

**EXPERIENCES OF BLACK WOMEN BREAST CANCER SURVIVORS' RISK AND
RESILIENCE: A GROUNDED THEORY STUDY**

By

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A DISSERTATION

Submitted to
Michigan State University
In partial fulfillment of the requirements
for the degree of

Human Development and Family Studies—Doctor of Philosophy

2020

ABSTRACT

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Breast cancer is the most common cancer diagnosed among all women in the US and the second leading cause of cancer death (DeSantis, Ma, Gaudet Newman, et al, 2019). Black women in the US are less likely to survive breast cancer with death rates 40% higher than White women (DeSantis, Ma, Gaudet Newman, et al, 2019; DeSantis, Fedewa, Goding Sauer et al, 2016). Black women younger than age 40 have the lowest survival rate of all groups, representing an ongoing and significant health disparity (Sheppard, Llanos et al, 2013).

Background/Objective: To explore the experience of Black breast cancer patients.

Methods: 25 African American breast cancer survivors ages 41-79 participated in a qualitative study. Age at diagnosis ranged from 31-70 years, with mean survival time since diagnosis ranging from 3 months to 24 years. Women participated in a semi-structured interview format. These studies were guided by the following primary research question: ***What are the risk and protective factors for African American women with breast cancer?***

Results: Interview data was analyzed using qualitative software NVIVO and coded for recurrent themes reported. African American cancer survivors drew on inner resources including spirituality, cognitive reframing, personal agency, and racial socialization. Coping resources in their environment included relational supports, medical resources, financial resources, and engaging in community health education and mentoring other survivors.

African American cancer survivors reported individual and environmental risks in the categories of emotional distress, help-seeking barriers, medical mistrust and cultural silence about cancer. Younger women reported greater distress regarding relational and caregiving strain, negative impact on social network and functioning, and distress related to body image and fertility concerns.

ACKNOWLEDGEMENTS

So many people wonderful people have accompanied me on this journey and have made all the difference in my life. With a humbled and grateful heart, I first thank my parents Barbara O. Ingram and Jesse Ingram, Jr. for all the sacrifices they have lived and for all the love they have given to make my appearance in a doctoral program possible. I wish to thank my dearest children Calixthe, Nigel and Hyacinth for motivating me on this journey and for their patience and understanding whenever my time and attention was divided to pursue this work. Thank you, Jesse and Jameelah, my beloved brother and sister, for your steadfast love and encouragement. I wish to thank my precious husband Edward Walker, without whose love and support I would not have made it this far. Thank you, Ned for always valuing my voice, believing in my abilities and surrounding me with love from sunrise to sunset.

I wish to thank the inspiring academic force of women on my Committee, Dr. Carolan, Dr. Johnson, Dr. Osuch and Dr. Wittenborn. Thank you for your support, guidance and encouragement along each step of this process and for the invaluable contributions you make to academics, to students and to communities. I offer special gratitude to Dr. Marsha Carolan, my committee Chair, for teaching me the value of qualitative research and of privileging voices that often go unheard. Thank you for your limitless encouragement and guidance as I navigated doctoral studies. This journey would not have been possible without your support, from beginning to end. Most of all I want to thank the beautiful, wise and resilient black women breast cancer survivors in this study who generously shared their vulnerability and strength through remarkable stories of courage, hope and helping others.

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CHAPTER ONE: INTRODUCTION

Background

Health Disparity Research

Breast cancer is the most common cancer diagnosed among all women in the US and the second leading cause of cancer death (DeSantis, Ma, Gaudet Newman, et al, 2019). According to the American Cancer Society, over 40,000 women will die annually from this disease. Black women in the US, however, are less likely to survive breast cancer with death rates 40% higher than White women (DeSantis, Ma, Gaudet Newman, et al, 2019; DeSantis, Fedewa, Goding Sauer et al, 2016). Even though breast cancer death rates have dropped consistently over the past 30 years, the survival gap for black women has widened during this same period and then remained stable since 2011 (DeSantis, Ma, Gaudet Newman, et al, 2019). Black/African-American ethnicity persists as a significant predictor for poorer outcomes with breast cancer, including shorter survival and earlier recurrence (Lannin, Matthews, Swanson et al, 1998; Newman, 2005; Newman, Griffith, Jatoi et al, 2006). Black women younger than age 40 have the lowest survival rate of all groups, representing an ongoing and significant health disparity (Sheppard, Llanos et al, 2013).

Study Rationale

There are few studies available on African American women's breast cancer experiences examining their unique coping, psychosocial needs, and social role adjustment (Barton-Burke et al, 2006; Roff et al, 2009). Past literature on Black women and breast cancer focused predominately on screening, early detection, and breast self-exams with limited research on their experiences with breast cancer from a multidimensional framework (Barton-Burke et al, 2006). This research will examine other contributing factors, including psychological and social aspects

to Black women's experience with breast cancer. This research also seeks to address practice implications for psychosocial interventions that can improve health outcomes for Black women with breast cancer including help-seeking, coping and increasing community support (Whitehead & Hearn, 2014).

Purpose of Study

Understanding mechanisms of risk and resilience can help inform interventions which enhance resilient functioning and quality of life for African American cancer patients. This inquiry can help clinicians begin to address and integrate the psychosocial needs of these patients in their care with the goal of improving outcomes (Sheppard et al, 2013). Proper assessment of the unique contextual factors, risks and distress of African American breast cancer patients can help support coping, recovery and quality of life in this group.

Literature Review

Psychological Distress, Cancer and Survival

Greater emotional distress among breast cancer patients has been associated with poorer physical and mental health during treatment (Whitehead & Heard, 2014). Depression has been identified as the most prevalent mental health problem for cancer patients (Shapiro et al, 2001). Links between emotional distress after diagnosis and survival may shed light on Black women's greater vulnerability to poorer cancer outcomes. Brown, Rosberger & Edgar (2003) assessed 205 cancer patients with repeated psychological assessments over 15 months following diagnosis, and found that depressive symptomology was the most consistent predictor of shortened survival time at a ten-year follow-up. Shapiro et al (2001) reported a meta-analysis of psychosocial variables related to breast cancer and found a significant association between stressful life events

and breast cancer. Williams et al (2016) also reports emerging literature suggesting that psychosocial stress may increase breast cancer risk through a physiological stress pathway.

Greater Impact on Younger Women

Costanzo, Ryff, and Singer et al's (2009) study of 398 cancer survivors found that younger survivors (less than age 50) showed the most adverse impact in mental health and psychological well-being since diagnosis. Reasons for this age-related difference, which may shed light on the disparities found in younger Black women with breast cancer are significant. They include the lack of anticipation for the health adversity, greater work and parenting demands at younger ages, and diminished social support of others in their age group dealing with similar problems (Costanzo et al, 2009).

Older breast cancer survivors of all races report less life impact than younger survivors (Baquet et al, 2008) with striking disparities in impact for younger Black women. Shapiro et al (2001) found that younger cancer patients sustain the greatest impact in adjustment and distress from their disease, whereas advanced age is associated with more social contacts, better mental health, functioning and perceived quality of life.

Depression and anxiety are higher in younger African American women with breast cancer (Sheppard, Llanos et al, 2013; Sheppard, 2013). Younger patients face additional challenges with their younger children for whom they are still caring. More information is needed about the particular concerns of younger African American patients and interventions that specifically address this group who may have more concerns about caring for young children, future fertility, and sexuality than their older counterparts (Ashida et al, 2009, Sheppard, Llanos, et al, 2013).

Coping Differences

Cultural differences in coping may also contribute to prognosis disparities. Yoo et al (2014) cite some differences in coping between Black and White cancer patients who were given an uncertainty management intervention for coping with fear of cancer recurrence. African American patients showed more pronounced improvements in cognitive reframing regarding uncertainty than did their White counterparts and were less likely to envision catastrophe. Few other studies have examined differences in coping among Black breast cancer patients and to date, these differences are not fully understood.

Differences in Perceived Social Support

Ganz, Leedham, Rowland, et al (2002) found that among all groups of breast cancer survivors, quality of perceived social support was an important predictor of better health-related quality of life. Barton-Burke et al's (2006) literature review of Black women and breast cancer found differences in perceived social support among racial and ethnic groups. Black women were disproportionately held caretaker roles and experienced less social support outside of their own community, than did other groups when dealing with breast cancer.

In general breast cancer patients who are socially isolated have a significantly elevated mortality risk compared with those who identify more close relatives and friends and who have more support providers (Kroenke, Kubzansky, Schernhammer, holes, & Kawachi, 2006, Weihs, Enright, & Simmens, 2008). In Black breast cancer patients, Ashida et al (2009) found that support providers were even more important to psychological well-being of younger patients than older ones.

Race-Related Stressors

Regarding Black women's resilience and the multidimensional impact of stresses they experience, Jeffries (2015) summarizes the situation as follows:

“the psychological stresses of living Black and female manifest as physical ailments for many Black women. High blood pressure and breast cancer affect Black women at rates far above their racial and gender counterparts and the mortality rates of these diseases, along with pregnancy complications/mortality as a health condition; far outpace the rates of other women in the U.S. Attempting to address every problem in their immediate and extended families and suffering in silence at work are practices utilized to cope with home life and provide economic stability that contribute significantly to the internalized emotions directly compromising Black women's health. As women who are excessively single, Black females often have no built-in source for consolation or support to assist with handling the multiple stressors that come from multiple angles” (p. 82).

Cumulative stress exposure theory has generated the term “biological weathering” to describe the phenomenon of poorer prognosis across multiple chronic diseases as found in people of color resulting from the “cumulative impact of repeated exposures to psychological, social, physical, and chemical stressors” (Williams et al, 2016, p. 2140) associated with racism or living in disadvantaged environments.

Even when access to care and insurance issues are adequately addressed, The Institute of Medicine (2003) found that minority patients still receive a lower quality of health care than Whites. The Institute cited evidence for discrimination, racial bias and stereotyping in health care disparities, concluding that “many factors are complicit in health care disparities, including policies and practices of health care systems and the legal and regulatory climate in which they operate” (Smedley, 2012, p. 934).

Protective Factors: Sense of Coherence and Racial Socialization

Resilience. Resilience highlights positive factors which allow an individual to continue to function and thrive even in the face of adversity. It is an important consideration as a protective factor for Black women at risk for disease (Holden et al, 2013). The literature offers multiple definitions of resilience, including individual cognitive and behavioral skills used to recover from adversity (Coleman, et al 2016) and as a process of overcoming adversity through transactions with the environment (Bradshaw et al, 2007). Intrinsic resilience is most commonly

identified (Elm, Lewis, Walters, & Self, 2016). Resilient qualities that support people in successful coping have been referred to as protective factors. Resilience has also been linked to spirituality as part of an inner striving that leads people to spiritual strength and self-actualization (Bradshaw et al, 2007).

Elm et al (2016) propose resilience as multilevel process involving spirituality, culture, community, family, and resilience as applied to American Indian and Alaskan Native populations. This intersectional or “braided resilience framework” includes individuals’ ability to draw on cultural and community resilience. Similar cultural strengths of the African American family, interdependent community orientation, spirituality and kinship networks integral to resilience (Marbley & Rouson, 2013), also make this framework relevant to Black women’s experience.

Psychological traits such as resilience and optimism buffer the effects of stressful life experiences in African Americans (Baldwin et al, 2011). Lackey et al. (2001) found that African American women with breast cancer expressed a strong fear of dying but used inner resources identified as a sense of coherence, spirituality and hope for positive coping (Roff et al, 2009). Sheppard (2013) found that women reporting higher self-efficacy or confidence in their ability to cope positively with their diagnosis, also reported less anxiety and depression.

Sense of Coherence Antonovsky (1987) first conceptualized sense of coherence as part of a salutogenic health model which focuses on health promoting factors rather than factors which increase disease risk. It helps address the question why some people stay well in the face of great adversity and other do not (Eriksson & Lindstrom, 2005). Eriksson and Lindstrom (2005) found that sense of coherence is strongly related to health, making it a relevant perspective for

public health and health promotion. In general, people reporting a high sense of coherence also reported better health. Antonovsky's scales have been used in at least 49 different languages in at least 48 different countries. Research supports the Sense of Coherence scale as a reliable, valid, and cross-culturally applicable instruments (Van Schalkwyk & Rothmann, 2008).

The strength of sense of coherence has also been linked to social support, spirituality, and social class throughout childhood and adolescence, with older people showing a stronger sense of coherence than younger ages (Boscaglia et al, 2007). Antonovsky's salutogenesis theory draws together, then dimensions identified as significant to the experience of Black breast cancer survivors. Experiences of discrimination intersect these dimensions of social support, coping and sense of order and purpose in life. Salutogenesis theory helps explain why younger breast cancer survivors who may have less strong sense of coherence, may also have poorer health outcomes. Understanding the impact of this particular stress and ways to mitigate this distress can promote health and recovery.

Racial Socialization and Resilience

Racial socialization may impact Black women's experience coping with a breast cancer diagnosis. A phenomenon termed "Strong Black Women Blues" (Greff, 2011) describes the Black women's socialization as strong, self-reliant, ultimate caretakers, who do not to complain or express vulnerability. Coping responses of women of Color are strongly affected by their concerns regarding caring for close family. Women reported coping by not burdening spouses, children, and family with their diagnosis (Yoo et al, 2014; Ashing-Giwa & Ganz, 1997). This mantle of invulnerability and strong orientation toward the caretaking contributes to isolation, exhaustion, self-neglect and therefore poorer health among this group. Culturally-informed

interventions may reduce mental health risks for minority groups who are at increased risk for not engaging in services, experiences greater medical mistrust, and at higher risk for poorer health outcomes (Reynolds & Gonzalez-Backen, 2017).

