

FORD, YVONNE RATCHFORD, Ph.D. Stories of African American Women Who Are Long-term Breast Cancer Survivors. (2016)
Directed by Dr. Susan A. Letvak. 111 pp.

The purpose of this study was to report the stories of African American (AA) women who are disease-free survivors of breast cancer, 10 or more years after initial diagnosis, and consider themselves to be thriving after cancer. Narrative inquiry was used to develop the stories into a cohesive whole. A womanist framework (Walker, 1983) was used as a lens through which to consider the data.

In the narrative inquiry tradition, one blended story was derived from the data including an abstract for summary, orientation, complication to describe critical events, evaluation, result or outcome, and coda to relate the story of the past to the reality of today (Munhall, 2012). The story was developed from the following themes: (1) I'm still here; (2) And then I had cancer; (3) Can we talk?; (4) Peace in the valley; (5) They call it the red devil; (6) You are not alone; (7) The new normal; and (8) When I learn something, I share it.

Findings from this study have implications for nursing research and practice, as well as care for long-term survivors of breast cancer. Using culturally relevant interventions can be helpful in caring for physical and spiritual needs. If researchers and clinicians can tailor their communication style and value the historical underpinnings of health-seeking behaviors in AA long-term breast cancer survivors, more support can be made available for this population.

STORIES OF AFRICAN AMERICAN WOMEN WHO ARE LONG-TERM
BREAST CANCER SURVIVORS

by

Yvonne Ratchford Ford

A Dissertation Submitted to
the Faculty of The Graduate School at
The University of North Carolina at Greensboro
in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Greensboro
2016

Approved by

Committee Chair

This dissertation is dedicated to the following people:

- James E. Ratchford and Ardelle D. Ratchford, RN, my parents, who always stressed the value of education.
- Bernard L. Ford, my long-suffering spouse, who contributed his support and love throughout the process.
- The African American women who shared their private stories.

APPROVAL PAGE

This dissertation written by Yvonne Ratchford Ford has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

Committee Chair _____
Susan A. Letvak

Committee Members _____
Jie Hu

Yolanda Hyde

Paige Smith

Date of Acceptance by Committee

Date of Final Oral Examination

ACKNOWLEDGEMENTS

While my name appears alone on the cover of this scholarly work, this was not a solo pursuit. It would not have been possible without a cadre of people who supported this labor of love.

Dr. Susan A. Letvak, my advisor, committee chair, and mentor has my most sincere gratitude. She understood why this topic was important from our first conversation and her expertise with qualitative inquiry helped push me past the artificial limits I imposed upon this important research.

Dr. Jie Hu helped me understand the enormity of health disparities in the United States and my role in beginning to lessen those disparities.

Dr. Yolanda Hyde, another valued mentor, was an energizing force for completing this doctoral program in three years. She is also an outstanding editor and APA sage.

Dr. Paige Smith gave invaluable input from a non-nursing point of view. She brought a fresh perspective to this research and challenged me to fully explore the selected theoretical framework.

Dr. Debra Wallace is always willing to teach those who wish to learn. I am grateful for the experience I gained while working with her in the School of Nursing's Research Office.

There are many, too numerous to name, who helped me either through their support or their skepticism. I appreciate all of you.

TABLE OF CONTENTS

	Page
LIST OF TABLES	vii
LIST OF FIGURES.....	viii
CHAPTER	
I. INTRODUCTION.....	1
Theoretical Considerations.....	3
Purpose of the Study	7
Research Questions	8
Definition of Terms.....	9
Assumptions.....	9
Delimitations	10
Significance of the Study	10
Summary	11
II. LITERATURE REVIEW	13
Introduction	13
Cancer Survivorship.....	13
Quality of Life.....	15
Stress, Appraisal, and Coping	19
Barriers to Long-term Survival	20
Spirituality and Storytelling in AA Traditions.....	24
Gaps and Opportunities.....	26
III. METHODOLOGY AND DESIGN	29
Introduction	29
Methodology	29
Specific Aim.....	34
Sample.....	35
Setting	36
Protection of Human Subjects.....	37
Data Collection.....	38
Data Analysis	39
Trustworthiness and Credibility	41
Delimitations	42

IV. FINDINGS	43
Description of the Sample	45
The Interwoven Narrative	51
V. DISCUSSION	71
Introduction	71
Provider Communication and Trusting Relationships	72
Social Support	74
Cancer, Stigma, Secrecy, and Fear.....	75
Spirituality	76
Implications for Practice	78
Implications for Research	79
Limitations	80
Significance of the Research	81
REFERENCES.....	82
APPENDIX A. DEMOGRAPHICS FORM	107
APPENDIX B. INFORMED CONSENT DOCUMENT	109

LIST OF TABLES

	Page
Table 1. Characteristics of AA Long-term Breast Cancer Survivor Sample (n=12)	44

LIST OF FIGURES

	Page
Figure 1. Quality of Life: Conceptual Model	16
Figure 2. Quality of Life: Conceptual Model, adapted	18

CHAPTER I

INTRODUCTION

Because of advances in early detection of breast cancer, increasing use of targeted therapy, and improved long-term surveillance of breast cancer survivors (Syse & Geller, 2011), more women are surviving breast cancer five years or longer after being diagnosed (Siegel, Miller, & Jemal, 2015). The survival rate of African American (AA) women, however, continues to lag behind that of all other women. This population group difference in incidence, prevalence, and survival is known as cancer health disparity (Center to Reduce Cancer Health Disparities, 2014) and has been studied extensively over the past 10 years.

Only 77% of AA women diagnosed with breast cancer in 1996 survived until 2004 compared to 90% of Caucasian women (National Cancer Institute, 2014). In fact, the survival rate of AA women today is comparable to that of white women 25 years ago (Warner et al., 2015). African American women also have a higher incidence of breast cancer before age 40, the age recommended to begin screening for breast cancer by mammography (American Cancer Society, 2014). Current projections about death from breast cancer estimate that overall 231, 840 women will be diagnosed with breast cancer in 2015, with 40,290 dying from breast cancer in 2015 (Siegel et al., 2015, p. 8). Additionally, when observing rising trends in survival rates between 1975 and 2010 (*p*

<0.05), 92% of Caucasian women survive five years post-diagnosis, but only 80% of AA women make it to the five-year survival milestone (Siegel et al., 2015, p. 14).

There are many theories about why this disparity in survival exists; especially considering that the overall incidence of breast cancer in AA women was previously much lower than that of Caucasian women (National Cancer Institute, 2015). Biological factors, socio-demographic characteristics, healthcare system factors, and cultural considerations have all been researched in an attempt to explain the disparity in breast cancer mortality for AA women. Despite grim statistics that paint a bleak picture replete with negative outcomes for AA women with breast cancer, there are AA women who consider themselves to be thriving after the diagnosis and treatment of breast cancer. Further, when examining mortality, researchers must also consider long-term survival in AA women, how it has been defined in the literature, and what the components of long-term survival are for these women.

The disparity in breast cancer survival is multifarious. There are biological, socio-cultural, and cancer care factors that have all been shown to contribute to poorer prognosis and higher mortality from breast cancer for AA women. Biological factors, such as more aggressive disease at an earlier age, later stage at diagnosis, hormone receptor negative disease, and physiological differences (Braithwaite et al., 2009; Kroenke et al., 2014; Wheeler, Reeder-Hayes, & Carey, 2013; Wu et al., 2013) may affect the efficacy of current treatment modalities. Further, socio-cultural factors such as delayed screening and treatment; mistrust of providers, socioeconomic status and racism may contribute to shorter survival time (Hall et al., 2015; Pullen, Perry, & Oser, 2014).

Finally, cancer care systems have been found to offer AA women treatment not consistent with best practices in the management of cancer, present barriers for the uninsured, and reveal difficulties in patient-provider communication with AA women (Gorey et al., 2009; Sail, Franzini, Lairson, & Du, 2012; Wittayanukorn et al., 2015).

Theoretical Considerations

In undertaking research with African American women, one must be cognizant of and sensitive to some innate differences in their view of the world and ways of knowing. Some researchers posit that health disparities may be partially attributable to using a Eurocentric model that is ill fitting for this population and does not acknowledge their many social roles and the historical context of their worldview (Banks-Wallace, 2000; Lekan, 2009). There are several theoretical frameworks that have been used for studying and understanding the AA woman; The Sojourner Syndrome (Lekan, 2009; Mullings, 2002), Superwoman Schema (Woods-Giscombe, 2010), Strong Black Woman Collective (Davis, 2015), and Womanist theory (Banks-Wallace, 2000; Walker, 1983). For the purpose of this research, Womanist theory has been chosen to frame AA women's perspectives of breast cancer diagnosis, treatment, and long-term survival.

There are few theoretical frameworks that use race and gender as a contextual thread, despite evidence that race and gender impact psychosocial and physical health. Womanist theorists suggest that the experiences of AA women are unique and divergent from those of Caucasian women and that researchers should seek integration of the complexity of their lives with their unique worldview (Walker, 1983). A womanist framework can provide a way of knowing that encompasses gender and racial bias and

includes the impact of health disparities along with the importance of community and the extended family.

The roots of womanist thought are imbedded in AA literature and theology. While Walker (1983) coined the term womanist in an essay about the effect of white pornography on the AA marriage, womanist theology focused on the role of faith in articulating the position of women in a largely male representation of AA history (Williams, 1986). African American writers, such as Zora Neale Hurston, Clenora Hudson-Weems, and Alice Walker influenced the formation of Katie's Canon (Cannon, 1995), a work that explicates the formation of womanist theory from slavery through the black liberation movement and into the AA church culture.

Nursing scholars have also embraced womanist theory as important in correctly articulating the experiences of AA women in the search for health, wellness and community. Evidence exists which suggests race/ethnicity and class significantly affects people's ways of knowing (Banks-Wallace, 2000). African American women share a lived experience, with a perspective stemming from living in a society that degrades both women and people of African descent. Moreover, the nature of truth in a womanist epistemology centers on the acknowledgement of the daily experiences of AA women as a prerequisite to dialogue about philosophical matters related to truth and knowledge (Banks-Wallace). By opening dialogues with AA women that have common social experiences, nurse researchers can gather richer data with which to inform nursing science and craft culturally relevant interventions.

Womanist theory is centered on three central themes: the interactive and multiplicative nature of gender and race oppression; the AA woman's self-definition and self-valuation that provides concrete, accurate images of these women; and identifying and owning the AA woman's culture (Littlefield, 2008). Gender norms that are used in nursing research do not adequately address these themes thus the need for a conceptual framework that can reflect this difference in the lived experience of AA women. Further, AA women can define themselves through both their personal experiences and the collective experience that comes from women sharing similar societal norms (Banks-Wallace, 2000) that exist at the intersection of racism, classism, and sexism. Taken together with feminist theory, a womanist theory framework can be helpful in building knowledge of women in both races in their search for health maintenance and healing after breast cancer.

Four fundamental dimensions of womanist epistemology have been described: 1) experience as a measure of meaning; 2) narrative used as a means to assess knowledge assertions; 3) the necessity of a belief in caring; and 4) the existence of personal accountability (Banks-Wallace, 2000). The experiences of AA women enable their transition from wisdom to knowledge and by articulating these experiences they can give nurse scholars a new lens through which to view their collective experience. Story telling and oral traditions were a critical component of passing down knowledge through generations of AA people who lived in oppression and can be used to frame the health experiences of these AA women in a traditional format (LeBron et al., 2014; McQueen, Kreuter, Kalesan, & Alcaraz, 2011; Palacios, Salem, Anaebere, & Hayes-Bautista, 2014).

The semantics AA people use has been called Ebonics, but it is a common dialect used in conversation, theology and music to discuss and bond through shared experiences throughout the community (Cannon, 1995). Caring and empathy are important to womanist epistemology as the AA woman may have nurtured not only just her family, but also the families of the oppressors. Finally, a feeling of personal responsibility can spur AA women to participate in research to advance knowledge of their experiences and help others who follow them in seeking care that is specific to their culture, biology, and history (Banks-Wallace, 1998).

Having anecdotal knowledge of the difference of long-term breast cancer survivor experiences does not add to nursing knowledge. Without a conceptual framework, there is not a scholarly basis with which to make the inquiry about a difference in the perspective of AA women based on their history and culture. Using this framework can allow researchers to acquire knowledge about both subtle and overt manifestations of oppression, and better appreciate the AA woman's definition and valuation of self and other members in their larger community.

Womanist theory provides a new way of knowing AA women who are long-term survivors of breast cancer. Rather than trying to fit these women into traditional ways of knowing in nursing, womanist theory gives nursing science a new lens with which to view them. Some might argue that there is no difference between Caucasian and AA women, and that cancer is cancer. Using womanist theory in building nursing knowledge about AA women offers nurse scholars an approach to hear the narratives of AA women about their journey through breast cancer and into long-term survivorship.

An advantage of using womanist theory is honoring the societal history of these women, acknowledging the importance of narrative in their cultural tradition, and viewing their experiences with breast cancer survivorship through a conceptual framework that honors their unique worldview. Further, there has been research with AA women using the narrative of their lives to provide contextual grounding. Also, it enables women to bond with others having like experiences, have catharsis, and use advocacy through educating others (Banks-Wallace, 1998; Palacios et al., 2014). A disadvantage of using womanist theory with long-term AA breast cancer survivors is that it has not been used before with this population. However, allowing these women, through the freedom of their cultural identity, to share their journey with breast cancer can yield rich data and inform interventions for newly diagnosed and long-term AA breast cancer survivors.

Purpose of the Study

While quantitative methodology is a way to measure, predict, and explain phenomena, there are some topics that cannot be measured quantitatively until there is an exploration through qualitative inquiry. In order to learn more about AA women who are long-term breast cancer survivors, there must be some foundational knowledge of their experiences. The current literature on long-term breast cancer survivorship is not very representative of the AA woman who has achieved longevity. Additionally, while spirituality has been identified as important to the AA cancer survivor, scant attention has been paid to spiritual well-being in this population of long-term survivors (Hamilton, Galbraith, Best, Worthy, & Moore, 2015; Tate, 2011; Yoo et al., 2014).

There have been qualitative studies conducted about social support (Hamilton & Sandelowski, 2004), surveillance and health-seeking behaviors (Halbert et al., 2009; Thompson et al., 2006), and ways of coping (Hamilton, Stewart, Crandell, & Lynn, 2009). There is not, however, a narrative addressing their journey noting difficulties and celebrations. Research about the experience of long-term breast cancer survivorship in AA women and the role of spirituality in their journey needs to be undertaken.

This research study will report the stories of AA women who are disease-free survivors of breast cancer, 10 or more years after initial diagnosis, and consider themselves to be thriving after cancer. Narrative inquiry will be used to develop the stories into a cohesive whole.

Research Questions

The Central Qualitative Question

What are the stories of AA women who are long-term survivors of breast cancer?

Other Areas of Interest

Other areas of interest in this research study were (a) determining the process of and the factors involved in an AA woman becoming a long-term breast cancer survivor, (b) describing the trajectories of illness from diagnosis to long-term survivorship for AA women with breast cancer, (c) using womanist theory to examine race, class, and gender as they have impacted the trajectory of survival, and (d) examining the role of spirituality throughout their personal trajectory of living with breast cancer.

