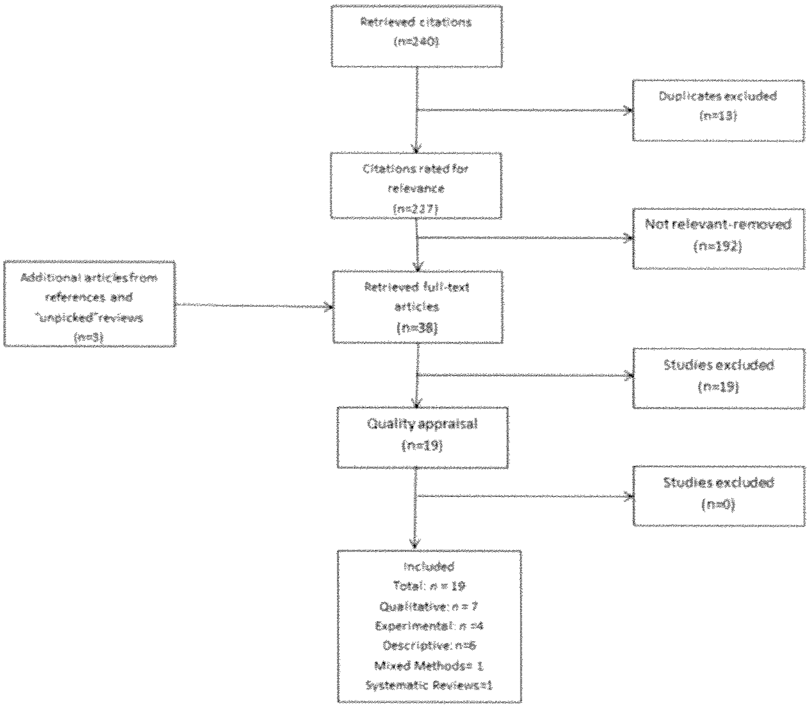

Table 1. Research on Factors Contributing to Quality Of Life in African American (AA) Breast Cancer Survivors (BCS)

Source	**Purpose, Setting, Sample, Framework**	**Design and Methods**	**Appraisal Tool % Items Met on Checklist (Rating)**	**Specific Factors Reported** (instrument if applicable)	**Domain Represented by Factors**
Ashing-Giwa & Lim (2011)	*Purpose:* Describe emotional concerns of breast cancer survivors; *Setting:* California; *Sample:* 703 multiethnic BCS (n=135 AA); *Framework:* HRQOL	*Design:* Quantitative cross-sectional, descriptive; *Methods:* self-report survey	STROBE Rating: 77% items	**Emotional outcomes** (FACT-G emotional well-being subscale, SF-36 mental health subscale)	Psychological
Brewster et al. (2007)	*Purpose:* To characterize perceived risk perceptions in AA breast cancer survivors at increased risk for BRCA1/2 mutation; *Setting:* Pennsylvania; *Sample:* 95 AA BCS *Framework:* not stated	*Design:* Quantitative descriptive; *Methods:* structured telephone interview	STROBE Rating: 81% items	**Breast cancer perceived risk** (validated Likert scale) and **Temporal orientation** (Temporal Orientation Scale)	Psychological
Darby et al. (2009)	*Purpose:* Explore financial burden of breast cancer on AA medically underserved survivors; *Setting:* Tennessee; *Sample:* 36 AA BCS; *Framework:* not stated	*Design:* Grounded theory; *Methods:* Four focus groups with semi-structured discussion guide and thematic analysis to reveal salient themes	CASP Rating: 80% items	**Financial burden** and **emotional impact** post treatment (open-ended questions)	Social Psychological
Germino et al. (2013)	*Purpose:* Determine the effect of an uncertainty management intervention on uncertainty, concerns, and psychological outcomes in AA BCS; *Setting:* Rural and urban clinic and community groups; *Sample:* 313 BCS (117 AA); *Framework:* not stated	*Design:* 2 x 2 randomized block, repeated-measures design; *Methods:* uncertainty management	CONSORT Rating: 65% items	**Uncertainty-cognitive reframing and problem solving, knowledge, self-disclosure, sources for helpfulness of info, fears of recurrence, intrusive thoughts, symptoms; affect, personal growth, self-efficacy** *13 instruments utilized	Psychological

Gil et al. (2004)	*Purpose:* Explore sources of uncertainty in long-term BCS; *Setting:* rural and urban North Carolina; *Sample:*244 BCS (73 AA); *Framework:* not stated	*Design:* quantitative longitudinal descriptive; *Methods:* 10 monthly telephone calls, triggers and symptoms reported as frequencies	STROBE Rating: 86% items	**Triggers of uncertainty** **Physical symptoms**	Psychological Physical
Gil et al. (2006)	*Purpose:* Evaluate uncertainty management intervention; *Setting:* urban and rural North Carolina; *Sample:* 483 BCS (141 AA); *Framework:* not stated	*Design:* 2 x 2 randomized block, repeated measures design; *Methods:* Uncertainty management intervention and usual care control groups	CONSORT Rating: 63% items	**Uncertainty-cancer knowledge, social support satisfaction, patient-provider communication, coping strategies, positive life change, problem solving** *11 instruments utilized	Psychological Social
Leak et al. (2008)	*Purpose:* Examine relationships of symptom distress, spirituality and QOL; *Setting:* churches in Southeast US; *Sample:* 30 AA BCS; *Framework:* Interaction Model of Client Health Behavior	*Design:* quantitative descriptive; *Methods:* face-to-face interviews, data analysis: descriptive statistics and Pearson correlation coefficient	STROBE Rating: 91% items	**Symptom Distress** (Symptom Distress Scale), **Spirituality** (Spiritual Perspective Scale) and **QOL** (QOL Index)	Physical Spiritual
Lewis et al.(2012)	*Purpose:* Explore psychosocial concerns of young AA BCS; *Setting:* Texas cancer hospital; *Sample:* 33 AA BCS age 45 or younger; *Framework:* not stated	*Design:* Mixed-methods descriptive; *Methods:* semi-structured phone interviews, concerns reported as frequencies after descriptive analyses, thematic analysis of open-ended questions	STROBE and CASP Rating: 81% items on STROBE 90% items on CASP	**Impact of cancer, need for support, fertility, sexuality, anxiety, emotional concerns**	Physical Social Psychological
Mosavel et al. (2010)	*Purpose:* Understand barriers experienced by AA BCS after treatment; *Setting:* Northeastern, urban city; *Sample:* 20 AA low-income BCS and caregivers; *Framework:* not stated	*Design:* qualitative descriptive/explorative using photovoice; *Methods:* BCS given four sessions to photograph and discuss needs, data analyzed with thematic analysis	CASP Rating: 90% items	**Financial concerns, social support, continued cancer care, perception adjustment, services available**	Social

Royak-Schaler et al.(2008)	*Purpose:* Investigate patient-physician communication in breast cancer care for AA BCS; *Setting:* Medical centers eastern US; *Sample:* 39 AA BCS; *Framework:* not stated	*Design:* qualitative grounded theory; *Methods:* Four focus groups, inductive thematic analysis	CASP Rating: 90% items	**Involvement in medical decision making, concerns about recurrence, preferred sources of breast cancer information delivery**	Social
Russell et al.(2008)	*Purpose:* Review of studies that investigate AA women's experiences after breast cancer; *Setting:* NA; *Sample:* 22 qualitative and quantitative studies; *Framework:* Brenner's QOL proximal-distal continuum	*Design:* systematic review; *Methods:* included studies that focused on QOL issues in AA BCS, results reported in comparison to other racial and ethnic groups	N/A	**Physical symptoms, life stressors, fear of recurrence, body image, provider-patient relationship, spirituality, positive growth**	Psychological Social
Rust et al.(2011)	*Purpose:* Explore importance of health literacy and medication adherence; *Setting:* urban city in South US; *Sample:* 24 medically-underserved AA BCS; *Framework:* not stated	*Design:* qualitative, exploratory; *Methods:* Two focus groups, data analyzed with grounded theory methods	CASP Rating: 80% items	**Access to health information, acquisition of medication information, medication adherence, barriers to access**	Social
Schover et al.(2006)	*Purpose:* Evaluate peer counseling program to improve sexual function, increase knowledge and decrease symptoms for AA BCS; *Setting:* Texas cancer center; *Sample:* 60 AA BCS > 1 yr post treatment; *Framework:* not stated	*Design:* randomized, delayed control trial; *Methods:* Peer counselor intervention or 3 month delayed intervention group, analyzed with linear mixed model regression	CONSORT Rating: 79% items	**Spiritual well-being** (FACIT-Sp), **sexual function** (FSFI), **symptoms** (BSI), **fertility knowledge**	Spiritual Physical
Schover et al.(2011)	*Purpose:* Assess effectiveness of peer counseling program for reproductive health compared with brief telephone counseling condition; *Setting:* Texas cancer center; *Sample:* 300 AA BCS post treatment; *Framework:* not stated	*Design:* randomized trial; *Methods:* Participants assigned to peer counseling or brief telephone counseling group, mixed-model analysis	CONSORT Rating: 84% items	**Spiritual well-being** (FACIT-Sp), **emotional distress** (BSI-18), **sexual function** (FSFI), **menopausal symptoms, use of reproductive health care**	Spiritual Psychological Physical
Schulz et al.	*Purpose:* Examine if and how AA BCS use spirituality to cope; *Setting:*	*Design:* qualitative exploratory; *Methods:*	CASP Rating: 90%	**Spirituality; becoming a better person, new**	Psychological Spiritual

(2008)	Alabama hospital; *Sample:* 23 AA cancer survivors; *Framework:* not stated	Semi-structured interviews, content analysis	items	**perspective, changes in priorities, stress, helping others**	
Shaw et al.(2008)	*Purpose:* Identify needs of AA BCS; *Setting:* US; *Sample:* 62 AA BCS post treatment; *Framework:* QOL model applied to cancer survivors	*Design:* qualitative exploratory; *Methods:* Delphi technique for consensus building; open coding analysis	CASP Rating: 80% items	**Physical, emotional, spiritual and financial needs**	Physical Psychological Spiritual Social
Shelby et al.(2008)	*Purpose:* Examine how optimism and social support are associated with adjustment following treatment; *Setting:* Pennsylvania and DC; *Sample:* 77 AA BCS post treatment; *Framework:* not stated	*Design:* quantitative descriptive; *Methods:* self-report questionnaires, bivariate analyses and intercorrelations	STROBE Rating: 95% items	**Optimism** (LOT), **social support** (ISEL-SF), **psychological distress** (MHI), **QOL** (CARES-SF)	Psychological
Taylor et al.(2012)	*Purpose:* Explore extent and nature of fear of recurrence in AA BCS; *Setting:* US; *Sample:* 51 AA BCS post treatment; *Framework:* not stated	*Design:* quantitative exploratory; *Methods:* self-reported questionnaire; ANOVA, correlations, t-tests	STROBE Rating: 86% items	**Fear of recurrence** (CARS), **psychological distress**(BSI-18), **QOL** (FACT-B)	Psychological
Thompson et al.(2006)	*Purpose:* Explore extent and motivators of post treatment surveillance and follow-up care; *Setting:* New York urban; *Sample:* 20 AA BCS 1 yr post treatment; *Framework:* Anderson's Behavioral Model for Health Services Utilization	*Design:* qualitative exploratory pilot study; *Methods:* Semi-structured interviews, open-coding to explore themes	CASP Rating: 90% items	**Knowledge of surveillance, participation in surveillance, motivators of follow-up care, participation in follow-up care**	Social

Table 2. Priority Factors Related to QOL for Future Research

Domain	Outcome Measure
Psychological well-being	Enjoyment/leisure Cognition/attention Control post treatment
Social well-being	Employment concerns Financial burden
Physical well-being	Strength Fatigue Sleep/rest Pain
Spiritual well-being	Uncertainty in faith Inner strength Meaning of illness in faith

MANUSCRIPT II: FORMATIVE QUALITATIVE STUDY

This paper was accepted for publication in *Cancer Nursing* (reprinted with permission). Mollica, M., Nemeth, L. (2014). Transition from patient to survivor in African American breast cancer survivors. DOI: 10.1097/NCC.0000000000000120

Abstract

Background: Breast cancer is the most common cancer among African American (AA) women, with a survival rate of 79%, lower than for other ethnic and racial groups in the United States. Minorities experience disparities in timeliness of care, delivery of culturally sensitive care, and outcomes. Transition from active treatment to survivorship presents an opportunity for exploration.

Purpose/Objectives: This qualitative, grounded theory study examined the experiences and coping of AA women as they transition from being a breast cancer patient to being a breast cancer survivor.

Methods: This study included 15 community-based AA women aged 35 to 75 years in Charleston, South Carolina, and Buffalo, New York, who had completed treatment for primary breast cancer between 6 and 18 months prior. A semi-structured interview explored experiences as they finished treatment, support from family, role of spirituality, physical and emotional concerns, needs of the survivor, as well as suggestions for possible interventions for other survivors. Two investigators reviewed transcripts and coding to confirm and refine the findings.

Results: Four main themes were identified: perseverance through struggles supported by reliance on faith, persistent physical issues, anticipatory guidance needed after treatment, and emotional needs as important as physical.

Conclusions: The transition from cancer patient to survivor is a pervasive time filled with stress, loss of safety net, and significant coping measures. Participants expressed the need to have support from another AA breast cancer survivor as they complete treatment.

Implications for Practice: Nurses and providers can assess and address stressors in transition. Nurses should design patient-centered interventions using peers as direct support to promote effective coping strategies.

Introduction

Population estimates indicate that African American (AA) women have a 1 in 9 lifetime probability of being diagnosed with breast cancer, making it the most common cancer among AA women (American Cancer Society, 2013b). While AA women have a lower breast cancer survival rate of 78%, compared with other ethnic and racial groups in the US, there are still an estimated 2.9 million breast cancer survivors (American Cancer Society, 2013a). Differences experienced by racial and ethnic minorities persist, including timeliness of healthcare delivery, culturally centered care and effectiveness of treatments, (Agency for Healthcare Research and Quality, 2012). AA women are particularly vulnerable and experience poorer functional health after cancer diagnosis; have an increased risk of late diagnosis of second primary cancers, as well as recurrence (Miles, 2005; Wilder Smith, et al., 2009). The transition from cancer patient to survivor may be a particularly important point in recovery because it could affect how much stress cancer survivors' experience. This 're-entry phase', refers to the phase after treatment ends until 6 months to a year post treatment, where cancer patients are expected to return to normal life activities and patterns, and survivors often find themselves unprepared (Allen, Savadatti, & Levy, 2009).

Few studies have investigated the experience and needs of minority women during this transition period (Allen, et al., 2009). The present study was designed to address the gap in scientific literature, and investigate this phenomenon in AA women after cessation of treatment. This qualitative grounded theory study explores the question: *What is the experience of the transition from cancer patient to survivor in African American breast cancer patients?*

Background

After treatment ends, survivors may have many fears regarding loss of medical monitoring, risk of cancer recurrence, and changes in social support from healthcare providers and caregivers. Cancer survivors can experience long-term as well as late side effects from their chemotherapy, radiation, or surgical treatments (Bellury et al., 2011). Chronic stressors persist among long-term cancer survivors, including concerns about survival, fear of recurrence, emotional distress, disturbed body image, and loss of medical follow-up (Lauver, et al., 2007); psychological distress and risk factors include vulnerability, disappointment, and frustration over persistent fatigue (Coggin & Shaw-Perry, 2006). AA breast cancer survivors have expressed a sense of burden to appear strong when they are in fact not feeling strong after treatment (Hamilton, et al., 2007). Females entering survivorship may not feel they are the source of strength that their family depends on them for. AA breast cancer survivors need more emotional support after diagnosis, and reported negative effects on employment, romantic replacements and sexual issues related to treatment (Lewis, et al., 2012).