Previous research has identified ethnic-racial socialization as a protective factor against racism, discrimination experiences, and negative mental health outcomes (Hughes et al, 2006; Reynolds & Gonzalez-Backen, 2017). For young women in particular, racial socialization messages focused on cultural pride and cultural legacy promote identity formation, self-esteem, positive coping and psychosocial well-being (Hughes et al, 2006; Reynolds & Gonzalez-Backen, 2017). Womack and Sloan (2017) found that both mindfulness and culturally-based racial socialization messages promoted adaptive coping against stressors in young African American women.

Racial socialization including an “understanding of the social scripts and structures” (Bartoli et al, p, 248) have been identified as protective factors in African American resilience (Brown et al; Bartoli, Bentley-Edwards, Garcia et al, 2015) in the face of intersecting experiences of gender, sexuality, race and class. Clarke et al (2016) report that receiving racial socialization messages and having high perceived social support predicted higher resilience in African Americans with depression. There is a lack of research on psychological and social protective factors for African Americans that may support their health and resilience (Williams et al, 2016).

Risk factors: Low sense of coherence, Provider Reports and Discrimination

Sense of Coherence. Loss of feelings of control and confidence in having resources to manage a health crisis, or low sense of coherence, is associated with feelings of helplessness, hopelessness,

anxiety and depression related to cancer. Shapiro et al (2001) found that having a helpless attitude towards breast cancer is related to poorer prognosis. These authors highlight literature in which acceptance or “positive yielding” is a unique and important feature when balanced with positive assertive control, for reaching healthy sense of coherence and an optimal psychosocial adjustment, whereas a negative yielding mode of control defined by hopelessness and helplessness was associated with greater emotional distress. Similarly, findings regarding sense of control and acceptance in a qualitative study by Blow, Swiecicki, Haan, Osuch et al (2011) found that arriving at a point of acceptance of their diagnosis and treatment was beneficial and that “women who were more at peace with their circumstance had strong support systems and beliefs that allowed them to cede control to an outside entity” (p. 1332).

It remains to be understood how coping of Black women, who deal with intersections of caretaking stress, discrimination, quality of care differences, less social support, relates to health-promoting yielding of control. For example, how readily available and confident do Black cancer patients feel about the care they receive and how might this impact their sense of hopelessness and emotional resilience? Barton-Burke et al (2006) found three inner resources: spirituality, hope and a sense of coherence, that contributed to psychological well-being for Black women. Swinney (2002) found positive associations between self-esteem and internal health locus of control and an overall positive relationship between self-esteem and health status in Black women.

Provider interactions

Black women may have less positive and participatory interactions with their providers

and these differences in interactions may contribute to disparate treatment outcomes for Black breast cancer patients (Sheppard, Wallington, Willey et al, 2013; Gengler & Jerrell, 2015). Gengler & Jerrell (2015) report studies of provider-patient interactions in which cancer patients of Color report shorter visit times, less empathy and positive affect, and more verbally dominant communication from their provider. Consequently, Black women patients reported sharing less information and being less active in treatment decisions. Barriers to effective communication may contribute to treatment differences and have been targets for psychosocial interventions for Black breast cancer patients (Holden et al, 2013; Sheppard, et al, 2013). Medical mistrust influences anxiety levels in Black breast cancer patients. Women with higher medical mistrust reported higher anxiety and depression. A strong patient-provider relationship after diagnosis may help reduce distress in African American patients and predict their healthcare use (Sheppard, 2013).

Discrimination

Discriminatory experiences may increase Black women's sense of loss of control when facing a cancer diagnosis threatening their sense of coherence. and improve patient-centered care, Sisters Informing Sisters, a peer-led decision support intervention to assist Black women in communicating more effectively with their providers and empower them to make decisions in concert with their values and needs, found that participants reported 70% increased self-efficacy in communicating with providers and in making treatment decisions. Increasing communication between patients and providers may help reduce disparity by improving treatment received, increase adherence to treatment and help decrease historic mistrust of the medical community by patients of Color (Jones et al, 2015). Gengler & Jarrell (2015) cite Janet Shin's concept of "cultural health capital" to describe the "repertoire of cultural skills, verbal and nonverbal

competencies, attitudes and behaviors, and interactional styles” that patients bring to interactions with medical providers and suggests that more investigation is needed to better understand how patients can positively leverage their cultural health capital for the benefit of their health care (Gengler & Jarrell, 2015, p. 724). Cancer providers play an important role in giving emotional support to breast cancer patients (Sheppard, 2013).

Creating an Environment for Recovery

According to Whitehead and Hearn (2014) the most successful interventions for Black women have “created a cultural environment in which Black women feel welcome, have established trust, and use resources valued in the community such as spirituality, kin networks, and oral storytelling” (p. 503). However, there are currently no clear practice guidelines for incorporating spiritual interventions in psychotherapy with African American women (Mengesha et al, 2012). Davey, Kissil, Lynch, Harmon & Hodgson (2012) found that a psychoeducational support group for Black families coping with parental cancer and their school-aged children which incorporated cultural pride and spiritual themes, and led to better communication between parents and children. Through the distress of a chronic illness like breast cancer, resilience skills in families can support coping and increase “a sense of connectedness and control” (Walsh, 2006). Some of these skills in families include managing trauma and loss, stress management, emotion regulation and collaborative problem solving (Saltzman, 2011). Such coping can be supported and enhanced through interventions such as individual or family psychotherapy. Cultural and ethnic differences influence ways families communicate emotions and the cultural framework of each patient and their family would need to be considered (Saltzman, 2011). Interventions for African American families may need to be adapted and customized to meet the unique needs of this group.

Using a resilience and sense of coherence framework, the following primary questions has guided this research: ***What are the risk and protective factors for young African American women with breast cancer?*** The conceptual model proposed a framework for understanding how risk and protective factors may influence the process (see Figure 1). In Table 1, I provide an organized approach to how the theory and research questions influenced my interview guide.

Research questions

- 1) What are the risk and protective factors for AA women with breast cancer?**
- 2) What beliefs and strategies do AA women with breast cancer use to make sense of and cope with their health crisis?**
- 3) What do kinds of support do African American women with breast cancer most need from family, partner and extended support systems?**
- 4) How do AA women access these supports? What promotes or hinders their access to these supports?**

Table 1: Conceptual Framework

Theory	Primary Research Questions	Secondary Research Questions	Sample Interview Questions
Resilience theory	What are the protective and risk factors for young AA women diagnosed with breast cancer?	Protective: What are the influences of partner, familial, social support? What are the influences of spirituality?	How has your life changed since your diagnosis? What helps you when you are feeling depressed or discouraged? How important is your belief in God or something greater than yourself in coping with cancer? What is most helpful in your recovery?
Sense of Coherence Theory	What are the protective and risk factors for young AA women diagnosed with breast CA?	How does quality of partnered relationship and family closeness influence recovery from breast cancer?	How has your cancer diagnosis affecting your couple relationship? How has your cancer diagnosis affected your family relationships? <hr/> How do you ask for help when you need it?

Table 1: (cont'd)

Sense of Coherence Theory	What are the protective and risk factors for young AA women diagnosed with breast CA?	Risk: What are influences of discrimination? What are influences of health care provider interactions? What is your sense of being socially supported at home and in the community? How do intersections of being AA and woman influence your recovery from breast cancer?	What beliefs and strategies do you use to make sense of and cope with breast cancer? How do you describe your interactions with health care providers? What do you most need from social support people in your life? How supported do you feel in your family, community and with health providers?
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Research Approach and Design

A multi-dimensional perspective was utilized to better understand the uniqueness of these African American breast cancer survivors' experiences of race, gender and class intersections on their resilience and coping with breast cancer. To that end, I proposed a qualitative, grounded theory study. Resilience theory was used with a focus on sense of coherence to capture the lived experiences of Black women with cancer through semi-structured interviews.

A resilience focus is relevant to studies of Black women given their historical positions of strength in their families and communities and capacity for resilience. Sense of coherence, first conceptualized by Antonovsky (1987) as part of salutogenesis theory of how people cope with lack of control in their lives (inner resources) and draw on resources in their environment (external) to remain healthy. Sense of coherence is strongly linked to health and has been identified across diverse study populations regardless of sex, ethnicity, nationality or age (Eriksson & Lindstrom, 2005). Sense of coherence offers insight into psychosocial coping and

health promotion practices and has been positively correlated with increased self-care practices (Ahola et al, 2012).

Descriptive research data was also gathered from a demographic questionnaire, and from health assessments measuring depression and psychosocial distress in cancer patients.

Data collection and Instruments

This study received IRB approval. To be respectful of participant's time and health status, recruitment protocol involved written informed consent, and interviews were arranged to accommodate participants' preferences. Fourteen interviews were conducted by video-conferencing (Zoom or Skype), one interview was conducted in-person, and ten were conducted by telephone either due to participant preference or because of difficulties accessing video-conferencing platforms. Interviews lasted between 40 minutes to two hours. The average length was about 1 hour. The interview guide can be found in Appendix C. Interviews focused on the experience of sense of coherence, coping, meaning-making, encounters with medical providers, mental health, and social supports, with the goal of expanding the research on African American cancer survivors and address issues of health disparity issues. All interviews were audio-recorded and later transcribed verbatim.

Participant Description

Twenty-five African American women who were survivors of breast cancer ranging in age from 41-79 participated in this study. The majority of participants (16) had undergraduate or graduate education, 8 had attained an associate's degree or some college education, and 1 participant reported less than 12th grade education. Eleven participants were married or widowed, thirteen were single, and one divorced. The majority of participants reported Stage 2 breast cancer (13), followed by Stage 1 (7). One participant had Stage 3 and one participant, Stage 4

breast cancer. Nineteen of twenty-five reported “cancer-free or in-remission” while six described themselves currently in treatment. Four participants had survived recurrent diagnosis of breast cancer, and two participants had survived other cancers previous to their breast cancer diagnosis. See Tables 2-5 below.

Table 2: Participant Diagnosis Age and Years Survival Post-Diagnosis

Number of Participants	#Diagnosed at ≤50y	#Diagnosed at >50y	Median Diagnosis Age (years)	Diagnosis age Range (years)	Median Current Age (years)	Current Age range (years)	Mean Years Survival Since Diagnosis	Survival Years Range
25	16	9	44	31-70	60	41-79	9 years	3 mos-24y

Table 3: Participant Education Level

Education Level	# of Participants
Less than 12 th grade	1
Some College	5
Associate’s Degree	3
Bachelor’s Degree	4
Graduate/Professional Degree	11

Table 4: Participant Income Level

Income Level	# of Participants
\$25,000 or less	5
\$25,000 - \$50,000	6
\$50,000 - \$75,000	4
\$75,000 - \$100,000	5
\$100,000 or more	5

Table 5: Participant Marital Status, Child Status and Diagnosis Stage

Marital Status	Number of Participants
Married	10
Single	13
Divorced	1
Widowed	1
Child Status	
Have children	18
No children	6
Stage/Diagnosis	
Stage 1	8
Stage 2	15
Stage 3	1
Stage 4	1
Estrogen + cancer	10
Triple negative cancer	7
HER 2 positive cancer	2
Cancer-free/In remission	19
Currently in treatment	6

Assessments

The instruments below have been found to be valid and reliable in diverse populations (Conway-Phillips, 2014; Tang et al, 2011) and were used to further enhance understanding of the experience of participants, and also to assess in what ways participants may have differed from one another.

- **The Patient Health Questionnaire (PHQ-9)**, 9-item self-report screening tool of depressive symptoms. zero to 3 scale with max score of 29,. Scores of 5, 10, and 20 represent mild, moderate, moderately severe and severe depression (Kreonke, Spitzer & Williams, 2001)
- **National Comprehensive Cancer Network Distress Thermometer and Problem List**, zero to 10 scale, screening tool for measuring psychosocial distress in cancer patients. Scores of 4 or higher suggest psychosocial distress levels that have clinical significance and warrant further evaluation and treatment (NCCN, 2013)

Data Analysis

NVIVO software was used to evaluate qualitative data for emerging themes. I began analysis by identifying all open codes, then clustered open codes into categories. In consultation with my advisor, I created selective codes from the axial codes categories. The lens of resilience and intersectionality was used to help interpret generated themes that reflect unique experiences of Black women and acknowledge their multilayered experiences of race, gender, class and social position. In accordance with grounded theory methodology, I memoed throughout the study.

Trustworthiness/reliability and validity

Through consultation with my advisor who is experienced in qualitative research, we were able to determine final themes. I then created an elaborate grounded theory map reflecting these results.

Manuscript Summary

Two manuscripts were generated from the data.

STUDY ONE: *Exploring Resilience and Psychosocial Protective Factors for African American Breast Cancer Survivors: A Grounded Theory Study*

STUDY TWO: *Psychosocial Risk Perspectives from Young and Older African American Breast Cancer Survivors: A Qualitative Study with Implications for Practice*

CHAPTER TWO: STUDY ONE

STUDY ONE: Exploring Resilience and Psychosocial Protective Factors for African American Breast Cancer Survivors: A Grounded Theory Study

ABSTRACT

Background/Objective: To explore the experience of Black breast cancer patients

Methods: 25 African American breast cancer survivors ages 41-79 participated in a qualitative study. Age at diagnosis ranged from 31-70 years, with mean survival time since diagnosis ranging from 3 months to 24 years. Women participated in a semi-structured interview format. This study was guided by the following primary research question: ***What are the protective factors for African American women with breast cancer?***

Results: Interview data was analyzed using qualitative software NVIVO and coded for recurrent themes reported. African American cancer survivors drew on inner resources including spirituality, cognitive reframing, personal agency, and racial socialization. Coping resources in their environment included relational supports, medical resources, financial resources, and engaging in community health education and mentoring other survivors.

Conclusion: AA breast cancer survivors use inner resilience, environmental resources, and external motivating purposes to cope with their diagnosis. This group also reported both individual and environmental risks which challenge their recovery, including emotional distress and cultural silence about cancer.