Definition of Terms

For the purpose of this study, the following definitions are used:

1. Long-term survivor: A person who has been diagnosed with cancer and remains disease-free 10 or more years after that diagnosis and accompanying treatment.
2. Long-term survivorship: Remaining disease-free 10 or more years after an initial diagnosis of cancer and the accompanying treatment.
3. Black or African American: Self-identification as belonging to a socially constructed group identified as being of African origin, acknowledging the heterogeneity within the group (Ford & Harawa, 2010).
4. Spirituality: “Experiencing a meaningful connection to our core selves, others, the world, and/or a greater power as expressed through reflections, narratives and actions” (Schulz et al., 2008, p. 105).

Assumptions

The following assumptions were made for this study:

1. The stories of AA long-term breast cancer survivors are based on their perception of the events, people and circumstances surrounding their experiences with breast cancer diagnosis, treatment and survival.
2. Using individual interviews will allow exploration of the woman’s perception of her diagnosis, communication with providers, support from healthcare providers, family, faith, and community.

3. Participants may have perceptions related to the effects of race, gender and perceived or actual social class that color their perception of the journey through diagnosis and treatment, and into long-term survival.
4. Spirituality is central to the AA long-term breast cancer survivor experience from diagnosis through disease-free survival.

Delimitations

The study was limited to:

1. Individuals who are disease-free survivors of female breast cancer 10 or more years after initial diagnosis.
2. These individuals must self-identify as black or AA and be 18 years of age or older.
3. Participants must consider themselves thriving after breast cancer.
4. Participants must speak and understand English.

Significance of the Study

There is a clear interest in health outcomes of long-term survivors of cancer and more specifically female breast cancer (Blanch-Hartigan et al., 2014; Hewitt, Greenfeld, & Stovall, 2005). Research funding has facilitated more interest in and knowledge of the experiences and issues associated with the breast cancer treatment and survivorship past the five-year clinical marker of cure (Bloom, Stewart, Oakley-Girvan, Banks, & Shema, 2012; Bowman, Rose, & Deimling, 2006; Natarajan et al., 2009; Oliveri et al., 2008; Zebrack et al., 2006). While researchers have described physical and psychosocial effects of long-term breast cancer survivorship, there have been few randomized controlled trials

that include AA survivors in sufficient numbers to generalize that knowledge. In fact, research that was purposefully designed for or oversampled to include AA women found that their experiences have some differences, particularly with the role of social support and spirituality (Gibson & Hendricks, 2006; Hamilton & Sandelowski, 2004; Porter, Belyea, Mishel, Gil, & Germino, 2006; Tate, 2011; Thompson et al., 2006; Yoo et al., 2014).

Despite these efforts, there remains a paucity of information about AA long-term survivors of female breast cancer. While it is known that spirituality is important to AA long-term breast cancer survivors, the narrative of how spirituality and the belief in a higher other has impacted their journey through diagnosis into long-term survivorship has yet to be articulated. Further, new ways of measuring the influence of living with cancer beyond the quality of life concept (Dow, Ferrell, Leigh, Ly, & Gulasekarem, 1996) have been developed (Crespi, Smith, Petersen, Zimmerman, & Ganz, 2010; Zebrack et al., 2006), however the psychometric performance of these tools has not been assessed in AA women.

Summary

Breast cancer survivors constitute the largest group of cancer survivors (American Cancer Society [ACS], 2015), and with advances in early detection, increasing use of targeted therapy, and improved long-term surveillance (Coughlin, Yoo, Whitehead, & Smith, 2015), the number of breast cancer survivors is projected to continue to rise. Approximately 89% of women diagnosed with breast cancer from 2004-2010 survived at least five years, with 80% surviving at least 10 years after diagnosis (ACS, 2015). While

mortality from breast cancer has declined in all races since 1975, the survival rate of AA women continues to lag behind that of other women (Wu et al., 2013).

Only 78% of AA women diagnosed with breast cancer in 1996 survived until 2004, compared to 90% of white women, with the survival rate for AA women comparable to that of White women 25 years ago (ACS, 2015). AA women also have a higher incidence of breast cancer before age 40, the age recommended for beginning screening for breast cancer by mammography (ACS, 2015, p. 52). While we know about higher mortality for AA women diagnosed with breast cancer, what do we know about their long-term survival? This qualitative, descriptive study will be used to explore long-term survival from breast cancer in AA women.

This chapter provides an overview of the proposed study and the contribution it will make to nursing science. There is an opportunity to add to the knowledge about long-term survivors of breast cancer to include descriptive, qualitative research conducted with AA women. The narrative of their journey from receiving a diagnosis of breast cancer through disease-free survival needs to be known. Further, because many AA survivors have expressed the necessity of telling their individual stories in hopes of assisting other AA women with a diagnosis of breast cancer (Ford, 2016; Kooken, Haase, & Russell, 2007; Wells, Gulbas, Sanders-Thompson, Shon, & Kreuter, 2014), a qualitative narrative methodology would be a means to this end.

CHAPTER II

LITERATURE REVIEW

Introduction

This review is designed to explore long-term cancer survivorship, in particular female breast cancer. Additionally, this review is a search for the long-term survivorship experiences of AA women, about whom the literature seems fairly silent. First, the concept of cancer survivorship will be examined, and then literature about long-term survivorship in female breast cancer will be presented to synthesize findings that examine survival. Secondly, because mortality due to breast cancer is higher in AA women, the survivorship literature will be explored to present findings about barriers to survival including biological factors, issues with access to care, disparity in treatment, and perceived or actual discrimination related to care. Thus, strengths and gaps in the literature, with regard to AA breast cancer survivors, can be identified, through conducting an integrative and comprehensive review of long-term survivorship literature.

Cancer Survivorship

The National Cancer Institute (NCI) defines a survivor as “One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life.” (National Cancer Institute [NCI], n.d., Chapter S). Many researchers use the American Cancer Society’s definition of five-year relative survival

rate as the “percentage of people who are alive a designated time after a cancer diagnosis, usually five years.” (ACS, 2015, p. 2). Still others refer to long-term survival as more than five or more years after (Gibson, Thomas, Parker, & Wetsel, 2014; Lash et al., 2014), five to ten years after diagnosis (Crespi et al., 2010; Paskett et al., 2008), or greater than 10 years after diagnosis.

The concept of cancer survivorship has also been explored in an attempt to define the attributes, antecedents, consequences, surrogate terms, and related concepts using Rodger’s method of evolutionary concept analysis (Rodgers & Knafl, 2000). The attributes of cancer survivorship have been identified as the process, uncertainty, life-changing experience, both positive and negative aspects, and an individual experience that has similarities for each person that survives breast cancer (Doyle, 2008). Moreover, additional attributes from a cultural perspective involve complex, relational, and dynamic perceptions of the experience (Best et al., 2015; Farmer & Smith, 2015; Miller et al., 2002). Further, recently there has been renewed attention to the well-being of survivors of cancer (Denlinger et al., 2014).

The antecedent of survivorship is a breast cancer diagnosis. The consequences of this diagnosis can affect physical, social, psychological, and spiritual well-being (Dow et al., 1996; Ferrell, Hassey Dow, & Grant, 1995). Further while these outcomes are disruptive to a survivor’s life, in long-term survivorship there can be positive consequences. There may be meaning found through enduring the experience, adapting to new biophysical realities, and realizing a vulnerability that can be used to care for self or advocate for others beginning the same journey (Peck, 2008; Sterba et al., 2014).

Surrogate terms identified include living after a diagnosis of cancer (Doyle, 2008), exceptional patient, adjustment and adaptation (Farmer & Smith, 2002, p. 783). Quality of life is also a concept frequently used to examine breast cancer survivorship (Ashing-Giwa et al., 1999; Maly, Liu, Liang, & Ganz, 2014; Powe, Daniels, & Finnie, 2005).

Quality of Life

Quality of life (QOL) in long-term breast cancer survivorship has been defined as “a term which refers to a general sense of well-being and addresses multiple dimensions of life.” (Dow et al., 1996, p. 262). This foundational model was also adapted for use in the landmark report from the Institute of Medicine (IOM) concerning cancer survivorship (Figure 1). Much of the QOL research has centered on physical well being in disease-free survival from breast cancer. In these studies, findings indicate that above average pain can persist and is positively associated with obesity and sedentary lifestyles (Forsythe et al., 2013). Further, disparity persists in the trend toward implant-based reconstruction, with AA women being more than twice as likely to undergo autologous reconstruction with excess skin due to obesity (Nelson et al., 2012; Rubin, Chavez, Alderman, & Pusic, 2013). African American long-term survivors are more likely than other women to have impaired physical functioning as cancer occurs in combination with other comorbid conditions (Ashing, Rosales, Lai, & Hurria, 2014; Avis & Deimling, 2008; Griffiths, Gleeson, Valderas, & Danese, 2014). Finally, systemic adjuvant therapy and estrogen positive tumor classification have been associated with poorer physical outcomes in AA women than in other women (Natarajan et al., 2009; Santa-Maria et al., 2015). One problem with translating these findings to AA long-term survivors is poor representation

in study samples. With AA survivors being less than 10 percent of participants in many studies, there is not sufficient statistical power with which to make generalizations about the population.

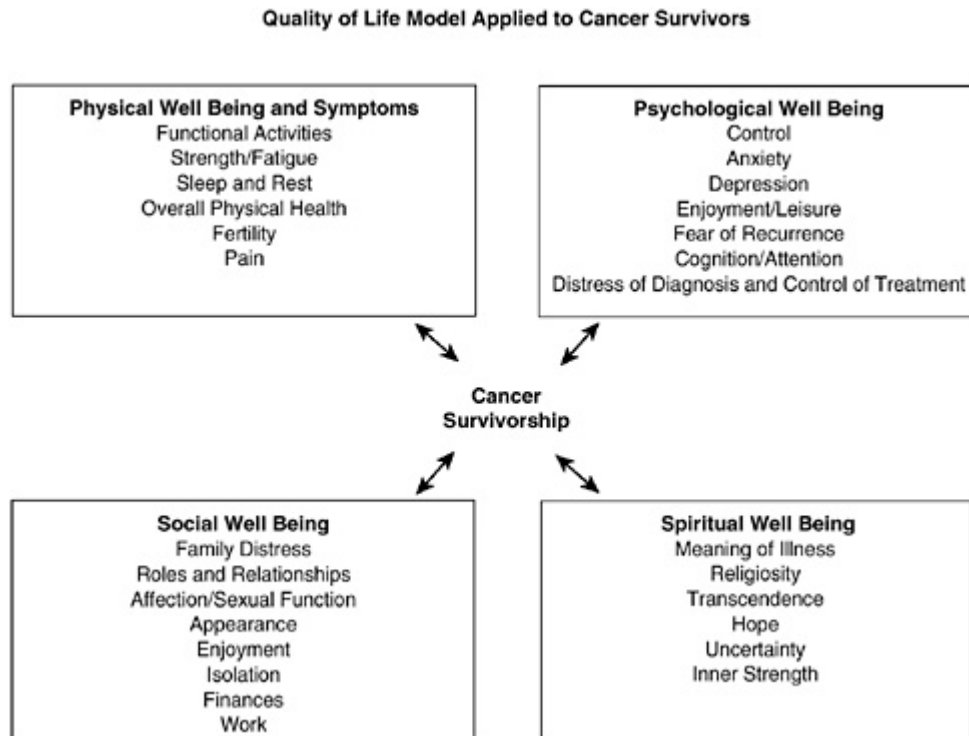


Figure 1. Quality of Life: Conceptual Model.

Physical well-being has been correlated with psychological and social domains of QOL. In studies of AA cancer survivors, social support is linked with better physical functioning, as well as fewer depressive symptoms (Von Ah et al., 2012; Sheppard et al., 2010). Psychological well-being has been positively linked with social support (Chavez, Haddock, & Rubin, 2014; Kent et al., 2013; Wells et al., 2014), and effective coping strategies (Best et al., 2015; Hamilton, Argawal, Carter, & Crandall, 2011; Hamilton, Stewart, Crandell, & Lynn, 2009; Yoo et al., 2014). Interestingly, AA women have been

found to have better psychological well-being than some Caucasian and Latina long-term breast cancer survivors (Janz et al., 2014; Mollica & Nemeth, 2013; Ashing-Giwa & Lim, 2011; Paskett et al., 2008). When AA breast cancer survivors were found to have poorer psychological well-being, it was associated with fear of recurrence, low social support, and poor quality of provider relationships and communication (Ashing-Giwa & Lim, 2011; Ashing-Giwa et al., 2013; Miller et al., 2015; Sheppard et al., 2014). Also, much of this research on AA women has been centered on the period immediately following diagnosis and treatment (Sterba et al., 2014; Whitehead & Hearn, 2015), not long-term survivorship.

One QOL of domain that has not been thoroughly explored in AA long-term breast cancer survivors is spiritual well-being. While there have been qualitative studies and systematic reviews of the current literature specifically examining the role of spirituality for AA breast cancer survivors (Sterba et al., 2014; Buck & Meghani, 2012; Tate, 2011; Yoo et al., 2014), there has not been much quantitative research work done in this domain with AA survivors, as compared to the study of physical and psycho-social concerns. Positive support has been associated with spiritual activities for AA with cancer (Green et al., 2014; Lynn, Yoo, & Levine, 2014). One reason posited for the dearth of research in this area is related to the lack of a concise conceptual definition and culturally relevant measure of spirituality (Holt et al., 2012; Lewis, 2008). Moreover, the correlation between spirituality and health outcomes in AA breast cancer survivors has rarely been studied. There is an opportunity for knowledge building within this area.

Research on QOL has advanced to include health-related quality of life (HRQoL), which adds economic well-being as a fifth domain for breast cancer survivors (Figure 2). Paskett et al., (2008) adapted the existing QOL model to include employment and health insurance issues (Figure 2). This model was introduced in a clinical trial conducted by the Cancer and Leukemia Group B (CALBG) and included a sample that was reported as 94% White and 4% other (Paskett et al., 2008). Despite this limitation, this study brought attention to sexual concerns and long-term effects of systemic adjuvant chemotherapy for breast cancer survivors. There is also an association between HRQoL, physical activity and body mass index in breast cancer survivors. African American women were found to be less likely to engage in physical activity though obesity did not have a strong association with HRQoL (Paskett et al., 2009), however again there was not sufficient statistical power with only 5% of the sample of AA origin.