Informing cancer patients about survivorship issues and potential resources is a key component to quality of care. Little guidance is available for survivors and healthcare providers to overcome the medical problems that may arise post treatment(Vachani, Hampshire, Hill-Kayser, Jacobs, & Metz, 2009). Despite Institute of Medicine (IOM) recommendations for addressing the psychosocial needs of cancer survivors(Harrop, Dean, & Paskett, 2011), population-based estimates concerning receipt of psychosocial care are lacking, particularly in minorities. While many women report receiving a vast wealth of treatment-related information, AA women rarely reported receiving survivorship information(Janz et al., 2008). Difficulty accessing information can have a negative impact on quality of life, including emotional and social well-being, vitality, and coping with diagnosis and implications of treatment. Some providers give less information on survivorship support to minority women with breast cancer, and differences were found by age, race, education and income(Siminoff, Graham, & Gordon, 2006). Such support includes information on anxiety and depression, relationships, sexual function and nutrition. Challenges also exist for AA women in being able to understand information and awareness of appropriate resources and guidelines for follow-up(Janz, et al., 2008).

Breast Cancer in Survivorship: Definition

Cancer survivor is a concept that appears frequently in the literature, designating a person who has received cancer treatment and is in a post-intervention phase. The National Coalition of Cancer Survivors proposes that from the time of diagnosis and for the balance of life, a person diagnosed with cancer is a survivor(National Coalition for Cancer Survivorship, 2011). Feuerstein defends, however, that the term extends from the completion of primary treatment up to end-of-life care(Feuerstein, 2007). For the purpose of this study, where the aim is to determine the experience transitioning from cancer patient to survivor (the re-entry phase), a cancer survivor will be operationally defined as a person who has completed primary treatment for their cancer. A gap in knowledge exists as to the effect that entering survivorship has specific to AA women, presenting a specific need for continued research and an impetus for the current study.

Purpose of Study

The purpose of this study is to examine the experience of African American women as they transition between breast cancer patient and survivor.

Methods

Design

This qualitative study investigated the experience of the AA women as she transitions from breast cancer patient to survivor. Investigators utilized an interpretive grounded theory design, where the goal is the discovery of theory from data systematically obtained and analyzed in social research (Glaser & Strauss, 2009). An open, exploratory approach was used to identify recurrent meaningful concepts through a systematic, inductive analysis of content, and constant comparison throughout the process of data collection and analysis(Strauss & Corbin, 1998). Grounded theory was appropriate in this study as the immediate aim was to gain perspective and understanding on the unique experience of this transition specific to AA women, which was not found in the literature. The Institutional Review Board at the Medical University of South Carolina (MUSC) approved this study, and reciprocity was recognized by Roswell Park Cancer Institute prior to sample recruitment.

Sample recruitment

Participants were recruited from community settings in Charleston, South Carolina, and Buffalo, New York, through community and support groups such as the National Witness Project (NWP) and the Embracing U group. Leaders of both groups disseminated study information to potential participants, who indicated their interest to participate. The NWP is a faith-based community group that utilizes AA breast and cervical cancer survivors to empower AA women to get screened for breast and cervical cancer, and Embracing U is an active community based support group based in Charleston, SC, that educates and supports AA women affected by breast cancer. In addition, the PI utilized participants of the START study, a cancer center-based pilot study examining healthy survivorship in AA breast cancer survivors[12], who agreed to be contacted for further research studies. A purposeful sampling technique targeted AA women between 35 and 85, who had completed active treatment (chemotherapy, radiation or surgery) within 6-18 months prior to interviews. It is important to note that the Embracing U group and START study participants are not specifically faith-based groups. All efforts were made to appropriately represent all age ranges (35-45, 46-55,56-65, 66-75, 76-85), both urban and rural participants (classified based on zip code),and income ranges as reported on demographic questionnaires. Participants were excluded if they have had recurrent breast cancer, metastatic disease, or other primary cancers.

Procedures: Data Collection

The PI explained the purpose and procedure of the study to eligible participants, who were informed they could stop the interview at any time, and after completion of the interview, could decide not to have their interview included within the study analysis. Interested participants were then mailed consent forms including a stamped, addressed envelope, and interviews occurred after receipt of all consents.

The investigator scheduled the 30 to 45-minute, audiotaped phone interviews at a time convenient for each participant. A demographic survey was administered to participants to gather information about the participants. The PI designed a semi-structured interview guide (Figure 1) based on frequently cited background literature on the transition from patient to survivor(Allen, et al., 2009), needs of the African American cancer survivor (Russell) and expert input. Participants were interviewed about their experience before and after the cessation of their treatment for breast cancer, as well as physical and emotional effects of cancer and treatments received. In addition, participants were asked how they cope with these concerns, the role of spirituality, and what materials, resources, or support they would like to see offered to other AA women finishing treatment for breast cancer. Reflexive memos were written during and after each interview to add to the interview transcripts. To situate the PI's biases as an experienced oncology nurse, these memos provided opportunity to reconcile previous assumptions and to refine the interview questions (theoretical sampling) based on questions emerging from previous interview responses (Glaser & Strauss, 2009). For example, several participants mentioned faith and spirituality in some way during their responses. Interpretations regarding the importance of spirituality added important specific context that was not initially considered. A question related to the difference between faith, spirituality and religion, was added to clarify meaning among participants. Recruitment and interviews continued saturation occurred, the point at which no new themes were emerging. The decision to conclude recruitment of additional participants was mutually agreed upon by both authors.

Data Analysis

The PI and experienced qualitative research mentor collaborated in a review of the data, recruitment of sample, and development of themes. The PI transcribed the interviews verbatim and verified the transcripts with the audio files. An iterative process of analysis using inductive, constant comparison was undertaken using NVivo 9.0 qualitative analysis software (QSR, International Pty, Doncaster, Victoria, Australia), until recurrent themes were apparent. Inductive analysis sought to discover the patterns and themes in the data, through interaction of the researchers in this data(Strauss & Corbin, 1998). By coding, categorizing and condensing themes, in iterative cycles, and seeking evidence to support or contradict preliminary themes during analysis of data, minor amendments to the original themes were made. The investigators reviewed transcripts and coding separately to ensure agreement of themes and consensus of ideas, and refined the final themes after several rounds of review of the coded qualitative data. Trustworthiness was established through this process of review to ensure that the interpretation of data was valid related to its intent. To ensure that the findings were credible, or congruent with reality, the authors discussed the findings with audiences that were very familiar with the population and community based research. The audit trail provided through the use of the NVivo software added rigor to the process of analysis, and provided the exemplar quotes to ensure the findings are confirmable from the participants, and not from the researchers own biases(Shenton, 2004).

Results

Participant characteristics

Fifteen interviews were conducted with AA breast cancer survivors, with a mean age of 51. All participants were between 6-18 months post cessation of treatment per inclusion guidelines, and the most represented stage at diagnosis was Stage I. Thematic analysis revealed congruent themes between both urban and rural participants. The Table represents socio-demographic and breast cancer data of participants. A grounded theory of the transition from breast cancer patient to survivor was developed, with four themes that explained the experience of AA breast cancer survivors within this study. Figure 2 highlights the experience of transition from cancer patient to survivor.

Interview Themes

Participants reported a loss of safety net, concern about recurrence and toxic effects of therapy, as well as the role that other AA survivors played in their coping. Four major themes identified were: Perseverance through struggles supported by reliance on faith, Persistent physical issues, Anticipatory guidance needed after treatment, and Emotional needs as important as physical. A summary of participant responses organized according to themes follows.

Perseverance through struggles supported by reliance on faith: Many participants (80%) specifically reported they felt they had persevered through the struggles in diagnosis and after treatment. There was a "choose life" mentality, where the survivors had the option to choose to persevere, or give into the hardships. Many (87%) relied on their faith and spirituality for the strength to get through. The following examples illustrate this theme.

> *I prayed more than I have in my entire life. Because once I found out what it was really about, I said, I have to do something, I can't just sit here. You have to encourage yourself to do what has to be done. Stay. Endure whatever it takes to survive, or live.*
>
> *Because I had an intimate relationship with Christ, when I was diagnosed I knew God was ready to propel me to the next phase of my life spiritually. He had plans for me, and testing my faith by having this health issue, and he sure tested me. But I surpassed that with God and my faith.*
>
> *I use cancer as a storm. I overcame that. You have two choices: you can go with it, and say I'm going to go ahead and die, or you can fight. I think God gives us the option to get up and fight.*

Persistent physical issues: Many (60%) of the participants reported a lingering physical issues after treatment ended. This was surprising to some, who assumed that after treatment was over, so were the complications of treatment. Some (33%) participants reported they did not receive information from their oncology providers that symptoms may continue past treatment, and many mentioned seeking information on the internet. The exemplar quotes below provide examples of these challenges.

> *I've been off of chemo for over a year....and it hasn't gone away. With the neuropathy, it's hard to button your clothes with your hands, it makes you hurt on your soles. You have a problem with cooking, because your hands aren't sensitive to hot and cold. You drop things, you burn yourself.*
>
> *I wish I had more energy-I'm just not where I should be. This is stuff that is ongoing long after you finish treatment. Even though the chemo is over, and radiation is over, you still have lasting effects. I am tired all of the time.*

Anticipatory guidance needed after treatment: Participant voiced many needs after they finished treatment, including the need for psychological support (47%), need for resources and more information (60%), and the need to give back (20%). In addition, a majority (60%) of participants cited the need for support and communication with another AA woman who had been through treatment for breast cancer. The quotes below demonstrate this need.

> *They might be devastated, you know, and they need someone to talk to that's experienced that. I think that pairing them during treatment-a survivor and a patient, We should have survivors talking to each other, from the beginning to the end-when you first find out, everyone thinks of cancer as a death sentence, you know. Take it all the way to the end. Make sure somebody's always there to support you. And who knows about it but someone who's been through it.*
>
> *I wish I had someone-a buddy-that had gone through it, to tell me that this was ok. That how I felt after treatment really was how she felt, or that other survivors felt. My parents didn't understand, my man didn't understand, and I couldn't burden my children. I don't think you know, until you really are going through it or are a survivor.*
>
> *I would have loved to have seen someone come into my room as I was ending treatment, while I was taking my last few chemos, and said to me, I was a survivor-I've been there, and here is what you can expect. You get a lot from the doctors, but what you don't get is*

> *someone who has been there and is a strong Black woman like yourself. You really need that voice that has been through it.*

Emotional issues as important as physical: Although physical issues were cited by some of the participants, the emotional and psychological needs of survivors were also prevalent after cessation of breast cancer treatment. Some survivors (27%) felt ready to combat the physical effects of chemo, but less prepared for the fear of recurrence, guilt, resulting depression, and loss of safety net that comes with the end of treatment. These emotional issues are exemplified in the following quotes.

> *I went into a depression I think a little bit, because you experience a lot of anxiety, it's very emotional, there is a lot of fear and being overwhelmed, things happening right behind each other. Guilt, um, that I survived and other's didn't, happiness that it's over, and sadness that I lost the support I had.*
>
> *More of the mental issues. Being young and being a mom, and dealing with that whole lifestyle of being a mom, being sick, and just trying to deal with that part. So for me, at the end of my treatment, I was believed to be over it, but for me at the same time, just dealing with the mental part of it.*

In summary, the four themes reflect the needs and experiences of AA breast cancer survivors. These women tapped into their strength using their faith to overcome struggles, and experienced their life in a new way after breast cancer treatments. Their experiences dealing with both physical and emotional issues after treatment ended were not fully expected, and they would have appreciated having the opportunity to talk about some of the life changing experiences with another woman like themselves that might have possibly prepared them for dealing with the transition to survivor.

Discussion

As cancer survivors, AA women receive care after cancer treatment that is often characterized by disparities in services, as women continue to report less information about subsequent self-management, be informed about sequelae, or receive peer support, and social, material, and emotional resources (von Friederichs-Fitzwater & Denyse, 2012). This study demonstrated many important experiences of participants, highlighting perceived support and needs for resources, as well as motivation and coping measures.

Perseverance through struggles supported by reliance on faith

The findings in this study indicate that an AA breast cancer survivor's experience and transition to survivor is greatly supported by their relationship with God. Research has shown that many cite their spirituality as a positive force in their healing (Hamilton, et al., 2007; Lauver, et al., 2007). Many AA women even perceive their survival from cancer as a gift from God, and report "meaningful transformations and changes of a spiritual nature"(Lauver, et al., 2007) (p. 109), when transitioning from patient to survivor. The strength of an individual's faith in coping is of particular importance when considering the participants' reports of pushing through their struggles and choosing to live. A review of literature supports this finding, where AA survivors more often identified their spirituality as a way to cope with breast cancer treatment, than other races and ethnicities (Russell, et al., 2008).

Persistent physical issues

Participants indicated they were not prepared for the persistent physical issues that lasted well after treatment had ended. Many assumed that because treatment was over, their treatment side effects would be also. This physical symptom distress is well documented(Russell, et al., 2008), and includes fatigue, pain, physical dysfunction, cognitive dysfunction, and sexual dysfunction. Many of the participants reported fatigue and neuropathy, two common side effects reported by long-term cancer survivors (Bellury, et al., 2011).

Anticipatory guidance needed after treatment

Perhaps this study's most important finding was that speaking to another AA woman who had survived breast cancer, may have helped them be better prepared for the stress of cancer survivorship. A qualitative study of 29 low-income AA women to explore barriers to breast cancer screening revealed a physician mistrust and negative interactions with healthcare providers (Peek, Sayad, & Markwardt, 2008). As a result, importance is placed on breast cancer survivors as an important component for support and motivation (McQueen & Kreuter, 2010). In addition, women report they most want to speak with someone who has the same cancer and lived through the crisis of treatment (Giese-Davis, et al., 2006). Cancer survivors can play a vital role as messengers of hope and information, and as advocates for prevention and continued screening, though their role as peer navigators for breast cancer requires investigation. Support groups do provide information, however groups specific to AA women are rare, and those with all races and ethnicities may fail to address individualized needs. The Sisters' Network is a national survivorship organization that is committed to the need of AA breast cancer survivors, and provides a social network to connect survivors. A qualitative study also revealed that peer-based support groups provide emotional, social, spiritual and informational support, which can extend care for underserved populations (Ashing-Giwa et al., 2012).

Emotional needs as important as physical

Although physical issues resulting from the AA woman's breast cancer and treatments are concerning, participants stressed that emotional issues were as important as physical. They felt unprepared for the mental and psychosocial challenges they faced after treatment. Previous research supports this finding, where AA women do not anticipate the stressors of financial difficulties, social disruptions, and stigma related to breast cancer (Janz, et al., 2008; Russell, et al., 2008). There is a need for anticipatory guidance by providers and nurses in order to prepare survivors for the upcoming emotional challenges.

Study Limitations

The goal of this grounded theory qualitative study was to gain perspective and identify potential theories related to a phenomenon. The population studied included AA breast cancer survivors, and as such, did not aim to be transferable to the total population of breast cancer survivors. It is recognized there are variations in experiences among participants of this population. Although all efforts were made to purposely recruit from each socio-demographic variable, some were over or under-represented in this sample. The recruiting of participants in part from the National Witness Project, a faith-based group, could have created bias in the theme relating to spirituality. In addition, the PI did not validate themes with participants through member checking, which would have strengthened findings.

Implications for Nursing

The knowledge gained from the study of the experience of AA women as they transition from breast cancer patient to survivor provides many implications for nursing and healthcare in general. Future qualitative research in this population, both in nursing and interdisciplinary, is needed to compare variations in themes among demographic variables. Nurses and providers can use this information to address and assess stressors in transition, such as the loss of social support and safety net after treatment. Patient centered interventions that address these stressors and promote effective coping strategies based on the information gathered in this study specific to this population can be designed by nurses (Lauver, et al., 2007). It is also necessary to utilize the spiritual strength and community that is prevalent among AA women and this increased awareness of the increased risk of distress in those who have had more extensive treatments and/or a depressive or anxiety history to prevent such a trajectory. Culturally competent interventions should be tailored to the community setting, whether urban or rural, in order to increase buy-in by community members. Collaboration among oncology physicians in urban and rural areas can be augmented to meet quality of life needs of all populations.