Introduction

The purpose of this study was to explore the experience of African American breast cancer survivors. Black women represent a unique population with the highest mortality rate with breast cancer. Their survival is 40% less than their white counterparts, a disparity that has

widened over the past 30 years and remained stable since 2011 (DeSantis, Ma, Gaudet Newman, et al, 2019).

Health Disparity With Complex Causes

Reasons for this disparity are varied and complex, including unique biological and genetic risks factors (Baquet et al, 2008; Williams et al, 2016). Black women are twice as likely to have triple-negative breast cancer, an aggressive subtype, as their White counterparts. Lifestyle factors such as reproductive history, length of breastfeeding, diet, (Aggarwal, Callahan, Miller, Tu & Loehrer, 2015; Baquet et al, 2008; Boggs, Wise, Spiegelman et al 2010; Whitehead & Hearn, 2015) social and economic adversity linked to experiences of racism (Williams et al, 2016), environmental exposures (Miller & Cole, 2009), and treatment disparities (Baquet et al, 2008; Hirschman et al, 2007), may all impact survival.

Several studies have documented the impact of race-related stress on health outcomes (Baldwin et al, 2011; Nazroo, 2003; Taylor, Williams & Makambi, 2007; Utsey et al, 2008; Williams et al, 2016). Taylor et al (2007) found a link between job-related discrimination and breast cancer based on information women reported in the Black Women's Health Study, a large prospective cohort study that examined risk factors for major illnesses in 64,524 African-American women ages 21–69 years. Particularly for young women under age 50, those who reported experiencing frequent, everyday discrimination were at higher risk for breast cancer than those who reported infrequent experiences. The incidence of breast cancer was also 31% greater in those who reported discrimination in housing, job, and police encounters, compared to those who reported no discrimination.

Access to health care due to poverty or lack of insurance is a contributor to poorer breast cancer outcomes. Though socioeconomic status measures are sometimes confounded by factors

such as lifestyle, cultural beliefs, and diet, this factor alone is insufficient to explain the significant race-related disparities in breast cancer (Campbell, 2002; Newman et al, 2005; Williams et al, 2016). In fact, black women currently report accessing mammography screening at a *higher* rate than do white women (CDC, 2012; Jones, Katapodi, & Lockhart, 2015). According to the National Cancer Institute, “the exact reasons for these persistent disparities are unclear, although studies suggest that they are the result of a complex interplay of genetic, environmental, and societal factors, including access to health care” (NIH, 2016, p. 1). Further investigation is needed into the complex interplay of biologic, sociocultural, psychosocial, or behavioral factors that influence disease outcome in this group.

Survival disparities for Black women still persist even after accounting for socioeconomic status, stage of diagnosis, earlier screening and standard of care, (Baquet et al, 2008; Bowen, Duffy, Ryan, Hart & Jones, 2008; Dignam, 2000; Newman et al, 2006). These recent findings warrant greater understanding of the impact of psychosocial factors on health and recovery. The National Comprehensive Cancer Network (NCCN) and the Institute of Medicine have issued New Quality Standards for integrating and addressing the psychosocial needs in cancer patient care. These standards include: determining modifiable risk factors for intervention, promoting quality of life and survival, and reducing stress and depression during recovery (NCCN, 2003; IOM, 2013). NCCN defines distress as “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment” (NCCN, 2013, p. 192).

Methods

Twenty-five African American breast cancer survivors ages 41-79 participated in this qualitative study. Age at diagnosis ranged from 31-70 years, with survival time since diagnosis ranging from 3 months to 24 years. This study used a qualitative, grounded theory methodology. Semi-structured interviews guided by a framework of resilience theory and sense of coherence were used to capture the lived experiences of Black women with cancer. This study was guided by the following primary research question: ***What are the protective factors for African American women with breast cancer?***

Inclusion and Exclusion Criteria

Inclusion criteria for these studies were self-identified African American women ages 18 and older diagnosed with stage I, II or III breast cancer, who speak and read English, and who were able to give written consent for participation.

Sampling and Recruitment

Recruitment was accomplished through flyers distributed at a hospital breast cancer awareness fair, breast cancer nurse navigator referral, through local breast cancer treatment clinics, and through e-mail invitation to national and local breast cancer support groups. Recruitment appeals were made to support groups on social-media platforms. An in-person recruitment appeal was also made at local Sister's Network gathering, a national African American breast cancer survivorship organization. Each participant received a \$20 department store gift card incentive for participating in the study. 100% (25/25) of participants recruited completed the study.

Data Collection and Instruments

IRB approval was sought prior to data collection. Participants gave written consent for participation in the study which involved completing written questionnaires and a semi-structured interview. Interviews lasted approximately one hour and focused on coping, meaning-making, encounters with medical providers, and social supports. Each interview was audio recorded and was conducted either in person, through video-conferencing, or by telephone when the other options were not available. All interviews were transcribed verbatim for qualitative analysis.

Participants completed a demographic questionnaire with age, marital status, household income, level of education, number of children, employment status, treatment status, cancer stage and type, and time since diagnosis. All paperwork was sent and returned from participants by mail. All participant information was secured in a lock and key physical file and a password-protected computer file.

Data Analysis

Interview data was analyzed using qualitative software NVIVO and coded for recurrent theme. A two-stage open and axial coding process was used to analyze the data consistent with grounded theory. The lens of resilience and sense of coherence was used to help interpret generated themes that reflect unique experiences of Black women and acknowledge their multilayered experiences of race, gender, class and social position.

Trustworthiness/reliability and validity

Through consultation with an expert qualitative researcher, we determined final themes. I then created a grounded theory map reflecting these results. Two hundred initial open codes of themes were generated from line by line review of each interview transcript. These initial open

codes were reviewed and grouped into eleven axial clusters groups. After further review, this clustered data was finally grouped into five main categories with seventeen subthemes of data reflecting protective factors and risk factors reported by African American survivors. This paper focuses on the protective factors. This extracted data was then analyzed to generate an inductive explanatory model of the social phenomenon of how Black women experience and cope with a breast cancer diagnosis.

Three of the final five categories of data describe major resource/protective factor themes of Inner Resilience, Environmental Resources, and External Motivating Purpose. This study explores findings of protective factors for African American breast cancer patients.

Inner Resilience

Themes representing Inner Resilience included spirituality, cognitive reframing, personal agency, and racial socialization.

Spirituality. Findings in this study were consistent with previous reporting in that most women endorsed belief in God as a significant part of their recovery and also engaged in some spiritual practice such as meditation or prayer. Connection to God helped women surrender a sense of control in a positive way that brought comfort and relief, and facilitated a more peaceful acceptance or “positive yielding” of the challenges brought on by their illness.

You know I felt like at the end of the day God's got the final say over my life . So there was nothing that a doctor could do, nothing that my mother could do...nothing that I could do or my father could do to save my life . I really had to totally...just trust Him with whatever the outcome was to be, whether or not I would have died. -Y.L.

Some things you just don't make sense of when God puts them in your life . Sometimes you don't understand what the master plan of it is but you just try to figure out your little small role in it . And what was meant for you--sometimes when you go through situations--sometimes it's not for you, but for others. - K.W..

Without my relationship with God, I probably would have literally lost my mind. I would literally just been spinning wheels and I don't think I would have been able to take care of myself the way that I have. –F.S.

You know, I never, I never thought it will take me out. I just can say I have faith. So, I feel this is in God's hands. This is bigger than me. Because, some things in your health is bigger than you and either you can have your faith, you trust the Creator who created, knows you better than you know yourself, and you have to trust what He's given to man, which is medicine. –B.B..

As has frequently been reported in the literature, African American women are more likely to use spirituality to cope with stressful life events (Djuric et al, 2009; Everett et al, 2010; Mengesha & Ward, 2012). These findings also hold true for a breast cancer diagnosis (Ashing-Giwa & Ganz, 1997; Gibson & Hendricks, 2006; Lynn et al 2014; Tate, 2011). Religious beliefs, meditation and prayer are among spiritual coping practices Black women report (Djuric et al, 2009). Spirituality is defined as a sense of transcendent, empowering connection within oneself, with others or with God or power greater than oneself (Djuric et al, 2009). Though it has been well documented that African American women often draw on spirituality for coping, this does not eliminate the need for other psychosocial supports (Sheppard, Llanos, et al, 2013).

Cognitive reframing. AA women in this study used various coping thoughts to promote optimism and relieve fear such as “be positive,” “I am not alone,” “God will help me,” “I am a fighter” or “cancer is not a death sentence, just a diagnosis.”

So I mean it is what it is. It's just the way things are. So I mean, it's not like some rare cancer that nobody gets, and you're like, how did I get this? What happened? It just, it is what it is. –K.J.

I know who I am and whose I am. God is not looking at my boobs. He's looking at my heart so it doesn't matter whether I have them on or not. I know who I am. –H.J.

That's why I'm still here. That's my number one thing. That's how I dealt with the breast cancer. I still remember when I got diagnosed. Most people cry and get emotional, I just said, "God got this," and "What's the next step?" Because I knew God had me. So my faith and my spirituality is the center of everything. And that's what helped me through

my journey, and that's how I was able to stay positive and be a light for other people that I would meet at the treatment center. People I would meet that, they couldn't believe I had cancer, because my attitude was just so positive, so happy. I smile all the time.—C.G.

I kind of prayed and talked a lot about it. And He let me know I love you all right. So I mean it was like a peace came over me and that peace...helped me to make it through the journey without a lot of stress.-D.C.

Personal agency: AA women in this study often used an assertive “take control” coping style in which they were proactive about seeking information and treatment options from their doctors or other sources. Women valued making empowered and informed medical decisions for themselves in consultation with medical providers. Personal agency can help combat feelings of helplessness associated with a cancer diagnosis Shapiro et al (2001).

When I was diagnosed, it was like I accepted it once I felt like I got over the initial shock and everything. I went through, like I said, my silent spell and everything. It's like, okay, I've accepted what has happened to me. Now, it's like I've got to go on and figure out how do I take care of this? –R.A.

So the more I educated myself about breast cancer, of what was actually happening to me, what was going on, that gave me peace and then that it gave me also better peace to know that God is in control at the end of the day anyway because I'm not in control of any of that. -- K.W.

I never blamed it on God. There was... I mean, he wasn't going to save me. It was going to be me and my medical team. –G.H..

I'm very motivated. I'm not shy at all. If I had questions, I needed some help, or whatever, I'm going to seek it out. I'm going to find a resource. I did a lot of research myself online...I would have a list of questions. I just always tried to stay on top of things, and I kept a notebook with questions, or side effects, or anything abnormal that was going on with me, that I could ask the doctor, and things like that.---C.G..

Get a handle of this now. Know what's going on with you. Start making your own decision. You can listen to what the doctor's say but you need to know for yourself. Read, do research, talk to other women, and don't just go with anybody's flow. Don't just say, 'Oh okay this is what you're going to do to me and this is what's going to happen next.-F.S.

I had done my homework. It was a very wise decision on my part even though I may only have needed radiation to have that foresight to want chemotherapy was a good decision on my part.—A.P.

I feel in control of this sense of understanding of what works for me and my body-.E.L.

Overall, participants were satisfied with their medical care once diagnosed, reporting few perceived barriers related to discrimination or other difficulty interacting with medical providers. Almost half of participants, however, described delays in their initial diagnoses when their cancers were not initially recognized on mammograms or were inaccurately dismissed as benign tumors on exam. Several participants attributed their personal persistence to saving their own lives. Attunement to one's own body and body changes was another element of assertiveness about getting diagnosed:

I did my mammograms faithfully...Before I left my exam I said 'You know I have a lump somewhere...So I showed [my doctor] where it was . She said if I hadn't have shown her, she would have missed it...it's probably been there a year or two but it never showed up [on the mammogram]. I had to get two biopsies [to conclusively diagnose].-P.O..

The doctor did a mammogram . They didn't see anything... I had an ultrasound. I had to actually show them where it was which was crazy to me . But the guy that read it said Well I'm pretty sure it's a fibroadenoma [benign fibrous tumor] ...Come in two weeks and we'll do a biopsy .And I said no . We're not doing that . We'll be here tomorrow . Because I'm not . I'm not waiting two weeks . So fortunately the [doctor] that was there the next day, she did everything over again...And did a biopsy in office that day.. For financial reasons or whatever commitments , I think when something comes up we may feel a little less, we may not be assertive enough to say, 'No it doesn't sound right to me . I think I'd like to push forward to the next step or oh if you can't do this then refer me to someone else and our concerns are dismissed sometimes you know. So we need to be able to talk to each other . To encourage each other to stand up .—D.C..

I said 'Hey I feel a lump in my breast and a lump in my right arm.' She [my doctor] said, "Okay I'm going to send you to get screened." I went to a local screening place, breast cancer imaging. I had a 3D mammogram done on my breast and ultrasound. They told me it's calcification and you have dense breast tissue. Come back in six months.... A few weeks later I found there were lymph nodes under my arm...so the lump I was feeling a year earlier spread to my lymph nodes under my arms... When you feel it and if it's palpable, you request an MRI and you don't follow a doctor's advice. You request an MRI. If I had known then, I would have requested an MRI...so that gap just didn't make sense to me. So I wondered what happens if there is a woman who doesn't get how

serious the disease is. Maybe she comes from a different background or culture. Maybe she is not knowledgeable. What happens to that woman who's just sitting waiting for the doctor to call? So I do believe it was race. —F.S..

I used to be a B cup and, when I was 35, my breasts started growing really quickly. So I was always cognizant that maybe something was up. I had talked to my doctor, he said everything looked fine. But I was still getting checkups. And nothing ever showed up on the mammogram. After my husband was diagnosed [with cancer], we were being intimate and he noticed a lump. And I went in for another mammogram, it never showed...until [another] physical exam.—G.H.

