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Breast Cancer Disparities in African American Women: Does Race or Place Matter?

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Breast Cancer Disparities in African American Women: Does Race or Place Matter?

Abstract

African American women are 42% more likely to die from breast cancer than their White counterparts. The purpose of this phenomenological study was to understand the lived experience of African American, female, survivors of triple negative breast cancer (TNBC) to determine if any of the key tenets of the social determinants of health, particularly race and place/social conditions, influenced their screening through treatment decisions or care. Through the interpretive description approach, six interviews were conducted with survivors of TNBC who either worked or resided in one of eight Monroe County zip codes: 14605, 14606, 14608, 14609, 14611, 14613, 14619, and 14621. These zip codes, home to 63% of the regions African American population, were selected because they had the highest rates of poverty, the worst health outcomes, and the lowest life expectancy of any other zip code in the nine county Finger Lakes region. The findings of this study revealed that the women did not believe their screening through treatment options were influenced by their race or place/social conditions. The following themes were identified: (a) the strength and resilience of the survivors was expressed through their faith and positive attitudes; (b) the importance of physician / patient relationships, including the dissemination of information and patient invalidation; (c) the need for self-advocacy; and (d) the role of support groups. Recommendations for future studies include suggested actions for researchers, physicians and patients to include: using measures of protective factors in research studies; training medical professionals in areas of cultural humility, implicit bias, and structural racism; and, encouraging women to be vulnerable and accept help.

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Breast Cancer Disparities in African American Women: Does Race or Place Matter?

By

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Submitted in partial fulfillment
of the requirements for the degree
Ed.D. in Executive Leadership

Supervised by

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Dedication

Prior to beginning my work in public health, I had no personal connection with breast cancer. Unfortunately, within the last 8 years, I have been touched by breast cancer four times: my mother, mother-in-law, and two aunts. Thankfully, all of my family members survived this horrible and devastating disease. Sadly, there are many women who are not as fortunate. I dedicate this dissertation to the breast cancer survivors in my family: Althea, Renee, Joycelyn, and Brenda, and the amazing survivors who participated in this study. You are truly gems in my eyes.

I also want to acknowledge the many people who supported me through this process. To my:

- Family whose support, sacrifice, patience, and love sustained me throughout this journey: My accomplishments are our accomplishments.
- Mentors who wrote letters of support, offered words of wisdom, and kept me encouraged throughout the program: I am, because you are.
- Friends and colleagues who showed up for me in ways I couldn't imagine, worked with me throughout this process, and offered their expertise, recommendations, and advice: I am forever in your debt.
- Classmates, especially my TCW² team, whose camaraderie, kindness, and work ethic inspired me to always do my best: We did it, Drs.!

- Professors and guest speakers who made each class memorable and broadened my awareness and knowledge of leadership, diversity, and justice: You have enriched my intellectual capacity, and I am forever grateful.
- Committee chair, Committee member and Executive mentor who guided me through this process. Your scholarly advice, honesty, and humor kept me steady throughout this program.

You each played a critical and instrumental role in my successful completion of this program. I could not have done of this if any one of you was not involved. Thank you!!!

Biographical Sketch

Candice A. Lucas, MBA is the Director of Community Health Services and the Cancer Services Program of Monroe County at the URMC Center for Community Health (CCH). In this role, she directs the operations of multiple community-based outreach programs aimed at improving the health of Monroe County residents. She promotes: physical activity and nutrition as a means of chronic disease prevention; screenings for prevention and early detection of breast, cervical, and colorectal cancers; career development and advancement of low-income workers in healthcare fields; and health literacy and education to empower patients and community members in being better self-advocates.

Additionally, Ms. Lucas chairs both the African American Health Coalition convened by Common Ground Health and the Race and Health Disparities Workgroup of the Facing Race, Embracing Equity initiative. Both coalitions bring together dozens of professionals from a broad cross-section of health, non-profit, and governmental organizations to address issues of health disparities, structural racism, and implicit bias that negatively impact the health outcomes of Monroe County residents.

Ms. Lucas received her Master of Business Administration and Bachelor of Science in Criminal Justice from Rochester Institute of Technology. She entered the doctoral program at St. John Fisher College in the spring of 2015. Under the guidance of Dr. Guillermo Montes and Dr. Christine Nelson-Tuttle, she completed her work on breast cancer disparities in African American women and earned her Ed.D in August 2017.

Abstract

African American women are 42% more likely to die from breast cancer than their White counterparts. The purpose of this phenomenological study was to understand the lived experience of African American, female, survivors of triple negative breast cancer (TNBC) to determine if any of the key tenets of the social determinants of health, particularly race and place/social conditions, influenced their screening through treatment decisions or care. Through the interpretive description approach, six interviews were conducted with survivors of TNBC who either worked or resided in one of eight Monroe County zip codes: 14605, 14606, 14608, 14609, 14611, 14613, 14619, and 14621. These zip codes, home to 63% of the regions African American population, were selected because they had the highest rates of poverty, the worst health outcomes, and the lowest life expectancy of any other zip code in the nine county Finger Lakes region.

The findings of this study revealed that the women did not believe their screening through treatment options were influenced by their race or place/social conditions. The following themes were identified: (a) the strength and resilience of the survivors was expressed through their faith and positive attitudes; (b) the importance of physician / patient relationships, including the dissemination of information and patient invalidation; (c) the need for self-advocacy; and (d) the role of support groups.

Recommendations for future studies include suggested actions for researchers, physicians and patients to include: using measures of protective factors in research studies; training medical professionals in areas of cultural humility, implicit bias, and structural racism; and, encouraging women to be vulnerable and accept help.

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Chapter 1: Introduction

The human body is made up of various types of cells that are distinct to certain parts of the body. Normal, healthy cells divide, grow, and die in a prescribed way (National Cancer Institute [NCI], 2016). However, in some instances, the normal growth and life cycle of a cell is disrupted and cells begin to grow or divide irregularly. In most cases, when cells develop in this way, an excess of tissue can form. This excess tissue is known as a tumor (NCI, 2016).

A tumor is classified as benign or malignant based on whether or not cancer is present (NCI, 2016). A benign tumor is not cancerous and usually does not pose a threat to the life of the individual. Conversely, malignant tumors are cancerous and can grow out of control and metastasize to other parts of the body. While not all cancers appear as tumors, cancer can be fatal if the growth and spreading of the disease is not controlled.

The term cancer is credited to the Greek physician Hippocrates (460-370 BC) who used the terms karkinos and karkinoma to describe the tumors finger-like spreading projections which, he thought, resembled the shape of a crab (American Cancer Society [ACS], 2016). Celsus (28-50 BC), a Roman physician, later translated the Greek term into the Latin word for crab, cancer (ACS, 2014). Cancer is now used as a generic term for a group of diseases that occur when cells begin to grow and spread abnormally (NCI, 2016).

There are more than 100 types of cancer and they can occur anywhere in the body (NCI, 2016). Cancers are classified by their histology (type of tissue in which the cancer

originates) or by their site (part of the body) of origination. There are five main histological categories of cancer: leukemias which are cancers of the blood and bone marrow; lymphomas, cancers of the lymphatic system, particularly the spleen, tonsils, and thymus; myelomas which originate in the plasma cells of the bone marrow; sarcomas which are cancers that begin in the supportive or connective tissues such as the bones, fat, tendons, cartilage or muscles; and carcinomas which begin in the skin or in the tissue that lines or covers body organs (NCI, 2016). More commonly, however, cancers tend to be described by the site of origin (NCI, 2016). Carcinomas, the most common histological category of cancer, include the most familiar sites for cancers to occur: colorectal, cervical, stomach, liver, lung, prostate, and breast cancers (NCI, 2016).