Conclusion

The perceived great benefit from a close relationship with another AA survivor is important in the experience of survivorship after breast cancer treatment. Peer relationships can be facilitated in AA women by capitalizing on survivors' needs to give back or 'pay it forward'. Peer navigation has become prevalent in cancer care, originally in response to disparities in late diagnosis in AAs, and aimed at increasing access to care, early detection, and simpler delivery of information (Robinson-White, et al., 2010). There is a lack of definitive research, however, that addresses the training and use of cancer survivors as navigators, and the ability of peer navigation to improve outcomes in breast cancer survivorship in AA women. This provides an important opportunity for future research to address the needs of the AA breast cancer survivor.

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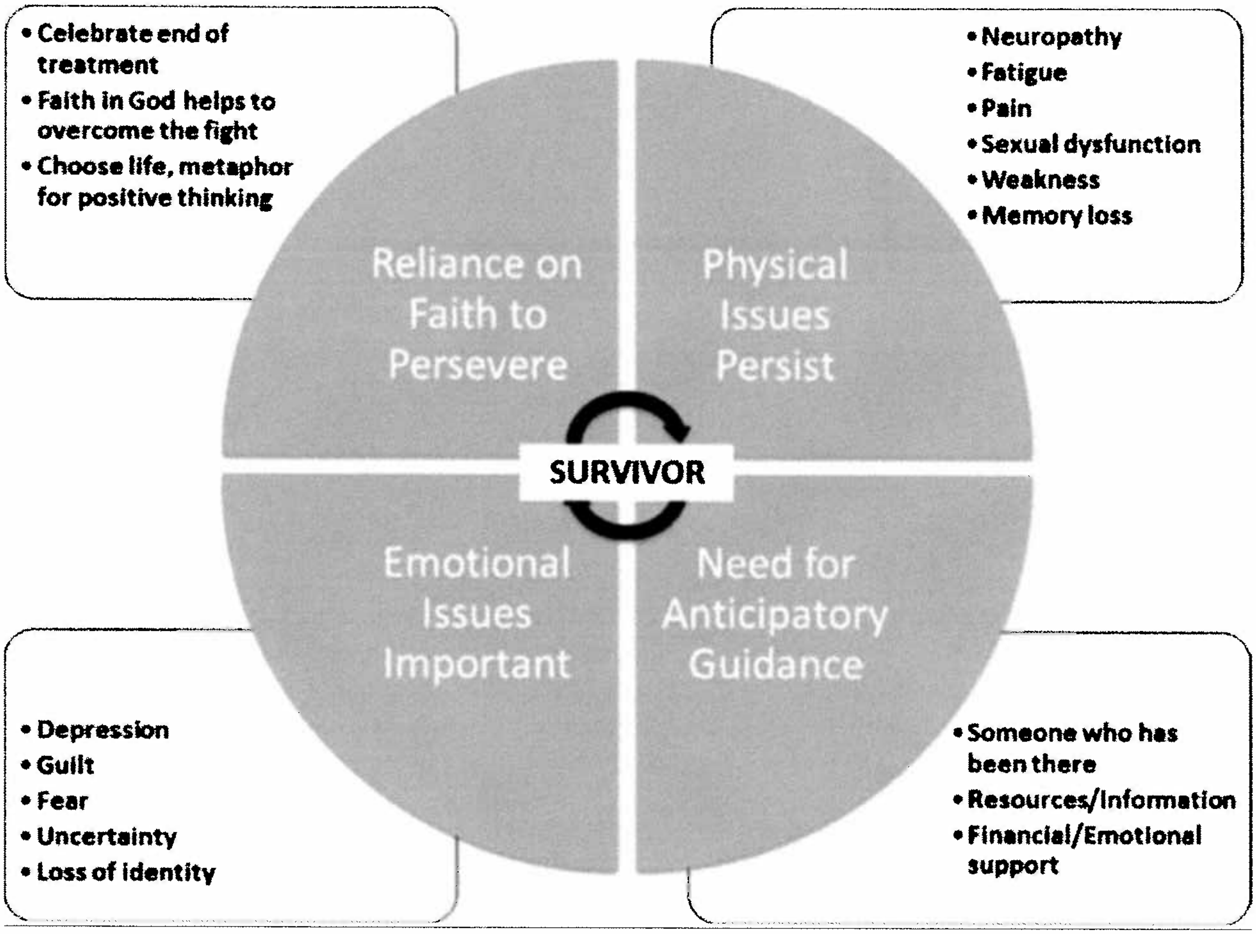
Figure 1. Semi-structured Interview Guide

1. Tell me about your experience at the end of your treatment for breast cancer.
2. What role has the support of your family played in moving from a cancer patient to cancer survivor?
3. If you are on or have taken hormone therapy, tell me about the effects of this therapy?
4. How do you cope with these effects?
5. What does it mean to you to be called a survivor?
6. What concerns do you have as you enter survivorship?
7. What physical complaints do you have now that treatment has ended?
8. How do you cope since you have stopped cancer treatment?
9. How does spirituality play a role in your life as you enter survivorship (if any)?
10. Given your experiences following treatment for breast cancer, what would you like to see offered to other African American women completing treatment?
11. What materials, if any, would you like to see offered to women finishing treatment for breast cancer?
12. When would you like these interventions offered?

Table. Socio-Demographic/Breast Cancer Characteristics (N=15)

Recruitment Group	
National Witness Project	46%
Embracing U Group	27%
START Study	27%
Age range (years)	
<50	46%
≥50	53%
Education level completed	
Associates	33%
Bachelors	33%
Income range ($)	
Less than 10,000	13%
10,000-19,000	7%
20,000-29,000	20%
30,000-39,000	13%
40,000-49,000	20%
50,000-59,000	7%
60,000-69,000	13%
100,000+	7%
Habitation	
Urban	66%
Rural	33%
Marital Status	
Married/Living with Partner	47%
Single/Widowed/Separated/Divorced	53%
Health Insurance	
Private/employer insurance	53%
Stage at Diagnosis	
Stage I	33%
Stage II	26%
Treatments received	
Chemo/Radiation/Surgery	60%
Surgery/Radiation	13%
Surgery/Chemo	7%
Surgery/Radiation	7%
Surgery/Radiation/Chemo/Hormone	7%

Figure 2. Experience of transition into survivorship.



MANUSCRIPT III: DISSERTATION STUDY

This paper was submitted for publication to the *Patient Related Outcome Measures*. Mollica, M., Nemeth, L.S., Newman, S., Mueller, M., Sterba, K. (2014). Peer Navigation in African American Breast Cancer Survivors.

Abstract

Purpose: The purpose of this study was to explore the feasibility and acceptability of a peer navigation (PN) survivorship program for African American (AA) breast cancer survivors (BCS) and its potential effects on selected short-term outcomes according to the Quality of Life Model Applied to Cancer Survivors.

Methods: An AA breast cancer survivor who completed treatment over one year prior to the study was trained as a PN, and then paired with AA women completing primary breast cancer treatment (n=4) for 2 months. This mixed methods, proof of concept study utilized a convergent parallel approach to explore feasibility and investigate whether changes in scores are favorable using interviews and self-administered questionnaires.

Results: Results indicate that the PN intervention was acceptable by both PN and BCS, and was feasible in outcomes of recruitment, cost, and time requirements. Improvements in symptom distress, perceived support from God, and preparedness for recovery outcomes were observed over time. Qualitative analysis revealed six themes emerging from BCS interviews: Learning to Ask the Right Questions, Start Living Life Again, Shifting My Perspective, Wanting to Give Back, Home Visits are Powerful, and 'We Both Have a Journey': Support from Someone Who Has Been There.

Conclusions: Results support current literature indicating that AA women who have survived breast cancer can be an important source of support, knowledge, and motivation for those completing breast cancer treatment. Areas for future research include standardization of training, and larger, randomized trials of PN intervention.

Implications for Cancer Survivors: The transition from breast cancer patient to survivor is a period when there can be a loss of safety net, and persistent support needs. AA cancer survivors can benefit from culturally tailored support and services after treatment for breast cancer. With further testing, this PN intervention may aid in decreasing general symptom distress and increase readiness for recovery post treatment.

Keywords: African American, breast cancer, survivor, peer support

Introduction

Breast cancer is the most common cancer among African American (AA) women, and the survival rate is 78 percent (American Cancer Society, 2013a), with an estimated 2.9 million AA breast cancer survivors in the US (American Cancer Society, 2013b). AA women who have survived cancer often receive post cancer treatment care that is characterized by disparities in services. While diagnosis and treatment-related disparities experienced by racial and ethnic minorities have been characterized and include lack of culturally appropriate care, timeliness of diagnosis, and effectiveness of treatment (Agency for Healthcare Research and Quality, 2012), less is known about disparities experienced after treatment completion. AA women do continue to report receiving little information about subsequent self-management, sequelae, peer support, and other social, material, and emotional resources (Mollica & Nemeth, 2014). AA women also experience a decreased level of functional health post cancer diagnosis, and have an increased risk of late diagnosis of recurrence and second primary cancers (Miles, 2005; Wilder Smith, et al., 2009) highlighting the potential need for tailored post-treatment interventions. While there is growing literature on survivor interventions (Ashing-Giwa & Lim, 2011), few are focused on AA women who may have unique needs for support after treatment.

Survivorship Definition

The National Coalition of Cancer Survivors (2011) proposed that from the time of diagnosis and for the balance of life, a person diagnosed with cancer is a survivor, yet others focus on survivorship beginning at the completion of primary treatment up to end-of-life care (Feuerstein, 2007). Due to the limited research that has been conducted with AA breast cancer survivors (BCS) after treatment and because differences have been observed when comparing quality of life (QOL) in AA women during and after treatment (Russell, et al., 2008), for the purpose of this study, the operational definition of a cancer survivor is from completion of primary treatment to end-of-life.

Cancer Survivorship Intervention Strategies: Patient Navigation and Peer Navigation

To date, there are increasing studies testing interventions for post-treatment cancer survivors but few have focused on AA BCS (Ashing-Giwa & Lim, 2011; Ashing-Giwa, et al., 2013; Ashing-Giwa, et al., 2012). One novel intervention strategy may be patient navigation using a peer mentoring approach. Navigation is a concept that encompasses many different roles and functions (Robinson-White, et al., 2010), filled by a variety of individuals, including nurses, social workers, peer supporters, and lay individuals. Survivor stories could be effective messages (Kreuter, et al., 2008), and increasing attention is placed on breast cancer survivors as an important group for support and motivation (McQueen & Kreuter, 2010). Cancer survivors can play a vital role as messengers of hope and information, and as advocates for prevention and continued screening, though their role as peer navigators for breast cancer survivors (BCS) requires investigation (Ashing-Giwa, et al., 2012). Follow up care for AA BCS may benefit from navigation efforts ; however, to date patient navigation in cancer care for African Americans has typically focused on access to services, screening, and treatment (Robinson-White, et al., 2010). Peer navigation (PN) with trained BCS as navigators into survivorship is currently undergoing preliminary evaluation for improving usage of survivorship care plans (SCP), though no manuscripts have yet been published.

The current study evaluated the feasibility of training AA breast cancer survivors (greater than 1 year post treatment) as peer navigators (PN) to other AA BCS completing treatment, and the impact of this pilot peer navigation intervention on multidimensional quality of life outcomes in AA BCS. Specifically, we developed an intervention using a community-based AA BCS as PN to provide social support, information/education, and resources, with the goal of reducing social isolation and improving adherence to evidence-based follow up with primary care appointments, quality of life, preparedness for recovery, and perspectives of support from God. Before a definitive efficacy study, this preliminary study enabled us to refine the intervention protocol, demonstrate feasibility of the intervention, and obtain preliminary evidence that the intervention might be effective. We evaluated the training, intervention implementation and measurement protocols, evaluated feasibility and acceptability of the proposed intervention, and ascertained whether changes in scores were favorable. The study explored an AA BCS Peer Navigator intervention through a 2-month, "proof of concept" trial (BCS n=4).

Methods

Study Overview

This mixed methods, proof of concept (POC) study employed a convergent parallel approach design to develop and test the feasibility of a survivorship peer navigation program for AA BCS and its potential effects on selected outcomes. A POC study is a short and/or incomplete realization of a certain method or idea to demonstrate its feasibility, whose purpose is to verify that some concept or theory is probably capable of being useful (Bowling, 2009). The POC is advantageous as an approach to investigate the feasibility of an intervention using a very simplified study design and lower number of subjects, thus reducing the amount of control required and time. A convergent parallel approach involves simultaneous collection of qualitative and quantitative data, followed by subsequent merging of multiple data sources (Creswell & Clark, 2011; J. W. Creswell, Klassen, Clark, & Smith, 2011).

Theoretical Framework

The dynamic social impact theory (DSIT) guided the PN intervention. Nowak, Szamrej & Latane (1990) developed the DSIT based on Latane's (1981) theory of social impact, which defines social impact as influence on one's thoughts, feelings or behaviors, exerted by the presence or actions of others. The DSIT carries this idea further, postulating that communication can better influence behavior change in an individual when the communication is similar and credible (Nowak, et al., 1990). The communication must be socially immediate and culturally relevant. Guided by the DSIT, our program trained a PN in cultural appropriateness, effective communication, and issues specific to AA BCS.

Peer Navigation Intervention

This 2-month PN program intervention paired a trained AA BCS with AA women completing primary treatment for breast cancer. Month 1 of the program consisted of weekly PN visits at the home of the BCS. Each week, the PN performed health teaching in one of the four domains of the QOL Model Applied to Cancer Survivors (Ferrell, et al., 1991). The PN aided the BCS in setting self-identified weekly goals such as social interactions, stress relief techniques, and making provider appointments, and then discussed barriers and challenges experienced in meeting each goal. Month 2 of the PN program consisted of weekly phone calls by the PN. These unstructured phone calls allowed the BCS an opportunity to voice any issues or concerns present. The PN was also available for other phone calls during both months of the study, as needed by the BCS. Table 1 details intervention components with targeted QOL outcomes and domains.

Peer Navigator Recruitment

Breast cancer experts in the community and the National Witness Project, a faith-based community group using survivors to increase cancer screening among AA women, provided information to AA BCS who were at least one year post treatment and could potentially be hired as PNs. Navigator selection involved an interview with the PI to determine appropriateness of the navigator "candidate". After interviewing with the PI, a PN was selected based upon predetermined criteria, which included being highly motivated, having cell-phone access, able to work with BCS, and willing to complete CITI training per protocol. Upon meeting criteria, one PN was hired as a temporary research assistant and worked with all four BCS throughout the 2-month navigation program. The PN was interviewed at the conclusion of the intervention for quality improvement/ process evaluation. Table 2 details the PN training and responsibilities.

Training Curriculum

A training manual and protocol were developed through communication with AA breast cancer survivorship experts, literature review, consultation with existing program coordinators, previous qualitative study results, and adapted from the Survivors In Spirit and NCI's Patient Navigation Training Programs (Freund et al., 2008; Thompson et al., 2009). Content included information on breast cancer survivorship, health disparities, barriers to care in AA women, cultural considerations, the role of a PN, and problem-solving and advocacy skills. In addition, the curriculum included content on establishing effective interpersonal skills such as understanding the language and cultural beliefs of patients, communicating with the interdisciplinary team and establishing trust with the BCS (Nguyen, Tran, Kagawa-Singer, & Foo, 2011), as well as HIPAA privacy considerations. Effective communication with the interdisciplinary healthcare team has been previously cited as a challenge of PN program implementation, and problem-solving strategies training addressed potential interactions with medical teams (Thompson, et al., 2009). Knowledge and skills were assessed in the PN with a post-test survey and evaluation of role-playing exercises during training sessions.