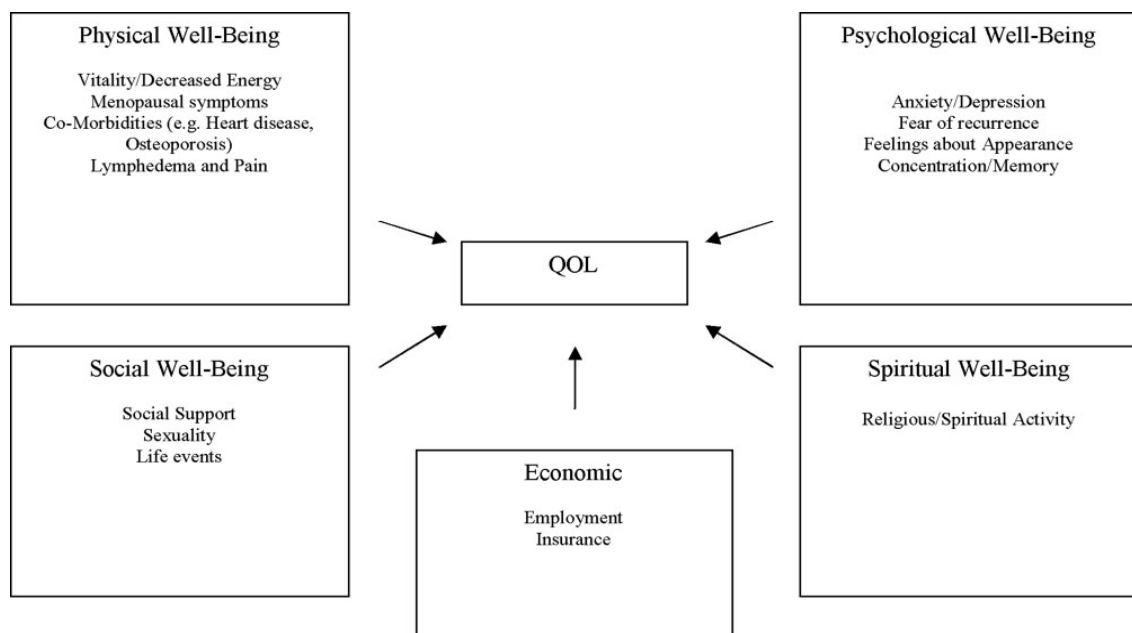


Figure 2. Quality of Life: Conceptual Model, adapted.

HRQoL can be adversely impacted when AA women perceive difficulty communicating with health care providers (Miller et al., 2015). Finally, with HRQoL in AA breast cancer survivors, it has been shown that there is increased fatigue, more hot flashes, and poorer sleep quality as compared to AA women without breast cancer, however more partner support was found in the breast cancer survivors (Von Ah et al., 2012).

Stress, Appraisal, and Coping

Researchers inquiring about long-term survivors of breast cancer have also used a conceptual framework of stress and coping as the context within which to examine this phenomenon. Stress and appraisal have been identified as a part of the process of coping and adaptation to adverse life events (Lazarus & Folkman, 1984). Cognitive appraisal has been associated with QOL and presented as a mediator of symptom distress in AA women with breast cancer. Further, coping can be positively affected by social support (Hamilton et al., 2011; Yoo et al., 2014), but when collectivism is used as a coping mechanism increased anxiety and cancer- related worry may result (Hamilton, Deal, Moore, Galbraith, & Muss, 2013).

When considering stress and adaptation in long-term survival, AA women may prefer not to use close family members, but instead find distracting activities, offers of prayers, and support groups with other breast cancer survivors to be more effective coping strategies (Chavez et al., 2014; Davis et al., 2013). Finally, cultural differences must be considered when considering coping behaviors and interventions for AA breast cancer survivors. Spirituality, belief in divine control over life, and positive reframing

have each been identified as important coping mechanisms with AA survivors (Gibson et al., 2014; Maly et al., 2014; Yoo et al., 2014). These beliefs move beyond the traditional model of stress, appraisal, and coping (Lazarus & Folkman, 1984) to identify ways of coping coupled with cultural rituals.

There is also another view of the stress process found in the breast cancer survivorship literature. Instead of focusing on the immediate event that causes stress, there can be a longitudinal view of the relationship of stressful events and stress over time, without focusing on a single cause of the stress such as depression (Pearlin, 1989). Also, among AA long-term breast cancer survivors, spirituality can have a positive effect on the use of cancer aftercare (Hamilton, Galbraith, Best, Worthy, & Moore, 2015), ease distress of mastectomy-related issues (Rubin et al., 2013) and fear of recurrence (Best et al., 2015). African American women who consider themselves to use spirituality in coping with breast cancer have been found to identify positive social support and exhibit positive coping behaviors (Lynn et al., 2014; Sterba et al., 2014).

Barriers to Long-term Survival

It would be remiss to conclude a review of long-term breast cancer survival in AA women without consideration of barriers to healthy, long-term survival in this population. Research on disparities in deaths from breast cancer, and optimal health for AA women with breast cancer has been increasing for this underrepresented group. Biophysical concerns, access to care, and perceived discrimination should all be considered when reviewing the state of the science for AA women who are disease-free survivors of breast cancer.

From a biological perspective, AA women tend to have more aggressive tumors that occur at an earlier age (Akinyemiju, Moore, & Altekruze, 2015; Danforth, 2013; Wheeler et al., 2013), present at a later stage at initial diagnosis (Kang et al., 2008; Lin et al., 2012), have dissimilar tumor genetics (Ma et al., 2013), and physiological differences (Sturtz et al., 2014; Lacey et al., 2009; Wheeler, Reeder-Hayes, & Carey, 2013). These biological differences also affect access to and efficacy of newer therapies and to date there has not been a clinically effective treatment for these hormone receptor negative and human epidermal growth factor receptor (HER2) negative tumors (Abramson, Lehmann, Ballinger, & Pietenpol, 2014).

Breast tumors have been classified according to gene expression via immunohistochemical testing with genetic subtypes correlated with severity of disease and availability of targeted treatments (Keegan et al., 2015; Ma et al., 2013). Specifically, protein expression of estrogen receptors (ER), progesterone receptors (PR), and HER2 have been linked to negative outcomes among women having hormone receptor negative (ER-, PR-, HER-) breast cancer, and associated with worse outcomes than hormone receptor positive (ER+, PR+, HER2+) breast cancer (Abramson et al., 2014; Lin et al., 2012; Ma et al., 2013). Triple negative tumor status (ER-PR-HER2-) or TNT is least likely to be diagnosed in Stage I; thus women with TNT status have poorer overall survival (Akinyemiju et al., 2015; Brewster, Chavez-MacGregor, & Brown, 2014; Wheeler, Reeder-Hayes, & Carey, 2013). Research has shown that there is a greater prevalence of TNT status among AA women as compared to other women (Churpek et al., 2015). Genetic mutations in the p53 tumor suppressor gene have also been correlated

with decreased survival from breast cancer (Akinyemiju et al., 2015). African American women are three times as likely as White women to have p53 genetic alteration (Muller & Vousden, 2014; Walerych, Napoli, Collavin, & Del Sal, 2012).

Access to care and difference in cancer treatment have also been examined for AA long-term breast cancer survivors. African American women may exhibit health care avoidance, which may cause a delay in diagnosis and treatment (Spleen, Lengerich, Comacho, & Vanderpool, 2014). This avoidance may be due, in part, to difficulty in accessing appointments and care, negative encounters with health care providers or competing family priorities. Disparity in cancer treatment is well documented in the research literature (Connors et al., 2014; Reeder-Hayes et al., 2015). Lack of inclusion in clinical trials may serve to extend disparity as new therapies and interventions are researched (Sturtz et al., 2014; Wallace & Bartlett, 2013). Differences exist in breast-conserving treatment versus mastectomy, with AA women undergoing more mastectomies perhaps due to differences in counseling from general surgeons and geographic regional variances (Nelson et al., 2012; Reeder-Hayes et al., 2015). While AA women are as likely as White women to receive adjuvant chemotherapy, they deal with delays in timeliness of therapy, may receive non-standard therapy, and have a lower probability of receiving endocrine therapy, which has been associated with longer survival (Advani et al., 2014; Ashing-Giwa et al., 2013; Reeder-Hayes et al., 2014). Stage at diagnosis has also been shown to be predictive of outcome with AA women diagnosed at later stages having worse mortality (O'Keefe, Meltzer, & Bethea, 2015; Parise & Caggiano, 2015).

Moreover, perceived and/or actual discrimination faced by AA long-term breast cancer survivors may also contribute to disparity. Racism has been modeled by levels with institutionalized, personally mediated, and internalized racism as the three levels that may offer a lens with which to view race-associated differences in health outcomes (LaVeist & Isaac, 2013). Racism, perceived or actual, at any of these levels may hinder the willingness of the breast cancer survivor to engage in health-seeking behaviors. Further, perceived discrimination has also been identified as a stressor that can have a negative effect on health outcomes (Benjamin & Whitman, 2014; Williams & Mohammed, 2009). Oncology patient satisfaction has been linked to the cultural competence of the provider (Davey, Waite, Nunez, Nino, & Kissil, 2014), while perceived discrimination is associated with poorer health outcomes and increased mortality. However, this hindrance to patient satisfaction and use of cancer surveillance after initial treatment can be mediated by perceived provider impartiality and developing a relationship of trust between AA breast cancer survivors and providers (Tucker, Moradi, Wall, & Nghiem, 2014).

Finally, cancer Survivorship Care Plans (SCP), a recommendation of the IOM (Hewitt, Greenfield, & Stovall, 2006) and mandate of the American College of Surgeon's Commission on Cancer, have not been widely available and not fully implemented by the 2015 deadline (Stricker & O'Brien, 2014). This inability to realize this SCP goal may have been due to a lack of coordination between oncology and primary care physicians, and the distances some patients have to travel to receive care at an accredited breast cancer care facility (D. W. Ollila, personal communication, August 27, 2015). The effect

on the AA long-term breast cancer survivor may include unfulfilled information seeking, unrecognized later systemic effects of cancer therapy, and continued fear of recurrence (Advani et al., 2014; Ashing-Giwa et al., 2013; Mayer et al., 2015).

Spirituality and Storytelling in AA Traditions

Spirituality has been linked to health and patient outcomes in the literature of nursing and other disciplines in healthcare. While there is much interest in the role of spirituality and belief in a higher power, precisely defining the concept has remained difficult and debatable. Additionally, spirituality is not a static concept, as its meaning may depend on a particular worldview and faith tradition. Spirituality has been defined in nursing literature as being focused on the human relationship with a higher power, the definitive creator of life (Toivonen, Stolt, & Suhonen, 2015). Further, with storytelling there is a connection to others that provides meaning and purpose to one's life (Buck & Meghani, 2012). For many AA women, spirituality is a central part of their lives and is thought to provide guidance, support, hope, and security (Lynn et al., 2014).

Spirituality differs from religiosity. Where religiosity can be defined as belonging to a group with similar beliefs and attending scheduled services with that group (Boyd-Franklin, 2010), spirituality provides a personal means to transcend difficult experiences and have hope for the future (Lewis, 2008). In the AA community, the Black Church has long been an institution that allowed socially marginalized people to experience dignity and access to resources for health, education, and well-being (Green et al., 2014). In fact, throughout slavery, discrimination, segregation, and the continued struggle for civil

rights, spirituality has been a source of comfort and a buffer against the effects of racism for AA people (Boyd-Franklin, 2010).

With AA women diagnosed with breast cancer, qualitative research has been used to explore with the role of spirituality through the trajectory of diagnosis, treatment, and survival. There is documented evidence of the disparity that exists with AA and white women in breast conserving surgery and reconstruction after mastectomy (Nelson et al., 2012). Some AA women refuse implants, instead opting for autologous reconstruction, preferring to “use what God has given me...” believing the body is “a beautiful gift from God” (Rubin et al., 2013, p. 1108). There was also comfort derived from the prayers of others, and biblical scriptures (Lynn et al., 2014), with importance attached to God, prayer, and feeling blessed despite their breast cancer diagnosis (Buck & Meghani, 2012). Finally in long-term survivorship, AA women were found to have a strong belief in God’s ability to heal through cancer care providers and the conviction that whatever happens after cancer is a manifestation of God’s will for their lives (Hamilton et al., 2013). Thus, stories are an important part for AA long-term survival from breast cancer.

Within the AA cultural tradition, stories have been a way of communicating and passing on history and cultural priorities (LeBron et al., 2014). Cultural history can be contained within stories and those stories are used for interaction and teaching within the collective or community (Palacios, Salem, Anaebere, & Hayes-Bautista, 2014). Storytelling is an interaction used to share stories with others through an oral medium (Banks-Wallace, 1998) and is said to empower both the teller and the hearer by sharing

experiences through the unique expression of wisdom from living and passing on truths about life (Banks-Wallace, 2002).

In breast cancer prevention and care with AA women, storytelling was shown to have a positive effect on information processing and increase in health-seeking behaviors (McQueen, Kreuter, Kalesan, & Alcaraz, 2011). With AA women who are long-term breast cancer survivors, telling their stories can serve to provide contextual grounding of their experience, catharsis, validation and affirmation of their journey through breast cancer, and an opportunity to educate other AA women (Banks-Wallace, 1998). In short, through storytelling, these women are able to give voice to their experience.

Gaps and Opportunities

There is a clear interest in health outcomes of long-term survivors of cancer, and female breast cancer more specifically. Research funding has facilitated more interest in and knowledge of the experiences and issues associated with the breast cancer treatment and survivorship past the five-year clinical marker of cure (Bloom et al., 2012; Natarajan et al., 2009; Crespi et al., 2010). While researchers have described physical and psychosocial effects of long-term breast cancer survivorship, there have been few randomized controlled trials that include AA survivors in sufficient numbers to generalize that knowledge. In fact, research that was purposefully designed for or oversampled to include AA women found that their experiences have some differences, particularly in the role of social support and spirituality (Best et al., 2015; Gibson & Hendricks, 2006; Tate, 2011; Yoo et al., 2014).

Despite these efforts, there remains a paucity of information about AA long-term survivors of female breast cancer. While it is known that spirituality is important to AA long-term breast cancer survivors (Green et al., 2014; Lynn et al., 2014; Sterba et al., 2014), the narrative of how spirituality and the belief in a higher other has impacted their journey through diagnosis into long-term survivorship has yet to be told. Further, with new ways being developed to measure the influence of living with cancer, beyond QOL, (Crespi, Ganz, Petersen, & Smith, 2013; Crespi et al., 2010; Zebrack et al., 2006), the psychometric properties of these tools need to be assessed in AA women.

Moving beyond the domains of HRQoL can enable researchers to more appropriately measure cancer's impact on daily living and craft interventions that address these impacts (C. C. Crespi, personal communication, October 23, 2014). The Impact of Cancer Scale (Crespi et al., 2013; Crespi et al., 2010) has not been tested in an AA long-term breast cancer sample and therefore the validity and reliability of the scale in an AA breast cancer survivor population has not been assessed. Psychometric testing of the Impact of Cancer, version 2 will help to establish whether this instrument can measure this construct in this population as developed or whether revisions to the instrument should be made with subsequent repeat testing.

There is an opportunity to add to the knowledge about long-term survivors of breast cancer to include descriptive, qualitative research conducted with AA women. The narrative of their journey from receiving a diagnosis of breast cancer through disease-free survival needs to be known. Further, because many AA survivors have expressed the necessity of telling their individual stories in hopes of assisting other AA women with a

diagnosis of breast cancer (Ford, 2016; Wells et al., 2014), a qualitative narrative methodology would be a means to this end.

CHAPTER III

METHODOLOGY AND DESIGN

Introduction

Because of advances in early detection of breast cancer, increasing use of targeted therapy, and improved long-term surveillance of breast cancer survivors (American Cancer Society [ACS], 2015), more women are surviving breast cancer five years or longer after being diagnosed (Siegel, Miller, & Jemal, 2015). The survival rate of AA women, however, continues to lag behind that of all other women. This population group difference in incidence, prevalence, and survival is known as cancer health disparity (Center to Reduce Cancer Health Disparities, 2014) and has been studied extensively over the past 10 years. Despite increased attention to breast cancer disparities (Akinyemiju, Moore, & Altekruze, 2015; Danforth, 2013; Keegan et al., 2015; Wheeler, Reeder-Hayes, & Carey, 2013), relatively little work has been done regarding long-term survivorship in AA women. Using qualitative inquiry, there is an opportunity to add to the knowledge about AA women who are long-term breast cancer survivors.