Breast Cancer

Not including skin cancers, breast cancer is the most common cancer found in women, and the second leading cause of cancer death for women in the US (ACS, 2016). It is estimated that 1 in 8 women will develop invasive breast cancer in her lifetime (ACS, 2016). Approximately, 246,660 new cases of invasive breast cancer, alone, will be diagnosed in women, and close to 40,450 women will die from the disease annually, with the majority being African American (ACS, 2016). Historically, African American women have had a lower incidence rate of breast cancer, but a higher mortality rate than White women (ACS 2016).

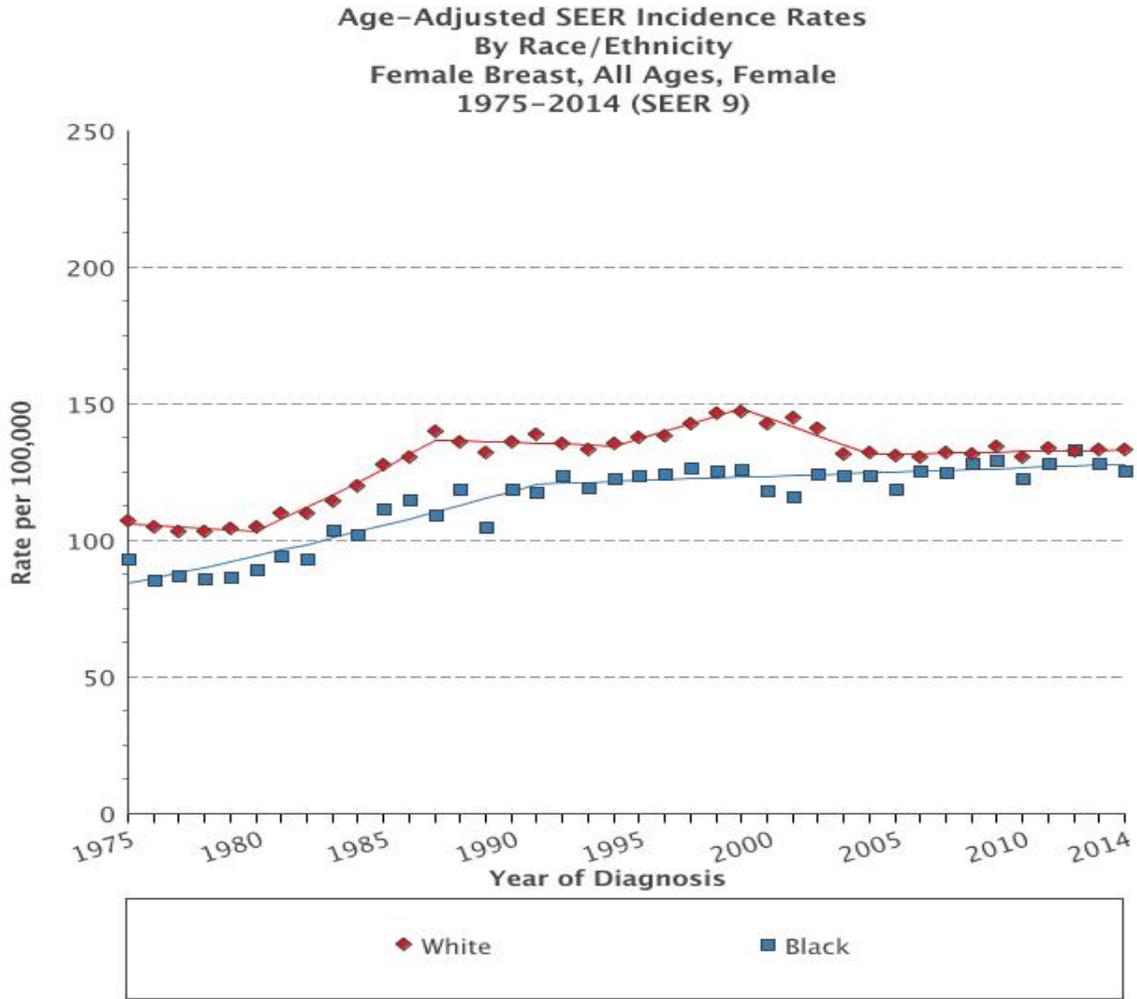
Breast cancer history. The world's oldest recorded case of breast cancer dates back to 3000 BC and is documented in the Edwin Smith papyrus. The Edwin Smith papyrus, part of an ancient Egyptian textbook on trauma surgery, contained descriptions of incurable tumors in the mummies' bones and breasts (ACS, 2016). It describes eight

cases of tumors of the breast in an Egyptian mummy (ACS, 2016). According to the inscriptions there was no treatment for the disease (ACS, 2016). It would take centuries before advances in science and increased public awareness would change opinions about: who could get the disease, how the disease should be treated, and the characteristics of the disease.

Well into the mid-20th century, breast cancer was thought to be a disease of affluent, White women (Wailoo, 2010). While a few cases of Black women with breast cancer were known, the incidence of disease was reported overwhelmingly in White women of high socioeconomic status (Wailoo, 2010). It was not until the 1970s, when the famed singer, Minnie Riperton publicized her bout with the disease, that the public's awareness about the effects of breast cancer on African American women was raised (Wailoo, 2010).