BCS Sample

BCS participants were AA women in the Buffalo, NY area, with a diagnosis of Stages I, II, or III breast cancer, ages 18-75, who completed treatment within a month prior to study enrollment, had no self-reported history of anxiety, depression, or mental health diagnosis, or reported substance abuse on interview, and were English speaking. Subjects were excluded if they had metastatic disease, recurrent breast cancer, or other primary cancers.

BCS Recruitment

A purposeful sampling technique was employed, targeting AA women who were completing active treatment (chemotherapy, radiation or surgery) at the time of enrollment in navigation. The PI approached support group and community leaders in Buffalo, NY, explained the study and requested they provide potential participants with information about the study. Brief written explanations of the study were provided, with two options to learn more about the study: 1) Information flyer with instructions to call the PI to gain more information; or 2) Agree to be contacted by PI by e-mail or phone. Additionally, flyers with study team contact information were posted in local settings likely frequented by AA BCS. The PI screened interested participants for eligibility. Participants were compensated with local store gift cards at the completion of the 2-month PN intervention.

Study variables

Table 3 details the measures used to evaluate outcomes and feasibility of this program. The PI collected all of the baseline and post intervention measures.

Feasibility Outcomes

The feasibility of the PN intervention was measured using the number of potential PNs approached to have one participate in training and complete the navigation program, expressed ability of PN to take more than two BCS in future, and retention of PN in the 2-month program. BCS feasibility measures included number of potential BCSs approached to have 4 participate and complete the navigation program, and number retained for the 2-month program. In addition, the cost of the PN program was evaluated as number of PI hours, cost of total PN hours, resources and materials.

Instruments

The main outcome variables for this study were guided by Ferrell and colleagues' (1991) QOL in Cancer Survivors Model which was created and validated through studies involving bone marrow transplant survivors and BCS. In this model, physical well-being includes intermediate and late effects associated with cancer treatments. Psychological well-being includes emotional issues, anxiety, and mental distress post treatment. Social well-being considers the financial implications of going through treatment, availability of follow-up care, and the evolution of roles and relationships after cancer treatment. Finally, spiritual well-being includes religiosity, power, and self-transcendence. All four domains are hypothesized to have a specific and important effect on the QOL of the cancer survivor.

Quality of Life-Breast Cancer.

The Quality of Life-Breast Cancer instrument (QOL-BC) was created for long-term cancer survivors and has since been adapted for all survivors to measure health-related quality of life in physical, emotional and social dimensions (Ferrell, et al., 1995). The QOL-BC has demonstrated adequate internal consistency reliability with Cronbach's alpha estimates greater than 0.70 for subscales and total scale. QOL-BC mean scores can range from 0-10, with higher mean scores indicative of better QOL.

General Symptom Distress Scale.

The General Symptom Distress Scale (GSDS) is a brief, 4-item instrument assessing ranking of specific symptoms, overall symptom distress, and management of symptoms (Badger, Segrin, & Meek, 2011). This instrument was validated with cancer patients and demonstrated satisfactory internal consistency and test-retest reliability, and good construct validity and predictive validity. GSDS summative scores can range from 13-65, with higher summative scores indicating higher levels of distress.

Preparedness for Recovery Scale.

The Preparedness for Recovery Scale (PRS) assesses perceived preparedness for "re-entry" after acute illness or stress (Stanton, et al., 2005), and includes two items: "Overall, I feel very well-prepared for what to expect during my recovery", and "Overall, I feel the medical team has done a great deal to prepare me for what to expect during my recovery from breast cancer treatment" (p. 6011). Responses are rated on a Likert-type scale, and the items show high correlation (n=415; r=0.84; P= .0001). Mean scores for the PRS can range from 0-4, with a higher score indicating greater preparedness for recovery.

Perspectives of Support from God Scale (PGS).

The PGS quantifies spiritual support believed to come from God (Hamilton, et al., 2010), in contrast to other spiritual instruments that assess spiritual support believed to come from religion, including the community, clergy, or healthcare providers. It was created specifically for AA cancer survivors, and was first cognitively pre-tested in a small sample of AA cancer survivors, utilizing the "think aloud" method to determine how respondents understood the items and their responses. The PGS is divided into two subscales, the Support from God (PSG-SFG) and God's Purpose for Me (PSG-GPM) (Hamilton, et al., 2010). The PSG-SFG reflects the perspective of a direct connectedness to God, with an emphasis on looking beyond self and less on illness to the powerfulness of God. Summative scores for the PSG-SFG can range from 0-36. The PSG-GPM reflects strategies used to cope with the earthly realities of illness, with an emphasis on how God is working through the illness to build character within one's self. Summative scores for PSG-GPM can range from 0-24. Test-retest assessment showed Pearson's correlations of 0.94 for the Support from God subscale, and 0.88 for the God's Purpose for Me subscale. Results also indicated that the PGS had an inter-item correlation greater than 0.30, and Cronbach's alpha for reliability for both the Support from God Factor and God's Purpose for Me Factor were greater than 0.70, indicating reliability.

Additional Measures

Follow-up appointments.

Follow-up appointments with health care providers (primary care and oncologists) were self-reported based on primary-care and oncology appointments made and attended by BCS during the follow-up period. Follow-up appointments by BCS were categorized as scheduled (yes or no) and completed (yes or no).

Social Network Mapping.

Social isolation was self-reported by the BCS, who was instructed to draw a social network map, indicating all contacts considered by the BCS to be a source of support. The number of each BCS's social contacts was reported and compared pre- and post-navigation intervention.

Qualitative Data Collection

A PN interview was conducted after the completion of the 2-month intervention, utilizing a semi-structured interview guide (appendix). The interview explored the PN's perceptions concerning the acceptability of the intervention, emotional effects of participating in the program, and expressed ability of PN to navigate more than four BCS at the same time in the future.

Interviews were also conducted with all BCS after completion of the intervention to explore acceptability of the PN program and suggestions for improvement of the intervention.

Data Analysis

Quantitative Analysis

Due to the nature of a proof of concept study and resulting small sample sizes, power analyses were not appropriate (Leon, Davis, & Kraemer, 2011), and effect sizes (pre-to-post changes in scores) were not assessed. Data were reported as medians, and ranges for the BCS Preparedness for Recovery, PGS, General Symptom Distress, and QOL-BC at baseline (Pre) and post PN (Post) program.

Qualitative Analysis

Open-ended interviews with BCS were recorded and transcribed verbatim by a professional transcriptionist, using a secure HIPAA compliant file transfer. Utilizing descriptive iterative analysis, a content analysis was performed using NVivo 10.0 software (QSR International, Pty, Doncaster, Australia), as described by Mayring (Mayring, 2000) through an inductive and deductive approach. Mayring's inductive analysis is driven by constant comparison, where categories are tentative and delineate the aspects of the textual material. The deductive analysis, guided by the theoretical frameworks of the QOL Applied to Cancer Survivors (Ferrell, et al., 1991), and the DSIT (Nowak, et al., 1990), works with the prior formulated, theoretical derived components of the analysis. The categories were then revised and reduced to main categories, and then checked for their reliability. An experienced qualitative mentor reviewed transcripts and codes separately, in order to ensure agreement of descriptions and reach consensus of ideas.

Merging Qualitative and Quantitative Data

The PI combined quantitative and qualitative data after separate initial analysis to best understand Peer Navigator (PN) experiences with training and participation in the navigation program. Data were merged in a comparative matrix, and both sets of results were compared and analyzed (J. W. Creswell, et al., 2011). This allowed integration of both data sources to understand the feasibility and acceptability of the PN intervention. Complementary data served to triangulate findings where appropriate (Ostlund, Kidd, Wengstrom, & Rowa-Dewar, 2011).

Results

Quantitative Findings

BCS Characteristics

The PN intervention was carried out with 4 survivors, ages ranging from 40-59, who had been diagnosed with stage II (n=2) and stage III (n=2) breast cancer. Two BCS had no high school degrees, and two BCS had a high school degree. The income ranges represented were less than $10,000 (n=2), and $10,000-$19,000 (n=2).

Feasibility of Recruitment

The PI had contact with four eligible potential navigators, with one (25%) agreeing to participate as a PN and completing necessary human resources paperwork. Those who didn't agree to participate cited time and limited knowledge on breast cancer as reasons for not participating. It is important to note, as well, that because of the extensive background check needed to secure the PN as a temporary employee, there was a delay of two months to start the intervention. Eight potential BCS participants were approached to identify four eligible BCS participants (50%). Reasons for exclusion of non-eligible participants included being on active treatment, having a recent recurrence of breast cancer, and having a Stage IV breast cancer diagnosis.

Feasibility of Retention

One PN was enrolled who completed all trainings and attended all required meetings for implementation of the navigation program. This PN navigated four BCS, and expressed a perceived inability to take on more than four BCS at a given time in future program implementation. All of the four BCS who were originally enrolled in the PN program completed the program after two months, for a 100% completion rate. No adverse events occurred during the implementation of this program.

The PN completed a total of 64 hours of program activities including training (8 hrs) and implementation of the PN program (56 hrs), and was compensated for the training ($160) and navigation ($1120) components of the program, respectively. The entire program cost, including compensation of BCS, was $1600 over a four-month period.

Preliminary Comparison of Quantitative Outcomes

Seventy one percent of all appointments were made and kept. Fourteen percent of all appointments were scheduled but not completed, and an additional fourteen percent of appointments were not scheduled at all. Barriers to attending follow-up appointments included lack of childcare and transportation. The PN did reach out to the resource center at the BCS's cancer center to attempt to address these issues.

Table 4 provides study outcome data; due to the small sample size in this proof-of-concept study, data are reported as median and ranges for all measures. Although it is not possible to make inferences due to the small sample size and potential for variability, we observed an increase in the median social contacts from 1.5 pre PN program to 3.0 contacts post PN program and increases in the median scores for the PRS and the two PRS subscales (PSG-SFG and PSG-GPM) from pre to post, while the median general symptom distress scores of the

GSDS decreased from 42.0 to 21.0. The only variable that showed an unexpected change was the QOL-BC, with a decrease in the median score from 6.03 to 5.55 pre to post.

Qualitative Findings

BCS experiences.

Six main themes were identified in the analysis of the BCS qualitative interviews in two areas including 1) direct benefits derived from program participation (*Learning to Ask the Right Questions, Start Living Life Again, Shifting My Perspective, Wanting to Give Back)*, and 2) mechanisms of program benefit (*Home Visits are Powerful, and 'We Both Have a Journey': Support from Someone Who Has Been There*). Table 5 depicts excerpts that illustrate each of the themes, taken from BCS interviews.

Learning to ask the right questions.

All of the BCS indicated that the PN encouraged them to be informed at their follow-up appointments with both primary care providers and oncologists. They had previously felt uninformed during their appointments, often leaving with unanswered questions. Based on the urging of the PN, however, they described reading educational materials from the American Cancer Society that were provided before their appointments and could come prepared with questions, and be active in their follow-up care.

Start living life again.

All of the BCS indicated some level of self-perceived anxiety and/or depression as they entered the program. Most (3/4) described feeling angry about their diagnosis and having subsequent difficulties going through treatment and now survivorship. After the completion of the PN program, however, all four of the BCS felt more prepared to start "living life" again.

They indicated they were more willing to wear "regular" clothes (described as more form-fitting), attend social events at their respective churches, and start to adjust to their new sense of normality in life.

Shifting my perspective.

Most of the BCS (3/4) indicated at the beginning of the PN program that they felt alone in their journey after cessation of treatment, confirming some level of isolation. There was a "Why me?" perspective that was shared among the BCS participants. Through conversations with the PN, who had endured significant complications with surgery and treatment, the BCS began to shift their perspectives and recognized that they were not alone, realizing that their battle was no greater or lesser than another BCS.

Wanting to give back.

Based on the benefits they received from the PN, all of the BCS stated that they would like to get to the point where they would also be willing to share their own story with others. One BCS felt empowered to look into speaking about her diagnosis and treatment experiences to others, in hopes of encouraging their own screening efforts. The shift in perspective also contributed to this want and need to give back to others. Many BCS stated that now that they knew their journey could be used for good, they were more willing to talk about it.

Home visits are powerful.

When asked about the organization of the program, 3 out of 4 BCS expressed a need for more home visits. BCS stated that they felt decreased isolation from sitting with the PN, and from the face-to-face conversations, versus phone calls that occurred in month 2. In addition, all

BCS indicated they looked forward to seeing the PN, and that having her in their home made her feel like "family".

'We both have a journey': Support from someone who has been there.

All BCS expressed a great deal of support from the PN because they shared a common journey. Per the BCS, three of four indicated they had at least one source of social support, though the level of support from their own family and friends was not comparable to the support from the PN. The fact that they were both AA breast cancer survivors immediately bonded them. All BCS wanted to hear from someone who had been through and "successfully" survived breast cancer and treatment, and had been through what they had been through. Although all of the BCS and PN treatment trajectories differed, there was a distinct commonality among them because they were all breast cancer survivors.

PN Experiences

PN training.

The PN indicated that the training sessions were helpful to understand what to expect when meeting with the BCS. Initially, the PN expressed anxiety speaking with the women, because she claimed that she did not have prior medical knowledge, and *"was afraid that she wouldn't know how to answer their questions"*. The training session allowed her to have greater insight into what she did have to offer, stating that *"it allowed me to assist the ladies in a more productive way. I knew what my limits was, and what my limits wasn't"*. The PN expressed that role-playing sessions were extremely beneficial to demonstrate how to handle difficult situations.

PN program implementation.

The PN felt that she was a source of support for the BCS, both in dealing with their cancer survival, and the stressors that exist in other aspects of life. There was a mutual relationship and bond that formed quickly, per the PN, because they had both endured breast cancer and could share in a common journey.

> *We talked about everything-not just cancer, but their day-to-day life. Because that has a lot to do with cancer-you know, stress. So I just tried to talk to them about every aspect of their lives...I wished I had someone who had gone through it, because so much is going through your mind. Like I said, I had the family support, but talking to someone who has walked that mile is different.*

The PN encouraged all BCS participants to ask questions and continue with routine preventive screening. She stressed the importance of follow-up care, colorectal cancer screening, as well as being informed at appointments so that the BCS knew the appropriate questions to ask. The PN also gave each BCS a small notebook to keep track of medications, appointments, and questions for upcoming appointments.

> *I tried to stress with them, is make sure they stay on top of their appointments, and while they're in their appointments with the doctor, say, if there is something they do not understand. They have all rights to ask questions, and do not stop asking questions until they fully understand.*

There were also benefits that the PN perceived she received as a result of participating in this program. She felt that she was here as a survivor, put here by God, to be an example and model for other women enduring this struggle. The PN stated that she felt strong and confident as a "warrior" that had survived cancer, and she wanted to inspire others to live their life in a similar fashion. By helping the BCS, she stated, she was also helping herself.

The PN suggested changes to improve format of the PN program. She felt that an extended length of the overall program would be helpful for the BCS. Some BCS participants took two weeks or more to really open up to the PN, and a longer program could allow for richer, more meaningful relationships, per the PN. In addition, the PN felt that two hours were needed for each in-person meeting, to allow for discussion and reflection of goals and BCS experiences.