Methodology

While quantitative methodology is a way to measure, predict, and explain phenomena, there are some topics that cannot be measured quantitatively until there is an exploration through qualitative inquiry. In order to learn more about AA women who are long-term breast cancer survivors, there must be some foundational knowledge of their

experiences. The current literature on long-term breast cancer survivorship is not very representative of the AA woman who has achieved longevity. Additionally, while spirituality has been identified as important to the AA cancer survivor, scant attention has been paid to spiritual well-being in this population of long-term survivors (Hamilton et al., 2013; Tate, 2011; Yoo, Levine, & Pasick, 2014).

There have been qualitative studies conducted about social support (Hamilton & Sandelowski, 2004), surveillance and health-seeking behaviors (Ashing-Giwa et al., 2013; Hamilton, Galbraith, Best, Worthy, & Moore, 2015), and ways of coping (Hamilton et al., 2009) for AA breast cancer survivors. There has not been, however, a narrative addressing their journey noting difficulties and celebrations. Research about the experience of long-term breast cancer survivorship for AA women and the role of spirituality in their journey needed to be undertaken.

Narrative knowing is a means for people to relate knowledge and make sense of an event (Polkinghorne, 1988). It has been described as the verbal recounting of events in one's life, told chronologically, and containing rich description (Hardy, Gregory, & Ramjeet, 2009). In fact, in illness narratives the sequence of events, feelings and relationships allow researchers to make a composite whole from a series of events (Vindrola-Padros & Johnson, 2014). Using descriptive narrative techniques, the researcher was able to describe the story of the journey through breast cancer to long-term survivorship and the effect of this journey on their current lives (Sandelowski, 1991).

There are few theoretical frameworks that use race and gender as a contextual thread, despite evidence that race and gender impact psychosocial and physical health. Womanist theorists suggest that the experiences of AA women are unique and divergent from those of Caucasian women and that researchers should seek integration of the complexity of their lives with their unique worldview (Walker, 1983). A womanist framework provided a way of knowing that encompasses gender and racial bias and includes the impact of health disparities along with the importance of community and the extended family.

The roots of womanist thought are imbedded in AA literature and theology. While Walker (1983) coined the term womanist in an essay about the effect of white pornography on the AA marriage, womanist theology focused on the role of faith in articulating the role of women in a largely male representation of AA history (Williams, 1986). AA writers, such as Zora Neale Hurston, Clenora Hudson-Weems, and Alice Walker influenced the formation of Katie's Canon (Cannon, 1995), a work that explicates the formation of womanist theory from slavery through the black liberation movement and into the AA church culture.

Nursing scholars have also embraced womanist theory as important in correctly articulating the experiences of AA women in the search for health, wellness and community. Evidence exists which suggests race/ethnicity and class significantly affects people's ways of knowing (Banks-Wallace, 2000). African American women share a lived experience, with a perspective stemming from living in a society that degrades both women and people of African descent. Moreover, the nature of truth in a womanist

epistemology centers on the acknowledgement of the daily experiences of AA women as a prerequisite to dialogue about philosophical matters related to truth and knowledge (Banks-Wallace). By opening dialogues with AA women who have common social experiences, nurse researchers are able to gather richer data with which to inform nursing science and craft culturally relevant interventions.

Womanist theory is focused on three central themes: the interactive and multiplicative nature of gender and race oppression; the AA woman's self-definition and self-valuation that provides concrete, accurate images of these women; and identifying and owning the AA woman's culture (Littlefield, 2008). Gender norms that are used in nursing research do not adequately address these themes, thus the need for a conceptual framework that can reflect this difference in the lived experience of AA women. Further, AA women can define themselves through both their personal experiences and the collective experience that comes from women sharing similar societal norms (Banks-Wallace, 2000) that exist at the intersection of racism, classism, and sexism. Taken together with feminist theory, a womanist theory framework can be helpful in building knowledge of women in both races in their search for health maintenance and healing beyond the breast cancer diagnosis.

Four fundamental dimensions of womanist epistemology have described: 1) experience as a measure of meaning; 2) narrative used as a means to assess knowledge assertions; 3) the necessity of a belief in caring; and 4) the existence of personal accountability (Banks-Wallace, 2000). The experiences of AA women enable their transition from wisdom to knowledge and by articulating these experiences they can give

nurse scholars a new lens through which to view their collective experience. Story telling and oral traditions were a critical component of passing down knowledge through generations of AA people who lived in oppression and can be used to frame the health experiences of these AA women in a traditional format (Banks-Wallace, 2002). Caring and empathy are important to womanist epistemology as the AA woman may have nurtured not just her family, but also the families of the oppressors. Finally, a feeling of personal responsibility can spur AA women to participate in research to advance knowledge of their experiences and help others who follow them in seeking care that is specific to their culture, biology, and history (Banks-Wallace, 1998).

Having anecdotal familiarity with the difference of long-term breast cancer survivor experiences does not add to nursing knowledge. Without a conceptual framework, there is not a scholarly basis with which to make the inquiry about a difference in the perspective of AA women based on their history and culture. Using this framework can allow researchers to acquire knowledge about both subtle and overt manifestations of oppression, and a better appreciation of the AA woman's definition and valuation of self and other members in their larger community.

Womanist theory provided a new way of knowing AA women who are long-term survivors of breast cancer. Rather than trying to fit these women into traditional ways of knowing in nursing, womanist theory gives nursing science a new lens with which to view them. Some might argue that there is no difference between Caucasian and AA women, and that cancer is cancer. Using womanist theory can give voice to the unique stories of AA women who are long-term survivors.

There is a growing body of nursing knowledge about women diagnosed with breast cancer, due to an emphasis on screening and early detection, advances in targeted therapies, and better outcomes that result in increasing numbers of long-term survivors. However, the breast cancer survivor literature has been relatively silent about AA women. Much of existing research about long-term breast cancer survivorship research used samples that have 75% or higher Caucasian participants and thus may have lacked statistical power for nurse researchers to generalize these findings to AA women (Forsythe et al., 2013; Maly et al., 2014). If nursing science accepts the premise that AA women experience breast cancer survival differently, it made sense that using a conceptual framework that acknowledged this difference could help with building knowledge about this population. The womanist framework was used as a lens through which to consider the data.

Specific Aim

The purpose of the research study was to explore the stories of AA women who are disease-free survivors of breast cancer, 10 or more years after initial diagnosis, and considered themselves to be thriving after cancer. Narrative inquiry was used to develop the stories into a cohesive whole. The central qualitative question was, what are the stories of AA women who are long-term survivors, of breast cancer? Other areas of interest included; 1) Determining the process of and the factors involved in an AA woman becoming a long-term breast cancer survivor. 2) Describing the trajectories of illness from diagnosis to long-term survivorship for AA women with breast cancer. 3) Using womanist theory to examine race, class, and gender as they have impacted the

trajectory of survival. 4) Examining the role of spirituality throughout their personal trajectory of living with breast cancer.

Sample

Twelve participants were recruited using purposive sampling to reach women who are disease-free, and perceive that they are long-term survivors of breast cancer 10 or more years after diagnosis. A purposive selection approach was appropriate since the preferred participants are AA women who consider themselves thriving 10 years or more after their initial breast cancer diagnosis and who have been disease-free since completion of their initial treatment. Because these women may not be a part of the oncology care system, participants were recruited from the AA community using community resources such as churches, services organizations, breast cancer support groups, and by referrals from other participants. There were no participants recruited from churches. Recruitment continued until data saturation was reached and no new information was revealed (Munhall, 2012). It was anticipated that 20 AA long-term breast cancer survivors would participate. While this number was consistent with other qualitative studies examining AA long-term breast cancer survivors (Ashing-Giwa et al., 2013; Kookan et al., 2007), data saturation was reached with fewer participants.

The inclusion criteria were self-identification as AA, age 18 years and older, diagnosed with and treated for breast cancer, self-identification as thriving after breast cancer, and 10 or more years of disease-free survival. Demographic information was collected from personal data sheets completed with participants, by the researcher. Demographic data included current age, time since diagnosis, age at diagnosis, stage at

diagnosis, treatment modalities (i.e. surgery, radiation, chemotherapy), method by which lesion was discovered (i.e., routine mammogram, breast self-examination, clinical breast exam), co-morbid conditions, highest level of education completed, annual income, insurance status, and marital status (Appendix A).

The stories of AA long-term breast cancer survivors are based on their perception of the events, people and circumstances surrounding their experiences with breast cancer diagnosis, treatment and survival. Using individual interviews allowed exploration of the woman's perception of her diagnosis, communication with providers, support from healthcare providers, family, faith, and community. Additionally, these women may have had very specific concerns related to education and support regarding long-term survivorship, as well as long-term and late effects of certain cancer treatments.

Further, in qualitative research, perceptions are key to understanding the assumptions participants hold related to defining their experiences in concrete terms. Thus, while perceptions are not facts, they gave insight into what participants believe to be important in defining their experiences (Bloomberg & Volpe, 2012). These women may have had perceptions related to the effects of race, gender and perceived or actual social class that color their perception of the journey through diagnosis and treatment, and into long-term survival.

Setting

Semi-structured interviews were conducted at a time and place of the participant's choosing with the caveat that it was free from interruption and provided privacy and comfort (Wengraf, 2001). Participants were advised that the interviews should take more

than one hour but less than two hours. If they preferred not to be interviewed in their homes, the researcher agreed upon a suitable location of their choice.

Protection of Human Subjects

Prior to beginning recruitment and data collection for this study, an application was submitted to the University of North Carolina at Greensboro Institutional Review Board for approval to conduct the study. This approval was required to protect the rights and welfare of the individuals participating in the research study, and assure that the benefits of conducting the study outweighed the risks. Participants were informed about the study, including potential risks and benefits, prior to obtaining a written informed consent (Appendix 2). The consent document was read aloud to each participant to ensure the researcher was able to answer any questions that arose.

Participants were also informed that the researcher is a doctoral student, and the research was being conducted to complete requirements to obtain a Doctor of Philosophy degree in nursing. They were further informed that the dissertation committee chair, Susan Letvak, PhD, is also a registered nurse, and actively supervised the conduct of the research study.

All study materials, including informed consent documents, completed demographics data forms, recordings and transcripts of interviews, were retained in a locked cabinet within the purview of the School of Nursing's Research Office. The researcher retained possession of the sole key needed to access the cabinet. All study documents were stored on a password protected external drive. An outside transcriptionist was employed and this person signed a confidentiality agreement with the

University of North Carolina at Greensboro. Instead of actual names, participant numbers were used during the interviews to further provide participant confidentiality.

Data Collection

Semi-structured interviews were conducted in the participant's home or other location of their choice. Breaks were scheduled if needed by the participant. Participants were also informed that they may stop participation in this study at any time. Data were collected after obtaining informed consent from the subject. A demographic tool was administered as previously described. There were also questions about specific co-morbid conditions such as arthritis, hypertension, diabetes, heart disease, etc. These demographic data are commonly collected in research with breast cancer survivors. Individual interviews were conducted to enable each woman to tell her story, at her own pace, to the investigator.

Each interview was recorded using a primary digital audio recorder as well as a secondary digital audio recorder as a back-up device. Each participant was assigned an identification number in order to assist with de-identifying the data. Participant names were not used in order to preserve anonymity and to ensure confidentiality. Field notes were recorded and analyzed along with the primary data. Participants received \$25 at the conclusion of the interview, in compensation for their time.

Using a single question has been described as a means to induce narrative sharing with the researcher relinquishing control of the interaction (Wengraf, 2001). The grand tour question was, "Tell me about becoming a long-term survivor (LTS) of breast cancer." Additional questions were asked if needed, including inquiring about initial

diagnosis and treatment; the factors involved in becoming a LTS; how the process of becoming a LTS evolved; the role of spirituality in their survival; how being an AA woman affected this process; the people or organizations that provided support, etc. The investigator made brief notes about the interview that were added to the field notes.

At the conclusion of the interview, participants were provided with a copy of the informed consent document, as well as separate contact information for the investigator and were encouraged to call or email if there was additional information they wished to discuss. Field notes were recorded immediately following the interview to describe the setting, participant body language and behaviors, and the investigator's reaction to the interview and data collected. These notes were also used during data analysis to help with recollection of interactions and non-verbal behaviors. Interviews were transcribed at the conclusion of the interviews. Additionally, each interview was used to inform the next interview, using an iterative process (Sandelowski, 2002).

Data Analysis

Data analysis was concurrent with data collection. The data set was managed using a word processing program with manual coding undertaken to begin analysis. Manual coding is appropriate to decide how to divide the data and search for and assemble codes arising from partitioned sections of the data (Sandelowski, 1995). Using the verbatim text, first level coding was begun by looking at chunks of participant responses and marking these portions of text with the meanings derived from the responses as initial codes (Sandelowski, 1995). Subsequently, portions of the text containing themes related to the theoretical framework were retained for further analysis.

It was anticipated that some of these themes would be associated with societal and cultural roles related to gender, opportunities afforded to those of higher economic status, and perceived differences related to being of AA heritage.

A narrative approach is useful to analyze data gathered through discussions with marginalized groups and interpretation of these data is mandatory, as the data cannot speak without analysis. Participant stories were constructed from their memories of events and thus events were not reflected, as much as constructed and reconstructed with each telling of the event (Sandelowski, 2002). Further, since stories were conveyed through the teller's point of view, the listener was pulled into the teller's perspective as interactions were described and storied (Sandelowski, 2002). In reconstructing the narrative of their journey through breast cancer diagnosis to long-term survival, the participants not only explained the diagnosis and treatment experience, but also reconstructed the disruption of the social processes in their normal daily lives (Yoo et al., 2014). A narrative approach to the data was appropriate because the participants were asked to story their experience with breast cancer. The goal of data analysis was to deconstruct the individual accounts and create a narrative, a blended story or composite narrative, in effect a synthesis of the accounts (Polkinghorne, 1988).

A codebook was constructed using the themes of interest and cataloging the context of these themes as they appeared in the data. After these initial codes were identified, the codes were combined in order to trim the number of codes and identify the themes that were of most interest and most closely related to the collective narrative. There was an extraction of facts from the chunks of data which decreased the chance of

errors related the researcher's interpretation of the data (Sandelowski, 1995). Even with employing these initial techniques, it was still possible that attempting to continue analysis with an extremely wide range of codes might be unwieldy.

In the narrative inquiry tradition, one blended story was derived from the data including an abstract for summary, orientation, complication to describe critical events, evaluation, result or outcome, and coda to relate the story of the past to the reality of today (Munhall, 2012). In this spirit, structural analysis was used to code the data according to where they fit in the schema previously noted.

Trustworthiness and Credibility

Qualitative research must have rigor in order to be trustworthy and credible. With the researcher as the instrument, the researcher's skills are an important part of rigor (Richards & Morse, 2013). Through academic coursework and conducting a qualitative exploratory study to inform the present research, the researcher has shown adequate attention to preparation for the conduct of the present study. Describing decisions made during data collection, data analysis, and construction of the larger narrative enables other scholars to follow an audit trail and promote credibility of the research report. Trustworthiness in its essence is the researcher's persuasion of the consumer that research processes are visible and auditable (Sandelowski, 1993).