I think in the beginning I took for granted, I just, you know, went to the doctor for everything and you know if I just waited here until the regular insurance shows you don't get a mammogram until you're 40...I would've never made it.—C.Y.. (diagnosed at age 37)

Participants expressed regret whenever they felt denied a treatment option about which they were less informed or did not know was an option:

In the beginning, I was like an obedient child. Now, I am more of a challenging adult. You want to do what, and you want to do why, what are the effects of... I questioned everything now, because I realize that I had options that I gave my doctor the power to make the choices, whereas I could have made other choices.—O.P.

Personal agency also included sub-themes of adopting healthy habits such as exercise and yoga in recovery, setting boundaries for self-care, reducing stress, and coping through staying busy and active.

Racial socialization: Positive cultural messages about themselves as black women reinforced resilience for participants. These messages included beliefs that enduring struggles as a culture has made AA women strong and equipped them to handle adversity. Related to these messages were women's tendency to report using personal strength to push through their health challenges.

The one thing I've said is that cancer really don't stand a chance against me because I've overcome so many other obstacles. Well, I'm ready for whatever comes next. Not wishing anything horrific but it's like, okay, what's next? This is just something that happened.—W.D..

This quality served to support resilience but may also have contributed to help-seeking barriers and conflicts around personal and cultural narratives of independence and strength. Racial socialization messages also highlight a purpose-driven perspective that challenge can be transformed into a positive contribution.

But the strength that we have in knowing and understanding how we're treated differently and all of that stuff, I think gives or has given me the fuel to even go harder...You know as a woman of Color . What has been instilled in me also makes me really go hard for my community. All of that has given me the fuel, to be the voice [for others].-Y.L..

Environmental Resources

Environmental resources included relational supports such as family support, community support, support group and survivor mentor networks. Other significant environmental resources included medical resources and financial resources.

Relational support. All AA survivors described importance of support from family and community members. Many reported support from their church community for offering visits, preparing meals, and sharing prayers. Family members were vital in providing help with chores, accompanying survivors to medical appointments, or sometimes providing financial support. Many described their family members as “fighting with them,” sharing messages that supported their resilience, and sharing some of the recovery burden with them. AA especially appreciated proactive family support—especially assistance offered without being solicited. This action helped participants overcome identified internal help-seeking barriers such as fear of burdening others or being judged as overly dependent or weak.

I still struggle with that. I still struggle with allowing people to... I'm tired but I don't like asking people for help.-F.S.

My mom is my best friend and so she was extremely supportive . You know . I mean I actually moved in with her. So there was nothing that I needed that you know I could not get from her if I needed it but I still felt strong through most of it .

I would say it kind of actually brought my family back. Maybe closer, because like I said, my family, they was there for me. I told you my sister is a doctor. Family made sure I went to my treatments, took me to my surgery, just whatever I needed, they were there. Cooking meals. Especially my mother, she cooked meals for me.—C.G.

And so what are those weapons that I chose to fight with you know having my family around as a support team.—Y.L.

My faith communities smothered and covered me . They made sure I had food to eat. If I needed to get out, they would come and take me out...even my work family. They were bringing food over and coming by to visit. I have a lot of support I have a good support system .-H.J.

Many participants noted that their cancer diagnosis brought them closer to family members, and especially closer to children. Eighteen participants were mothers. 10 out of 25 women diagnosed under age 50 years were caring for young children during treatment. While these women reported extra caregiving-burdens, they described their children as a significant motivating force. They wanted to live to see their children grow.

You know I just I'm grateful . I look at the girls and I'm grateful I'm still here to do that and be mom and watch them grow and do silly weird stuff to experience the world around them. I mean the girls got me through 90 percent of the way through a lot of it.—G.R.

And my whole thing was my son was three and a half at the time. And I'm like I least have to make until he's 18. —G.I..

I always say I want to make sure I see my babies graduate Yes high school and that just happened . Now I'm shooting for you know retirement in five years and being able to just travel and not worry.-C.Y.

Older participants had the added resource of support from their older children who could assist with driving, navigating medical appointments, caregiving and errands.

Certain people I have that one-on-one relationship that I can just say, "I need some help. If you don't mind, would you come help me?" That's like my children. When I call them, "Well if you don't mind, what are you doing today? If not, can you help me do this and help me do that?-H.J.

But yeah, my two sons, they were here for me in chemo treatment, whatever I needed. Somebody to clean the house.—C.G.

And then I had my daughter right there with me at all times with all my treatments. They're a very good support, my family.—N.A.

Spousal Support. Eleven participants were married during their diagnosis and treatment.

Married participants reported both support and constraints with presence of spouses. Spouses provided support navigating the wealth of information and treatment decision-making. Spouses also helped with practical caregiving, such as transportation to appointment and doing household chores. Spouses were also sources of emotional support and encouragement.

And so my husband grabbed me by my hand and he says 'honey we're going to get through this'. – D.C.

And then he was there and he was an advocate. So he went with me to the doctor's appointments, asked questions, and stuff...Because I knew he understood and we were on that journey together. So that that was the most helpful.-G.H.

So that is what really keeps us [my husband and me] strong, because we talk.-B.B.

Of note, as many as reported support in the presence of a spouse, also reported aspects of relational strain, such as when partners experienced emotional stress coping with their illness, were emotionally unsupportive, or needed caregiving due to their own health challenges. Two participants concurrently cared for spouse also diagnosed with cancers at the same time of their own diagnosis.

Support groups. Support groups served as an integral part of recovery for most women in this study. Support groups offered important emotional support, information-sharing opportunities and social support. These groups also offered reliable understanding of the experience of breast cancer when participants were concerned they might burden others, who might not fully appreciate their experience. Support groups, in particular Sisters Network, a survivor support group focused on black women, provided an avenue for giving back to their community and embracing a larger meaning from their health challenge.

Oh I think support groups are very important, at least for me it is through the challenge and I went because I wanted to talk to survive, I wanted to release the feelings and the thoughts and the things that I was going through and that I was not alone...you know they can give you encouragement and help you through your journey and that's what we do we help and we help each other, boost each other up.-M.C..

So I think that I'm drawn to getting that comfort from women. I call the Sister's Network my group of wise women. They don't even know that. I love being in their company even if it's traditionally an older woman's disease, so it's a group of very wise and mature women. And even if we're not talking about breast cancer, I get something from being in their company. I think that's one of the things that I ... I guess if you could say enjoyed about this disease, but that's one of the things I've enjoyed and something that I've gained.-F.S.

Because we need an outlet to assemble and be understood by others in the same situation or someone who can be empathetic or someone who is not tired of talking about it . Sometimes you can kind of burden your family and friends because it's like when you're done with treatment you're done with everything. 'Why are you still talking about that. What's the deal?'... So it's important to reach out or to be a part of other groups who are not ever burdened with that.-K.W.

Support groups are wonderful. Especially you have people there you may not have gone through the same thing, or you may, in a conversation say, "Well, I was really constipated but I used such and such a thing natural that I tried to," say just for instance I drank prune juice every 12 hours. Just interacting with other people during their journey and the conversation with them.-N.A.

For those who chose not to be active in support groups, having a survivor mentor-- someone further along in recovery--to offer encouragement, support, and advice was significant. Survivors reported that having survivor mentors and support group members who were also AA added another dimension of support.

Being in touch with a survivor is crucial, and a survivor that is confident, strong, accepting that this is more of a blessing than a curse...-O.P.

I had a male friend, his wife had gone to breast cancer and she had a mastectomy and when I told her about [my diagnosis] she actually showed me her breasts. And somehow her being so forthright with it just made it seem like 'oh, no big deal' a little you know...I'm thinking, 'oh my gosh you know--she's fine.'-D.C.

When you're around somebody that looks like you and going through the same thing you're able to talk and kind of let down your guard a little bit .-C.Y.

Medical resources. Overwhelmingly participants reported satisfaction in the medical care they had available to them after diagnosis and during treatment, sometimes describing medical doctors (radiologists, surgeons, oncologists) and staff as their advocates and part of their team. Participants valued doctors who were not rushed to hear them, respected their own treatment decision, demonstrated care, or even prayed with them. Other integral medical staff mentioned were nurses and nurse navigators who assist patients in managing the multiple medical specialist visits throughout treatment.

I never blamed it on God. There was... I mean, he wasn't going to save me. It was going to be me and my medical team.—G.H.

I love my health care providers. Everyone last one of them. I love them to the moon and back, they have been such a great resource.—H.J.

I have to give credit also to the providers my health care providers, they've kept me going.—A.S..

My oncologist said here's what we can do to reduce that 25% of recurrence. I love my team. I do. Everyone's not as personable as he is but to me they're just as caring as he is. He's awesome. He's awesome.—F.S.

Very positive. Very positive. They're receptive. They are supportive. They're available 24/7. But that's because they've demonstrated extremely... A level of compassion that I normally don't see, and they made sure that I have a top notch doctor. The chief oncologist is my oncologist. The chief surgeon, a breast surgeon, is my surgeon. And I just feel good.—W.D.

I have no complaints at all. I felt like they were responsive, and helpful, and they treated me as a real person. That's how I felt throughout my treatment. I never felt like they don't really take me seriously. They're not listening to my concerns. If I called, I got called back, if I had concerns, and those types of things.—G.I.

So, they're all very, very accommodating. I felt like I was in good hands, which I have been for 18 years in good hands. Evidently everything they've done has worked well for me.—R.A.

I got a call from the surgeon on Thanksgiving talking about, he was reviewing things and he just wanted to call me and let me know everything was going to be okay. And I was like, "What?". I said, "Thank you. I needed to hear that." He was like, "You're going to

be just fine. Everything's okay, I just wanted to touch base with you and just let you know.' I said, 'On Thanksgiving?', he said, 'Yeah, and happy Thanksgiving.' And while I was talking to him, my mother had buzzed in on the other line...My doctor and my mom at the time that I needed comfort called me..I told my husband, 'Things are going to be great because God let us know He's thinking about us and He sees us and He put us on someone else's heart. He put us on the doctor's heart and He put us on my mom's heart at that time. So I call it the Thanksgiving miracle.—B.B.

All women advocated the value of mental health care for support during treatment. Only five participants disclosed having visited a mental health provider for support during their breast cancer journey. Barriers to treatment included cost, coordination and time, but stigmas to using mental health treatment were not explicitly endorsed.

That's the first thing [mental health care] that most survivors let go, and that's the thing that they need the most. That should be... I think somehow it should be worked into whatever the cost is, that it should be not a financial burden because fewer people are seeking it out so that is why support groups are very important, because you need to have someone there that says, "Oh, it's okay. It's okay. You can cry in this group, and what you say in this group is to going outside of this group.—O.P.

I actually found someone else when I finished treatment and I liked her...I liked it so much that I traveled like 30 miles to go and see her . Once a month . Yeah that was very helpful...I don't go to support groups but I'm open to therapy if I have issues .-D.C.

Anybody who's been through any trauma, cancer is trauma. I think you need to talk to somebody. You need to talk to somebody. Because if you don't talk to somebody it can really hurt you. It can drive you crazy. It can put you into depression.-B.B.

Nothing wrong with going to talk to someone. A counselor, a therapist, psychiatrist, whatever you want to call them, whoever you want to see. There's nothing wrong with going to talk to someone to help you sort out your thoughts, your feelings, especially someone like me, that has hormones raging...Yes, well I think there's a need for counselors, especially those who specialize in breast cancer or chronic illnesses, so there's a role for that...-C.G.

Financial resources. Financial resources that benefited AA breast cancer survivors were insurance coverage and supportive workplaces that accommodated missed job time. Some women found aid resources such as the Cancer Fund or other groups to help with mounting costs

of co-insurance payments for multiple doctor's visits. Financial impact from their cancers varied depended on income level, insurance, job and benefits available to survivors.

I'm blessed in terms of my job, my salary . So I haven't needed any great financial support, I haven't had any issues financially so I haven't used any resources other than my job...My benefits are amazing. F.S. (judge)

I think again because I was insured as well .Personally I didn't need any thankfully grateful so I didn't have any challenges in the area. K.W.

My insurance was really good so I didn't have any financial problems at all. Everything was taken care of, treatments, surgeries, and even time off work and everything. I think that part, the financial part, was fine as far as I'm concerned.-H.J.

But it's so expensive to take care of yourself and to continue to go to doctors even with insurance ...there are so many you just can't afford to keep going to all of them.—E.L.

External Motivating Purpose

Most survivors sought meaning and purpose in their cancer journey through educating family and community members about breast cancer and preventative care or through mentoring other newly diagnosed patients. Participants expressed a desire to address a cultural tendency toward silence about cancer, chosen to be more open about their experiences to dispel shame and myths about cancer. Support group networks and churches provided a medium for this type of contribution such as through walk-a-thons, fundraising, door-to-door community educating campaigns about early detection, importance of body awareness, and through community talks. Women described optimism through seeing their breast cancer journey as an example or testimony to inspire and uplift others.

100% 100% this is totally a faith journey for me, a faith walk to me. I am truly encouraged that I'm going to be able to add to my testimony. --W.D.

And will continue to be, I think that's been my biggest help, because it keeps me busy. It still gives you a purpose that you have a big purpose, and you have an obligation. I don't want to say an obligation to others to make sure they understand the seriousness of the disease.-R.A.

Then I've gone to and I'm a part of Sister's Network. I'm a helps person. I'm a giver. So for me it was ... because Sister's Network is not necessarily about the therapy but it is therapy because it gives you an opportunity to give back. It gives you an opportunity to be in the position where you can educate others and develop the relationships where if you meet someone that does need to call you and cry in the middle of the night, you can be there for them.-F.S.

As a [support group] community were able to go out and do the walk and go to neighborhoods knocking on doors you know making sure people know about breast cancer awareness and breast health.—A.S.