Discussion

Feasibility of the Intervention

This is the first known published study of its kind that evaluated the implementation of a peer navigation intervention in African American breast cancer survivors. This study was informed by our prior qualitative study describing AA BC survivors' quality-of-life after treatment leading to the development and preliminary testing of a peer navigation survivorship program (Mollica & Nemeth, 2014). Results indicate that the intervention is feasible in terms of cost, required time commitments, and acceptability by both PN and BCS. It was somewhat challenging to find the appropriate person to fill the role of the PN. Some of the potential PNs had issues related to previous work commitments and inability to commit to the responsibilities, and this precluded them from the position. The PI did note extensive lag time required for the PN to complete the background check and employment process, both on the part of the PN and the employer system, which hindered the progress of the program. In addition, the PN and BCS both indicated that more home visits and an extended length of the program itself might be beneficial.

Outcomes Assessment

While sample size limits the inferences that can be made in terms of program outcomes, and this was not the primary aim of the study, we examined the median scores at baseline and post intervention in quality of life outcomes. An increase was observed in the median scores for participants' ratings of preparedness for re-entry into survivorship, as well as their reports concerning having a closer relationship with God post intervention. In addition, a decrease in median general symptom distress scores was observed. While it is not possible to attribute these outcomes to the PN intervention, these results do indicate that the distress perceived by the BCS from the symptoms may decrease, which would be a favorable outcome. The QOL-BC did show an unexpected change with a small decrease in the median score of quality of life. It is possible that there may have initially been a false inflation of QOL scores at the pre-intervention data collection. During the intervention the PN worked extensively with the BCS on being honest about symptoms, distress, anxieties, and other issues, and this could have had an effect on the post-intervention QOL decrease, which may have more accurately represented the true QOL for the BCS. Overall, however, these results do support further testing of the intervention.

Future Research

The results from this POC study support the feasibility of a PN intervention in AA BCS and demonstrate largely favorable changes in outcomes related to QOL in the BCS. The study results also provide several areas for further research. Building on findings from this study, next steps should include alterations to the PN intervention to lengthen the program (4-6 months) and increase the number and duration of home visits. Future studies will include a subsequent pilot study with an updated iteration of the intervention, and eventual adequately powered randomized controlled trials investigating efficacy of the PN intervention.

Future research should also focus on examining the maximum number of BCS that can be adequately supported by a PN. While the PN in this study indicated that four BCS was appropriate and feasible, it is possible that two BCS to one PN may allow for more quality interaction and time spent. In addition, future iterations of the navigation program will attempt to closely pair navigators with BCS who are similar in stage of diagnosis and SES, based on the likelihood that effective communication will occur when individuals identify with a common goal or condition (Nowak, et al., 1990).

Design Strengths and Limitations

This mixed-methods approach was carefully constructed to explore feasibility issues related to peer navigation training and to inform a future pilot study of the intervention. Combining both deductive and inductive approaches in convergent parallel design strengthens the study design and allows for greater insight into peer navigation training (Creswell & Clark, 2011). While we recognize that involvement of the PI in all parts of the study may lead to bias, the PI conducted all data collection, entry, qualitative interviews, and analysis to increase standardization of the study and decrease the potential for variance (Waltz, Strickland, & Lenz, 2010).

The small sample size limited the inferences that could be made from the findings of this proof-of-concept study. In addition, several potential moderating and mediating factors associated with quality of life outcomes could not be considered in this study but should be examined in future larger studies. Due to the sample size of this proof-of-concept study, the PI was unable to closely pair navigators with BCS who were similar in stage of diagnosis and SES, although it is likely that enhanced communication could occur when individuals identify with a common goal or condition. In addition, interactions among interdisciplinary team members were not examined in the study.

When measuring a latent variable such as QOL, preparedness for recovery, symptom distress, or perspectives of support from God, participants could have inflated their self-assessment of these constructs, based on knowledge of the purpose of study and social acceptability biases (Moorman & Podsakof, 1992). The PI explained the purpose of accurate answers by all respondents, and discouraged discussion of their participation in this study with other potential participants. There is potential for random and systematic error within this study design. Utilizing self-assessment instruments that have demonstrated internal reliability (Badger, et al., 2011; Ferrell, et al., 1995; Hamilton, et al., 2010; Stanton, et al., 2005), limits random error; however it is expected that there will be slight errors in any measurement. None of the instruments used in this study had been previously tested in AA breast cancer survivors, with the exception of the PSG (Hamilton, et al., 2010).

Conclusions

This mixed-method, POC study evaluated the feasibility, acceptability, and the direction of changes in outcomes of a PN intervention among AA BCS. Results indicate that the intervention is feasible and acceptable to both PN and BCS. Several areas for future research are noted, but results support current literature that indicates that AA women who have survived breast cancer can be an important source of support, knowledge, and motivation for those completing breast cancer treatment.

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Table 1. Intervention components and targeted outcomes

Intervention component (or Curriculum Module)	Intervention Content	Targeted Outcome/Instrument
Social Concerns	Social support needs after treatment Interactions with health care provider Resources available	Social network mapping (SNM)
Physical Concerns	Common physical complaints after treatment Late vs long-term side effects Breast Cancer recurrence Resources available Health Promotion Follow-up care Questions to ask provider	Follow-up care with provider General symptom distress (GSDS) (Badger, et al., 2011)
Emotional Concerns	Common emotional symptoms after treatment cessation Importance of follow-up care for emotional concerns Resources available	Quality of life (QOL-BC) (Ferrell, et al., 1995), Preparedness for recovery (PRS) (Stanton, et al., 2005)
Existential/Spiritual Concerns	Importance of spirituality and self-efficacy in recovery Return to normal/identity crisis/uncertainty issues Resources available	Perspectives of support from God (PSG) (Hamilton, et al., 2010)

GSDS: Symptom Distress Scale
PRS: Preparedness for Re-Entry Scale
PSG: Perspectives of Support from God Scale
QOL-BC: Quality of Life-Breast Cancer
SNM: Social Network Mapping

Table 2. PN training and responsibilities

	Time required/Component	Content
PI/PN training	1 hour screening/informational session Length/CITI training session 2 hours/ training sessions x2	Role play Communication Open discussion
PN/BCS program	1 to 2 hours/weekly meetings for month 1 2 hours per month/Weekly reinforcement phone calls during month 2	Establish communication and goals of program Health teaching, expected survivorship challenges Assess and provide support Interview participation at end of 2-month intervention for process evaluation

Table 3. Intervention component and targeted outcome

Stakeholders	Feasibility Outcomes	Preliminary Evaluation Outcomes
Peer Navigators	• Number of potential PNs approached to have 2 participate in training and complete the navigation program • Ability of PNs to assess preliminary evaluation outcomes • Acceptability, interactions with interdisciplinary team members-qualitative interview • Expressed ability of PN to take more than two BCS in future-qualitative interview • Retention in program with BCS for 2 months	• Emotional and physical effects of PN post program-qualitative interview • Satisfaction with participation-qualitative interview
Breast Cancer Survivors	• Number of potential BCSs approached to	• QOL-BC-baseline and post intervention

	have 4 participate and complete the navigation program • Retention in program with PN for 2 months • Expressed acceptability by BCS-qualitative interview	• Preparedness for Recovery-baseline and post intervention • Follow-up appointment-% of BCSs who visit primary care provider (PCP) within 2 months post treatment • General Symptom Distress Scale-baseline and post intervention • Social network mapping-baseline and post intervention • PGS-baseline and post intervention
System/community	• Cost of PN program (number of PI hours, cost of total PN hours, resources and materials)	

Table 4. Comparison of quantitative outcomes at baseline and post PN program (median and range)

Instrument	Pre	Post
GSDS	42.0 (31.0-51.0)	21 (7.0-27.0)
QOL-BC	6.03 (5.16-6.87)	5.55 (4.4-5.82)
PRS total	1.75 (1.5-4.0)	2.75 (2.0-3.5)
PSG-SFG	29.0 (18.0-36.0)	33.0 (29.0-35.0)
PSG-GPM	18.0 (15.0-24.0)	23.0 (21.0-24.0)
SNM	1.5 (0.0-3.0)	3.0 (2.0-5.0)

GSDS: Symptom Distress Scale (ranges from 13-65; higher summative score indicates higher levels of distress)
QOL-BC: Quality of Life-Breast Cancer (0-10; higher mean score indicates higher quality of life)
PRS: Preparedness for Re-Entry Scale (0-4; higher mean score indicates greater preparedness)
PSG: Perspectives of Support from God Scale (Divided into two subscales: Support from God (PSG-SFG: Summative scores can range from 0-36; God's Purpose for Me (PSG-GPM): Summative scores can range from 0-24.
SNM: Social Network Mapping

Table 5. Excerpts illustrating themes-BCS Interviews

LEARNING TO ASK THE RIGHT QUESTIONS
✓ *It helped me out a lot. She gave me a lot of knowledge, and stuff like that. And anything I don't understand, she gave me, you know, she said, just ask questions if I don't understand. Ask questions, don't just sit back and, oh, ok. So now she's got me asking questions, especially when it comes to my health.*
✓ *She told me to ask questions. Of every person that is taking my blood or doing a test, or the doctors and nurses. She told me that I have to ask questions when I don't understand. And before, I really would just do what they told me to do, without knowing why. They said to take a medicine, I took it, and they said, you know, to go here for this test, and I did it. But I never asked why. I just went, and was angry when I didn't understand what I was doing.*
✓ *Now I ask questions all the time. I make extra appointments if I don't feel right. I never wanted to ask for help.*
START LIVING LIFE AGAIN
✓ *It helped me stop being so depressed. Stop being so down. She taught me, uh, to start living. To be myself, you know, to start back dressing, and everything else. Stop laying around and feeling sorry for myself and stuff like that, you know, cause there's no purpose for that. You know, so that's what I'm starting to do, I'm starting to live.*
✓ *She was telling me that there's other things out there that we can do, you know, support groups and all that, and, um, ever since then, you know, I've been looking forward.*
✓ *I, just like last week or so, I had bought these pajamas, and it comes down to here (points to thighs), and I said, I'm gonna put these on. So my girl, she said, where'd you get that? And I said, I done had this, and she said, you look real nice in it.*
SHIFTING MY PERSPECTIVE
✓ *The one thing that I'm taking away, you know, is knowing that I'm not the only one. That there's people that was worse than I am. And it's making me realize to stop feeling sorry for myself, you know.*
✓ *And every woman went through their battle, but every woman was none less than the other. Because what I went through is any less than anyone else, to me, you went through your battle, and you have mental scars, I have physical. One is no less than the other.*
✓ *I was pretty depressed before. I felt like what I was going through was terrible, and I said, why me? And then I talked to her about it, and she said that she never asked herself that question. She said that she said, why not me? And she's right, you know? It*

might as well have been me than anyone else, and then things changed. It's like the light bulb happened. And I didn't feel so terrible anymore.

WANTING TO GIVE BACK

- ✓ *And then wanting to help others and stuff, too. She makes me want to go out and speak, you know, and stuff. She got me feeling like I could go out and do talks and stuff now, to people now.*
- ✓ *How blessed I feel now that I've heard her story and can start to share mine with others.*
- ✓ *I'm really looking forward to giving back, now that I know my journey isn't as bad as it could have been. I want to give to other women who are going through this.*

HOME VISITS ARE POWERFUL

- ✓ *I could have did it for, like, two days out of a week. Yeah, but I would have preferred all home visits instead of the phone calls.*
- ✓ *I would do all home visits. I really got a lot out of sitting with her, and we talked and talked, and I really found that to be really helpful. The phone calls were ok, but the home visits really helped because I looked forward to them. Man-we had some really great times.*

'WE BOTH HAVE A JOURNEY': SUPPORT FROM SOMEONE WHO HA S BEEN THERE

- ✓ *Wish I would have met her when I was diagnosed. Somebody who's been through it. Or even she went through it, and I would have known what to expect. And then, she's a good inspiration as well. I would have wished I would have met somebody like her a long time ago.*
- ✓ *To tell you the truth, I didn't think I needed it. I was like, please, I don't need this. I got my family's support. But it aint NOTHING (emphasis) like support, too, of another woman who has been through the same thing. I can get the support of my family all day long, but they can't give me something that I want to hear from someone who has been through what I've been through. You need to hear that, you know what, I hadn't been through what these women been through. That would give me more courage, and it would make me feel more better.*
- ✓ *We need to have someone who has gone through it. My boyfriend doesn't understand, and my children don't understand, even though they are supportive. I needed to hear from another woman who had been through it. That's why we are so close now-we both have a journey.*
- ✓ *She told me about all of the things I could expect now that I was finished with treatment. And I really felt like she was giving me so much information so that I could be prepared. That's the thing. I felt so good about it, because before, they just say,*

congratulations, you're done with chemo. And now, I really knew that it was ok that I wasn't feeling great, that I wasn't happy all the time. I thought something was wrong with me before, but she told me that it's all totally normal. Man. It made me feel so much better.
✓ *Yeah, cause some people might be like me at first, all shy, and quiet, and didn't really want to say nothing. It took time, to break me out like that (PN nods her head). She broke me out of my shell.*

CONCLUSION

This dissertation consists of three manuscripts; (1) an integrative review and synthesis of factors contributing to quality of life (QOL) in African American (AA) breast cancer survivorship, using the QOL Model by Ferrell and colleagues (1991), (2) a qualitative grounded theory study exploring the experience and coping sources of AA women as they complete treatment for breast cancer and transition into survivorship, and (3) a mixed-methods proof-of-concept study exploring the feasibility, acceptability, and the direction of changes in outcomes of a peer navigation (PN) intervention for AA breast cancer survivors (BCS). The information presented within this dissertation creates the foundation for future, larger studies implementing the peer navigation intervention with AA BCS to increase adherence to guideline-directed follow-up care and improve quality of life outcomes.

The integrative review of factors contributing to QOL in AA BCS included a total of 19 articles that met the relevance criteria (Mollica, Nemeth, Newman & Mueller, 2014). The review showed a lack of research exploring factors affecting spiritual and physical well-being domains, demonstrating a need for future research. In addition, the lack of community-based studies signaled a need for community engagement in the research process, starting with the spiritual community. Researchers must focus on factors from a multi-domain perspective to truly understand the varied dimensions influencing QOL of AA breast cancer survivors. The peer navigation intervention closely follows this multi-domain perspective in design and evaluation.

The subsequent qualitative grounded theory study aimed to explore and describe the experiences and coping sources of AA women as they complete treatment for breast cancer and transition into survivorship. Four major themes emerged from analysis of the interviews:

Perseverance through struggles supported through reliance on faith, persistent physical issues, anticipatory guidance needed after treatment, and emotional needs as important as physical (Mollica & Nemeth, 2014). Findings suggested that AA women prefer guidance and support from another AA woman who has survived breast cancer, and that other support needs must be culturally tailored to the survivor. The results supported the use of the peer navigator to increase effective communication and follow-up care, as predicted by the Dynamic Social Impact Theory (Nowak, et al., 1990).

The Peer Navigation proof-of-concept study aimed to explore the feasibility, acceptability, and the direction of changes in outcomes of a peer navigation intervention for AA breast cancer survivors. Results indicated that the PN program was feasible in terms of cost, required time commitments, and acceptability by both PN and BCS. Although it was not possible to make inferences of effectiveness due to the limited sample size, preliminary results showed favorable changes in the PSG, PRS, and GRS (Badger, et al., 2011; Hamilton, et al., 2010; Stanton, et al., 2005). Only the QOL-BC score decreased slightly from pre to post intervention, potentially due to inflation of self-perceived QOL prior to participating in this intervention (Ferrell, et al., 1995).

Implications

The results of this dissertation point to several implications for clinical practice for the care of African Americans completing treatment for breast cancer. Both the integrative review and qualitative study (Mollica & Nemeth, 2014; Mollica, Nemeth, Newman, & Mueller, 2014) substantiate the need for increased support and coordination of care post cessation of treatment. The use of survivorship care plans (SCPs) in combination with peer support may improve adherence to follow-up care and quality of life outcomes after treatment. Providers should be aware of cultural considerations in this population and future research should investigate a tailored approach to SCPs to address the underlying behavioral, psychosocial and clinical risks for poor outcomes experienced by AA women (Ashing-Giwa, et al., 2013).