When considering validity, transactional validity is defined as a collaborative process between the participant, the researcher and the data within which a higher level of accuracy in interpretation can be achieved (Cho & Trent, 2006). Further, during the interview process, the researcher employed constant validity checks by checking for

participant accuracy, negative evidence, and disagreement amongst knowledgeable informants (Bernard & Ryan, 2010). Finally, through triangulation with exploratory research and implementation of recommendations post-study, scientific rigor was demonstrated (Richards & Morse, 2013).

Delimitations

The following delimitations were imposed on the research to ensure the research questions could be answered:

1. AA women who were diagnosed 10 years or more earlier and are in disease-free survival. This definition of long-term survival was necessary since the issues faced in survivorship can be temporally founded based on the time since the end of primary treatment (Ford, 2016; Janz et al., 2014).
2. These women must have considered themselves as thriving in long-term breast cancer survivorship. While it is known that AA women die at a higher rate from breast cancer, it was important to know about those women who beat the odds and transition into long-term survival.
3. The women must speak and understand English.
4. The women must self-identify as Black or AA.
5. The participants must be willing to be interviewed about their experience through the diagnosis of breast cancer into long-term survivorship.

CHAPTER IV

FINDINGS

The purpose of the research study was to explore the stories of AA women who are disease-free survivors of breast cancer, 10 or more years after initial diagnosis, and considered themselves to be thriving after cancer. Data analysis was concurrent with data collection. Using the verbatim text, first level coding was begun by looking at chunks of participant responses and marking these portions of text with the meanings derived from the responses as initial codes (Sandelowski, 1995). Subsequently, portions of the text containing themes related to the theoretical framework were retained for further analysis. The goal of data analysis was to deconstruct the individual accounts and create a narrative, a blended story or composite narrative, in effect a synthesis of the accounts (Polkinghorne, 1988).

A total of 13 women were interviewed for the study, with 12 being retained for analysis. The one not included did not have 10 years of disease free survival. Each interview was audio recorded with 12 conducted in the homes of the participants. The remaining interview was conducted in an area of a restaurant, chosen by the participant, which provided privacy. Interviews lasted between 25 and 75 minutes. Participants ranged in age from 51 to 87 years (mean = 47). Years of survivorship varied from 11 to 32 years (mean = 18) (Table 1). All participant names are pseudonyms and the women

will be described individually followed by an interwoven narrative of the path of an AA woman from breast cancer to long-term survival.

Table 1

Characteristics of AA Long-term Breast Cancer Survivor Sample (n = 12)

Characteristic	N (%) or Mean (Min, Max)
Age (years)	66 (51, 87)
Relationship status	
Married	5 (42)
Separated	1 (8)
Divorced	6 (50)
Stage at diagnosis	
0	1 (8)
I	3 (25)
II	6 (50)
IV	1 (8)
Unknown	1 (8)
Age at diagnosis	48 (29, 67)
Time since diagnosis	18 (11, 32)
Type of Surgery	
Lumpectomy	10 (83)
Mastectomy	2 (17)
Chemotherapy	9 (75)
Radiation therapy	11 (92)
Co-morbid conditions	
Hypertension	9 (75)
Type II diabetes	4 (34)
Arthritis	7 (58)
Overweight	5 (42)
Education	
Some college	2 (17)
2 year degree	3 (25)
4 year degree	4 (33)
Master's degree	3 (25)
Household Income	\$67,800 (\$12,000, \$112,000)
Insurance status	
Medicare	2 (17)
Private	6 (50)
Medicare and private	4 (33)

Description of the Sample

Angela

Angela is a 72-year-old divorced woman who was diagnosed with Stage II breast cancer while in her late 50's. She has been a breast cancer survivor for 14 years and received a lumpectomy. She also received chemotherapy, radiation therapy, and adjuvant therapy with an aromatase inhibitor to decrease the chance of recurrence of her estrogen-receptor positive disease. She credits having a positive outlook and using humor with helping her become a long-term survivor.

I was never downtrodden. I never wondered, why me or cry or anything like that. It's just another illness and you get through it; you deal with it. You do what you have to do. ... Anything I find that can help me, I pull it, and I collect it, and I use it, and I keep it and I share it. ...I just use humor. As people asked me a lot of questions, I tell them some of the things I went through and laughed about it. They just, you're laughing about that? Yes, because it's not going to pull me down. I'm going to beat this illness, and I want you to beat it as well.

Betty

Betty is a 51-year-old woman who was diagnosed with Stage II breast cancer in her late 20's while she was in the military. She had a young child at the time and was primarily concerned about living and not letting her treatment negatively affect her young child. She discovered the lesion during breast self-examination, and received a lumpectomy along with chemotherapy and radiation. She declined the proffered elective estrogen receptor modulator tamoxifen.

...At the time that I was diagnosed, like I said, my daughter was four years old. I'm like, okay, I'm trying to be around here; I'm 29 and so therefore, I needed to do what I needed to do to try to still be here. That's the way I kind of explained it

to her in little kid language, I guess, to let her know that mommy will have to get this medicine so that I could be around and do some things with her.

Charlene

In her early 60's, Charlene is a 20-year survivor of Stage I breast cancer. She discovered her lesion via breast self-examination, despite years of regular screening mammograms. She received a lumpectomy, radiation therapy, and chemotherapy. Like most of the women, she credits her faith in God with getting her through this difficult time. Particularly poignant was being married only a short time when diagnosed.

We went into surgery and I was just laying down. He said, 'you don't seem concerned or afraid of anything.' I'm like, 'It's out of my hands at this point. This is in God's hands. There's nothing I can do with it.' I believe God brought me through this, yes, I do ...Yes, I believe in God and I believe He healed me. ...

Dorothy

After nearly 50 years of marriage and a diagnosis of breast cancer, Dorothy has a positive outlook despite having a type of cancer that does not respond to traditional hormonal therapy. She was diagnosed with Stage I breast cancer 18 years ago at age 50 and had two lumpectomies, a double mastectomy without reconstruction, chemotherapy and radiation therapy.

...He sent me to the surgeon. He looked at it and he wanted to do a biopsy, did a biopsy and said it was cancer, confirmed it. He said he'd seen this before. After they took it out, it was truly breast cancer. I started chemo. I had four regimens of chemo, three weeks apart... and then I started radiation. Then it was gone so I was happy. ...Raise yourself up through your inner spirit and say, 'Look; I'm going to be fine.' I'm going to be as fine as God let me be. If it doesn't turn out that way, I've had a good life. That's the way I look at it. ...You're never alone in this.

Elizabeth

Elizabeth lives in a lively multigenerational household. Twenty years ago when she was in her mid-30's, she was diagnosed with incurable breast cancer. She found the lesion, and after a negative mammogram, she immediately pressed for another one that revealed the lesion she had palpated. In the 20 years since being diagnosed, she has been through multiple surgeries, chemotherapy, and radiation therapy. Throughout all of this, she maintained humor as a way to get through breast cancer for her two young children.

...I'm looking at him, looking at me and like, 'You don't know who you're dealing with. I just buried my father. I have two young kids. I just moved here from [another state] and I don't give up that easy on life.' I told him, 'I'll be back. I'll see you in about three to six months.' He was like, 'No'. He said, 'Really, a lot of people don't accept certain things' but I said, 'Well, I'm not going to accept death.' If it don't succeed, at least, we can say we tried. I'm still here; I got life. That's how I got by, just making humor for them, for me.

Gertrude

At 70 years old, with 32 years since diagnosis, Gertrude is upbeat with plenty of advice for others who are breast cancer survivors. After finding her own lesion, she was diagnosed at Stage II, had a mastectomy without reconstruction, and one year of tamoxifen therapy. Although married at the time of diagnosis, she subsequently divorced her spouse. She has recurring social commitments and didn't want her surgery to affect that part of her life.

...My advice to you is be happy that you're still alive, for one. Two, it's somebody always out to help you if you talk. I find talking to people we learn a lot.... I was married at the time. Had a baby in '79, cancer in '84... He was offered support but he said he didn't need support and that's pretty much when my marriage started going downhill ...we're on the road a lot, and I have a lot of

formals that my tailor make me look very proud and honored of myself as being a lady again.

Hattie

Fifteen years ago, Hattie was diagnosed with Stage I breast cancer after her annual screening mammogram in her mid 50's. She received a lumpectomy and radiation therapy, but refused chemotherapy. She also chose to go through the experience without telling her family members and continued to work as a means of coping but urges others to seek support.

They kept up with me for a while and said the radiation to be sufficient and they just monitored me... I just wasn't prepared for it, and didn't have family members here to help me along, so I kept working. It's important to get in a support group, or to talk with a counselor or someone... Because years later, I ended up in counseling ... I had gotten so down and out, I had to seek professional help.

Inez

Inez is in her late 80's and was diagnosed 20 years ago with Stage 0 breast cancer. Her lesion was found through regular screening mammograms and she wondered later if she had really had breast cancer. She was treated with a lumpectomy, radiation therapy and five years of tamoxifen, but still wondered if she had really had cancer.

One time I called and I said didn't really have cancer? And they said yeah you had it, you had it, it was just the beginning stage of it and I was just very happy that they treated it, and I would suggest that to anyone if it's in 0 stage and they want to treat it, ... Some doctors think it should be some think it shouldn't, but I myself I was happy. I would like to be treated. If I have it, treat it, and if possible get rid of it.

Josie

Sixteen years ago, in her mid-40's, Josie was diagnosed with breast cancer after she found a lesion with breast self-examination. She does not remember at what stage she was diagnosed but was treated with chemotherapy, radiation therapy, and 10 years of tamoxifen followed by five years of aromatase inhibitor therapy. She was divorced prior to her diagnosis and had plenty of support during therapy. She uses humor to give perspective to her journey and is an advocate for women's breast health and breast cancer survivors.

...I divorced my husband in 1999 and I guess the devil says, 'Ok, you are doing too good'. ...And I got diagnosed a couple of days before Valentine's Day.... my ex-husband flew in out of town. And we always joke about that, I say "he just thought I was gonna die, and he had to take our daughter!" ...I just think that it needs to be emphasized even though you have been through your cancer treatment and you are finished. You still have work to do. ...You have to be a person who is proactive about yourself and what you need.

Kenya

Kenya is married with two adult daughters and was diagnosed with Stage IV breast cancer 11 years ago while in her mid 50's. She had a mastectomy, chemotherapy and radiation therapy. She discovered her lesion with breast self-examination just two weeks after a negative screening mammogram. Although she had stopped attending organized religious services after being diagnosed, she has rejoined her faith community. She shared that she is concerned about the secrecy surrounding breast cancer in the AA community and encourages a positive outlook in survivorship.

... When I was diagnosed, I actually was on hiatus from practicing my religion. I felt like I had gotten too busy... I kind of felt like, and I still do, that this was God's way of getting my attention. And then...after this happened, I said 'You got my attention, I hear you, I hear you.' So, I did go back, ...I did start participating and so yeah, spirituality did play a part, because that is actually when I met my best supporter.... Some people still don't want you to know. You don't know they have ever had it. Don't let anybody give you a prognosis that you are going to get out of, you are going to be leaving this earth, nobody knows that. ...Be positive and go ahead on and live your life as normal as you can.

Lilly

Lilly, who is in her early 70's, was diagnosed 14 years ago with Stage II breast cancer. She underwent a lumpectomy twice, received chemotherapy, radiation therapy, and an aromatase inhibitor for five years. She found support through her spirituality and with her minister and believes survivorship is a gift.

I prayed, I talked to my minister, and I um, I got a lot of encouragement from that. I must say that I have been blessed and the support I have gotten when I accepted it [laughs] has been really tremendous. Praise the Lord. It's been 14 years and going into my 15th year. I know that it was a gift from God, because I have experienced so many young people that are diagnosed and they don't make it.

Monica

Monica was diagnosed with Stage II breast cancer when she was 40 years old after a screening mammogram. Although married at the time, she has since divorced. She received a lumpectomy, chemotherapy, radiation therapy, five years of tamoxifen and five years of aromatase inhibitor therapy. She laments the lack of AA role models for long-term breast cancer survivorship. She also thinks there should be more support from the medical community for long-term survivors.

...My survivorship framework really consisted at looking at a White women that was doing quite well. I did not have people in the African American community that could be what I call a role model. The ones that were models were the ones that were going through really terribly. So that's why everyone would say, 'Oh you are gonna get sick, you are gonna lose weight and ... gonna die.'... We have made it and we are out here and we made it, but I don't think they thought we would make it and they didn't prepare. It's like, ...the children of Israel, how they perished in the wilderness because they didn't have a get out of Egypt plan. So when you think about breast cancer survivors, they didn't think...that we were gonna live. And so they didn't have a "How you survive breast cancer after ten year plan."

The Interwoven Narrative

Long-term survivorship from breast cancer is more like a never-ending saga than a neat short story with a predictable ending. There are new milestones and experiences that add to the wonder and mystery of thriving after diagnosis and treatment.

And Then I Had Cancer

A majority of the women reported finding their own lesion, despite having regular screening mammography. Some of the women were younger than the recommended age to begin mammography and depended on breast self-examination to detect a change in their breast tissue. They encouraged women to continue to examine their breasts on a monthly basis and be mindful of their breast health to catch changes that may be missed by mammography.

I went to the doctor because I felt the lump because my doctor told me that I didn't have to do mammograms ... every year.... I didn't have to them every year because everything has been good. I'm like; I better start doing self-exam so I started. That first year, I felt a lump. I called him and told him I found a lump. He got me scheduled for a mammogram and everything took place, the mammogram, the biopsy and it was malignant.

I had felt the lump about six, seven months prior being diagnosed while my father was sick, so I had to take care of him until he passed away. I was a smoker... I decided one day I'm not going to smoke anymore, ...I still don't feel well. I went to the doctor ...had the mammogram ...they said there was nothing there. I knew there was a lump there. I didn't feel comfortable with that answer. ... I went ... back to the same place. What I did was, I drew a circle with the ink pen around the knot and I told them beam it there.

The initial reaction after the news of breast cancer ranged from disbelief to thoughts of premature death. After absorbing the enormity of the diagnosis, the priority was getting a treatment plan and starting treatment according to that plan.

...I couldn't believe I had it. I had no symptoms or anything.

...It was a routine ... clinical breast exam, ... she felt something in my right breast. ...I was diagnosed ... Left breast cancer and that was frightening, because ... I am being diagnosed, all you know are people that have died. And so I was really, really afraid!

...When ...I got that phone call, I immediately thought about my grandchildren, what I would say to them. What I wanted to will to them.

...When I was diagnosed and I had no idea, I just went in for my routine checkup and they found a mass. It was a pinpoint they said, it was small, point of a pen.

I said, well, I want everything. ... If we were going to do it, I wanted to start it right away. ...I don't need a second opinion. ... We know that it was cancerous. I don't have to mess around with this. I'm a do-it-now person. Let's get this over with.

The idea of breast sparing surgery was not entertained, but instead the priority was to get rid of the cancer by any means necessary. Only one of the women had breast reconstruction surgery. While some women had concerns about body image, most of these women just wanted to know the cancer was gone and they could get on with their lives.