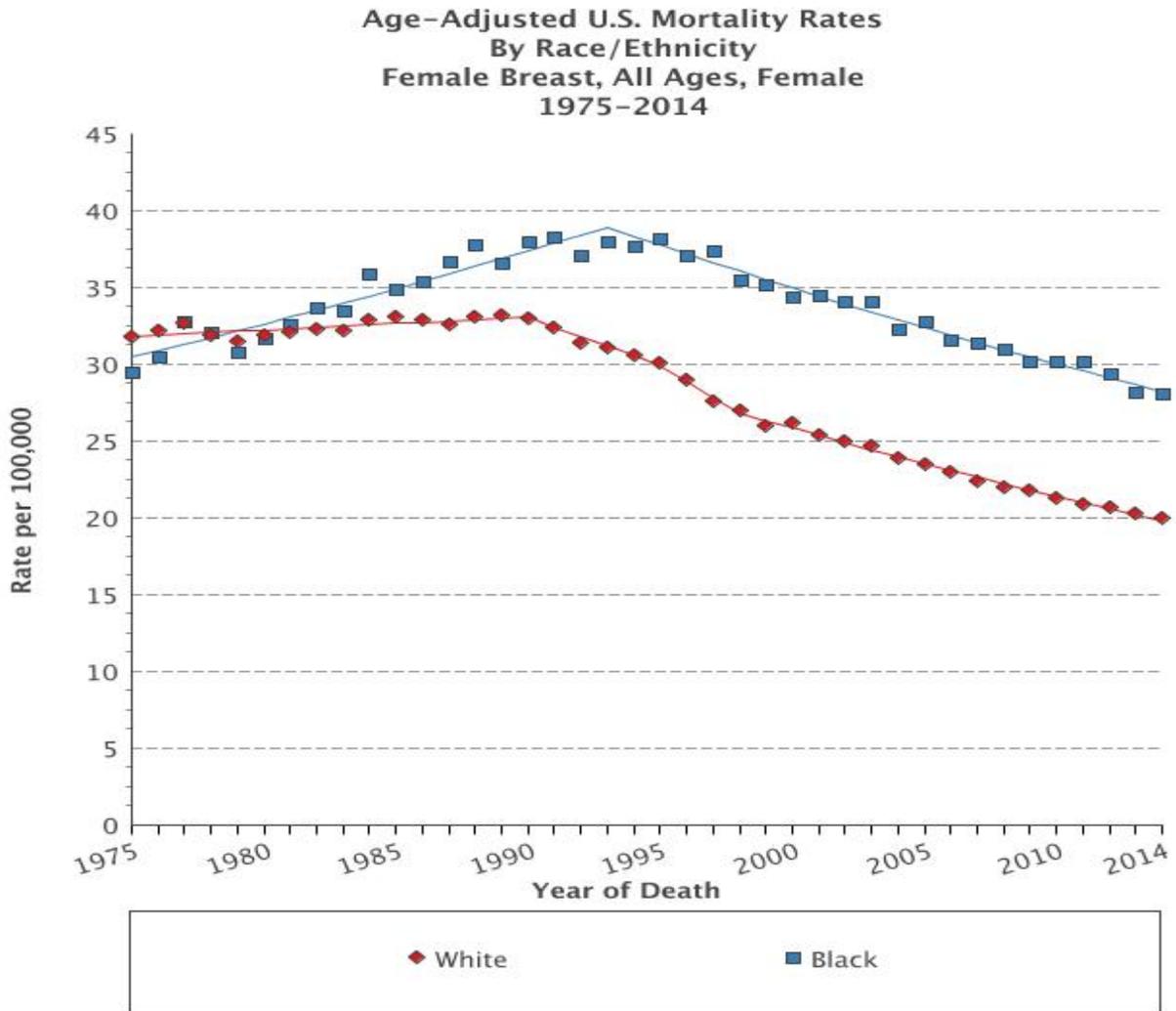
In the three decades between 1975, when data first started being collected, and 2006, when the incidence rate for White women was the lowest, Surveillance, Epidemiology and End Results (SEER) data, a national source for information on cancer incidence and survival in the United States (National Institutes of Health, 2016), showed the shift in incidence and mortality between Black and White women. During that time, Caucasian women had a 16% increase in breast cancer incidence and a 28% decrease in mortality rate, while African American women experienced a 29% increase in incidence and a 6% increase in mortality. After decades of misinformation, this data marked the awareness that not only did African American women get breast cancer, but that they were more likely to die from it, as well (Hunt, Whitman, & Hurlbert, 2013). This can be

seen below in Figures 1.1 and 1.2 retrieved from the National Cancer Institute's SEER database.



Cancer sites include invasive cases only unless otherwise noted.

Figure 1.1. Age-adjusted Incidence Rates by Race/Ethnicity. Retrieved from the Surveillance, Epidemiology, and End Results (SEER) database of the National Institutes of Health. Available for public use.



Cancer sites include invasive cases only unless otherwise noted.

Figure 1.2. Age-adjusted Mortality Rates by Race/Ethnicity. Retrieved from the Surveillance, Epidemiology, and End Results (SEER) database of the National Institutes of Health. Available for public use.

Furthermore, for centuries, there was no standard of treatment for breast cancer and there was thought to be no cure (Lerner, 2001). Until the development of the radical mastectomy by Dr. William Stewart Halsted in the 1890s (ACS, 2014), attempts at treating breast cancer resulted in poor outcomes for the women. The radical mastectomy,

which called for the complete removal of the breast, underarm lymph nodes and chest wall muscles, standardized the way breast cancer was treated. This disfiguring procedure remained common place until the 1970s when new research showed that less extensive surgery was effective for curing breast cancer in most women (Lerner, 2001).

Also, around this time, other technological advances were being made for screening and treatment of breast cancer. White women were able to take advantage of mammography for the early detection of breast cancer, and the use of Tamoxifen as the systemic treatment therapy for breast cancer. Both of these advancements started to improve the health outcomes for White women while African American women did not reap these benefits (Hunt et al., 2012). Hunt et al. suggests that African American women could not take advantage of these advances in technology and treatment therapies because they were disproportionately poor and lacked access to resources and insurance that would allow them to afford the improved care. The researchers explain that medical advances contribute to disparities when the knowledge, technology, and effective medical interventions for controlling diseases exist, but are not easily accessible by all individuals due to social circumstances (Hunt et al., 2012).

The third misperception centered on the characteristics of the disease. Until about a decade ago, breast cancer was thought to be one disease (Boyle, 2012). Only recently have multiple studies exposed breast cancer as a heterogeneous group of diseases that are distinguished by multiple histological and molecular characteristics (Gautam, Zhao, Band, & Band, 2010). Histological factors identify if the disease originated in the tissue, nodes, or ducts of the breast, and whether it is contained within the breast (in situ) or has spread (invasive) (Gautam et al., 2010). These distinctions allow the diseases to appear

differently, have varying risk factors, unique responses to treatment, and divergent outcomes (Weigelt, Geyer, & Reis-Filho, 2010). Additionally, malignant cells can invade the entire breast and spread to other parts of the body (ACS, 2015).

Breast cancer subtypes. More recently, breast cancers have started to be categorized by their molecular characteristics (Irvin & Carey, 2008). The presence or absence of the estrogen (ER) or progesterone (PR) hormone receptors and the overexpression of the human epidermal growth factor receptor (HER2) determine the specific types of breast cancers (Irvin & Carey, 2008). These molecular subtypes are categorized into distinct groups known as: luminal A and luminal B which tend toward being hormone receptor positive, basal type which tends toward being hormone receptor negative and includes the triple negative sub-type, and HER2 type which have an overexpression of the HER2 gene/protein (ACS, 2015). The various subtypes also determine the treatment options and prognosis for each disease (Irvin & Carey, 2008).

As much as 70% of breast cancers are diagnosed as hormone receptor positive and fall under the luminal A and B subtypes (Irvin & Carey, 2008). The luminal subtypes tend to have better prognoses because these cancers grow slowly, are considered lower grade, and have multiple, available treatment options which make survival more likely (ACS, 2015). These breast cancers are more likely to be diagnosed in postmenopausal, Caucasian women of higher socioeconomic status (Adams et al., 2012).

Approximately 15%-20% of breast cancers are diagnosed as triple negative. Triple negative breast cancers (TNBC) are absent the estrogen (ER) and progesterone (PR) hormone receptors and the normal expression of the HER2 gene/protein (Irvin & Carey, 2008). Unlike the luminal subtypes, these basal type cancers tend to grow more

aggressively and are resistant to current treatment options and hormonal therapies (Agurs-Collins, Dunn, Browne, Johnson, & Lubet, 2010). The lack of the ER and PR make this form of breast cancer more difficult to treat with conventional medicines (Irvin & Carey, 2008), leaving chemotherapy as the predominant form of treatment. TNBC are more likely to be diagnosed in premenopausal, African American women (Adams et al., 2012). Table 1.1 outlines the characteristics of each breast cancer subtype and its prevalence in the population.