Findings from the current work also lead to implications in policy and advocacy areas. As noted, there are continued significant disparities in behavioral, psychosocial, and physical outcomes according to race/ethnicity (Agency for Healthcare Research and Quality, 2012). African American cancer survivors have a higher risk of late diagnosis of recurrence and second primary cancers, and delays in follow-up and continuity of care (Ademuyiwa, et al., 2011). While recent policies aim to increase cancer screening in underserved minority population, the results of this dissertation also suggest the need for legislation that promotes and prioritizes continuing survivorship care for AA women as well. The National Cancer Survivor Resource Center, funded by the Centers for Disease Control and Prevention (CDC), conducted a workgroup to discuss recommendations for key policy initiatives (2011). The preliminary results of this dissertation work support their call for policies focusing on barriers to meeting surveillance guidelines post treatment, employment after cancer, and coordination of care. Experts, including the American Society of Clinical Oncology, also cite recommendations to promote policy change that ensures underserved cancer survivors have appropriate access to health care services, including adequate reimbursement for counseling, interventions, and survivorship support (Grunfeld, Earle, & Stovall, 2011; McCabe et al., 2013).

Future Research

There are several areas for future research based on this dissertation work. It is clear from the integrative review and qualitative study that there is a significant need to develop and test interventions related to follow-up care post cancer treatment. Research also indicates that promoting spiritual well-being in this population can have protective effects on quality of life (Mollica & Newman, 2014). In addition, research focusing on survivors' social context (e.g., the needs of patients and their caregivers) points to the need for interventions supporting the caregiver as much as the survivor (Given, Sherwood, & Given, 2011; Sterba et al., 2014). Future research should also incorporate a level of community-engaged research to truly incorporate the survivor as stakeholder.

Future research is needed to further refine this PN program. It is necessary to explore the timing of in-person home visits, to compare weekly visits versus every other week. In addition, matching the PN closely to BCS in variables such as age, stage at diagnosis, treatments received, and other demographics, may increase the level of communications per the Dynamic Social Impact Theory (Nowak, et al., 1990). Exploration of the number of BCS that the PN can successfully support at the same time throughout the program, and the effect of a standardized training curriculum is also warranted. Research questions for further exploration of this intervention could also include:

- *What is the effect of a 4-month peer navigation intervention on African American women completing treatment for breast cancer, versus African American women completing treatment and receiving standard supportive materials, on follow-up care and quality of life?*

- *What is the experience of the PN's interactions with healthcare team members while supporting an African American breast cancer survivor?*

Summary

Research has demonstrated significant disparities among race/ethnicity for AA women after completion of primary treatment for breast cancer (Ademuyiwa, et al., 2011; Miles, 2005). The three manuscripts in this dissertation explore the existing body of research examining quality of life outcomes in AA BCS, the experience of the AA BCS post-primary treatment, as well as the feasibility of implementing a PN intervention aimed at increasing quality of life and attendance at follow-up care. The PN intervention is novel and innovative in that it is the only known community-based program that pairs trained AA women who have survived breast cancer with AA women completing primary treatment. This dissertation has provided preliminary evidence for the need for subsequent follow-up support after breast cancer treatment in this population and areas for further research on future PN intervention iterations. The entrance into survivorship presents a time of persistent stressors, and community-based interventions, such as the PN program, that capitalize on the protective factors inherent to AA BCS, can aid in providing the necessary support for this population.

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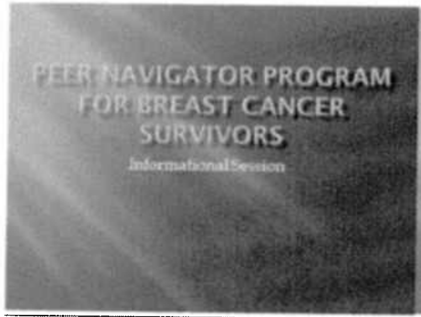
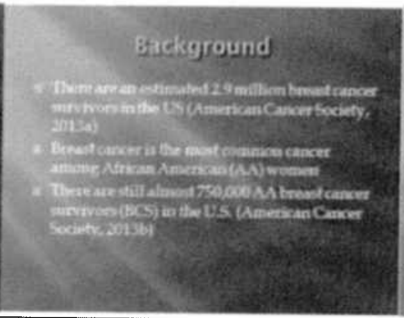
APPENDIX A. Training Materials used in Dissertation Study



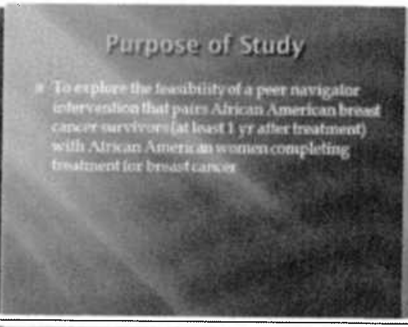
PEER NAVIGATOR PROGRAM FOR BREAST CANCER SURVIVORS

Informational Session



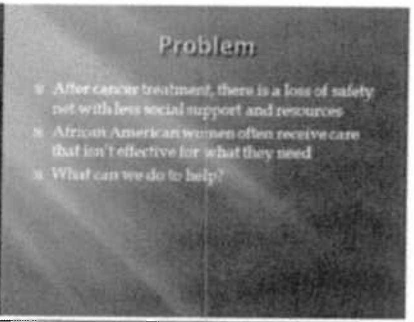
Background

- There are an estimated 2.9 million breast cancer survivors in the US (American Cancer Society, 2013a)
- Breast cancer is the most common cancer among African American (AA) women
- There are still almost 750,000 AA breast cancer survivors (BCS) in the U.S. (American Cancer Society, 2013b)



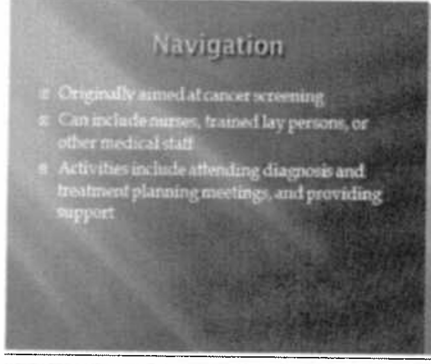
Purpose of Study

- To explore the feasibility of a peer navigator intervention that pairs African American breast cancer survivors (at least 1 yr after treatment) with African American women completing treatment for breast cancer



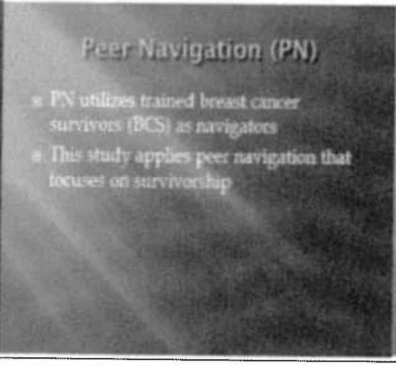
Problem

- After cancer treatment, there is a loss of safety net with less social support and resources
- African American women often receive care that isn't effective for what they need
- What can we do to help?



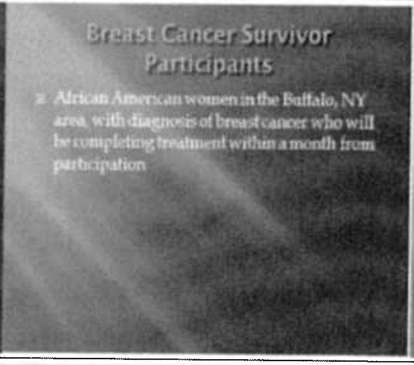
Navigation

- Originally aimed at cancer screening
- Can include nurses, trained lay persons, or other medical staff
- Activities include attending diagnosis and treatment planning meetings, and providing support



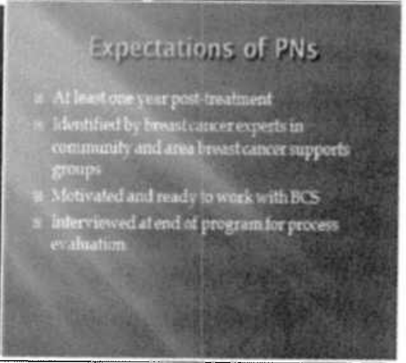
Peer Navigation (PN)

- PN utilizes trained breast cancer survivors (BCS) as navigators
- This study applies peer navigation that focuses on survivorship



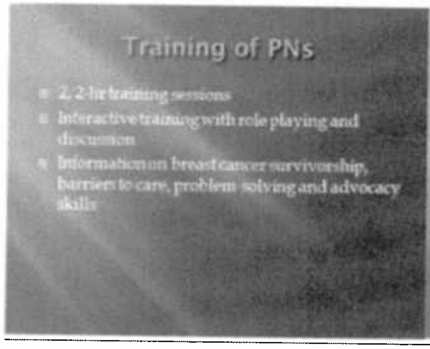
Breast Cancer Survivor Participants

- African American women in the Buffalo, NY area, with diagnosis of breast cancer who will be completing treatment within a month from participation



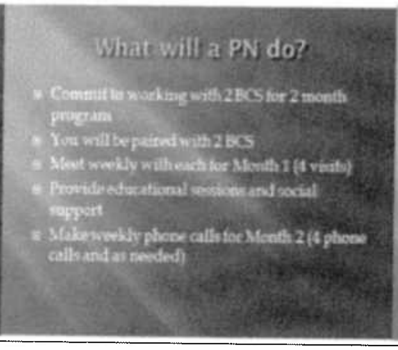
Expectations of PNs

- At least one year post-treatment
- Identified by breast cancer experts in community and area breast cancer supports groups
- Motivated and ready to work with BCS
- Interviewed at end of program for process evaluation



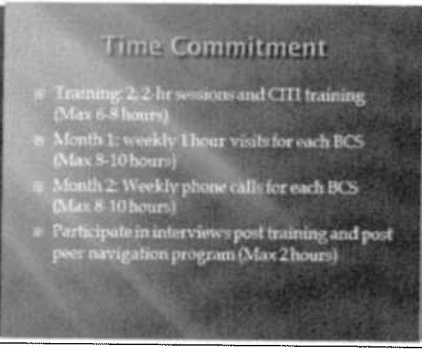
Training of PNs

- 2, 2-hr training sessions
- Interactive training with role playing and discussion
- Information on breast cancer survivorship, barriers to care, problem solving and advocacy skills



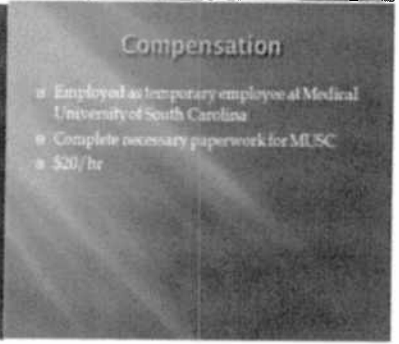
What will a PN do?

- Commit to working with 2 BCS for 2 month program
- You will be paired with 2 BCS
- Meet weekly with each for Month 1 (4 visits)
- Provide educational sessions and social support
- Make weekly phone calls for Month 2 (4 phone calls and as needed)



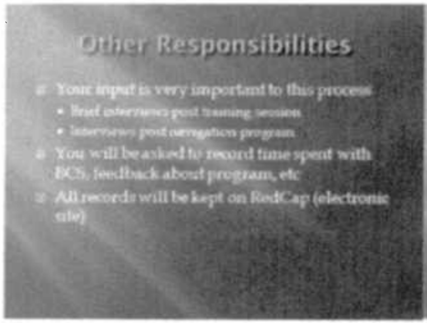
Time Commitment

- Training: 2, 2-hr sessions and CITI training (Max 6-8 hours)
- Month 1: weekly 1hour visits for each BCS (Max 8-10 hours)
- Month 2: Weekly phone calls for each BCS (Max 8-10 hours)
- Participate in interviews post training and post peer navigation program (Max 2 hours)



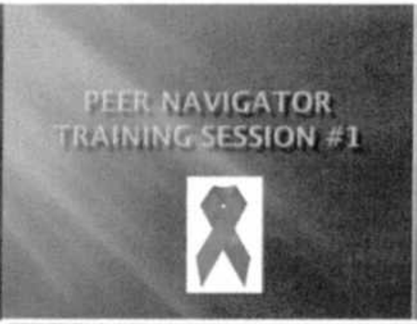
Compensation

- Employed as temporary employee at Medical University of South Carolina
- Complete necessary paperwork for MUSC
- $20/hr

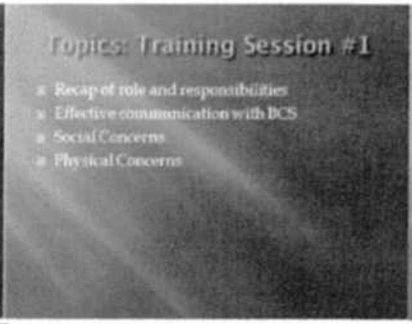


Other Responsibilities

- Your input is very important to this process
  - Brief interviews post training session
  - Interviews post navigation program
- You will be asked to record time spent with BCS, feedback about program, etc
- All records will be kept on RedCap (electronic site)

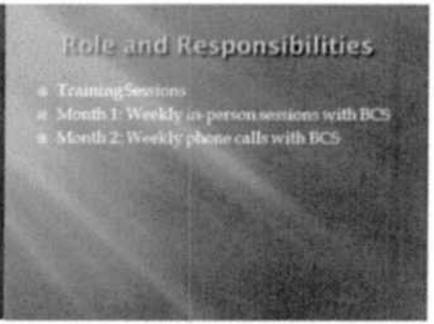


PEER NAVIGATOR TRAINING SESSION #1



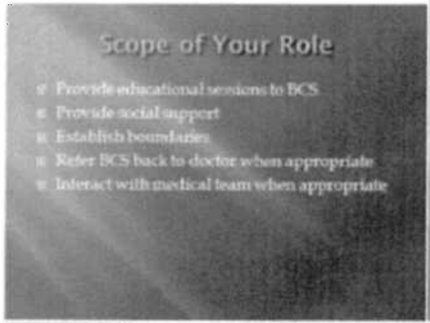
Topics: Training Session #1

- Recap of role and responsibilities
- Effective communication with BCS
- Social Concerns
- Physical Concerns



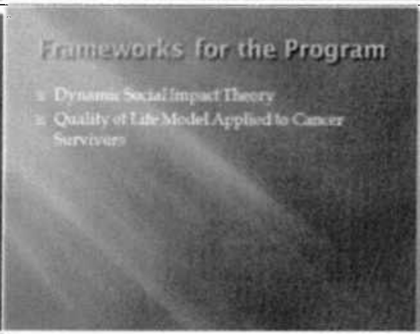
Role and Responsibilities

- Training Sessions
- Month 1: Weekly in-person sessions with BCS
- Month 2: Weekly phone calls with BCS



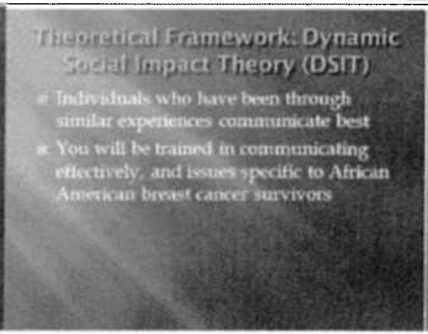
Scope of Your Role

- Provide educational sessions to BCS
- Provide social support
- Establish boundaries
- Refer BCS back to doctor when appropriate
- Interact with medical team when appropriate



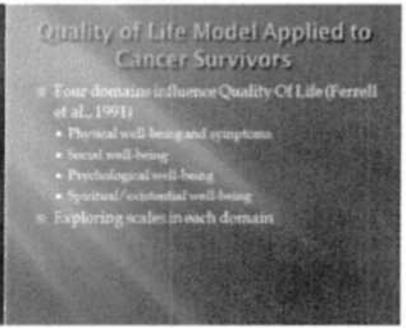
Frameworks for the Program

- Dynamic Social Impact Theory
- Quality of Life Model Applied to Cancer Survivors



Theoretical Framework: Dynamic Social Impact Theory (DSIT)

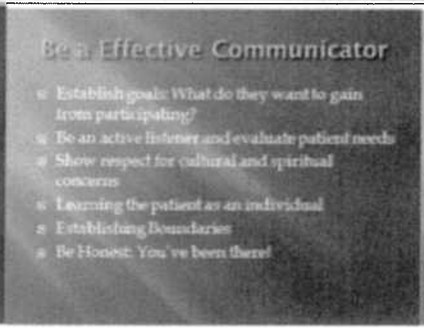
- Individuals who have been through similar experiences communicate best
- You will be trained in communicating effectively, and issues specific to African American breast cancer survivors



Quality of Life Model Applied to Cancer Survivors

- Four domains influence Quality Of Life (Ferrell et al., 1991)
  - Physical well-being and symptoms
  - Social well-being
  - Psychological well-being
  - Spiritual/existential well-being
- Exploring scales in each domain

Quality of Life Model

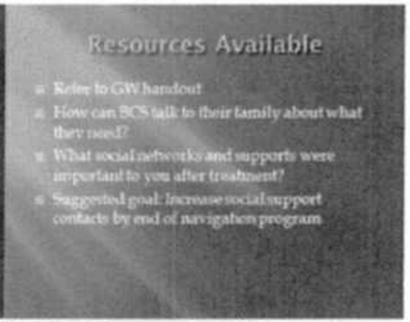


Be a Effective Communicator

- Establish goals: What do they want to gain from participating?
- Be an active listener and evaluate patient needs
- Show respect for cultural and spiritual concerns
- Learning the patient as an individual
- Establishing Boundaries
- Be Honest: You've been there!