... 'We are gonna try to save your breast.' And I told him; it's no big deal to me. You do what you have to do, if you have to cut it off, cut both of them off. Put them in the trashcan, no problem, I got no problem with it. And he looked at me like, this woman is crazy.

...If I'm going to go through a mastectomy, I need to have them both removed.

Along with the diagnosis of cancer, there was a sense of urgency for resolution of the problem. The surgery and any other necessary treatment became a priority. There was no time for long contemplation because there were others depending on most of these women and they wanted to get finished with treatment and get back to their lives.

I said get this over with. I have got to go! ... I said, well, I want everything. ... if we were going to do it, I wanted to start it right away. ...I don't need a second opinion. ... We know that it was cancerous. I don't have to mess around with this. I'm a do-it-now person. Let's get this over with.

I had the folks take the tissue right then and do it to test it out, not wait for two weeks to three weeks. ... I said, 'what I want you to do is take the breast. I have young kids. He said, 'Oh, that's what we're going to do because your motto is if it don't belong there, get rid of it.' Take the breast and put it in a bucket and seal it and kick it somewhere. That's what I used to tell him.

...My daughter was four years old. I'm like, okay, I'm trying to be around here; I'm 29 and so therefore, I needed to do what I needed to do to try to still be here. The whole time I was going through treatment, I was taking care of my mom. She wasn't home with me but she was in a nursing home. I will go there every day and help with her.

Can We Talk? A Complication

Many in the AA community refrain from speaking of cancer. It can be regarded as a death sentence and there is secrecy and silence about being diagnosed with cancer. This attitude may also contribute to poorer breast cancer outcomes with AA women,

since screening and early detection may not be discussed in family or community settings.

...Everybody's got the breast cancer. You just don't know it.... They don't talk about it. That's another thing about talking about it. You free up that person from being standoffish, I might say, silent. You kind of bring them back to reality of years that happened way back where you didn't talk about anything. Oh, Aunt Susie, she passed. Well, what happened? She got sick. What was wrong with her? Oh, we don't talk about that.

I have a girlfriend that I finished high school with and she was talking about somebody one day and she was like you know she has the big C. And I said well why do you talk about it like that, I said just about everybody I hear about passing, they have cancer, cancer, cancer, cancer. ... I don't know what they died from but they never said cancer.

There is a perception of having a stigma attached to the woman diagnosed with breast cancer. It's something you do not talk about. Women are afraid to tell their families, friends, and employers about the diagnosis. Because of this silence, there may not be sufficient social support for these women.

...I didn't even tell my family until afterwards. ... I didn't know how much of a support they could be, even though you'd think the family would be a tight knit group of supporters. ... Really didn't have a chance to really discuss it or think about it. I wouldn't even think about it I just concentrated on going to work and concentrated on my job.

...Some people still don't want you to know. There is still such a stigma on this disease that some people are still whispering. You don't know they have ever had it. And that is surprising to me. Even that this day, some people are still ashamed that they don't want their employers to know.

...She would ask questions about the disease in the third person as she wasn't talking about herself. It took my daughter a while to realize that she was talking about herself, because she didn't want anybody on the job to know that she was a cancer patient.

Getting beyond the fear and stigma is a key to thriving, not merely surviving breast cancer. If there is something that can help more AA women remain well after breast cancer diagnosis and treatment, it is breaking the silence surrounding the disease. With more conversations in AA families and the community, more support may be available for people diagnosed with cancer.

So in African American community...this whole stigma, about cancer and the diagnosis. So those women that were survivors were not even telling people. You know? That they were cancer survivors, so the people that could have been our role models and our mentors, and our shepherds, they were silent. And so we didn't know that people could make it ten, fifteen, twenty years.

... 'Cause a lot of people are afraid of that "C" word. And a lot of families back in the day, older people feel the same way! ... That is what a lot of the older people call it. That "C" word, we don't talk about the "C" word. Cancer! ...I have heard of other people's families that ...don't want to talk about it. ...I think it's because they're afraid.

A lot of times, when people get cancer, they say, oh, I was told I had the big "C". What I want people to know, the big "C" is Christ; the little "c" cancer. It's not the little "c" ...it's the big "C" who counts.

Another common thread in the stories was communication with providers. Effective communication can help build a trusting relationship between patient and provider. When women learned the news of this serious diagnosis, the way it was relayed was usually not using a therapeutic, compassionate approach. A majority of the women revealed they learned they had cancer via a telephone call.

I didn't like the way this was done but she called me on the phone, and said I had cancer. ...Yeah, on the phone. Yep... she sure did. I didn't particularly care for that, but you know, that was a devastating blow to hear because I had not been sick.

...Your cells that came out, were malignant and they need to come out as soon as possible. And I am like; you're telling me this, over the phone? I am in the medical profession, no matter, you don't tell people this kind of stuff over the phone. Not knowing if they are getting ready to leave to get in their car, go somewhere, or whatever! That's really bad.

Even when the news of malignancy was delivered in person, many times the women perceived a lack of compassion on the part of the physician. While dealing with cancer may be commonplace for oncology professionals, it is outside the range of normal for the patient and their family or support network. Again, this method of discourse could hamper forming a trusting patient/ physician relationship and hinder the patient forming a positive outlook on living past the diagnosis.

...He said 'this don't look good.' That was the first thing out of his mouth.... of course that was devastating to me, 'this don't' look good.' So that almost blew away the hope that everybody else had given me.

I went back to see my doctor thinking that we were gonna, I don't know what I was thinking! Thinking about we were gonna just talk more about the plan, but in actuality that visit he said to me 'Are you ready to have your first chemotherapy?' And I was like, HUH?

I met with the oncologist. He says, Well, I don't know why he told you to come here because there's no cure for you. Go home, get your affairs in order and just take care.

Having a considerate and empathetic physician and treatment team was seen as a positive and engendered trust and hope for the future. Women felt they were not alone in the fight for their life when there was a trust that developed from the beginning.

...He says we can try it. We're going to take our time. We're not going to rush this and we're going to see where it comes out.... He believed in me. I believed in

his hands and he always said, no one knows their body better than that person, than you yourself.

I said, 'did you find out the result?' She said, 'yes, that's why I'm calling you.' She said, 'are you alone?' I said, 'No. My husband is here.' She said, 'Well, I didn't want to tell you bad news if you were by yourself.' She was so thoughtful. I said, 'Well, go ahead and tell me.' She said, 'Well, it's breast cancer.'

I think what they should have said was, when you come back, if you can come back with a friend or family member. You know, and not necessarily that it is bad news but both of you guys can celebrate it if it's really good news.

They Call it the Red Devil

Chemotherapy and radiation therapy are necessary evils when treating some breast cancers. Most of these women had both treatment modalities and had vivid memories of difficulties and triumphs along the way. Chemotherapy was an unpleasant experience for most of the women, although not for all.

...The chemotherapy, which is the killer... I had to have what is called the red devil. The thing they emphasized to me the most and I try to tell other people, they let us know, do not let the chemotherapy out of your body by vomiting.

I have taken care of people who have had chemotherapy, so I told them, I would just refuse the chemotherapy under any conditions, simple refusing it, I couldn't see myself going through that. ...weakness, confined to bed or chair, hair loss and just feeling lousy.

I never got sick. I worked. I never got sick, drove myself, drove myself back home. They gave me refills of the nausea medicine. I took one only because I was scared that I would be sick but I [have] never been sick, never lost any hair or anything like that. My experience was pretty good compared to others.

With chemotherapy, there was also an expectation of a loss of hair. While it was expected, losing their hair was traumatic for some women. Others turned it into a

celebration having hair-cutting parties with family and friends. One woman's attitude was that it was only hair, so no big deal.

I called my mom and say, 'you know what, mom, I'm not going to take that chemotherapy because it's going to take my hair out.' I had long hair. She started crying. She was like, 'Oh, baby, it don't matter.' She said, 'I'd rather ...have her see a bald head momma than no momma at all.'

I got my hairdresser at the time, ...Buzz it off! So, all of her clients were there, she had a lot of other people there. So she started buzzing my hair off and everybody was going like, this chick is buzzing all of her hair off, and so I said 'It's okay, I have cancer!'

When I was told the day my hair would start to come out, I wanted to be in charge of this thing. I didn't want my hair to just fall out and me be worried... so we just had a hair cutting party.... I really felt like I would be in charge of this. I'm gonna take my own hair off.

Yes, I'm going to lose my hair, but the thing about it was... I know how to buy some. If it doesn't come back, it's okay. You buy a wig.

Radiation therapy presented different challenges. Women experienced changes in the appearance of their skin. Particularly troubling for some women was the darkening of the skin upon which the beam of radiation was focused. However, others were able to find humor throughout experience and its aftermath.

...that particular breast although was dark and charred, it was like really firm. I was like, okay, but it's still dark and I know cancer was in it so that didn't really cheer me.

I would have 33 treatments of radiation. They said the first 28 would be just fine, but those last five were going to be a killer diller...because they were more potent.

My right breast was burnt pretty bad and I was trying to hide my breast from my husband. I didn't want him to see it. I would tell him what was going on with me

but I wouldn't let him see what was going on with me. Then he said, 'It's great that that thing is burnt, ain't it?' We busted out laughing.

There were some unexpected side effects of therapy that were challenging for the women to handle. There were odd smells, odd tastes, unanticipated physical issues and cognitive concerns. Some even found out that they had weight issues that were the reverse of what they were prepared to manage.

...What your body goes through and the smells... Yes, it comes through your skin... I hadn't put a name to it but yes, you smell bad.

I had four rounds of chemotherapy, and um, they didn't make me sick. I didn't have nausea or anything...The only thing that I had was a metallic taste in my mouth and I didn't have an appetite.

The nurse says, 'this is going to hurt. This [chemo] is going to burn you.' I said, 'Okay.' She said, 'but it's going to burn you down in your vaginal area.' I said, 'that's rare.' She says, 'yes, but it's going to hurt.' I thought I was on fire. My grandmother is running around, telling my husband, 'Get ice, get a rag, get water. What can we do for her?'

...Memory loss. ... It does happen. That is an issue. Like I said, I forgot to tell you. I forgot tell you that there's memory loss, but that's one of them.

I kept waiting to get sick. Because I had heard all these stories, people lose all this weight, and you look sick and all that. That never happened to me! In fact, I gained about thirty pounds. I did! Because I was banking food, so if I ever got to that point I wouldn't lose so much weight that I looked sick. I just gained, gained, gained.

The survivorship literature alludes to some AA women receiving non-standard therapy for breast cancer (Gorey et al., 2009; Keegan et al., 2015). Many participants had stories consistent with that assertion. Additionally, some received non-standard therapy by choice.

...Because I was so young, they wanted to treat me aggressively to go after that cancer. That's what they did. ... Typically, they would do chemotherapy first, then radiation. For some reason, they allowed me to do the radiation first.

...an oncologist... told me I didn't have to have chemotherapy but it would be advised for me to do so... I could choose not to get it.

This one particular cousin... She did not have to do the chemo. She only had to do the radiation and she had a lumpectomy. I still worry about her, I still do. I did my little research and um, I found that from reading and if I believe it, that the survival rate seems to be basically about the same for mastectomy as it is for, um, a lumpectomy. So I opted not to have the mastectomy.

...He said to me, 'we don't have to treat you with the hard stuff. You know, we could do a lighter dose.' And so I was talking to my brother and he said, 'you know what? Just take it, take the hardest dose cause you are psychologically prepared for it, your body is prepared for it and if you are going to take chemo, take it!' If you are gonna fight it, gonna be on the battlefield, put the big guns out.

Peace in the Valley

No one should go through the diagnosis and treatment of breast cancer alone.

Some women had support in their lowest times from family, friends, and co-workers.

Others decided it was an experience best made as a solitary journey. There were also women who expected support from others that was not there when they needed it.

Mothers, they always heal everything. I'm from a family of 10, so they would all come and do fun stuff, family stuff. So, that's where I got my upbeat and support from. And I was all...everything was all well.

My neighbors made me feel good. I'd dress up; I'd have different colored turbans on when I went to church. She was like, look at you looking all jazzy, you know, with matching turbans and stuff. That really helps. When people give you positive affirmation and things like that, it really does help when you got that support like that, and you're not saying, oh, woe is me. It's like, okay, why not me? I can get through this.

They were there for me at any time. At a drop of the hat, moment's notice, my church members was there. That support system really plays a major part; it really does because I think without any type of support system, as well as your team, your oncologist, your surgeon and all of them, a person will just worry themselves to death, literally worry themselves to death without that support.

I didn't even tell my family until afterwards. ... I didn't know how much of a support they could be, even though you'd think the family would be a tight knit group of supporters.

Everybody that talked to me, they was like I'm dying, I'm sorry you know, they talk to you like are dying. I'm like, Wait a minute; I'm not dead yet.

Sometimes humor can get a person through tough times. Quite a few of the ladies related that humor played a large part in helping them remain upbeat, despite going through a rough time.

I didn't see it but my mom brought it to my attention, and afterwards, that he was over in the corner crying. And I told my mom, he was crying cause he thought he was gonna have to take [our young daughter]!

... 'Mom, you're going to be mad when I tell you this.' He's like, 'Touch your head.' It was naked. It was just, 'oh, my God. Get some tape; we're going to go patch some hair. Cut that hair off that dog and we're going to put it on my head.' He was like, 'oh, that's not going to help.' That's how I got by, just making humor for them, for me.

...I said, 'well, how are you going to feel when I have no breasts?' He said, 'Well, I didn't marry you for your breasts but tell them don't touch your thighs.' I said, 'okay.' All right.

For many, a source of peace in the valley of breast cancer diagnosis and treatment was their belief in a higher power, a spiritual overseer. They derived strength, hope, and, joy from their spiritual connection to One who was more powerful than them and the cancer they had.

We went into surgery and I was just laying down. He said, 'You don't seem concerned or afraid of anything.' I'm like; 'It's out of my hands at this point. This is in God's hands. There's nothing I can do with it.'

I got back in touch with myself. During that entire process, I would pray to God every night just like just wake me up, just wake me up and I guarantee You, You'll get another laugh out of me. You will get another laugh out of me. After I regurgitate this chemo up, You'll get another laugh out of me, You'll get another smile out of me and I guarantee You, I will get closer and closer to You as every day that I live. That's happened.

...That's why I say...it's nothing but God. God just took me through. ...And then it just got to the point where I still believed but I was questioning God about that...to bring this on. And that's when I said, you know I can't do this without You God; You have to help me through this.

And I remember saying 'Lord, let this be good' and I said, 'just show me a sign that everything is gonna be alright.' And I remember I was sitting beside a small little table and it was a Time magazine that had Jesus Christ's picture on it. And I said, 'that's all I need, I don't need nothing big.'

The women did see a difference in their needs based on cultural norms. The groups established with the cancer treatment centers were not useful for many. They saw it as a difference in outlook and mood. There was also a need for culturally appropriate devices.

I was able to attend one class. And their [pity] party was worse than mine and I'm a cheerful person. And I didn't take the tears very well. I know every day is not peaches and ice cream, but I needed the peaches and ice cream more so than the tears.

I don't know if we have different issues... The way we support each other, I think is different... I have never gone to any other support group, but I have heard from, stories from people at our meetings that had gone and they said ours is more upbeat. It is more positive, we don't come away feeling like we are on our way to a funeral or we just left one.