Table 1.1

Delineation of Breast Cancers by Subtype

Subtype	Tumor type	Prevalence
Luminal A	ER-positive and/or PR-positive HER2-negative	30-70%
Luminal B	ER positive and/or PR positive, HER2+ or HER2-	10-20%
Triple Negative (Basal-type)	ER-negative PR-negative HER2-negative	15-20%
HER2 type	ER-negative PR-negative HER2-positive	5-15%

Triple negative breast cancer (TNBC). As previously explained, TNBC gets its name because it is void the estrogen and progesterone hormone receptors, and the overexpression of HER2/neu protein (Irvin & Carey, 2008). While anyone can get

TNBC, the Carolina Breast Cancer Study showed that premenopausal, African American women are two to three times more likely than Caucasian women to be diagnosed with this form of breast cancer (Sturtz, Melley, Mamula, Shriver, & Ellsworth, 2014). Data show that women, who carry the BRCA 1 gene mutation, are under age 40, or African American tend to have higher incidence rates (Irvin & Carey, 2008) of TNBC. Of the study group, TNBC comprised 39% of the tumors in premenopausal, African American women compared to 14% in postmenopausal African American women and 16% in non-African American women of any age (Carey et al., 2006).

As stated, TNBC tends to grow faster and metastasize quicker than other mutations of breast cancer (Irvin & Carey, 2008). The lack of hormone receptors makes this form of breast cancer resistant to current treatment options that target the ER and PR positive subtypes of breast cancer leaving chemotherapy and radiation as the predominant option for treatment (Irvin & Carey, 2008). Due to its aggressive nature, presence at ages younger than 40 which is the recommended age for women to start screening for breast cancer (NCCN, 2016), and lack of treatment options, women diagnosed with TNBC have a higher recurrence rate within the first 3 years after treatment and a poorer prognosis for survival (Irvin & Carey, 2008). Some researchers have suggested that the high mortality rates for African American women from breast cancer may be due to TNBC (DeSantis, et al., 2015).

Breast cancer incidence. As demonstrated in Figures 1.1 and 1.2, African American women have a lower incidence rate of breast cancer (Amirikia, Mills, Bush, & Newman, 2010), but a higher mortality rate than White women (ACS 2016). However, a

noticeable change in incidence rate of breast cancer occurred between 2008 and 2012 for African American women (DeSantis et al. 2015).

DeSantis et al. (2015) conducted a study on incidence rates of breast cancer among Black and White women. Data were collected on incidence trends, probabilities of developing cancer, and cause-specific survival information from the SEER database, which has been collecting clinical, pathological, and demographic information on patients since the early 1970s. Additionally, the National American Association Central Cancer Registries was used to obtain data on incidence rates by race and ethnicity, stage at diagnosis of breast cancer, and the distribution of breast cancer by sub-type, including the overexpression of HER2. DeSantis also looked at state level data for incidence rates, stage at diagnosis, and subtype of breast cancer. Analysis of these data by age, race/ethnicity, stage at diagnosis, and mortality trends revealed an increase in incidence rates of breast cancer for African American women while there was a decline in incidence for White women (DeSantis et al., 2015).

Data pertaining to screening rates were available from 2008-2012 from all 50 states for White women and from 34 states for African American women. Sixteen states were not included for African American women because they did not have large enough sample sizes. Screening rates ranged from 66% in Wyoming (lowest) to 89% in Massachusetts (highest) for White women age 45 and older, while screening rates for African American women ranged from 68% in Colorado (lowest) to 89% in Maryland (highest). The screening rates for both groups appear to range similarly, or slightly higher for African Americans (DeSantis et al., 2015).

During the same time period, the overall incidence for breast cancer ranged from 107.7 cases in Arkansas to 164.4 cases in Washington D.C. for White women, and 94.0 cases in Minnesota to 141.7 cases in Alaska for African American women (DeSantis et al., 2015). Of the 42 states and the District of Columbia, where the rate ratios for incidence were examined, the incidence rates of breast cancer were significantly higher for African American women than for White women in seven states (Alabama, Kentucky, Louisiana, Mississippi, Missouri, Oklahoma, and Tennessee). In 11 states and the District of Columbia, the rates for African American women were lower than White women, and in 24 states there was no significant difference. Although African American women traditionally had lower incidence rates, in this study, the incidence rates were relatively equal. While the increase in incidence rates could not be explained explicitly, DeSantis et al. noted that when there is an increase in screening rates, it is expected that there will be an increase in incidence rates because more women are undergoing mammograms to find cancer early. This argument can be supported as we see the ranges for screening rates between African American and White women are relatively similar.

Consequently, the increase in incidence rates could translate into an even greater increase and disparity in mortality rates for African American women. While there has been a decrease in mortality rates for both races over time, the decline has been much slower for African American women (Hunt, Whitman, & Hurlbert, 2013). Mortality rates for both races were virtually equal until the mid-1980s (Figure 1.2) when the gap between these two populations began to widen. During that time, it is evidenced that the mortality rate for African American women started to increase while the mortality rate of Caucasian women decreased rapidly.

In a study of the largest U.S. cities, Hunt et al. (2013) examined the breast cancer mortality rates of women from 1990-2009. The researchers measured the disparity by calculating the African American: White rate ratio (RR) for each city at varying 5 year intervals: 1990–1994, 1995–1999, 2000–2004, and 2005–2009. The researchers noted that of the 41 cities included in the study, 35 cities had a significant increase in the mortality gap between African American and White women over the 20 year time period. For example, in Los Angeles between 1990 and 2009 the mortality rate for African American women increased from 45.1 to 45.6. Conversely, the rate decreased from 36.5 to 26.7 for White women. So, while the African American rate increased marginally, the White rate decreased drastically by 27% (Hunt et al., 2013). Thus, the researchers showed that African American women bear much higher breast cancer mortality than White women (Hunt et al., 2013), and this gap may worsen in light of the increase in incidence rates for African American women.

Race/African Ancestry

In a study examining high risk breast cancer in a sub-Saharan African population (Newman, 2014), it was suggested that in the case of TNBC, women with African ancestry may have a biological predisposition to getting this form of breast cancer. Researchers have identified a pattern of molecular biomarkers in the mammary stem cells of sub-Saharan African populations that may be linked to African American women. In the US, roughly 20% of White women with breast cancer are diagnosed before age 50 compared to 33% of African American women with breast cancer (Newman, 2014). Additionally, the BRCA 1 gene mutation is disproportionately found in African American women, and those women are more likely to be diagnosed at younger ages

(Newman, 2014). While socioeconomic factors may contribute to worse health outcomes, Newman argues that it does not account for the age specific patterns of breast cancer incidence seen in women with TNBC (2014).

Other studies have also reported evidence that genetics may be a contributor of TNBC in African American women with breast cancer. One study of patients in Florida identified a BRCA1 gene mutation unique to African American women with Caribbean/African ancestry (Akbari, Donenberg, & Lunn, 2014). Another study of 148 Nigerian women with breast cancer found that 67% of the women were under age 50 with a mean age of 44 (Ikpatt et al., 2005). The Black Woman's Health Study looked at genotyping and identified patterns in breast cancer that correlate with TNBC and are associated with African ancestry (Newman, 2014). The University of Michigan-Ghana partnership also identified new patterns of molecular markers which have shown to be increased in the breast specimens of sub-Saharan African populations (Newman, 2014).