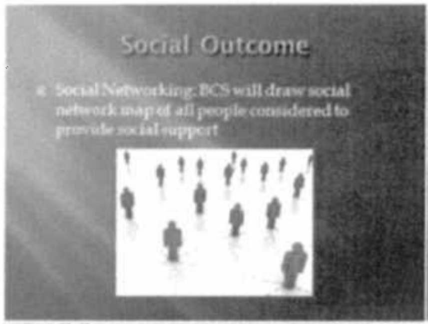
Social Concerns of African American BCS

- Pressure to appear strong
- Seeking safe sources of support
- Adjusting to the role of cancer survivor
- Feeling comfortable about the future
- Serving as role models in family and community
- Overcoming fear
- Financial concerns



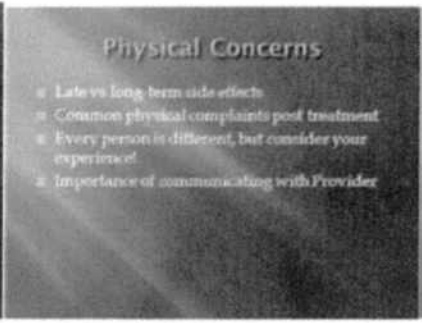
Resources Available

- Refer to GW handout
- How can BCS talk to their family about what they need?
- What social networks and supports were important to you after treatment?
- Suggested goal: Increase social support contacts by end of navigation program



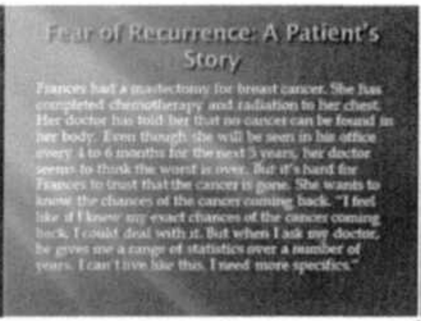
Social Outcome

- Social Networking: BCS will draw social network map of all people considered to provide social support



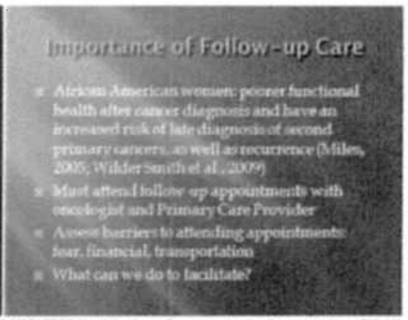
Physical Concerns

- Late vs long-term side effects
- Common physical complaints post treatment
- Every person is different, but consider your experience!
- Importance of communicating with Provider



Fear of Recurrence: A Patient's Story

Frances had a mastectomy for breast cancer. She has completed chemotherapy and radiation to her chest. Her doctor has told her that no cancer can be found in her body. Even though she will be seen in his office every 4 to 6 months for the next 5 years, her doctor seems to think the worst is over. But it's hard for Frances to trust that the cancer is gone. She wants to know the chances of the cancer coming back. "I feel like if I knew my exact chances of the cancer coming back, I could deal with it. But when I ask my doctor, he gives me a range of statistics over a number of years. I can't live like this. I need more specifics."

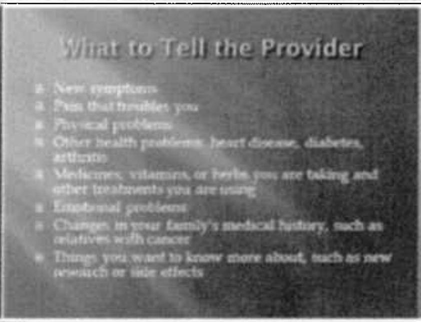


Importance of Follow-up Care

- African American women: poorer functional health after cancer diagnosis and have an increased risk of late diagnosis of second primary cancers, as well as recurrence (Miles, 2005; Wilder Smith et al., 2009)
- Must attend follow-up appointments with oncologist and Primary Care Provider
- Assess barriers to attending appointments: fear, financial, transportation
- What can we do to facilitate?

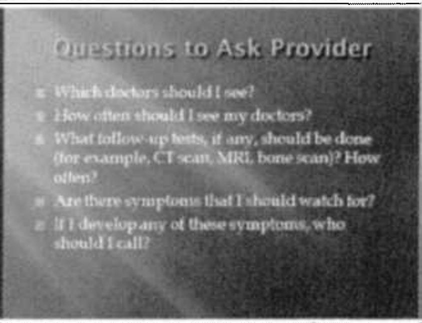
Health Promotion Activities

- Importance of nutrition and exercise
- Quit smoking and reduce alcohol
- What can we do to help?
- American Cancer Society Recommendations: http://www.youtube.com/watch?v=PVkOwtTQ-M4feature=youtu.be



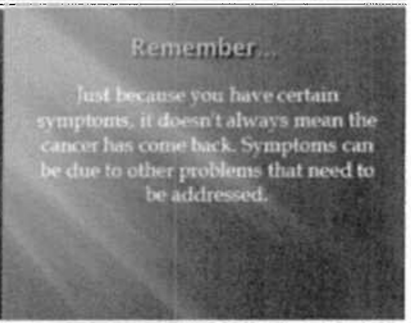
What to Tell the Provider

- New symptoms
- Pain that troubles you
- Physical problems
- Other health problems: heart disease, diabetes, arthritis
- Medicines, vitamins, or herbs you are taking and other treatments you are using
- Emotional problems
- Changes in your family's medical history, such as relatives with cancer
- Things you want to know more about, such as new research or side effects



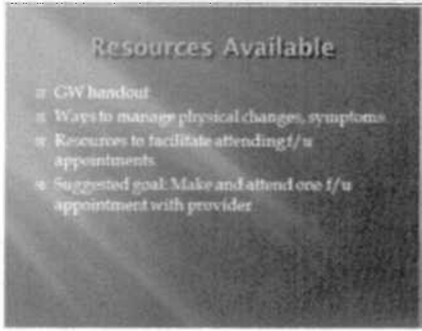
Questions to Ask Provider

- Which doctors should I see?
- How often should I see my doctors?
- What follow-up tests, if any, should be done (for example, CT scan, MRI, bone scan)? How often?
- Are there symptoms that I should watch for?
- If I develop any of these symptoms, who should I call?



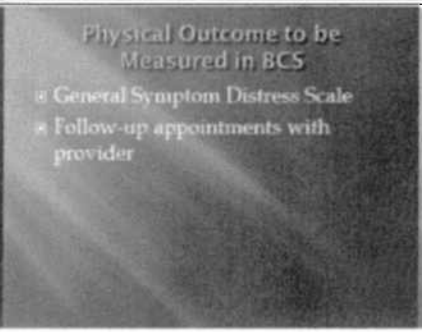
Remember…

Just because you have certain symptoms, it doesn't always mean the cancer has come back. Symptoms can be due to other problems that need to be addressed.



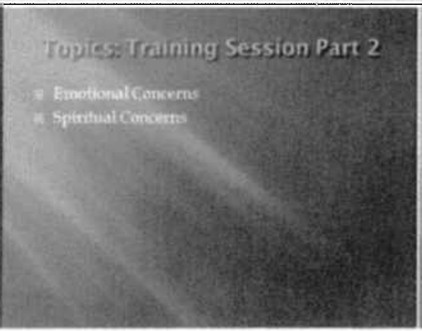
Resources Available

- GW handout
- Ways to manage physical changes, symptoms
- Resources to facilitate attending f/u appointments
- Suggested goal: Make and attend one f/u appointment with provider



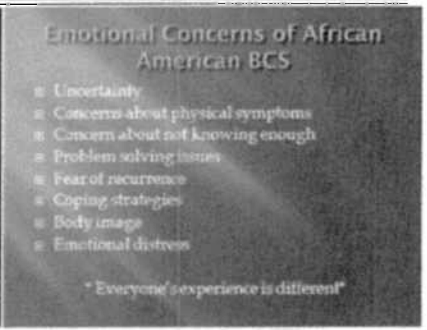
Physical Outcome to be Measured in BCS

- General Symptom Distress Scale
- Follow-up appointments with provider



Topics: Training Session Part 2

- Emotional Concerns
- Spiritual Concerns



Emotional Concerns of African American BCS

- Uncertainty
- Concerns about physical symptoms
- Concern about not knowing enough
- Problem solving issues
- Fear of recurrence
- Coping strategies
- Body image
- Emotional distress

* Everyone's experience is different*

Depression or Anxiety

- Feelings of worry, anxiety, or sadness that don't go away
- Feeling emotionally numb
- Feeling overwhelmed, out of control, or shaky
- Having a sense of guilt or feeling unworthy
- Feeling helpless or hopeless
- Feeling short-tempered or moody
- Having a hard time concentrating, or feeling scatterbrained
- Crying for long periods of time or many times each day
- Focusing on worries or problems
- Having a hard time getting certain thoughts out of your mind
- Finding it hard to enjoy everyday things, such as food or being with friends
- Finding yourself avoiding situations or things that you know are really harmless
- Thinking about hurting or killing yourself

Resources Available

- GW handout
- Support Groups
- Ways to reduce stress
- What resources were useful for you after treatment?
- Suggested goal: Find one method that works to reduce stress/anxiety

Emotional Outcomes

- Quality of Life Breast Cancer Scale
- Preparedness for Recovery

Spiritual Concerns

- Relationship with Church/community
- Finding meaning of illness
- Uncertainty in faith
- Relationship with God
- Seeking God's presence
- New found spirituality
- Adjusting to a new normal

"After treatment for breast cancer, I knew my life had changed forever. Nothing could ever be the same. I was very sad at my losses, but I felt I had been given the gift of a new life."
- Linda

Spirituality in Recovery

- Read uplifting stories about the human spirit
- Pray or meditate to help you gain perspective
- Take part in community or social gatherings for your own support and to support others
- Talk with others
- Find resources at a place of worship for people dealing with chronic illnesses like cancer
- Grieve your losses

Finding Meaning in Survivorship

- Assess your life
- Seek spiritual support
- Keep a journal
- Think about helping others who have had cancer
- Think about taking part in a research study

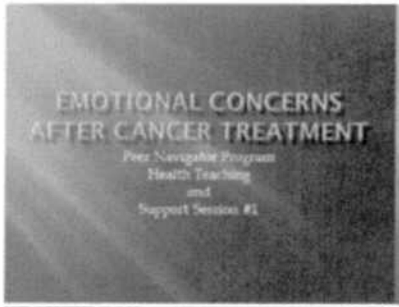
Resources Available

- GW handout
- Contact a religious or spiritual leader in your community
- Contact the chaplain at your local hospital or treatment facility
- Where did you find spiritual support after cancer treatment?

Spiritual Outcome

- Perspectives of Support from God Scale

APPENDIX B. Educational PN Sessions with BCS

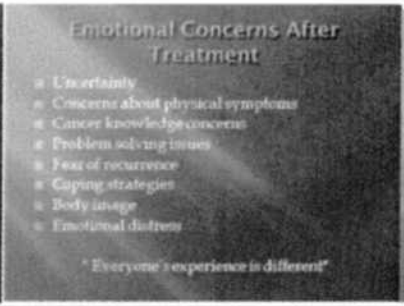


EMOTIONAL CONCERNS AFTER CANCER TREATMENT

Peer Navigator Program
Health Teaching
and
Support Session #1

Goals of Today's Session

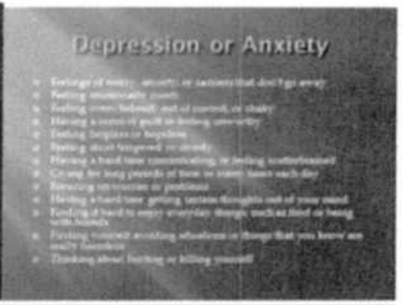
- Establish communication
- Assess concerns
- Set goals for program
- Discuss possible emotional challenges



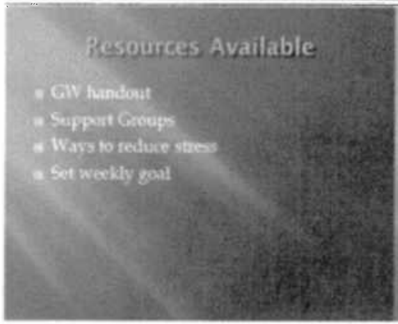
Emotional Concerns After Treatment

- Uncertainty
- Concerns about physical symptoms
- Cancer knowledge concerns
- Problem solving issues
- Fear of recurrence
- Coping strategies
- Body image
- Emotional distress

" Everyone's experience is different"



Depression or Anxiety



Resources Available

- GW handout
- Support Groups
- Ways to reduce stress
- Set weekly goal

SOCIAL CONCERNS AFTER CANCER TREATMENT

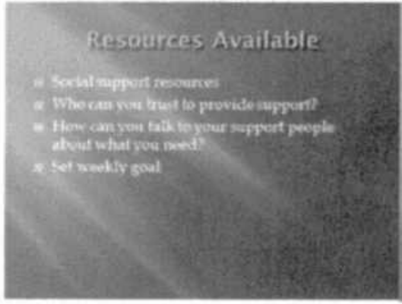
Peer Support Program
Health Teaching
and
Support Session #2

Goals of Today's Session

- Address questions or concerns since last week
- Assess ongoing needs
- Discuss possible social challenges
- Set weekly goal

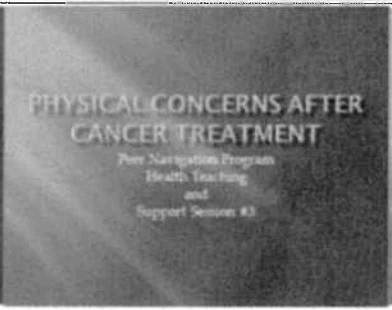
Social Concerns after Treatment

- Pressure to appear strong
- Seeking safe sources of support
- Adjusting to the role of cancer survivor
- Feeling comfortable about the future
- Serving as role models in family and community
- Overcoming fear
- Financial concerns



Resources Available

- Social support resources
- Who can you trust to provide support?
- How can you talk to your support people about what you need?
- Set weekly goal

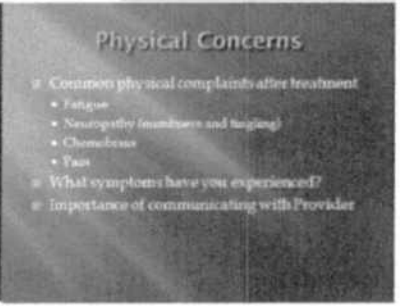


PHYSICAL CONCERNS AFTER CANCER TREATMENT

Peer Navigation Program
Health Teaching
and
Support Session #3

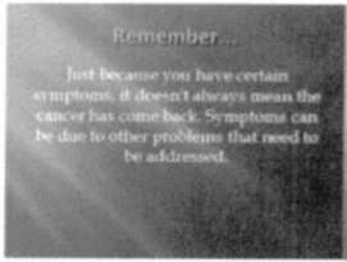
Goals of Today's Session

- Address questions or concerns since last week
- Assess ongoing needs
- Expected physical challenges
- Set weekly goal



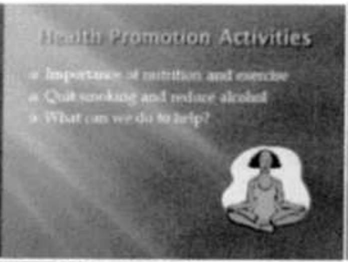
Physical Concerns

- Common physical complaints after treatment
  - Fatigue
  - Neuropathy (numbness and tingling)
  - Chemobrain
  - Pain
- What symptoms have you experienced?
- Importance of communicating with Provider



Remember…

Just because you have certain symptoms, it doesn't always mean the cancer has come back. Symptoms can be due to other problems that need to be addressed.