I'm into my first white prosthesis. It's okay but I like body color tone. And they are out there. So I asked and am also told that not a lot of people request them.

So I'm not sure whether the technician is aware, or is it something they save money on, or they're limited to what they can and cannot do. The only time I think I was treated differently was when I go to purchase a prosthesis.

And I have heard at other groups, it was more of something else. And I can't even remember exactly what it was, but when people came to ours, it was like oh good, this is what I was looking for. Not the other. It was more about cosmetic things, they were more concerned about their hair growing back or the kind of makeup that was going to be effective and stuff like that. And that was not so much our concern. We just want to feel better and know we are gonna be alright, and we can get back to our lives.

You Are Not Alone

Being able to help other women through the breast cancer experience was another common thread in the stories. Almost all were willing to give advice and support to women who were newly diagnosed and overwhelmed with the both diagnosis and treatment decisions. Some felt compelled to be there for others because no one was there for them who had experienced the journey.

I'll be speaking to a young lady this evening who, unfortunately at the age of 19, has just been told she was diagnosed with breast cancer. I feel like I'm a living testimony to where I can help others get through this thing.

My advice to you is be happy that you're still alive, for one. Two, it's somebody always out to help you if you talk. I find talking to people we learn a lot.... it's not always easy speaking with people in the hospital because you don't know where their state of mind is. But eventually when they're comfortable with you, you'd be surprised what they will share with you. And you become very attached as friends.

People didn't come. They just didn't come. That's why I have gone out of my ... way to visit people when they are sick because it was kind of like, if people came or saw you, they didn't know what to say. And maybe they thought like I thought in the beginning, it meant that you were...it was a death sentence. But I come to know, that that is not true!

I just want women to know that it's okay to feel bad, it's okay to ask these questions but just know that you have family, friends, people you go to church with, you just have a whole slew of people you can pull from to help you with this journey.

There is value in having a newly diagnosed woman see someone who has come through the valley of diagnosis and treatment and looks good and feels good. These AA women need to know and believe that they have not just been sentenced to death from cancer but with life beyond that diagnosis. They also need to know there will be some bumps in the road along the way.

But when [a survivor] said, 'you are gonna be fine.' and I am standing there looking at her. She is several years out and she is fine, so I felt, this may not be a death sentence.

They don't want to feel like they're going to die. I said, 'It's not a death sentence, hon. Cheer up. Go on with your life. You just got some little projects you need to take care of: picking your doctor, doing what he tells you to do, the right questions to ask'...

I tell people when you get diagnosed...first talk with your physician, whether it's the surgeon, oncology or whoever, take people with you. Because you have all of this information coming to you. Everybody before that, I had asked them to write down questions and if it is something that I missed, that they could just openly ask. And it worked out really fine.

From the beginning, I ask them, I said, do you want the good, the bad and the ugly or you just want me to give you a sweet talk?

It is important for newly diagnosed women to know that they must participate in their care planning and treatment. They have to be their own advocate, if possible, because it is their life. Further, they must realize that having surgery and other treatment does not change who they are as a person.

I won't let nobody influence what I'm going to do. I do listen but in the end, I'm going to do what I want to do. If they've given me good advice and I think I need to take it, I will take it but I'm still going to do what I'm going to do.

You just got some little projects you need to take care of: picking your doctor, doing what he tells you to do, the right questions to ask'...

New doctors have a tendency to be a little bit more progressive than some of the older doctors who would use the same thing year in and year out; they're not willing to change easily.

Don't take 'no'. If you feel like you're sick and you know that your body is not getting better, don't take no for it. Do something about it because I wouldn't be here if I had just listened to them. I wouldn't be here.

...Just because if you have something cut off, doesn't mean you are a less person than someone that has everything that you had. That this is what you have to face, reality. It can happen, it is real!

Serving as an advocate is not limited to AA women who are newly diagnosed and going through treatment. It is also important to be an advocate for screening and early detection in the AA community. Getting the word out that there is life after a diagnosis of breast cancer is a priority, as well.

...One good thing that has come out of it, we have a family reunion every two years... one meeting is devoted to health issues... As we go up our family tree, we're able to find out what has happened to other family members in terms of illnesses. We spend that time looking at our tree, and trying to see what can we do to help each other... We're constantly talking to everybody's children about cancer, diabetes, high blood pressure and other things that are life-threatening and things that can be controlled and eradicated if they do the right things.

I'm looking for things that can help people. It's not about me. It's about, what can we do to help the next person and get early detection and not fear the exams, not fear your family history. Embrace it...accept it and fix it.

If we don't talk about it, people won't know about it and if they don't know about it, they are still gonna be afraid of that "C" word. And the more we get out there and talk about it, especially to our young people, that they will know. Just to

know that if I can go through what I went through, you can too! And you can be a survivor!

The New Normal

After the conclusion of treatment for breast cancer and achievement of the five-year clinical marker of survival, the AA long-term survivor has to put the experience in perspective related to her current life. The perspective on life and the world has changed and in turn so has the woman. Some women say they cherish their family and love even more fiercely than before breast cancer touched their lives.

...That's the thing with having this long term survivorship, you really do have to create a new norm. And since no one is teaching us, it's like a trial and error kind of thing for us.

I am going to live each day as it comes. Because I was encouraged to just stay positive. And along with staying positive I stayed busy. And so my work schedule and life, I tried to keep it as normal as possible.

I had to try to make things a little bit easier for them, meaning that save money, be around them more often, love them more love them hard, love on them hard, get close to my family, get close to God, do everything that I wanted to do.

Another area of emphasis after surviving breast cancer and having to view it as a chronic health issue is paying more attention to health seeking behaviors. The focus may be nutrition and exercise, maintaining cancer surveillance activities, or managing symptoms related to cancer therapy. The important thing is to make self-care a priority.

I've eaten, since 1984, better than I ate in my life, eating more healthier. Now every now and then I might stray away but something tells me, all right pull yourself back in line. And my eating habits consist of mostly fruits and vegetables, chicken, fish, maybe every now and then hamburger. Turkey is good for you.

Breast cancer means you have to prevent it, do your self exam, go see a licensed practicing doctor, have a mammogram at least once a year and if you have something like, anything that looks like a little tumor, let them do a sonogram right then and there and go back to your doctor. If he feels you need a biopsy, go ahead. Don't be afraid of things. Go ahead and get the biopsy. Take care of yourself. Doing your self-exam, learn and know your own body.

I still do my arm exercises and believe it or not, when I wear jewelry, bracelets, or even sleeves that are below the wrist, if they are too tight it will let me know. If my prosthesis is placed in wrong position, it will also let me know. So I know what I need to do to make the adjustment and my uncomfortable feelings are all resolved.

Many of the women talked about working on the inner woman. After breast cancer, they were concerned with moving forward in survival with a positive outlook on life. Very deliberate actions were taken to meet this need.

I'd just been living. I try not to be stressful, try to let no stress bother me. I know some people think that I might be just don't care but it's not that. I just that's how I handle my stress. I just [say] okay, whatever and moving on because life has been really good. I've had a good job. I got a nice husband, younger.

You know how we're younger, we get involved in he-say she-say mess and we always want to know what's going on with somebody's life. I don't care what's going... it's not that I don't care what's going on in somebody's life. I just don't have time for that anymore, in he-says, she-says, you know you can keep it.

I was like, 'I am going to live each day as it comes'. Because I was encouraged to just stay positive. And along with staying positive I stayed busy. And so my work schedule and life, I tried to keep it as normal as possible.

The Collective: When I Learn Something, I Share It

True to a womanist framework, the stories of these women indicate experience as a measure of the meaning of long-term survival from breast cancer. The narratives give a vehicle to understand the knowledge gained and pass on their stories in the oral tradition.

Just to know that if I can go through what I went through, you can too! And you can be a survivor! And when I say survivor, you do have a story to share with others, to pass that along to help somebody and bring somebody else up to help them.

...You know what, I don't think of it as a long-term survivor. ... I am better, ... I know what I went through to get to this point and I like it. And I will say this, I would not have changed anything. That was a great journey for me, that let me know totally [I am] not in charge. God is in charge!

Further, in womanist tradition, they have a belief in caring for others as well as for themselves. They consider themselves to be the backbone of the family, the nerve center, the place of strength, and the person who holds the family together. That is a heavy burden to bear when trying to care for self but family was important and central to their responsibilities.

When I was sad, I wouldn't show it too much to them because I didn't want them to see it because I had to have that strength. I have to be the strong one to get us all through it and that's what I did.

And so I said to myself, and I said to them. Maybe I was chosen out of our group of five (sisters), to do this because I had more support than everybody else.

I have young kids. They would come, you know, get cleaned up, put the mask on there, come sit on the bed and talk to me and all. I was just getting closer with them and stuff. My thing was fighting to the end. I want to see them graduate from high school. I just want to get better.

Finally, personal accountability figures prominently in the womanist framework. In long-term survivors, it may take the form of advocating for others or participating in research that can benefit others. This personal accountability is not deterred by the personhood denies AA men in the Tuskegee Study of Untreated in the Negro Male

(Lombardo & Dorr, 2006; Warren, Williams, & Wilson, 2012). Instead, there is a sense of obligation to make things better for future patients by giving of themselves for research.

Back then, I wouldn't think nothing about being in no clinical trial but now, I've learned more now that I'm a 22 year survivor.... I didn't want to feel like I was part of like the Tuskegee treatment, you know, things like that. It was a bad situation back then so things like that kind of scare particularly African-American women.

As citizens in this world we live in today, we have a lot of responsibility. If you have children, it is your responsibility on some investigational drugs and some things of that nature. It's like you should if you want the next generation to live and be free of something that you've gone through

I'm Still Here

To summarize the story, many women rejoiced in still being alive and disease-free despite the grim prognosis for AA women with breast cancer. Some stated that you deal with breast cancer as you would anything other challenges in life. They were determined to get through diagnosis and treatment and to never give up hope or the desire to live. Almost every woman is willing to share information about their journey with breast cancer when asked to address others who have just been diagnosed.

I had to tell myself that the cancer was out because it was the one (lymph node) that had it in there that let me know it had not metastasized anywhere else. No matter what anybody else said, I told myself I had the cancer out.

I take each day at a time. Going through breast cancer, ... I have learned from it, I have grown from it. And I have gotten closer to God and ... I think that is the best thing that ever happened.

The quest for information goes beyond each woman seeking knowledge about her own survivorship issues. They also pull together information from different sources for different audiences. Sometimes it is to assist those newly diagnosed or going through treatment. Other times there may be updates on long-term survivor issues or new findings from research.

Anything I find that can help me, I pull it, and I collect it, and I use it, and I keep it and I share it.

I'm not one that holds on the information. When I learn something, I share it, because people don't know what they don't know.

One woman stated that she did the interview for the current study in hopes that other people will realize it is not a negative thing to be diagnosed with breast cancer. According to her, to think of it negatively could cause a downward spiral that the person will not survive. Breast cancer does not have to be a death sentence and to survive takes the effort and faith of the woman. The long-term survivor does whatever she needs to do to live and have the best life possible, for her as well as for others who depend on her continued survival.

...Don't let anybody give you a prognosis that you are going to get out of, you are going to be leaving this earth, nobody knows that. ... Be positive and go ahead on and live your life as normal as you can.

I'm looking at him looking at me and like, you don't know who you're dealing with. I just buried my father. I have two young kids. I just moved here from New York and I don't give up that easy on life. I told him, I'll be back. I'll see you in about three to six months. He was like, no. He said, really, a lot of people don't accept certain things but I said, Well, I'm not going to accept death...If it don't succeed, at least, we can say we tried. I'm still here; I got life.

CHAPTER V

DISCUSSION

Introduction

The purpose of this study was to explore the stories of AA women who are disease-free survivors of breast cancer, 10 or more years after the initial diagnosis, and consider themselves to be thriving after cancer. Thirteen women were interviewed using semi-structured interviews, however only 12 narratives were included for analysis. It was revealed during the excluded interview that the woman did not meet inclusion criteria, having only five years of survival, subsequently, those data were not included in the analysis. The narratives were analyzed using a story arc that looked at the beginning (diagnosis) through the present reality (long-term survival). This chapter will provide a discussion of the findings.

A womanist framework was used as a lens through which to consider the narratives. It was appropriate for these data because of contextual threads of race and gender inherent in the stories. Further, in a womanist framework, acknowledging the everyday experiences of these women opens a dialogue about their truths, knowledge, and spiritual well being. Finally, these AA women have a collective experience at the intersection of racism, classism, and sexism. In following womanist tradition, the survivors spoke about their search for health, wellness, and community.

The story arc revealed the following narrative topics: And then I had cancer; Can we talk? A complication; They call it the red devil; Peace in the valley; You are not alone; and, The new normal. The collective story was told as: *When I learn something, I share it and I'm still here.*

The AA long-term survivors who took part in this research were similar to other AA breast cancer survivors in having co-morbid conditions, needing information about nutrition and exercise, and wanting providers to consider the everyday demands in their lives (Ashing-Giwa et al., 2013). The long-term survivors had co-morbid conditions such as hypertension, overweight, and diabetes. The participants related that there is a need for provider guidance in nutrition and exercise along with long-term / late effects of treatment for breast cancer. Primary care and oncology providers need to collaborate more effectively in order to meet these needs. They also spoke about how social support can contribute to improved outcomes while cancer secrecy and stigma may contribute to poorer breast cancer outcomes among AA women. Finally, it is clear that these women perceived spirituality as key to long-term survival and thriving after breast cancer.

Provider Communication and Trusting Relationships

The women in this study reported difficulty in building a trusting relationship with some oncology providers. These providers were perceived as harsh or lacking compassion. Provider communication styles and patient- perceived discrimination have been shown to influence patient outcomes (Benjamin & Whitman, 2014; Maly et al., 2014). While some may excuse provider rudeness as inherent in their area of specialty, it is simply not acceptable when giving a woman the devastating diagnosis of breast cancer.

Finding out that the biopsy was positive and one has cancer should be conveyed in person when possible. When distance or timing prevents face-to-face delivery of bad news, providers should at least determine whether the person is alone or has some type of support available to them at the time.

Previous research has revealed the importance of patient-provider trust in treating cancer and other chronic illnesses (Rowe & Kellam, 2010; Tucker, et al., 2014; Wittayanukorn, et al., 2015). Trust can be established if information is freely shared with patients and patient opinions are acknowledged and respected, particularly in the face of vulnerability due to being diagnosed with cancer (Rowe & Kellam, 2010). Promoting trust has been defined conceptually as containing three central qualities: “interpersonal and technical competence, moral comportment, and vigilance”, all modifiable behaviors (Murray & McCrone, 2014, p. 20).

There may be perceptions of discrimination by AA patients with race-discordant providers, ironically because while those providers try to shape conscious intentions, the AA patient may be more attentive to non-verbal behaviors that convey racial bias (Penner et al., 2012). It has also been noted that there is a disparity in provision of information concerning treatment options and clinical trial availability to AA cancer patients as compared to Caucasian cancer patients (Eggly, Barton, Winckles, Penner, & Albrecht, 2013). Much research has shown that there are disparities in time to surgery with AA breast cancer patients due to both patient and provider delays (Sheppard et al., 2015).