Although studies of genetics in cancer are limited, there is some evidence that African American women are predisposed to an aggressive form of breast cancer thus providing an explanation for the disparities in mortality rates. However, further research is needed to examine if there is a biological basis for the development and progression of TNBC in African American women, or if it is an outcome of social circumstances, policies or individual behaviors.

Problem Statement

African Americans tend to have the shortest survival rates and highest mortality rates of any racial/ethnic group in the nation for most cancers (ACS, 2016). When all cancers are combined, the death rate for African Americans is 24% higher for men and 14% higher for women, than their White counterparts (ACS, 2016). When delving deeper into the disparity that exists for certain cancers, it is even greater. Mortality rates from colorectal cancer are 52% higher in African American men and 41% higher in African American women than White men and women, respectively; the death rate for African American men from prostate cancer is 2.4 times higher than that of White men, and is the highest of any ethnic group; African American women are twice as likely as White women to die from cervical cancer; and African American women are 42% more likely to die from breast cancer than their White counterparts (ACS, 2016).

It is evident, from the vast body of quantitative literature, that the reason for this health inequity is multifactorial. Researchers have cited a number of factors that include: technological advances (Hunt et al., 2013), biological predisposition to aggressive breast cancer subtypes (Agurs-Collins et al., 2010; Irvin & Carey, 2008; Newman, 2014), biased screening guidelines (Amirikia et al., 2010), lack of access to health care (Dai, 2010), and low socioeconomic status (Akinyemiju, Pisu, Waterbor, & Alkertuse, 2015) as driving forces for the disparity in breast cancer incidence and mortality. However, there is a gap in the literature because qualitative research that speaks to the African American woman's experience and beliefs about the causes of incidence and mortality due to breast cancer has not been identified. While there is a plethora of theories that attempt to explain why Black women have higher mortality rates, qualitative research to understand the

lived experience of women who are survivors of this disease would enhance the field of study.

Qualitative research would give voice to the survivors' awareness of factors that may have impeded their care, and their beliefs about race and place as they relate to their experience with TNBC. While quantitative researchers have pointed to social circumstances and various aspects of life as the reasons that Black women have higher mortality rates, qualitative research to understand the lived experience of women who are survivors of this disease was scarce.

Theoretical Rationale

Improving the health outcomes for the poorest people has long been a goal of the World Health Organization (WHO). Dating back to the WHO's 1948 Constitution, there was a push for collaboration between agriculture, education, housing, and social welfare sectors in order to achieve positive, health gains (WHO, 2010). In 1998, researchers contracted by the WHO identified the idea of using collective work to achieve better health outcomes as the social determinants of health (SDOH) (WHO, 2010). This concept, adopted in the field of public health, attempts to understand the multiple factors that affect a person's health in order to improve health outcomes. WHO defines the SDOH as "the conditions in which people are born, grow, live, work, and age," (2011). These determinants include: educational level, housing, employment status, family culture and traditions, community resources, physical environment, individual behaviors, access to health care, government policy, race, and others factors (Satcher, 2010). Hence, the conditions in which people live and/or work are a result of the social, economic, and political environment that helps shape their lives and is a manifestation of how money,

power, and resources are distributed in local communities. Reducing the impact of social and political conditions on health outcomes and mortality has been a public health priority for decades (Satcher, 2010).

McGinnis and Foege (1993) reasoned that the true cause of death has more to do with lifestyle and social conditions, than to genetics and health care. They reviewed a compilation of articles published between 1977 and 1993, as well as, U.S. vital statistics and surveillance data that identified and quantified the major contributors to premature death in the United States. They weighed factors such as use of tobacco products, poor diet and exercise, and alcohol use, and concluded that about half of all deaths that occurred in 1990 could have been prevented. The researchers found that the preponderance of premature deaths were not linked to biology or to the medical system, but to the factors that influenced how people lived (1993). The measure of years of potential life loss (YPLL) was derived from this research (McGinnis and Foege, 1993) and links to the high mortality rates of certain populations.

The social determinants of health framework is grounded in the understanding that a person's health status is impacted by the social conditions in which they live, work, and play. While it has been long argued, and well documented, that SES and poverty contribute to poor health outcomes (Marmot et al., 1991), the quantified contribution of SES, as it relates to lifestyle choices, was identified in 1993 (McGinnis & Foege). Accordingly, it has been maintained that about one-third of all cancers could be prevented with lifestyle changes including reduction in obesity, better nutrition, and increased physical activity (ACS, 2016). Researchers have linked the SDOH to the high breast cancer mortality rates in African American women by explaining that policy

(Amirikia et al., 2010), poverty, and social conditions (Akinyemiju et al., 2015) impact a woman's access to care, prior to, or in the early stages of the disease when it is most treatable.

Statement of Purpose

The purpose of this study was to understand the lived experience of African American women who survived triple negative breast cancer (TNBC). This study explored how these women experienced the key tenets of SDOH, specifically race and place, in regards to the quality of care they received during their cancer journey from screening through treatment. The focus was on survivors of TNBC who lived in neighborhoods with a high concentration of poverty, in the city of Rochester to understand if, and/or how, they believe race and/or place impacted their ability to access and receive quality health care.

Research Questions

Through qualitative methodology, the researcher explored how African American women experienced the key tenets of the SDOH, specifically race and place, as it related to their screening, diagnosis, and treatment for breast cancer. The interpretive descriptive research approach (Thorne, Reimer, Kirkham, & MacDonald-Emes, 1997) was utilized to give voice to the survivors' awareness of the SDOH and their beliefs about race and place. The following questions guided the research:

1. What are the African American women's experiences with TNBC from screening through treatment?
2. Do African American women believe race played a role in their screening through treatment options?

3. Do African American women believe that their place (social conditions in which they live or work) played a role in their screening through treatment options?

Potential Significance of the Study

Telling the stories of actual women behind the data will help to fill in the gaps left by the current quantitative research and add the substance of personal stories to data. Additionally, understanding the journey of African American women when coping with breast cancer may help health care professionals and community advocates understand how to better advocate for, and treat, this population of patients. Lastly, if women are able to recognize and identify social and institutional constructs that could have either impeded or facilitated their access to optimal breast cancer screenings and care, this could be a call to action for them to use their voice and power to work toward changing systems and practices that they deem harmful to their health and their communities.

Definitions of Terms

- Benign – tumors that are not cancerous
- Caucasian/White - these terms are used interchangeably
- African American/Black - these terms are used interchangeably
- Incidence rate- the total number of new cancer cases diagnosed annually in the population of interest, divided by the at-risk population and multiplied by 100,000 (CDC, 2015)
- Histology – type of tissue where the cancer originates
- Malignant – tumors that are cancerous and could grow and spread
- Metastasize - spread

- Mortality rate - the total number of cancer deaths annually in the population of interest, divided by the at-risk population and multiplied by 100,000 (CDC, 2015)
- Place – the social conditions in which a person lives or works
- Poverty – not having enough money to meet daily needs. The amount is set by the Department of Health and Human Services. Federal poverty guidelines for 2017 is \$12,060 for a single person (HHS.gov)
- TNBC - Triple negative breast cancer that is void of the ER, PR hormone receptors, and overexpression of the HER-2 gene/protein (Irvin & Carey, 2008)
- Townsend Deprivation Index – census based index of material deprivations calculated by the combination of four census variables: unemployment, overcrowding, and not owning a car or a home (Messer et al., 2006)

Chapter Summary

More research is needed to understand the experiences of African American women and their ability to navigate their cancer screening, diagnosis, and treatment options. This study explored women’s social environment in an effort to determine whether or not they believed any of the tenets of SDOH played a role in their health care options. In so doing, the specific tenets of race and place were analyzed to understand what role, if any, the women believed they played.