I think that's been my biggest help, because it[support group service] keeps me busy. It still gives you a purpose that you have a big purpose, and you have an obligation. I don't want to say an obligation to others to make sure they understand the seriousness of the disease.-R.A.

Sense of Coherence. Sense of coherence reflects confidence that one's inner and outer environments are structured, and predictable, and a belief that necessary resources will be available, and that challenges have meaning and are worthy of engaging. Comprehensibility, manageability and meaningfulness are three aspects of sense of coherence (Boscaglia et al, 2007). Sense of coherence is associated with the existential belief that life has order and purpose (Vickburg et al, 2000). Breast cancer increases psychological and social distress and uncertainty. Breast cancer survivors who reported high levels of sense of coherence also had greater hope and spiritual coping which positively influence their emotional well-being (Gibson 2003). Sense of coherence is a survival resilience strongly linked to health and has been identified across diverse study populations regardless of sex, ethnicity, nationality or age (Eriksson & Lindstrom, 2005).

Inner resilience corresponds with comprehensibility constructs of sense of coherence. Environmental resources reported in this study align with manageability constructs of sense of

coherence, or belief that external resources exist to help an individual respond to a crisis.

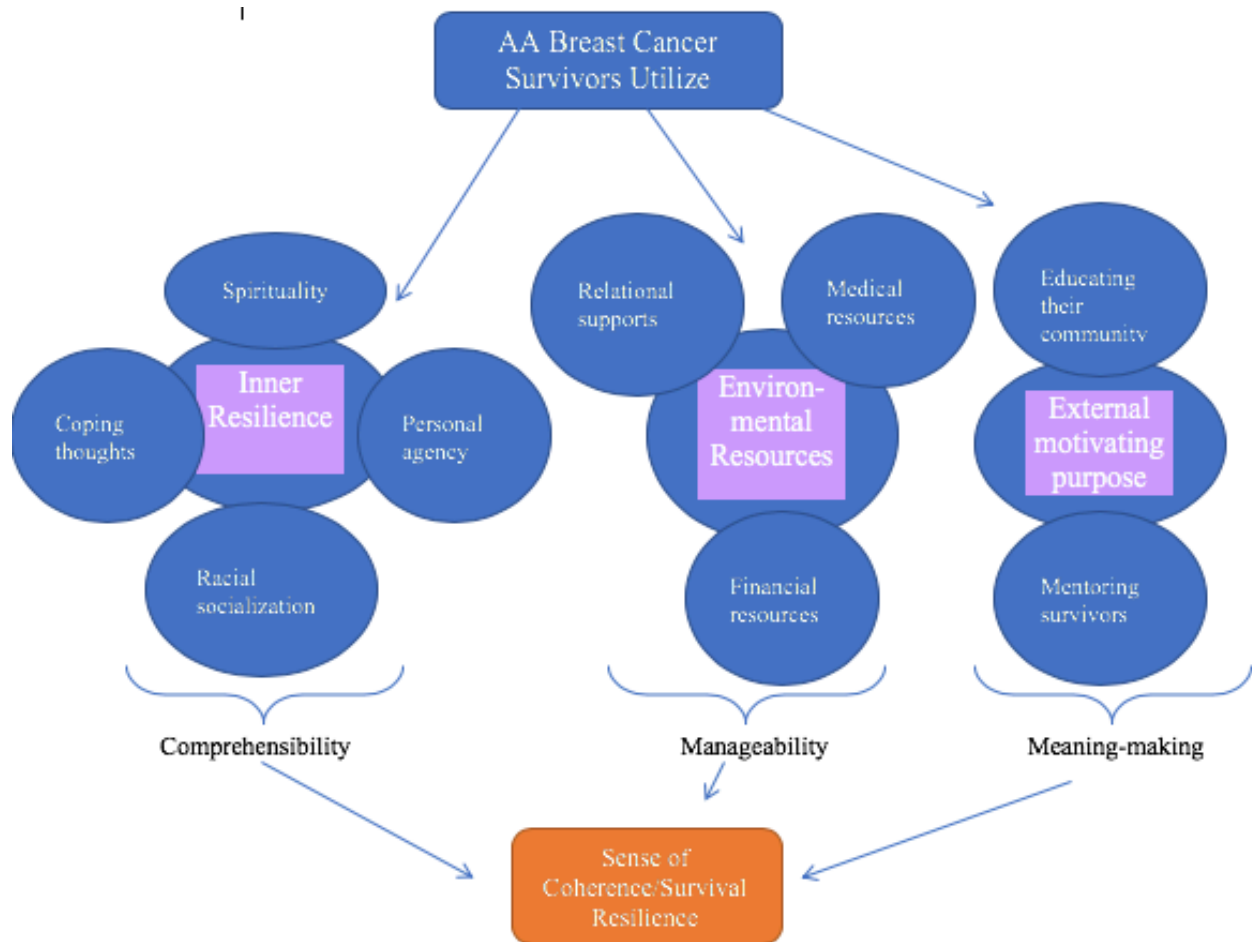
External motivating purpose through service to others, often expressed through support group involvement, reflects meaning-making aspects of sense of coherence.

Recovery Restraints

Women also described individual and environmental risks to their recovery. These included emotional distress, help-seeking barriers, limited self-care and physical distress as a result of their diagnosis. Environmental risks included financial or insurance insecurity, medical mistrust, cultural silence about cancer, and relationship or caregiving strain. These recovery challenges for African American breast cancer patients will be addressed further in a separate paper.

Based on these results, a grounded theory map of resilience for breast cancer survivors was generated. See Figure 1. Grounded Theory Map: Sense of Coherence as Survival Resilience.

Figure 1: Grounded Theory Map: Sense of Coherence as Survival Resilience



Discussion

AA cancer survivors use inner resilience, environmental resources, and external motivating purposes to cope with their diagnosis. Spirituality, social supports, positive cultural messages, personal agency and assertiveness, medical and financial resources and serving others all make up resilience and coping means for this group. Social support from family, spouse, children and community is particularly integral to navigating recovery during a time of physical and emotional vulnerability. Though having a spouse offers potential for close support, it does not necessarily guarantee existence of such support if partner is unwilling, unavailable, or himself needing care.

Conclusion

In total, these coping supports relate to sense of coherence concepts of comprehensibility, manageability, and meaning-making and can serve as buffers against individual and environmental risks to African American's women's recovery. This group also reported categories of individual and environmental risks which challenge their recovery, including emotional distress and cultural silence about cancer. Inner resilience coping related to personal agency was an instrumental strategy for successful diagnosis in almost half of women interviewed and may have contributed to their survival.

Implications for Medical Providers, Patients, and Mental Health Professionals

Supporting African American women's empowerment and participation in their medical care is one strategy to buffer the stress, fear and uncertainty that follows a cancer diagnosis. Involvement of patients in support groups with other African American women provides valuable social and emotional support, information, and mentoring through treatment. Beyond educating women about early detection, encouraging them to trust themselves and their bodies

and insist on follow-up tests when findings are inclusive, may be important. Getting both doctor and insurance for additional conclusive testing when warranted, may pose additional access and treatment issues in this population.

Available resources for financial support as needed relieve a common stress for many AA women going through treatment. About half the women who participated in this study attained graduate or professional degree education levels and had middle to upper income ranges, supporting their financial security through their health crisis. The majority carried private employer-based insurances. Though several women reported some financial strain, this population may be better off than other women with less education or resources. Additional studies examining the protective factors and risks of women in poverty may offer more information for a wider range of women.

Limitations and Future Directions

A large percentage of this study sample came from a support group network which may have overemphasized the value of participating in support groups. Almost all participants, however, endorsed the value of support from other cancer survivors, whether they or not they were active in a formal support group. Further study should examine if African American women are disproportionately discouraged from follow-up testing or encounter other treatment barriers after an inconclusive mammogram or self-exam.

CHAPTER THREE: STUDY TWO

STUDY TWO: Psychosocial Risk Perspectives from Young and Older African American Breast Cancer Survivors: A Qualitative Study with Implications for Practice

ABSTRACT

Background/Objective: To understand reported psychosocial risk factors for African American breast cancer patients through a qualitative, grounded theory study and identify modifiable individual or environmental risks.

Methods: 25 African American breast cancer survivors ages 41-79 participated in a qualitative study. Age at diagnosis ranged from 31-70 years, with mean survival time ranging from 3 months to 24 years. Women participated in a semi-structured interview format. Research data on current depressive and distress symptoms was gathered through two assessments, the Patient Health Questionnaire (PHQ-9) clinical screen for depression and the National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) designed to detect psychosocial distress in cancer patients. These screens are valid and reliable in diverse populations. This study was guided by the following primary research question: *What are the psychosocial risk factors for African American women with breast cancer?*

Results: Verbatim interview transcripts were analyzed using the qualitative software NVIVO and labeled for recurrent themes through open and axial coding process aligned in accordance with grounded theory methodology. African American cancer survivors reported individual and environmental risks in the categories of emotional distress, help-seeking barriers, medical mistrust and cultural silence about cancer. Younger women reported greater distress regarding relational and caregiving strain, negative impact on social network and functioning, and distress related to body image and fertility concerns.

Conclusion: African American women report multiple individual and environmental risks in their recovery from breast cancer. Younger women reported greater distress related to their social functioning, sexuality, financial strain, and body image.

Introduction

Survival disparities for Black women breast cancer patients still persist even after accounting for socioeconomic status, stage of diagnosis, earlier screening and standard of care, (Baquet et al, 2008; Bowen, Duffy, Ryan, Hart & Jones, 2008; Dignam, 2000; Newman et al, 2006). Though aggressive forms of breast cancer occur more frequently in African American women than in white women, biological differences cannot fully account for existing survival disparities. A recent NIH National Cancer Institute study of tumors from African American breast cancer patients found few genetic differences in breast cancer between blacks and whites after adjusting for the frequency of different breast cancer subtypes (Huo, Hu, Rhie, et al, 2017). These recent findings warrant greater understanding of the impact of other contributing factors, including psychosocial dimensions, on recovery and survival. The National Comprehensive Cancer Network and the Institute of Medicine have issued new quality standards for integrating and addressing the psychosocial needs in cancer patient care. These standards include: determining modifiable risk factors for intervention, promoting quality of life and survival, and reducing stress and depression during recovery (NCCN, 2003; IOM, 2013).

Young black women are underrepresented in breast cancer research (Bonner et al, 2015) and also carry the highest mortality burden of all women (Baquet et al, 2008; Campbell, 2002; DeSantis et al, 2016; Williams, Mohammed, & Shields, 2016). The purpose of this study was to understand reported psychosocial risk factors for African American breast cancer patients through a qualitative, grounded theory study and identify modifiable individual or environmental

risks. Some distinct differences in reported risks emerged between African American survivors who were older and younger than 50 years.

Methods

Twenty-five African American breast cancer survivors ages 41-79 participated in this qualitative study. Age at diagnosis ranged from 31-70 years, with mean survival time ranging from 3 months to 24 years. Women participated in a semi-structured interview format.

Research data on current depressive and distress symptoms was gathered through two assessments, the Patient Health Questionnaire (PHQ-9) clinical screen for depression and the National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) designed for detecting distress in cancer patients. These screens are valid and reliable in diverse populations. This study was guided by the following primary research question: ***What are the risk and protective factors for African American women with breast cancer? This article will focus on the risk factors.*** This study used a qualitative, grounded theory methodology.

Inclusion and Exclusion Criteria

Inclusion criteria for this study was self-identified African American women ages 18 and older diagnosed with Stage I, II or III breast cancer, who could speak and read English, and who are able to give written consent for participation.

Sampling and Recruitment

Participant recruitment occurred through flyers distributed at a hospital breast cancer awareness fair, local hospital nurse navigator referral, through a local breast cancer treatment clinic, and through e-mail invitation to national breast cancer support groups and support groups on social-media platforms. Each participant received a \$20 department store gift card incentive for participating in the study.

Data Collection and Instruments

IRB approval was sought prior to data collection. Participants gave written consent for participation in the study. Interviews lasted approximately one hour and focused on coping, meaning-making, encounters with medical providers, and social supports. Interviews were audio recorded and conducted in person, through video-conferencing, or by telephone when the other options were not available. All interviews were transcribed verbatim for qualitative analysis.

Additional measurements

The following instruments have been found to be reliable in studies with diverse populations (Conway-Phillips, 2014; Tang et al, 2011). These screens were used for descriptive purposes to better understand participants' emotional and psychosocial distress during their breast cancer journey.

- **The Patient Health Questionnaire (PHQ-9)**, 9-item self-report screening tool of depressive symptoms
- **National Comprehensive Cancer Network Distress Thermometer and Problem List**, zero to 10 scale, screening tool for measuring psychosocial distress in cancer patients. (NCCN, 2013)

About one third (8) of survivors endorsed 1) mild to moderate depressive symptoms based on the Patient Health Questionnaire, 2) reported clinically significant distress scores, and 3) listed 10 or more current psychosocial problems of concern on the NCCN Distress Screen. Survivors diagnosed at younger than age 50 reported the highest Patient Health Questionnaire-9 depression screen scores and NCCN Distress scores. These younger participants also listed the greatest number of current psychosocial issues (see tables below).

Table 6: Patient Health Questionnaire Score, Self-report of Depressive Symptoms

Age at Diagnosis	Score of 5-9 mild depression	10-14 moderate depression	15-19 moderately severe	20-27 severe depression	<5 none
<50 years (N=16)	4 (25%)	2 (12%)	0	0	10 (63%)
>=50 years (N=9)	2 (22%)	0	0	0	7 (78%)

Table 7: NCCN Distress Thermometer, Self-report of Current Psychosocial Distress

Age at Diagnosis	Distress score > 4 (clinically significant distress range)	Distress score < 4
<50 years (16)	5 (32%)	11 (68%)
>=50 years (9)	2 (22%)	7 (78%)

Additionally, a demographic questionnaire collected data on age, marital status, household income, level of education completed, number of children, employment status, treatment status (whether in treatment or remission), cancer stage and type.