Further, if providers are truly interested in decreasing the survival disparities in female breast cancer and promoting health-seeking behaviors in AA long-term breast

cancer survivors, there must be an effort to recognize and modify non-standard treatments plans. This effort is vital if prescribing these therapies is grounded in racial differences and stereotypes of compliance with treatment. Forming mutually trusting relationships between providers and these AA women may assist with decreasing stressors inherent in breast cancer surveillance care and improving self-reported health among this population (Brondolo et al., 2011). The interwoven narrative of these women has provided evidence that there is room for improvement in communication and therapeutic relationships.

Social Support

Evidence exists that positive social support can provide encouragement and reassurance after a diagnosis of breast cancer with women having positive social interactions reporting fewer physical symptoms and a perceived higher quality of life (Kroenke et al., 2013). Social support may look different for AA women, however.

In the current study, there were observations that Caucasian breast cancer support groups were perceived as maudlin, weeping groups of unhappy women indulging in self-pity. By contrast, the AA support groups some women attended were seen as uplifting, encouraging, and almost familial. Further, there was speculation that while Caucasian women derived support through treatment from their spouses, AA women leaned upon girlfriends, mothers, sisters, and ministers. Finally, there was the belief that because AA women tend to be diagnosed at a younger age, Caucasian women who were in the retirement phase of life had fewer comparable daily concerns (Bloom, et al., 2012).

While much breast cancer survivor support is focused upon women in active treatment, there is not much available for women who are long-term survivors. Any new treatments or research findings related to long-term survival should be made available to these women. Also, it is known that AA long-term breast cancer survivors have a higher body mass index and can benefit from physical activity and dietary interventions (Coughlin et al., 2015). Moreover, younger women who are long-term breast cancer survivors expressed a need to have support groups in which they had freedom to talk about sexuality, premature menopause, and fertility concerns.

Cancer Stigma, Secrecy, and Fear

For AA women who are long-term survivors, there have not been visible role models of women with long-term survival who look like them. This lack of role models may be due in part to the secrecy, stigma, and fear with which the AA community has traditionally viewed cancer. Cancer fatalism, the belief that a cancer diagnosis means certain death, has been explored in the AA community (Lebel et al., 2014; Powe et al., 2005; Sterba et al., 2014), and may contribute to the silence surrounding the diagnosis of breast cancer. Further, fear may hinder AA women from participating in clinical trials of cancer treatments, thus limiting the knowledge of outcomes for AA breast cancer survivors (Somayaji & Cloyes, 2015). Finally, a perception of stigma attached to a cancer diagnosis can result in AA women not seeking support during treatment, perhaps to their detriment.

With AA long-term breast cancer survivors, cancer fears may take a different form. Initial diagnosis and treatment may result in distress; long-term survival comes

with fear of recurrence, metastasis, and second diagnosis of cancer (Gibson et al., 2014). To further increase fear, breast cancer survivors face five times greater mortality from breast cancer than women who have never been diagnosed, even 10 or more years after initial diagnosis (Koch et al., 2014). While fear of death from cancer may loom in the background, participants in this study used strategies noted in the literature such as positive self-talk, avoiding people with negative attitudes, and belief in a higher power (Hamilton, Best, Galbraith, Worthy, & Moore, 2015). Further, interventions directed toward reducing fear and distress have been successful in breast cancer survivors (Lebel et al., 2014) and should be studied with AA long-term breast cancer survivors.

There has been a correlation between cancer fatalism and spirituality, with higher spirituality associated with a reduction in fatalism (Christman, Abernathy, Gorsuch, & Brown, 2014). This relationship is consistent with the participants in the current study as many stated their faith conquered their fear through diagnosis and treatment and into long-term survival. Narratives from survivors have been shown to make breast health information more meaningful in the context of the daily lives of other AA women, thus moderating cancer fear and fatalism using stories with positive outcomes (Yoo, Kreuter, Lai, & Fu, 2014). The interwoven narrative from this research may be useful for debunking cancer fatalism and encouraging breast health seeking behaviors in AA women.

Spirituality

Spiritual involvement may translate into better health outcomes and increased social support as compared to other cancer survivors (Hamilton et al., 2011). Spirituality

was seen by these women to serve many purposes. It gave hope for a positive outcome from breast cancer, belief that God would guide the hands and hearts of their treatment team, and faith that their lives would continue to be directed by God as they helped other AA women going through diagnosis and treatment for breast cancer.

Spirituality was beneficial in every aspect of the experience from diagnosis through long-term survival. Participant's told of the comfort derived from having a belief in a higher power being was in control when they were given the diagnosis of breast cancer. Many women related that their faith conquered their fear when facing an uncertain future because of having breast cancer. The women recounted that their faith took them through diagnosis and treatment and remains important in long-term survival.

Spirituality has been a foundation upon which the AA community built themselves up from slavery and discrimination. Storytelling has been described as a means to promote spiritual well being and organize and make sense of experiences (Taylor, 1997). The stories shared by the participants were entwined with their beliefs in a higher power that directs their lives and health. Even in the face of dire diagnoses with late stage or untreatable cancer, these women drew strength from their spiritual beliefs and became long-term survivors. Anxiety and depression have been identified with fatigue, insomnia, and other untoward symptoms related to breast cancer (Coughlin et al., 2015). Spiritual beliefs and prayers can help alleviate the severity of these symptoms, thus relieving physical and emotional burdens.

Spirituality for AA long-term breast cancer survivors provides social support, hope, and faith in having a future. God has been identified as a major source of support

through diagnosis and treatment with many women talking to God about their experiences, rather than to family and friends (Tate, 2011). Participants in the current study shared that they used God as a source of strength and shared feelings with Him frequently throughout the experience of diagnosis, treatment and long-term survival from breast cancer. While Caucasian women have been shown to rely on support from their spouses, AA women may find it easier to cope with their experiences by relying on God (Lynn et al., 2014; Tate, 2011; Sterba et al., 2014).

Placing the breast cancer experience in the context of spiritual meanings may assist AA long-term survivors cope with the changes in their lives secondary to cancer. Spirituality has been shown to help move newly diagnosed women from a place of cancer fatalism to one of hope and empowerment (Sadati et al., 2015). The long-term survivors in the current study used spirituality to give them hope and also to support other newly diagnosed AA women. Finally, a belief in the power of God can positively influence health-seeking behaviors in AA women who are long-term breast cancer survivors (Hamilton, Galbraith, Best, Worthy, & Moore, 2015). If the woman believes God is in control, there is less to fear from cancer treatment and subsequent surveillance.

Implications for Practice

Oncology professionals should be aware of the similarities and differences in AA women with breast cancer as compared with other women. As we develop breast survivor care plans, there needs to be a deliberate effort to address the unique concerns of younger AA women, as well as openness to the importance of spirituality in lives of many of these women. There should be a seamless transition from breast cancer patient to

breast cancer survivor, created with collaboration between oncology and primary care providers. Further, the patient should be involved in this planning, as they must be in the center of the care relationship.

With many AA women having co-morbid conditions of overweight or obesity when diagnosed or at the conclusion of treatment, there must be culturally relevant interventions to address this issue. Obesity can lead to poorer outcomes, as well as recurrence of breast cancer (Coughlin et al., 2015). Crafting nutritional interventions should take into account the woman's previous diet with attention paid to making those recipes healthier. Likewise, when developing physical activity interventions, attention must be paid to exercise that incorporates dance or other activities traditional for AA communities. Finally, because it is known that support groups may play an important role in health-seeking behaviors, established networks or communities should be used when intervening in nutrition and physical activity pursuits.

Implications for Research

While much is known about long-term breast cancer survivorship in Caucasian women, there have not been a representative number of AA women in these studies to provide sufficient statistical power to generalize findings to the population. There is now a small body of research about AA women who are long-term breast cancer survivors with investigators exploring adherence to survivorship surveillance guidelines (Advani et al., 2014; Pullen et al., 2014). More work is needed in this area, specifically exploration of explanations AA women give for non-compliance with recommendations and interventions to address those issues.

Spirituality in relation to health and cancer has been studied in AA communities (Best et al., 2015; Boyd-Franklin, 2010; Green et al., 2014), as well as among AA breast cancer survivors (Gibson & Hendricks, 2006; Hamilton et al., 2013; Lynn et al., 2014). Acknowledging and respecting the spiritual beliefs and practices of AA women with breast cancer is supported by the current study. Although every AA long-term survivor may not value spiritual practices, it is important to include spirituality with those who do, as appropriate.

Limitations

Participants in the current study were from two states in the southeastern United States. There may be regional differences in the experiences of AA long-term breast cancer survivors. The sample was also from an urban setting, with relatively high income and educational attainment. AA women from rural areas, or those with lower household incomes, may have different experiences than the women in this study.

Another limitation is that many of the participants were active in AA centered breast cancer support groups. Availability of social support may be positively affected by membership in these groups. Further, advocacy activities within these groups may have influenced the women to reach out to newly diagnosed women, and provide breast health information in their communities. Finally, while the participants' stories may resonate with other AA long-term breast cancer survivors, because of the qualitative nature of this study, findings are limited to only these participants.

Significance of the Research

This study adds to the growing body of knowledge about AA women who overcome the odds of mortality from breast cancer. Before interventional research can be conducted, there is a need to do descriptive work to find out what it means to be an AA long-term breast cancer survivor. The current findings will give researchers more information about what it is like to be treated by individuals within care systems that may not share the same values and beliefs. The narratives of the journey through diagnosis and treatment to long-term survival provide new knowledge about how clinicians can provide more culturally sensitive and relevant care to this population

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APPENDIX A
DEMOGRAPHICS FORM

Age in years: _____

Race: Black: _____ African American: _____

Other: _____

Height: _____ **Weight:** _____

Relationship status:

Married: _____ Committed relationship: _____

Separated: _____ Divorced: _____

Always single: _____

Insurance status: (Check all that apply)

Medicare: _____ Medicaid: _____

Private insurance: _____ Not insured: _____

Breast cancer information: (If known)

Age at diagnosis: _____

Stage at diagnosis: _____

Time since diagnosis: _____

Did you have surgery? Yes _____ No _____

If yes, type of surgery: _____

Reconstruction: Implants: _____ Own tissue: _____

Did you have chemotherapy? Yes _____ No _____

Did you have radiation? Yes _____ No _____

Did you receive tamoxifen or other medication to reduce chance of recurrence? Yes _____ No _____

How did you discover you had breast cancer? _____

Other medical conditions: (Check all that apply)

High blood pressure: _____ Diabetes: _____

Arthritis: _____ Overweight: _____

Lung problems (Specify): _____

Heart problems (Specify): _____

Other (Specify): _____

Yearly household income:

Less than \$20,000: _____ \$20,000- \$39, 000: _____

\$40,000- \$59,000: _____ \$60,000- \$74,000: _____

More than \$75,000: _____

Education (Check all that apply):

Less than high school diploma: _____

High School diploma/ GED: _____ Some college: _____

2 year degree: _____ 4 year degree: _____

Master's degree: _____ Doctoral degree: _____

APPENDIX B
INFORMED CONSENT DOCUMENT

UNIVERSITY OF NORTH CAROLINA AT GREENSBORO

CONSENT TO ACT AS A HUMAN PARTICIPANT

Project Title: **Stories of African American Women who are Long-term Survivors of Breast Cancer**

Principal Investigator and Faculty Advisor (if applicable): Yvonne R. Ford, RN and Susan Letvak, PhD, RN, FAAN

Participant's Name: _____

What are some general things you should know about research studies?

You are being asked to take part in a research study. Your participation in the study is voluntary. You may choose not to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. There may not be any direct benefit to you for being in the research study. There also may be risks to being in research studies. If you choose not to be in the study or leave the study before it is done, it will not affect your relationship with the researcher or the University of North Carolina at Greensboro.

Details about this study are discussed in this consent form. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. If you have any questions about this study at any time, you should ask the researchers named in this consent form. Their contact information is below.

What is the study about?

This is a research project. Your participation is voluntary. The purpose of this study is to learn what it is like to be an African American women and long-term breast cancer survivor. We are interested in the story of your experience with breast cancer through diagnosis to disease-free survival. There is not much known about African American

women who are long-term survivors of breast cancer and this study aims to report the stories of African American women who are disease-free survivors, 10 or more years after initial diagnosis, and consider themselves to be thriving after cancer.

Why are you asking me?

To participate in this study, you must:

Identify yourself as Black or African American.

Be 18 years of age or older.

Have been diagnosed with breast cancer 10 or more years ago.

Not currently be in active treatment for breast cancer.

Be able to speak and read English.

What will you ask me to do if I agree to be in the study?

If you agree to be in this study, you will be asked to sign this consent form. After you sign the consent form, you will be asked questions about your age, cancer diagnosis, cancer treatment and current medications to make sure that you are eligible to participate. The researcher will then interview you about your experiences as a breast cancer survivor.

Is there any audio/video recording?

The interview will be taped but your identity will be kept confidential. Because your voice will be potentially identifiable by anyone who hears the tape, your confidentiality for things you say on the tape cannot be guaranteed although the researcher will try to limit access to the tape as described below.

What are the risks to me?

The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risk to participants. There are no physical risks associated with this study. There is, however, the potential risk of loss of confidentiality. Every effort will be made to keep your information confidential, however, this cannot be guaranteed. Some of the questions we will ask you as part of this study may make you feel uncomfortable. You may refuse to answer any of the questions and you may take a break at any time during the study. You may stop your participation in this study at any time. The interview should take about one hour and a half to complete.

If you have questions, want more information or have suggestions, please contact Yvonne R. Ford, RN at (919) 949-5188 or faculty advisor Susan Letvak, PhD, RN who may be reached at (336) 256-1024.

If you have any concerns about your rights, how you are being treated, concerns or complaints about this project or benefits or risks associated with being in this study please contact the Office of Research Integrity at UNCG toll-free at (855)-251-2351.

Are there any benefits to society as a result of me taking part in this research?

We hope the information learned from this study will benefit other patients who are long-term survivors of breast cancer in the future.

Are there any benefits to *me* for taking part in this research study?

If you agree to take part in this study, there is not likely to be direct medical benefit to you. We hope the information learned from this study will benefit other patients who are long-term survivors of breast cancer in the future.

Will I get paid for being in the study? Will it cost me anything?

There are no costs to you for participating in this study. You will be reimbursed \$20 for your expenses related to study participation.

How will you keep my information confidential?

The information will be stored in a locked file cabinet; interview recordings and transcription will be kept on a password protected external drive. While the information and data resulting from this study may be presented at scientific meetings or published in a scientific journal, your identity will not be revealed.

The interview data will be kept until all analysis is completed and will then be destroyed. All information obtained in this study is strictly confidential unless disclosure is required by law.

What if I want to leave the study?

You have the right to refuse to participate or to withdraw at any time, without penalty. If you do withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data which has been collected be destroyed unless it is in a de-identifiable state. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

What about new information/changes in the study?

If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

Voluntary Consent by Participant:

By signing this consent form/completing this survey/activity (used for an IRB-approved waiver of signature) you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document and are openly willing consent to take part in this study. All of your questions concerning this study have been answered. By signing this form, you are agreeing that you are 18 years of age or older and are agreeing to participate, or have the individual specified above as a participant participate, in this study described to you by Yvonne R. Ford.

Signature: _____ Date: _____