This dissertation is organized in five chapters. The Chapter 1 discusses the background related to the research topic. The Chapter 2 provides a selective review of

empirical studies relating to the research topic. In Chapter 3 illustrates the design of the research methodology and data collection process. Chapter 4 outlines the findings of the research study and Chapter 5 provides a discussion of the findings and outlines recommendations for future studies.

Chapter 2: Review of the Literature

Introduction and Purpose

There is an old African American adage that says “when White folks catch a cold, African American folks get pneumonia” (unknown). This saying seems to hold true when examining the health status of African American people living in the United States. It has been well evidenced in the literature that African Americans tend to fare worse than their White counterparts across various health indicators such as diabetes, cardiovascular heart disease, hypertension, and obesity (Mays, Cochran & Namdi, 2007). African Americans are 40% more likely to have high blood pressure, have a 77% higher rate of diagnosed diabetes, and have a shorter life expectancy than non-Hispanic Whites (Centers for Disease Control [CDC], 2015).

These grim statistics also persist when discussing the burden of cancer endured by African Americans. As previously stated, African Americans have the highest mortality rate and shortest survival of any racial/ethnic group in the nation for most cancers (American Cancer Society [ACS], 2016). African American women are 42% more likely to die from breast cancer than their White counterparts (ACS, 2016).

Researchers have attempted to explain this inequity by citing factors such as: technology, genetics, policy, lifestyle, and poverty as driving factors of disparities in breast cancer mortality. It is evident from the literature that the reason for the disparities in incidence and mortality rates is multifactorial. However, even with the plethora of reasons, gaps in the literature have been identified.

Chapter 2 describes the state of the science as it relates to the high incidence and mortality rates of African American women from TNBC. The review of the literature included the following themes:

- the role of lifestyle and social factors on breast cancer incidence and survival rates
- the impact of policies and guidelines on cancer incidence and mortality
- racial differences that could account for differences in mortality
- the comparison of breast cancer subtypes to TNBC and their impact on survival rates

These four themes were explored to discuss the state of the science in this field.

Lifestyle and Social Factors

Socioeconomic status (SES). Numerous studies have sought to determine an association between breast cancer subtype, incidence rates, race, and SES (Adams et al., 2012; Akinyemiju et al., 2015; Sineshaw et al., 2014; Vainshtein, 2008) in an effort to explain the high mortality rates for African American women. While studies have shown a correlation between White women with high SES and ER+ breast cancer, studies have not been as conclusive for African American women. Table 2.1 outlines the studies that were used to discuss this topic.

Table 2.1

Articles Analyzing Socioeconomic Status and TNBC

Author	Year	Results
Vainshtein	2008	African American women showed no significant difference in breast cancer incidence whether high SES or low SES
Adams et al.	2012	Regardless of insurance type, or stage of disease, the risk of excess death was 2.14 times higher for African American women than White women
Sineshaw et al.	2014	The likelihood of being diagnosed with TNBC was 1.8 times higher for African American women versus White women, regardless of SES status
Akinyemiju et al.	2015	Breast cancer incidence follows SES except in the case of African American women with TNBC, because TNBC is more prevalent in African Americans regardless of SES

A meta-analysis of prior studies was conducted to see if SES could account for the difference in breast cancer incidence between races (Vainshtein, 2008). Using the PubMed database and multiple cancer registries, Vainshtein limited his findings to five studies between 1990 and 2006. All studies included in the meta-analysis compared differences in incidence rates for breast cancer at varying SES levels for women in four racial groups (White, African American, Asian, and Hispanic) or more. To compare SES across studies, Vainshtein calculated an incidence risk ratios (IRRs) for the highest SES and the lowest SES for each racial group (2008). IRR assessed SES using median household income, poverty rate, average education level, household crowding, employment rate and the Townsend deprivation index (Vainshtein, 2008).

The findings showed that across four racial groups, White women had the highest incidence of breast cancer followed by African American women, Hispanic, and lastly,

Asian (Vainshtein, 2008). The findings also showed a significant difference in incidence between the highest and lowest SES levels. There was a positive correlation between high SES and breast cancer incidence in White, Hispanic, and Asian women (Vainshtein, 2008). This disparity between race and high SES existed for White, Hispanic, and Asian women, but it did not appear for African Americans. African American women showed no significant difference in breast cancer incidence whether high SES or low SES (Vainshtein, 2008) suggesting that other factors may account for the racial disparity.

While Vainshtein's meta-analysis did not show a correlation between breast cancer incidence and SES for African American women, the findings could be skewed because the studies in the meta-analysis did not employ the same standards or definitions of SES. Vainshtein's attempt at calculating an IRR to standardize the comparison was based on inconsistent factors in the individual studies. Hence, the following articles in this review consist of independent studies with standardized measures of assessment.

A study of a multiethnic cohort of 1,209 women in South Carolina was conducted to understand the relationship between race and mortality rates of breast cancer patients (Adams et al., 2012). Data used were only for women identified as African American or White with a confirmed diagnosis of breast cancer between 2000 and 2002. Researchers used data from one local hospital tumor registry system in South Carolina. Breast cancer types were identified as either, ER+/ER- or HER2+/HER2-. Stage of disease followed the American Joint Committee on Cancer (AJCC) criteria for patients and ranged from stage 0 to stage V. The researchers controlled for some variables in SES, insurance status, and healthcare access by using a population receiving treatment at the same hospital with

standardized protocols for physician recommendations and treatment regimens (Adams et al., 2012).

Adams et al. (2012) looked at survival rates at both 3-year and 5-year for breast cancer specific mortality, as well as death from any cause, to determine racial disparities. The study showed that African American women had significantly lower survival rates for both breast cancer and all-cause mortality. After controlling for age, insurance status, SES, and tumor stage, for breast cancer mortality specifically, researchers found that African American women had 2.41 times higher risk of death than White women. Researchers were unable to identify an association between mortality and SES, and suggested biological factors may be at the root of this disparity. Delineation by subtype was not conducted because this study took place prior to the identification of TNBC as a tumor type. Estrogen receptor status was categorized as positive or negative, and HER2 status was classified as positive, negative, or borderline. PR was not used in this study. In later studies, TNBC is identified as a subtype to discern a correlation between SES, and race (Sineshaw et al., 2014).

In a 2014 study, researchers wanted to determine the likelihood of being diagnosed with TNBC in minority populations versus Whites (Sineshaw et al., 2014). A sample of 260,144 breast cancer cases was identified from the National Cancer Database (NCDB), a national hospital-based cancer registry which collects data on approximately 73% of US cancer cases (American College of Surgeons, 2016). Breast cancer cases in this sample were diagnosed between 2010 and 2011 (Sineshaw et al., 2014), the first two years that SEER uniformly collected data on tumor subtypes (NCI, 2016). Sineshaw et al. (2014) categorized the data into five age groups, six race/ethnic categories, and six

insurance status groups. SES was measured on insurance status and median household income as identified in the 2000 census. Stage of disease followed the AJCC criteria and ranged from stage I-IV and unknown, and tumors were classified into five subtypes: HR+/HER2-, HR+/HER2+, HR-/HER2+, HR-/HER2- (TN), and unknown (Sineshaw et al., 2014).