Interview data was analyzed using qualitative software NVIVO and coded for recurrent themes reported. A two stage open and axial coding process was used to analyze the data consistent with grounded theory.

Trustworthiness/reliability and validity

Through consultation with an expert researcher, we were able to determine final themes. I then created a grounded theory map reflecting these results. Two hundred open codes of themes were generated from each of 25 interviews. These initial open codes were reviewed and

clustered into eleven axial clusters groups. After further review, this clustered data was finally grouped into 5 main categories with 17 subthemes of data reflecting protective factors and risk factors reported by African American survivors. This extracted data was then analyzed to generate an inductive explanatory model of the social phenomenon of how Black women experience and cope with a breast cancer diagnosis. This study focuses on two of the final five categories of data representing categories of Individual Risks and Environmental Risks.

Data Analysis

African American breast cancer survivors reported individual risks to their recovery related to emotional distress, help-seeking barriers, physical distress from their diagnosis, and limited self-care. Reported Environmental Risks included medical mistrust, financial and insurance insecurity, relational strain, and cultural silence about cancer. Younger women reported greater relational and caregiving strain, including negative impact on social network and functioning, and emotional distress related to body image and fertility concerns.

Individual Risks

Individual risks included help-seeking barriers, limited self-care, emotional distress and physical distress caused by cancer diagnosis and treatment.

Help-seeking barriers. Most participants endorsed some form of barrier to asking for help during diagnosis and treatment. A central barrier was a strong belief in independence, that one should do as much as possible without assistance for as long as possible. Some other barriers to help-seeking included fear of judgement from others or belief that participants should no longer need help once surgery or treatments have stopped. Many identified not wanting to burden others, fear of rejection or satisfaction in their own independence. Women often concealed their diagnosis from friends and some family to protect their own privacy or concern that others would not

handle their diagnosis well. Some women felt that sharing vulnerability would be perceived as weakness, particularly in Black communities. Some participants described positive cultural messages of being strong and resilient as a double-edged sword. There was sometimes conflict between narratives of independence and personal strength through challenges, and their actual need for help:

I'm really independent and a lot of times you can't count on family to be there as much as you need them to be. They just don't understand a lot of the trauma is directly related to them and their experiences. So we're also dealing with family issues and the stress of life. And so it helps to have an external support system.-W.D.

I think it is a twofold blessing/curse kind of thing. Where it continues so allow me to keep moving forward because I know the expectation level is there [to be a strong black woman] and I want the expectation. And then again, sometimes the demand is too much.-E.L.

Maybe shame would come up, like a feeling of shame like I feel bad that I have to actually ask for help now.-E.K.

And I think sometimes you're just generally, you're worried about the response from people. I mean even now I'm way better at it but it is still very hard for me to say I need help.-G.R.

I guess for me somehow I'm scared of rejection. I'm like, I gonna give it everything I've got [before I ask for help].-P.O.

Limited self-care. AA survivors described often putting themselves last and prioritizing the caregiving of others. Younger survivors raising small children at the time of diagnosis had added caregiving burdens.

I didn't put a priority on it. I realized that most African-American women have priorities other than themselves, and we find out at a later stage than most, because we do not do annual breast exams, or monthly breast exams. We don't listen to our bodies. Talking to a lot of African-American breast survivors, we put ourselves last in any relationship or priority. I think that the world does too.--O.P.

I know the importance of taking care of yourself. But then again being a nurse, being a woman you tend to even though you're taking care of myself but I kind of put myself on the back shelf too many times...historically women have always taken care of everybody.

You want to nurture everybody in the family. They have not taken care of themselves . You know when something did happen to them they didn't want to talk about it because it's a sign of weakness . It was something to be ashamed of.—A.P.

Make sure that you pay attention to your body . You know sometimes your bodies give you signs that something is wrong . And you do have to listen and touch and feel and be connected to your body and stuff . And be proactive and do something about it, you know.—M.C.

Emotional distress. African American survivors described emotional distress in dealing with their diagnosis, described as sadness, anxiety, fear and loss. Women experienced overwhelm navigating the treatment process, multiple appointments and managing job and home life. Some participants also experienced anxiety, fear and vulnerability about possible recurrence:

It's just there's always an uncertainty about it. you know each year you go for your mammograms and you think 'I wonder if it's coming back.' So you you're really on high alert at all times.—G.B..

I didn't realize the emotional and the physical and that it's a forever journey. It's never over. You journey the cancer walk all the way until you leave this earth, because the possibility, once you've had cancer, your chances are...having it again.—O.P.

I think I'm more anxious after [my diagnosis] because that's always in the back of my mind, that worry. The, "I don't want to do this again. What if it comes back?"—G.H.

A woman I know was diagnosed with Stage 1 breast cancer and then a year later it came back stage four...I think about me because at any given moment that could be my story, you know. So when I have a pain or when I have whatever, you know, of course you're mind goes straight to cancer.—Y.L.

You know I don't like that word 'remission' because it makes people look over their shoulders for something traumatic and I just don't want to live my life that way.—I.Y.

Women also experienced distress relative to body image such as scarring and, breast loss, skin changes, and hair loss. Younger women frequently described distress over body image, appearance changes and impact on their sexuality, fertility and social life.

Because it kicked me into like early menopause and oh my God, I didn't have any hair. All my hair had fell out...And I was having hot flashes. I never experienced that, I didn't know what flashes were. So they explained it to me.—B.B.

Having had the lows of the side effects just going through it because you hit that low with chemo...it removes all of the estrogen...that's when you go through menopause that's when I learned firsthand what depression is.-E.L.

Several participants described their belief that stress contributed to or caused their cancer and the decisive steps they took to reduce their stress when possible, such as avoiding negative interactions.

When a person stays in fight or flight mode too long then you know things happen within the body. I don't think that the medical field touches on that at all.-E.K.

I believe stress can kill too. I believe stress feeds this disease.-I.Y.

Yes, I have a better sense of what stresses me because I do believe stress was the reason I got sick. So it's as if I have sort of a trigger. So I know when I'm doing too much or I'm getting overwhelmed now. I'm in tune today and I can bring it down.-D.C.

I started deleting stuff out of my life that was stressful. Yeah. I even changed my telephone number.-B.B.

Physical distress. All participants dealt with varying degrees of physical distress related to their breast cancer treatment, including the effects of surgery, radiation and chemotherapy. Lingering side effects such as fatigue, lymphedema and neuropathy were commonly reported.

Yes chemo was very difficult. It was very hard and it was very traumatic . Not only from the physical side, but from an emotional mental side as well. --P.C.

I [still] have a lot of pains, a lot of pains, on an almost daily basis.—E.K.

And then, after treatment, I had a lot of side effects. When you get diagnosed with cancer, everybody's so focused on "Let's try to get rid of this disease" that they don't talk about the afterlife. They don't talk about life after cancer.--C.G.

Well, my body certainly has changed. I have less feeling in my left arm, so I'm restricted as to what I can do with that arm. And the ride of the hormones up and down and off and on was really traumatic. I experienced menopause four times, basically.-G.H.

Environmental Risks

Survivors reported environmental risks related to the following categories: financial and insecurity, medical mistrust, relationship and caregiving strain, and cultural silence about cancer.

Financial/insurance insecurity. Financial stresses for this population included high out-of-pocket costs for treatment not covered by insurance, multiple insurance co-pays and costs of medically necessary items such as health aid equipment, lymphedema sleeves, medications, wigs, breast prostheses, and supplements.

Participants diagnosed younger than 50 years reported more job loss and work interruption with the attendant financial strain of insurance loss and additional financial burden. Overall, younger survivors experienced more financial insecurity.

But it's so expensive to take care of yourself and to continue to go to doctors even with insurance.—E.L.

My financial resources were a struggle...at a hospital I was able to apply for grants and get approved for grants that would pay for certain testing...and then certain medications I got were just pver-the-counter, so I think I was fortunate, considering that I'm looking at one income.—C.Y.

It's messed with things financially because, being put on disability...being sick puts you into a financial situation, with or without insurance.—B.B.

That was rough because at one point I thought I would have to stop the reconstruction just because of of the lack of money...even with good co-pays . It adds up.--G.R.

Compared to some, I mean it was very expensive being a cancer patient. I mean between your copays, between your gas, between things you got, like between compression bras to sleeves. I got breast lymphedema, and I'm going to physical therapy, and it's \$40 a pop with your copay.—K.J.

Medical mistrust: African American survivors described having less medical trust due to under-representation of African American-specific treatments, such as for skin responses to radiation, and lingering wariness about discrimination.

Just, I mean our skin is different. My skin is different as a black woman with breast cancer you know when we bruise...it's a permanent scar...So there's so many layers sometimes that we need to talk about, from caring for your hair to your skin.—D.C.

I wish it was more information on like African-American skin. Because our skin is different ... So like me, I'm going through radiation and it looks like I got a suntan on my right breast versus my left, which they said it's just going to be like that.—B.B.

Sometimes medical mistrust was expressed as suspicion that cancer treatments are unfairly priced with ulterior patient exploitation or money-making objectives. These concerns are consistent with prior research on barriers to participation in research or interfacing with medical resources. These constraints included lack of trust in clinical researchers, concerns of exploitation, and financial and structural barriers (Davey et al, 2012). In this study, medical mistrust and fear of medical procedures were reported as a barriers to participation in clinical trials:

The only thing I would say how [cancer] has affected our race, is that we don't do clinical trials. ...I know different groups try to encourage more people to do clinical trials. But I don't know, I think our people, a lot of it I think is trust. We don't trust. So, we won't do it. We don't get involved—R.A.

And a lot of time as African-American women we are afraid for one to go to the doctor and to you know to have a mammogram...but you know temporary discomfort could really save your life.-H.J.

African American survivors reported fear and mistrust in medicine as a community-wide barrier to survival and early detection. Reported incidents of negative medical interactions, however were few, and related to feeling a medical provider was not compassion or did not listen to the participant, rather than to overt discrimination. Only two such incidents were reported among participants. Survivors managed these by expressing their discontent directly to the provider or replacing that provider on their medical team. Survivors who had African American doctors expressed an added benefit of support:

I don't know if it makes a difference but it did for me. I had an African-American surgeon, a female. She was upset that I received a lumpectomy, so I immediately fell in love with her...She was like, "You wouldn't have known, but I don't understand why." She

wanted to say, "I don't know why they experimented on you." Then she built my [medical] team. I felt so comfortable with her that I let her build my team. –F.S.

Once they began receiving treatment, participants felt overwhelmingly positive about their medical care access, providers and interactions. One participant characterized her experience, however, as a struggle to be seen and heard, relative to her race:

I feel like we're kind of irrelevant. I mean just in the way the world views us . And so it really feels like nobody cares about us. So we have to care about each other ... I just think our pain is not viewed in the same way, our concerns are not viewed the same way. So we really have to dig deep for a medical professional that's going to hear us and take us seriously.--D.C.

Another participant experienced both medical mistrust and confidence in available medical resources, despite racial barriers:

But the resources are there. And I do think that we need to tap into them...on average, we die 15 to 20 years sooner than our counterparts...And so on the surface as a black woman, it looks like we're getting diseases and illnesses more rampantly, and we're being left to die.—W.D.

Relationship and caregiving strain. Participants caring for children without spouses described single-parenting stress of caregiving, greater energy demands during a time of health vulnerability, and needed greater reliance on family members to help such as their own parent or other extended family members. Younger survivors with young children had added caregiving burdens:

I think the younger women, we have a whole different set of issues. Or like trying to go through chemo and potty training your two year old...And you know it really was like a different set of circumstances because older women, if they're with somebody...at that point odds are they've been with that person for a few years...who's going to have their back no matter what . And they have older kids so they have support from that standpoint.--G.R.

I lived with my mom because I was a single parent and I needed all the help I could get in that village. –E.L.

Married participants (11 in this study, 55% of older survivors and 32% of younger survivors) reported both support and constraints with the presence of spouses. Spouses provided support navigating the wealth of information and treatment decision-making. Spouses helped with practical caregiving, such as transportation to appointments and doing household chores. Sometimes spouses were also sources of emotional support and encouragement.

And so my husband grabbed me by my hand and he says 'honey we're going to get through this'. – D.C.

And then he was there and he was an advocate. So he went with me to the doctor's appointments, asked questions, and stuff...Because I knew he understood and we were on that journey together. So that that was the most helpful.-G.H.

However, half of married participants also reported aspects of relational strain, such as when partners experienced emotional stress coping with their illness, were emotionally unsupportive, or needed caregiving due to their own health challenges. Two participants concurrently cared for spouses with cancers diagnoses at the same time of their own diagnosis. Additionally, being married did not appear to correlate with lower depressive symptoms, distress or psychosocial issues.

Relational strain also emerged when family members questioned a survivor's choice of traditional medical treatment or voiced suspicion of its effectiveness. Discouraging messages about others who had died from cancer shared by family or community members was a source of stress for many participants. Desiring to maintain a strong front for family members and protect them from worry projected a sense of looking stronger than participants actually felt.

That's important to me because everybody does not understand my journey. A lot of times people look at you and they think that everything is OK . Oh you look good. Oh God, how good you look. But what is happening is invisible. They can't see it .-P.C.

I realized that your outside appearance can fool a lot of people.-O.P.

So they don't really realize some of the side effects and some of the things that I may be going through, or the pain I may be going through. Or there's certain things...so that's my biggest thing right now. People think I'm acting like the victim [when I talk about my experience] because they don't see me... I don't look weak. You know what I mean? I don't look sick.-C.G.

To be truthful there are some things that people won't be able to give you in this particular journey and that's the hardest thing to sometimes to get through because you really need it. You don't know how to express it. They don't know how to give it... They don't know anything about on the inside. You know, I'm aching because I had not been to the gym for months but I can't talk about that.-E.L.