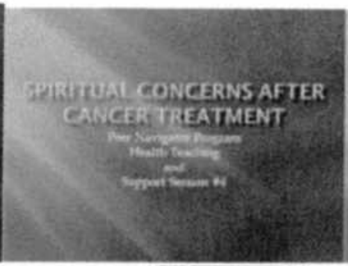


Health Promotion Activities

- Importance of nutrition and exercise
- Quit smoking and reduce alcohol
- What can we do to help?

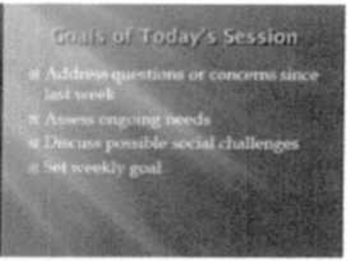
Resources Available

- Ways to manage physical changes, symptoms
- Resources to facilitate attending f/u appointments
- Set weekly goal



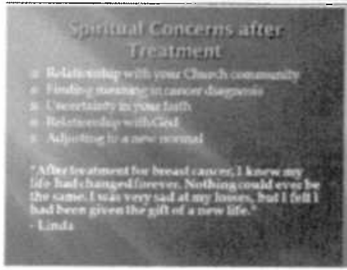
SPIRITUAL CONCERNS AFTER CANCER TREATMENT

Peer Navigator Program
Health Teaching
and
Support Session #4



Goals of Today's Session

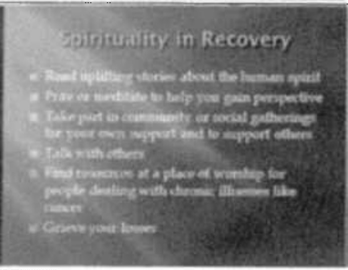
- Address questions or concerns since last week
- Assess ongoing needs
- Discuss possible social challenges
- Set weekly goal



Spiritual Concerns after Treatment

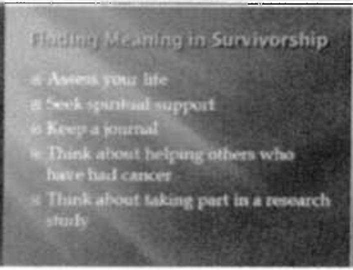
- Relationship with your Church community
- Finding meaning in cancer diagnosis
- Uncertainty in your faith
- Relationship with God
- Adjusting to a new normal

"After treatment for breast cancer, I knew my life had changed forever. Nothing could ever be the same. I was very sad at my losses, but I felt I had been given the gift of a new life."
- Linda



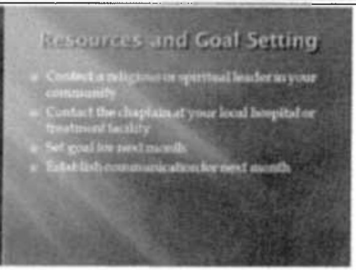
Spirituality in Recovery

- Read uplifting stories about the human spirit
- Pray or meditate to help you gain perspective
- Take part in community or social gatherings for your own support and to support others
- Talk with others
- Find resources at a place of worship for people dealing with chronic illnesses like cancer
- Grieve your losses



Finding Meaning in Survivorship

- Assess your life
- Seek spiritual support
- Keep a journal
- Think about helping others who have had cancer
- Think about taking part in a research study



Resources and Goal Setting

- Contact a religious or spiritual leader in your community
- Contact the chaplain at your local hospital or treatment facility
- Set goal for next month
- Establish communication for next month

APPENDIX C: Instruments utilized in Dissertation Study

General Symptom Distress Scale (Badger, Segrin, & Meek, 2011)

General Symptom Distress Scale

Put a check mark next to each symptom that the Depression

participant reports/indicates being present Anxiety

Fatigue

Shortness of Breath

Nausea

Vomiting

Pain

Sleep Difficulties

Bowel Problems

Difficulty Concentrating

Loss of Appetite

Cough

Other

If other, please specify ______________________________

Rank Depression out of all symptoms checked: 1-10

Rank Anxiety out of all symptoms checked: 1-10

Rank Fatigue out of all symptoms checked 1-10

Rank Shortness of Breath out of all symptoms checked 1-10

Rank Nausea out of all symptoms checked 1-10

Rank Vomiting out of all symptoms checked 1-10

Rank Pain out of all symptoms checked 1-10

Rank Sleep difficulties out of all symptoms checked 1-10

Rank Bowel Problems out of all symptoms checked 1-10

Rank Difficulties Concentrating out of all symptoms 1-10

Rank Loss of Appetite out of all symptoms checked 1-10

Rank Cough out of all symptoms checked 1-10

Rank other symptom out of all symptoms checked 1-10

Now on a scale of 1 to 10, with 1 not being at all 1 distressing and 10 being extremely distressing, In general how distressing are all of your symptoms to you?

Again on a 1 to 10 scale, this time with 1 being 1cannot manage at all and 10 being can manage extremely well, How well are you able to manage your symptoms?

Permission:

From: Badger, Terry A - (tbadger) [tbadger@email.arizona.edu]

Sent: Sunday, August 18, 2013 7:41 PM

To: Mollica, Michelle

Subject: Re: Permission to use the General Symptom Distress Scale

Michelle, absolutely you have permission. Please let me know your results when done, an abstract will do along with how the scale performed for you. Best wishes on a wonderful dissertation, Terry

Sent from my Verizon Wireless 4G LTE DROID

"Mollica, Michelle" <mollicam@musc.edu> wrote:

Dr. Badger:

I am a doctoral student, and currently planning my dissertation study, which involves an intervention for African American breast cancer survivors. I would like to use your General Symptom Distress Scale, and am writing you to ask permission for use of your instrument. I greatly appreciate your consideration. Thank you in advance-

Michelle Mollica

Perceived preparedness for re-entry (Stanton et al., 2005). Perceived preparedness for re-entry was assessed at baseline with two author-constructed items:

Overall, I feel very well-prepared for what to expect during my recovery

Overall, I feel the medical team has done a great deal to prepare me for what to expect during my recovery from breast cancer treatment

Responses rated on a 0 to 4 scale (not at all, a little, a fair amount, much, very much)

Permission:

From: Annette Stanton [astanton@ucla.edu]

Sent: Friday, August 16, 2013 3:52 PM

To: Mollica, Michelle

Subject: RE: Permission to use 2-item Preparedness for Recovery instrument

Dear Michelle, I would be happy for you to use the items. They are available verbatim in the article. Best wishes with your research---I'd appreciate learning about any relevant findings.
Annette Stanton

Annette L. Stanton, Ph.D.
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From: Mollica, Michelle [mailto:mollicam@musc.edu]

Sent: Tuesday, July 23, 2013 03:25 PM

To: astanton@ucla.edu

Subject: Permission to use 2-item Preparedness for Recovery instrument

Dr. Stanton:

I am a doctoral student, and am currently planning my dissertation study, involving an intervention for African American breast cancer survivors. I'm interested in utilizing the 2-item Preparedness for Recovery questions that you used in the following article:

Stanton, A., Ganz, P., Kwan, L., Meyerowitz, B., Bower, J., Krupnick, J., . . . Belin, T. (2005). Outcomes from the moving beyond cancer psychoeducational, randomized, controlled trial with breast cancer patients. Journal of Clinical Oncology, 23(25), 6009-6018. doi: 10.1200/JCO.2005.09.101

I am writing to ask for your permission to use these items in my assessment. Thank you for your consideration in advance-

Michelle Mollica

Perspectives of Support from God Scale (Hamilton, Crandell, Carter, & Lynn, 2010)

	Not at All=0	A Little =1	Sometimes=2	A Lot =3	All the Time =4
1. When I am troubled, I talk to God About It (godtalk)					
2. When I am troubled, I turn it over to God (godturn)					
3. Knowing that God is with me helps me not to worry (godwithme)					
4. Knowing that God is in control of my illness helps me not to worry (godcontrol)					
5. When it comes to my health, I believe that					

	Not at All=0	A Little =1	Sometimes=2	A Lot =3	All the Time =4
God is keeping me here for a reason (godkeep)					
6. Sometimes I think God allows me to suffer to get my attention (godatten)					
7. I think that God allowed me to have this illness so that I could be an example to others (godexample)					
8. When I am troubled, I talk to God first					
9. When I am troubled, I pray to God for answers					
10. Knowing that God can heal me helps me not to worry (godheal)					
11. My faith in God helps me to accept whatever happens (godfaith)					
12. I think that sometimes God allows me to suffer because it keeps me humble					
13. I think that my illness has made me a better person (godbetter)					
14. I think that my illness has made me stronger (godstrong)					
15. I think that God allowed me to have this illness so that I could help others (godhelp)					

Permission:

From: Hamilton, Jill Bridgette [jhamilto@email.unc.edu]

Sent: Tuesday, July 23, 2013 7:24 PM

To: Mollica, Michelle

Subject: Re: Permission to use Perspectives of Support from God Scale

Yes. Did I send the scoring information? There are 2 subscales. I can help you with that later.

Stay in touch. I would be very interested in your findings.

Sent from my iPhone

On Jul 23, 2013, at 7:16 PM, "Mollica, Michelle" <mollicam@musc.edu> wrote:

Dr. Hamilton:

I am a doctoral student at the Medical University of South Carolina, and I am planning my dissertation study, involving an intervention for African American breast cancer survivors. I am writing to ask your permission for use of the Perspectives of Support from God Scale, as a spirituality assessment tool. Last summer, I requested your instrument for a hypothetical study proposal for my measurement course, and you sent me the attached. I will utilize this, if it is still appropriate, and you grant me your permission. Thank you in advance for your consideration-

Michelle Mollica

Quality of Life-Breast Cancer (Ferrell, Dow, & Grant, 2012)

Quality of Life Scale/BREAST CANCER PATIENT

Directions: We are interested in knowing how your experience of having cancer affects your Quality of Life. Please answer all of the following questions based on your life at this time.

Please circle the number from 0 - 10 that best describes your experiences:

To what extent are the following a problem for you:

1. Fatigue

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

2. Appetite changes

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

3. Aches or pain

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

4. Sleep changes

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

5. Weight gain

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

6. Vaginal dryness/menopausal symptoms

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

7. Menstrual changes or fertility

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

8. Rate your overall physical health

extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

Psychological Well Being Items

9. How difficult is it for you to cope today as a result of your disease?

not at all difficult 0 1 2 3 4 5 6 7 8 9 10 very difficult

10. How difficult is it for you to cope today as a result of your treatment?

not at all difficult 0 1 2 3 4 5 6 7 8 9 10 very difficult

11. How good is your quality of life?

extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

12. How much happiness do you feel?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

13. Do you feel like you are in control of situations in your life?

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

14. How satisfying is your life?

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

15. How is your present ability to concentrate or to remember things?

extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

16. How useful do you feel?

not at all useful 0 1 2 3 4 5 6 7 8 9 10 extremely useful

17. Has your illness or treatment caused changes in your appearance?

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

18. Has your illness or treatment caused changes in your self concept (the way you see yourself)?

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

How distressing were the following aspects of your illness and treatment?

19. Initial diagnosis

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very distressing

20. Cancer chemotherapy

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very distressing

21. Cancer radiation

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very distressing

22. Cancer surgery

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very distressing

23. Completion of treatment

not at all distressing 0 1 2 3 4 5 6 7 8 9 10 very distressing

24. How much anxiety do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

25. How much depression do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

To what extent are you fearful of:

26. Future diagnostic tests

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

27. A second cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

28. Recurrence of cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

29. Spreading (metastasis) of your cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

30. To what degree do you feel your life is back to normal?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

Social Concerns

31. How distressing has your illness been for your family?

not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

32. Is the amount of support you receive from others sufficient to meet your needs?

not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

33. Is your continuing health care interfering with your personal relationships?

not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

34. Is your sexuality impacted by your illness?

not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

35. To what degree has your illness and treatment interfered with your employment?

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

36. To what degree has your illness and treatment interfered with your activities at home?

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

37. How much isolation do you feel is caused by your illness?

none 0 1 2 3 4 5 6 7 8 9 10 a great deal

38. How much concern do you have for your daughter(s) or other close female relatives regarding breast cancer?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

39. How much financial burden have you incurred as a result of your illness and treatment?

none 0 1 2 3 4 5 6 7 8 9 10 a great deal

Spiritual Well Being

40. How important to you is your participation in religious activities such as praying, going to church or temple?

not at all important 0 1 2 3 4 5 6 7 8 9 10 very important

41. How important to you are other spiritual activities such as meditation or praying?

not at all important 0 1 2 3 4 5 6 7 8 9 10 very important

42. How much has your spiritual life changed as a result of cancer diagnosis?

less important 0 1 2 3 4 5 6 7 8 9 10 more important

43. How much uncertainty do you feel about your future?

not at all uncertain 0 1 2 3 4 5 6 7 8 9 10 very uncertain

44. To what extent has your illness made positive changes in your life?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

45. Do you sense a purpose/mission for your life or a reason for being alive?

none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

46. How hopeful do you feel?

not at all 0 1 2 3 4 5 6 7 8 9 10 very hopeful

Permission:

From: Ferrell, Betty [BFerrell@coh.org]

Sent: Wednesday, July 24, 2013 2:08 AM

To: Mollica, Michelle

Subject: RE: QOL-BC

Hello

You are welcome to use any of our instruments. All are on our website http://prc.coh.org in the section titled QOL or under Research Instruments.

Betty Ferrell

From: Mollica, Michelle [mollicam@musc.edu]

Sent: Tuesday, July 23, 2013 4:06 PM

To: Ferrell, Betty

Subject: QOL-BC

Dr. Ferrell: I apologize, but I have one other question for you. I am planning my dissertation study, involving an intervention for African American breast cancer survivors, and I would like to use your QOL-BC instrument as an assessment tool. I am writing to request your permission for use of this tool. I do have a pdf (attached) of what I believe is general permission for use of the tool, but certainly did not want to assume. Thank you in advance for your consideration.

Michelle Mollica

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