Of the 260,174 cases, 11.7% were diagnosed as TNBC. Analysis of the TNBC cases showed that there were higher proportions of TNBC in women: under age 40, who were African American, of low SES, and with Medicaid insurance. After controlling for SES, the study showed the likelihood of being diagnosed with TNBC was 1.8 times higher for African American women than White women, regardless of SES status (Sineshaw et al., 2014). This study's findings were similar to that of Vainshtein as no correlation was identified between SES and incidence rates for African American women. Like Adams et al., Sineshaw calls for more research into genetic factors. However, in a 2015 population-based study of 47,586 women, a correlation between SES and breast cancer incidence in African American women was identified (Akinyemiju et al., 2015).

In 2015, researchers examined the association between SES, incidence rates, and breast cancer subtypes (Akinyemiju et al., 2015). While studies showed that a positive relationship existed between high SES and breast cancer incidence in White women (Vainshtein, 2008), new researchers wanted to know if that relationship existed within each subtype (Akinyemiju et al., 2015). Akinyemiju et al. examined data of 47,586 women diagnosed with breast cancer in 2010. This data were obtained from the SEER database which now contained information by tumor subtype. Of the breast cancer

subtypes, African American women comprised 22% of the TNBC cases and 61% of HR+, while White women were 11% of TNBC and 76% of HR+. Hispanics and Asian Pacific Islander were 13% and 14 % of TNBC cases, respectively. Twenty-five percent of women resided in the highest SES neighborhoods and 14% in the lowest. SES was based on the NCI SES census tract index which used measures of income, poverty, unemployment, occupational class, education, and home value. Comparisons were made by examining each racial/ethnic group, separately, from lowest to highest SES by tumor subtype.

As in Vainshtein's study, a significant, positive correlation between higher breast cancer incidence and increasing SES was seen for White women. Furthermore, the stratification by subtype showed this trend to be associated with HER2-/HR+ and HER2+/HR+ cancers (Akinyemiju et al., 2015). By stratifying by sub-type, an association between SES and breast cancer was also seen for African American women with HR+ tumors. However, there was no correlation between SES and incidence of TNBC for African American or White women (Akinyemiju et al., 2015). This finding led researchers to believe that the positive association between SES and breast cancer incidence is driven by the type of breast cancer tumor. This study did not look at differences in mortality rates, however.

As outlined, the 2008 meta-analysis demonstrated that SES did not correlate with incidence rate for African American women with breast cancer (Vainshtein, 2008). Adams et al. (2012) study could not identify an association between mortality rates and SES. The 2014 study (Sineshaw et al.) showed that African American women had a higher likelihood of being diagnosed with TNBC irrespective of SES. Finally, this 2015

(Akinyemiju et al.) study elucidated in its findings that breast cancer incidence does correlate with SES, except in the case of TNBC. Therefore, none of the studies were able to show a correlation between TNBC and SES.

These studies highlight one of the inaccuracies that occur when treating breast cancer like a homogenous disease. HR+ breast cancers are the most common forms of breast cancer found in women accounting for at least 70% of all cases (Irvin & Carey, 2008). This subtype is also more commonly found in post-menopausal, White women of higher SES. As cited above, the higher the SES, the more likely women are to get screened for breast cancer (DeSantis, 2015). Conversely, HR- breast cancers, like TNBC, are more likely to be diagnosed in premenopausal, African American women, in low SES conditions (Sineshaw et al., 2014), and only make up about 15% of cases. Since the number of TNBC cases is small in comparison to HR+ breast cancers, the disparity between race, breast cancer incidence, and SES is diminished when breast cancer is treated as a homogenous disease. More research should be done to understand why a correlation does not exist between SES and TNBC.

Obesity. Multiple studies have examined the relationship between TNBC and obesity (Cheng et al., 2015; Dawood et al., 2012; Mowad et al., 2013; Vona-Davis et al., 2008) in an effort to explain the disparity in breast cancer mortality rates. According to researchers, obesity is a modifiable lifetime risk factor for postmenopausal breast cancer and it is associated with attributes of the neighborhood in which women live (Cheng et al., 2015). Low socioeconomic neighborhoods tend to have high volumes of retail food outlets, minimal parks, and recreational spaces, and limited businesses within one mile of neighborhood residences (Cheng et al., 2015). Women who live in low socioeconomic

neighborhoods, are more likely to be obese or overweight (Cheng et al., 2015). Hence, researchers are trying to understand if low socioeconomic status correlates with obesity, and low socioeconomic status correlates with most breast cancers, except TNBC, is there a correlation between obesity and breast cancer. Table 2.2 outlines the studies that were be used to explore this question.

Table 2.2

Articles Analyzing Obesity and TNBC

Author	Year	Results
Vona-Davis	2008	The expression of TNBC in Appalachian women was almost identical to that of African American women in the general population
Dawood et al.	2012	Women with TNBC had similar prognostic outcomes regardless of BMI classification. There was no significant difference in outcome across race.
Mowad et al.	2013	Did not demonstrate an association between obesity, as measured by BMI, and the incidence of TNBC
Cheng et al.	2015	Some association between obesity and mortality, but it differs across racial/ethnic groups. No association for African American

To test the hypothesis of whether a relationship existed between TNBC and obesity, researchers looked to a population of Appalachian women with TNBC. Appalachia is a predominantly White, socioeconomically deprived, community in West Virginia with one of the highest obesity rates in the nation (Vona-Davis et al., 2008). In this retrospective study, researchers controlled for race by using a 95% White, female sample population (Vona-Davis et al., 2008). Researchers looked at 620 breast cancer patients who were treated in the Breast Care Clinic of the Mary Babb Randolph Cancer

Center between 1999 and 2004. Of the breast cancer patients in the study, 117 were diagnosed with the TNBC subtype (Vona-Davis et al., 2008). Of these 117 women, 38.9% were classified as obese and accounted for 49.6% of the women with TNBC tumors (Vona-Davis et al., 2008).

The results of the study showed that the expression of TNBC in this community was almost identical to those of African American women in the general population. Of this sample, 44.5% of the TNBC cases appeared in premenopausal women younger than age 50; 20% were younger than age 40. As a result of this study, Vona-Davis et al. (2008) reasoned that the higher frequency of TNBC in African American women could be attributed to their lifestyle choices and the prevalence of obesity in that population. Hence, they concluded that the over-expression of TNBC is not a matter of race, but a matter of choices women make that result in them becoming obese. Since African American women in the general population are twice as likely to be obese than White women (American Psychological Association, 2013), this conclusion could have merit.

In another study, investigating the prognostic outcomes of obesity on women with TNBC, specifically, Dawood et al. (2012) examined the relationship between the body mass index (BMI) of women with early stage TNBC and their survival outcomes. This retrospective study was conducted to determine if BMI impacted this cohort based on menopausal status and race. A total of 2,311 patients of the University of Texas M.D. Anderson Cancer Center with stage I-III TNBC diagnosed between 1990 and 2010 were identified (Dawood et al., 2012). BMI was calculated for this group and each person was classified as underweight (34.3%), overweight (30%) or obese (35.7%) (Dawood et al., 2012). The findings showed that women with higher BMI tended to be postmenopausal,

African American, and at higher stage of diagnosis. However, the prognostic outcome was no different between the groups based on BMI or menopausal status. Hence, women with TNBC had similar prognostic outcomes regardless of BMI classification (Dawood et al., 2012). There was also no significant difference in outcome across race.