This phenomenon of looking better than one feels contributed to experiencing lack of support from family members who did not realize that participants still needed help or were still suffering with debilitating effects of their illness. Some participants also felt some family members intentionally turned-away because they “could not handle” their diagnosis.

My relationship with family and friends changed. What I found out some people can deal with cancer or just a diagnosis like bad health...and some people cannot. Like, you have stronger people who want to be there and then you have people that, they just can't deal with it because, they got other things going on or they're in denial or that's just not something that they want to, they don't know how to respond to it.-B.B.

My sister, she just kind of tuned out. She just kind of checked out. She just stopped talking and stopped kind of communicating with me. She's got her issues going on or something.—C.Y.

When I was going through it, I lost some friends who just couldn't handle it. So my circle of friends has changed.-G.H.

Younger survivors were more likely to describe strain in their sexual relationships due to physical impact of treatment such as fatigue, dryness, and pain. Younger participants more often reported a negative impact on social functioning such as from not having others in their social network who could relate to having a severe health challenge and feeling more likely to isolate oneself and greater reticence about dating and fears of rejection. This finding is consistent with previous research showing that older women had more stable social networks to assist them through a health crisis than younger women (Shapiro et al 2001).

And to the point to where it just kind of took my desire. It didn't take away from me wanting to be intimate...It just took away for me even getting into the act of it. In my mind I want to be, but my body would not respond.—P.C.

Where I would feel comfortable being like I want to do something but, I can't do anything. You know, you want to have sex, I'm feeling it, my emotions is there, but my energy is down...Like how I feel, my body cannot make no juices. It can't make nothing [like] how I feel.—B.B.

Now because I had some severe reaction . I developed like eczema on my eyelids . I mean I really looked like a raccoon,. So here I am with no hair, no eyebrows, no eyelashes, and on my eye there's completely dark circles...It was nothing attractive about it for me...At one point I just thought well this is me. This is how I'm going to have to live. I will just check out of things socially. But that was depressing for me.—D.C.

I'm still youthful. I'm still vibrant but I can't have children and I don't have breasts, or I have breasts that aren't mine and they don't look real. I have these scars that you have to explain, so I think that's probably the social piece is a huge difference between younger versus older women.—F.S.

I don't go out like I used to. I was the girl that always went out when I had a social life. And so now I don't do that anymore. A lot of times I just sit in a house...I don't call my friends like I used to... I don't want to share all of what I'm going through with them because I'm just a Debbie Downer. I don't want to be that person.—Y.L.

Cultural silence about cancer. African American breast cancer survivors reported a cultural phenomenon of fear, stigma or lack of information in their community about breast cancer. Several women noted a tendency to avoid doctors, avoiding discussions of family history, and a stigma about discussing someone's cancer as if it were a "curse." Many women dedicated their "meaning-making" activities to educating women, dispelling stigmas, encouraging self-care and self-exams and talking about experiences with cancer as "a life sentence, not a death sentence."

There there's a lot of pride in privacy. Like I was saying what happens behind closed doors stays behind closed doors I think its slowly changing and evolving because I think it's backwards to think that ...If you don't pass on information I know you're not doing your generation your next generation good because they're walking in to a black hole ... and also I just think that it doesn't do us any good today even religiously to think that [cancer] must be a curse or something you've done wrong is the reason why this has happened. That too can play a role culturally.—K.W.

Black families tend to not talk about certain things...There is no shame here but there still seems to be from my perception of it from black communities, still a certain amount of stigma attached to having cancer and that it shouldn't really be talked about, it just should be endured... It's made me be more open about it because I feel like we're too closed now. But as a medical provider it makes me like very open to talk about it with women, very comfortable about it because they shy away from it to a certain extent. And they're like oh I don't need a mammogram. Yes you do... Well let's talk about it. I think it's made me a lot more open as far as that goes--G.R.

I mean you see the commercials, but ain't nobody really talking about it. You know you see somebody post it on Facebook or something like that, or once you have it then that's when to me people start coming forward and talking about it. Like you know I had this and that, she didn't tell her kids, or she didn't tell ... and I just feel like we hide it.—B.B.

Figure 2: Grounded Theory Map: Role of Risk Factors

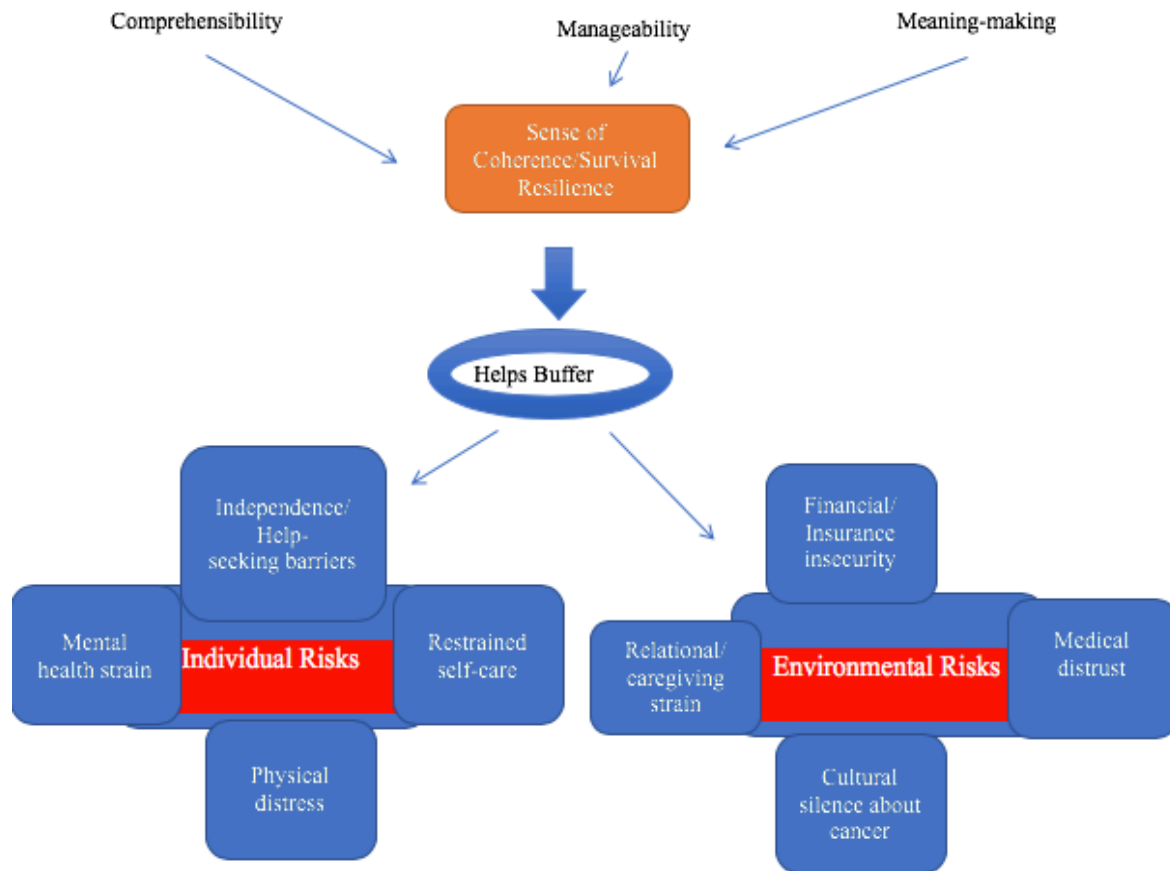


Table 8: Participant Demographics and Screening Scores

Participant	State of Residence	Diagnosis age	PHQ-9 depression score	Distress score	Problem list	Current age	Years survival	Marital status	Stage
G.R.	MI	31	9	7	19	42	11	M	1b
C.Y.	TX	37	3	3	5	50	13	S	3
Y.L.	GA	38	7	10	6	42	4	S	2
K.J.	PA	39	1	2	0	48	9	S	2a
F.S.	NC	40	0	0	0	41	1	S	2b-
D.C.	NC	40	4	5	12	50	10	S	1b
K.W.	TX	41	0	0	2	51	10	S	1
G.H.	MI	42	7	3	11	63	21	M	2
B.B.	MI	43	1	2	6	43	<1	M	2
P.O.	MI	44	14	5	24	43	1	S	2
K.J.	NC	43	0	1	1	61	18	M	2
C.G.	MI	44	11	7	16	49	5	S	2
E.L.	NC	44	2	0	2	50	6	M	2a +
A.P.	MI	45	0	1	1	69	24	D	2a
I.Y.	NC	47	0	0	1	55	8	S	1
W.D.	OH	47	6	1	9	47	<1	S	2b
H.J.	VA	50	0	0	0	58	8	S	1
E.K.	NC	51	5	0	8	55	4	M	2
P.C.	NC	55	5	6	14	61	6	M	2
A.S.	MI	55	0	0	1	62	7	M	4
M.C.	MI	56	1	0	0	64	8	M	1
G.B.	NC	59	2	0	4	77	18	S	2
O.P.	NC	60	3	4	10	69	9	M	1a
R.A.	MI	61	0	0	2	79	18	S	2
N.A.	SC	70	0	0	2	75	5	W	1

Discussion

Both younger and older survivors reported similar individual risks related to limited self-care and physical distress but differed in some sources of emotional distress. Both groups reported challenges with help-seeking. A characteristic that supported individual resilience--personal and cultural belief in one's strength and endurance--created a tension with the vulnerability women often perceived in asking for help. This may be addressed through psychoeducation by health care providers to normalize help-seeking and the difficulties surrounding it. Family and community resources can be encouraged to proactively offer help for these patients. The issue of help-seeking could also be addressed in African American-focused breast cancer support groups where available. Health care providers can encourage participation in these groups and offer referral information to patients whenever possible.

Both young and older survivors dealt with lasting physical effects and side effects of their breast cancer and treatment and the persistent fear of recurrence. Emotional support from groups or from trusted medical resources may buffer this risk of emotional distress. Women in both groups reported experiencing cultural stigma or silence about discussing cancer and its impact in the Black community. Support groups such as Sister's Network actively work to dispel such stigmas.

Key differences in experience for younger women include more distress in social functioning, body image, less well-established support/spousal network, less support from older children, more child caregiving, and more job loss/work interruption. Older women may have the benefit of more stable support networks, including church communities. This is another reason why support groups or mental health support may play an integral role in recovery.

AA patients can be encouraged to participate to the extent that is possible during their recovery and survivorship.

A companion study of protective factors for African American women found that about half of participants had to actively insist on additional medical exams and follow-up tests to get a conclusive and timely breast-cancer diagnosis. In light of reported medical mistrust in this study, there may exist a treatment barrier for AA women that warrants further study. Are racial inequalities underlying delays in diagnosis for AA patients or does lingering medical mistrust deter AA women from following-up on suspected breast abnormalities? Once women had entered treatment, overt experiences of racial discrimination were rarely reported in these studies. Future research may examine differences in paths to diagnosis among a larger sample of black and white patients.

Conclusion

African American women report multiple individual and environmental risks in their recovery from breast cancer in the areas of relationship strain, emotional distress, medical mistrust and cultural silence about cancer. Key differences in experience for younger women include more distress in social functioning, body image, less well-established support/spousal network, less support from older children, more child caregiving, and more job loss/work interruption. Encouraging survivor participation in support groups, mental health support, or limited psychoeducation from health care providers could help buffer some of these risks. Providing survivors with resources for financial support, such as grants or medical assistance may support those patients most impacted by the financial hardship of their illness. A Study of Protective Factors for African American breast cancer survivors suggests that key environmental

supports for this population are relational, medical, and financial resources. Future research may investigate the role of these risks to impact on survival for this patient group.

CHAPTER FOUR: CONCLUSIONS

These two studies expand the understanding of African American women's experience with breast cancer. This research elaborates psychosocial risk and resilience factors in the individual and environmental domains for these survivors. The second study unfolds additional layers of the experience of younger AA breast cancer survivors who face the greatest mortality risk. Effectively addressing psychosocial distress in African American patients may improve quality of life and treatment adherence (NCCN, 2013) and may result in survival advantage for this group.

Medical, mental health and social supports that help enhance identified protective factors may decrease psychosocial distress, increase individual sense of coherence and promote health and survivorship in this population. Support and encouragement related to spirituality, cognitive reframing, personal agency, racial socialization, relational, medical, financial supports, and meaning-making activities for survivors may buffer the individual and environmental risks they encounter. Many of these issues can be addressed in support groups focused on AA patients or through accessible mental health support. Support groups can enhance individual resilience, relational-environmental support, and provide avenues for meaning-making, the three main dimensions of health-promoting sense of coherence.

Implications for Practice and Research

Modifying risk factors where possible is an important strategy for addressing health disparities. Continued targeted research on psychosocial interventions is needed for AA breast cancer survivors. The National Comprehensive Cancer Network recognizes under-screening of psychological needs and lack of knowledge of community resources by medical providers as a barrier to optimal patient care. To that end, NCCN recommends integrating psychosocial

assessment into regular clinical care for all patients. Routine use of brief screening tools such as the PHQ-9 and Distress Thermometer can be used to identify patients who need more psychosocial care or referral to community, mental health or social resources. The Distress Thermometer has the added benefit of using “non-stigmatizing” language to assess mental health concerns and facilitate dialogue with medical providers about emotional wellbeing (NCCN, 2013). NCCN recommendations and standards of care for distress management include:

- at least one team member should be familiar with mental health or chaplaincy services available in the institution or community to inform patients, families and their treatment teams (NCCN, 2013). Expanding this to include familiarity with support groups, including AA-focused groups like Sister’s Network, would benefit AA survivors.
- Screen, monitor, and promptly treat or refer for treatment, psychosocial distress in patients.

“Initiating survivorship care planning early, establishing a baseline for sociocultural insights building trust, and providing evidence-based care are prime examples of where the healthcare system can be more targeted to Black women,” according to Dr. Timiya Nolan of the Ohio State University Wexner Medical Center (Forster, 2019, p. 1).

Integrating and acknowledging spirituality and religion which plays a significant role for many AA patients may also be important when treating this group. Such integration may be as simple as offering a referral to chaplain services or asking a patient “is there a source of comfort and peace you turn to during this time?” This signals that a patient’s spiritual beliefs can be voiced, acknowledged and accepted as an important part of their healing journey.

Reimbursement or low-cost availability of mental health services as part of hospital medical treatment would increase access and prevent this important dimension of mental health treatment from being overlooked.

Future research should examine differences in paths to diagnosis for African American patients and the impact targeted risks factors have on survival for this group. Sense of coherence as a “survival resilience” quality encompasses comprehensibility (inner resilience), manageability (environmental resources) and meaning-making pursuits. Related protective factors may buffer individual and environmental risks for African American cancer patients and promote health and survivorship.

APPENDICES

Appendix A: Consent Form

PSYCHOSOCIAL RISK AND PROTECTIVE FACTORS AMONG YOUNG AFRICAN AMERICAN BREAST CANCER SURVIVORS: AN EXPLORATORY QUALITATIVE STUDY

Michigan State University

**Department of Human Development and Family Studies/Couple and Family Therapy
Consent Form- Interview Participants**

A study entitled Exploring the Psychosocial Risk and Protective Factors among Young African American Breast Cancer Survivors: An Exploratory Qualitative Study, is being executed by a doctoral candidate at Michigan State University, with the intent to hear and learn from the African American cancer survivors, concerning their relationship with mental health, specifically depression. This study will consist of individual interviews with current or former patients of the MSU Women's Radiology (Eyde Building, East Lansing), the Breslin Cancer Center (East Lansing), and the Detroit Karmanos Cancer Institute. Interviews will focus on the experience of sense of coherence, coping, meaning-making, encounters with medical providers, and social supports, with the goal of expanding the research on African American cancer survivors and address issues of health disparity issues.

Interviews will take place in person and within an expected time frame of approximately 45-60 minutes in length.

Please note that participation in this project is completely voluntary. Participants may withdraw from the study at any time and/or refuse to answer any questions they do not want to answer. Refusal to participate and/or withdrawal from the study will not affect participants in any form. The incentive in participating in this study is the opportunity to candidly discuss your experiences with mental health, the intersection of being a woman and being African American and how those factor into the workplace experience. Participants will receive one \$20.00 Meijer gift card after completion of the interview.

The potential risks of participating in this study may include any distress and/or discomfort regarding discussion of mental health experiences and/or workplace incidents. Any study participant experiencing distress or discomfort will be provided with a referral to local mental health clinicians. If this applies to you please contact the Primary Investigator (PI) Jesslyn Ingram (517) 488-4659.

If you agree to participate, a fifth-year graduate student, from Michigan State University will conduct interview protocol. Each interview will be audio recorded, unless refusal of the arrangement. If you agree to be audio recorded, please circle your response and initial on the line below.

I agree to allow audio recording of the interview. YES NO Initials _____

Any responses you offer during the interview will be combined with other others, making your responses confidential, and your privacy will be protected to the full extent allowable

by the law. Identifying information will not be attached to any of your individual responses, when reporting results from interviews. All material will be kept in a password-protected laptop and only the principal investigator, her advisor and the University Research Protection staff will have access to the data.

Each interview will take approximately 45-60 minutes to complete. If you have concerns or questions about this study, such as scientific issues, how to participate, or to report an injury please contact:

- Dr. Marsha T. Carolan, Michigan State University, Human Ecology, East Lansing, MI 48823, (517) 432-3327, carolan@msu.edu

- Jesslyn M.C. Ingram, Doctoral Candidate, Michigan State University, Human Ecology, East Lansing, MI 48823, ingramje@msu.edu

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 202 Olds Hall, MSU, East Lansing, MI 48824.

Your signature below indicates your willingness to participate in this study. Thank you for your time. I look forward to talking with you about your experiences.

Signature: _____ Date: _____

**Michigan State University
Department of Human Development and Family Studies/Couple and Family Therapy**

Participation-Consent to Use a Direct Quote

The form gives your consent to use direct quotes from this interview, for the purposes of publishing this study. Your identity will be kept confidential and an identification number will be used to protect you. Only the researchers will know the number assigned to you. By signing this form, you allow for the use of direct quotes in publications of this study and understand that your privacy will be protected to the maximum extent of the law.

Your signature below indicates your willingness to voluntarily consent to the use of direct quotes in the publication of this study. Thank you for your time.

Signature: _____ Date: _____

Appendix B: Demographics Questionnaire

Participant #: _____

Date: _____

Directions: Please fill in the blank or circle the response that best describes you.

1. Year you were born: _____ Age: _____

2. Level of Education (please circle):

- a. Less than 9th grade
- b. Less than 12th grade, no diploma
- c. High School Graduate
- d. Some college, no degree
- e. Associate's Degree
- f. Bachelor's Degree
- g. Graduate or Professional Degree

Employment Status

3. Are you currently working?

- a. Yes, full time employment
- b. Yes, part time employment
- c. No, I am currently unemployed
- d. Other, please specify: _____

Relationship Status

4. What is your current relationship status?

- a. Single
- b. Married _____
- c. Cohabiting partner _____
- d. Dating/non-cohabiting partner _____

5. Do you have children?

- a. no
- b. yes ages? _____

Household members

6. Number of children living at home _____

7. Number of other adults or family members living at home _____

Health Status

8. Approximate date of diagnosis _____

9. Approximate date of beginning treatment _____

10. Stage of Breast Cancer _____

11. Type of Breast Cancer (i.e., estrogen + or estrogen -) _____

12. In remission? yes _____ no _____

Appendix C: Interview Protocol

INTRODUCTION TO THE STUDY

National research in focusing on ways to improve treatment and survival for African American Breast cancer patients. Young African American breast cancer survivors have a unique experience as they navigate medical treatment, seek social support, and cope with the added stress of a breast cancer diagnosis. This study seeks to better understand the lived experiences of breast cancer survivors and the social and psychological factors that help or hinder their recovery and quality of life. A goal of this study is to expand the research on African American cancer survivors and address issues of health disparity in this group.

What are the protective and risk factors for young African American cancer survivors?

Research questions

- 1) What are the risk and protective factors for AA women with breast cancer?**
- 2) What beliefs and strategies do AA women with breast cancer use to make sense of and cope with their health crisis?**
- 3) What kinds of support do African American women with breast cancer most need from family, partner and extended support systems?**
- 4) How do AA women access these supports? What promotes or hinders their access to these supports?**

Protective

1a. What are the influences of meaning making and sense of coherence?

2a. What are the influences of spirituality?

2a. What are the influences of relational support from family, partners, medical providers?

How has your life changed since your diagnosis?

What beliefs and strategies do you use to make sense of and cope with breast cancer?

How important is your belief in God or something greater than yourself in coping with cancer?

How in control do you feel about your recovery?

What is most helpful in your recovery?

If applicable, how has your cancer diagnosis affected your couple relationship?

How has your cancer diagnosis affected your family relationships and relationships with children?

Risk:

2a. What are influences of discrimination when navigating recovery from breast cancer?

2b. What are influences of medical care interactions?

2c. What influences help seeking from family or medical providers?

How do you describe your interactions with health care providers?

Have you experienced negative interactions with providers?

How do you cope with those types of experiences?

What is your sense of being socially supported at home and in the community?

How do you ask for help when you need it?

What types of social support to you most need?

What, if any, messages about racial and cultural pride have you received from your family?

How have these messages helped you cope with your diagnosis?

How do you feel about the medical, emotional and social resources you have for recovery?

What is your understanding of depression?

What has been your experience with depressed before and after your diagnosis?

What is your understanding of anxiety?

What has been your experience with anxiety before and after your diagnosis?

What helps you when you are feeling depressed or discouraged?

Appendix D: Recruitment Email

Dear Prospective Participant,

A study entitled Exploring the Psychosocial Risk and Protective Factors among Young African American Breast Cancer Survivors: An Exploratory Qualitative Study, is being executed by a doctoral candidate at Michigan State University, with the intent to hear and learn from the African American cancer survivors, concerning their relationship with mental health, specifically depression. This study will consist of individual interviews with current or former patients of the MSU Women's Radiology (Eyde Building, East Lansing), the Breslin Cancer Center (East Lansing), and the Detroit Karmanos Cancer Institute. Interviews will focus on the experience of sense of coherence, coping, meaning-making, encounters with medical providers, and social supports, with the goal of expanding the research on African American cancer survivors and address issues of health disparity issues.

Interviews will take place in person and with an expected time frame of approximately 45-60 minutes in length.

Please note that participation in this project is completely voluntary. Participants may withdraw from the study at any time and/or refuse to answer any questions they do not want to answer. Refusal to participate and/or withdrawal from the study will not affect participants in any form. The incentive in participating in this study are the opportunity to candidly discuss your experiences with mental health, the intersection of being a woman and being African American and how those factor into the workplace experience. Participants will receive one \$20 Meijer gift card after completion of the interview.

If you would like to participate or inquire about any more information regarding the study please email Principal Investigator Jesslyn M.C. Ingram, ingramje@msu.edu.

Appendix E: Patient Health Questionnaire-9 (PHQ-9)

Over the last two weeks, how often have you been bothered by any of the follow problems?

Not at all 0	Several Days 1	More than half the days 2	Nearly every day 3	
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or over eating	0	1	2	3
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite- being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

For office coding _____ + _____ + _____ + _____


= Total Score _____

If you checked any of the problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? (Use ☒ to indicate your answer)

Not difficult at all <input type="checkbox"/>	Somewhat difficult <input type="checkbox"/>	Very difficult <input type="checkbox"/>	Extremely difficult <input type="checkbox"/>
--	---	---	--

Appendix F: NCCN Distress Thermometer

Figure 3: NCCN Distress Thermometer



National
Comprehensive
Cancer
Network®

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress

10

9

8

7

6

5

4

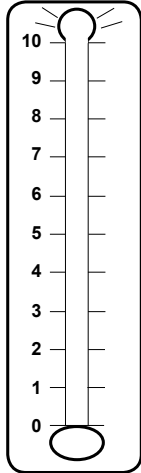
3

2

1

0

No distress



PROBLEM LIST
Please indicate if any of the following has been a problem for you in the past week including today.
Be sure to check YES or NO for each.

YES NO <u>Practical Problems</u>	YES NO <u>Physical Problems</u>
<input type="checkbox"/> <input type="checkbox"/> Child care	<input type="checkbox"/> <input type="checkbox"/> Appearance
<input type="checkbox"/> <input type="checkbox"/> Housing	<input type="checkbox"/> <input type="checkbox"/> Bathing/dressing
<input type="checkbox"/> <input type="checkbox"/> Insurance/financial	<input type="checkbox"/> <input type="checkbox"/> Breathing
<input type="checkbox"/> <input type="checkbox"/> Transportation	<input type="checkbox"/> <input type="checkbox"/> Changes in urination
<input type="checkbox"/> <input type="checkbox"/> Work/school	<input type="checkbox"/> <input type="checkbox"/> Constipation
<input type="checkbox"/> <input type="checkbox"/> Treatment decisions	<input type="checkbox"/> <input type="checkbox"/> Diarrhea
	<input type="checkbox"/> <input type="checkbox"/> Eating
	<input type="checkbox"/> <input type="checkbox"/> Fatigue
<u>Family Problems</u>	<input type="checkbox"/> <input type="checkbox"/> Feeling swollen
<input type="checkbox"/> <input type="checkbox"/> Dealing with children	<input type="checkbox"/> <input type="checkbox"/> Fevers
<input type="checkbox"/> <input type="checkbox"/> Dealing with partner	<input type="checkbox"/> <input type="checkbox"/> Getting around
<input type="checkbox"/> <input type="checkbox"/> Ability to have children	<input type="checkbox"/> <input type="checkbox"/> Indigestion
<input type="checkbox"/> <input type="checkbox"/> Family health issues	<input type="checkbox"/> <input type="checkbox"/> Memory/concentration
	<input type="checkbox"/> <input type="checkbox"/> Mouth sores
<u>Emotional Problems</u>	<input type="checkbox"/> <input type="checkbox"/> Nausea
<input type="checkbox"/> <input type="checkbox"/> Depression	<input type="checkbox"/> <input type="checkbox"/> Nose dry/congested
<input type="checkbox"/> <input type="checkbox"/> Fears	<input type="checkbox"/> <input type="checkbox"/> Pain
<input type="checkbox"/> <input type="checkbox"/> Nervousness	<input type="checkbox"/> <input type="checkbox"/> Sexual
<input type="checkbox"/> <input type="checkbox"/> Sadness	<input type="checkbox"/> <input type="checkbox"/> Skin dry/itchy
<input type="checkbox"/> <input type="checkbox"/> Worry	<input type="checkbox"/> <input type="checkbox"/> Sleep
<input type="checkbox"/> <input type="checkbox"/> Loss of interest in usual activities	<input type="checkbox"/> <input type="checkbox"/> Substance use
	<input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet
<input type="checkbox"/> <input type="checkbox"/> <u>Spiritual/religious concerns</u>	

Other Problems: _____

Version 2.2018, 02/23/18. The NCCN Clinical Practice Guidelines (NCCN Guidelines®) are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) makes no representations or warranties of any kind regarding their content, use or application and disclaims any responsibility for their application or use in any way. The NCCN Guidelines are copyrighted by National Comprehensive Cancer Network®. All rights reserved. The NCCN Guidelines and the illustrations herein may not be reproduced in any form without the express written permission of NCCN. ©2018.

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