Cheng et al. (2015) sought to answer the question of neighborhood attributes of healthy eating and physical activity, which according to SDOH, have an impact on an individual's life expectancy. This study was designed to explore the specific characteristics of a neighborhood environment that related to obesity, as well as, determine the association of breast cancer mortality in relation to obesity across diverse racial/ethnic groups. This study was conducted using data from the California Breast Cancer Survivorship Consortium (CBCSC), a composition of six breast cancer studies of diverse racial/ethnic groups, and the California neighborhoods data system (Cheng et al. 2015). A total of 8,995 women with breast cancer were identified, of which 47% were White, 20% Hispanic, 19% African American, and 14% Asian; 55% had HR- tumors; 24% lived in low SES neighborhoods as determined by geocoding patient addresses and linking them to census and business data (Cheng et al., 2015). BMI was used to determine normal weight, overweight, and obesity.

The study's findings showed that some features of the neighborhood environment influenced rates of obesity and mortality following breast cancer diagnosis for Latinas and White women, but not for African American and Asian American women. There was a correlation between neighborhood features of low SES environments and the prevalence of obesity and mortality for women diagnosed with breast cancer. This correlation was most pronounced for White and Latina women, but was not evident for

African American women. While Cheng's study was not TNBC specific, it did agree with the previous studies citing no demonstrated relationship between obesity, SES or mortality for African American women with breast cancer.

Finally, Mowad et al. (2013) studied a small dataset of 183 women diagnosed with TNBC at the Feist-Weiller Cancer Center, the Louisiana State Health Science Center Shreveport or the E. A. Conway hospital in Monroe, Louisiana (Mowad et al., 2013). Similar to Dawood et al., BMI was calculated and classified as normal or underweight, overweight or obese. African American women were more likely to be in the high BMI groups than White women (Mowad et al., 2013). To understand the relationship of BMI to health outcomes, the overall survival and the disease free survival rates were compared to the three BMI classifications (Mowad et al., 2013). The 5-year disease free survival rate was 63% for normal weight, 68% for overweight and 65% for obese. This study did not demonstrate an association between obesity and the incidence of TNBC as measured by BMI (Mowad et al., 2013).

Of the four studies cited above, none of them were able to show an association between ethnicity, obesity, and TNBC. Similarly, there was no relationship evidenced between race, SES, and TNBC. More studies must be done to determine why TNBC acts differently than HR positive subtypes regarding its correlation to SES and obesity.

Policies and Guidelines

The WHO (2010) places the responsibility on local governments and policy makers to play a key role in implementing policies that will decrease health inequities. However, in the case of screening guidelines for breast cancer, the policies are inconsistent and confusing (ACOG, 2015). While the literature is scant on this topic,

screening recommendations from the American Cancer Society (ACS), the American Congress of Obstetricians and Gynecologists (ACOG), the United States Preventive Services Task Force (USPSTF), and the National Comprehensive Cancer Network (NCCN) have all been reviewed to discuss inconsistencies in recommendations.

Screening mammography has proven to be the most effective method of detecting breast cancer early (Humphrey, Helfand, Chan, & Woolf, 2002). The earlier cancer can be found and treated, the more likely the chance of survival. As survival rates increase, mortality rates decrease, thereby reducing unnecessary deaths for women (Humphrey, et al., 2002). Regrettably, controversy exists regarding the age at which women should begin screening for breast cancer. Prior to 2009, the universally accepted recommendation was to start screening with annual mammography at age 40 (Amirikia et al., 2011). However, in 2009, the United States Preventive Services Task Force (USPSTF), a volunteer panel of national experts in prevention and evidence-based medicine, made its first recommendation to change the guidelines for routine screenings (USPSTF, 2009).

When the USPSTF changed its recommendation from annual mammograms beginning at age 40, to biennially starting at age 50 (USPSTF, 2009), the new guideline was met with controversy and criticism. Nonetheless, the USPSTF upheld its guideline in 2015 with its updated recommendation (Siu, 2016). This issue was triggered by the landmark study which showed a 24% decrease in breast cancer related mortality between 1989 and 2000 (Berry et al., 2005). The results of this study prompted the Cancer Intervention and Surveillance Modeling Network (CISNET) to conduct its own investigation to determine how mammography and adjuvant therapy contributed to the

significant reduction in breast cancer related mortality, the incidence of advanced breast cancer, and treatment-related morbidity (CISNET, 2006).

The CISNET study reported on the number of women who would need to be screened, in each age group, in order to save one life (Amirikia et al., 2011). Based on CISNET's calculations, approximately 1,900 women ages 40 to 49 years old would have to be screened in order to save one life compared to 1,300 women ages 50-59, or 400 women ages 60 to 69 years old. The authors of the CISNET report stated that if the goal is to reduce mortality in the most efficient way, then screening biennially beginning at age 50 would be the best way to accomplish that goal. However, if the goal is to maximize life, then screening at age 40 would be the preferred strategy based on the benefits to screening ratio (Amirikia et al., 2011).

In making its decision to recommend starting mammograms at age 50, the USPSTF considered the findings of the CISNET study and concluded that while mammography reduces breast cancer mortality, the least benefit is seen in women younger than age 50. Additionally, USPSTF cited that the psychological harm caused to women due to a false-positive (non-cancerous) or a false-negative (missed cancer) diagnosis could outweigh the potential benefit of screening (Siu, 2016). Therefore, it was determined that routine mammography would not be recommended for women ages 40-49 who are at average risk for the disease. For women in that age group who are at increased risk due to the BRCA 1 or 2 gene mutations, family history, or personal history of chest radiation, it was suggested that these women weigh their options and decide with their physician when to undergo mammographic screenings (Siu, 2016).

This decision was a contentious issue for researchers and advocacy groups like the American Cancer Society (ACS, 2009). They argued that by excluding screening recommendations for women age 40-49, the chance of missing cancers would be increased. Although the likelihood of getting breast cancer increases with age, 21% of new cases and 12% of deaths occur in women under the age of 50, and close to 5% of all breast cancers diagnosed are found in women under age 40 (ACS, 2016). Furthermore, African American women under the age of 35 have breast cancer rates two times higher than that of White women, and are three times more likely to die from the disease (CDC, 2015).

Some researchers took particular interest in examining the new guidelines in an attempt to inform the USPSTF of the adverse consequence their recommendations would have on women, and particularly, on African American women (Amirikia et al., 2011). Amirikia et al. (2011) analyzed data for 278,241 women diagnosed with invasive breast cancer from the California Cancer Registry between 1988 and 2006. The researchers found that the average age of diagnosis for African American women was 7 years younger than that of White women (2011). Additionally, African American women were more likely to be diagnosed with breast cancer younger than age 45, and those cancers were generally diagnosed in later stages than their White counterparts (Amirikia et al., 2011). Hence, increasing the screening age would disproportionately affect women who are prone to developing the disease in their younger years. Amirikia et al. (2011) contended that while the USPSTF was concerned with breast cancer mortality, their recommendation did not take the risk of disease to women age 40-49 into account.

Subsequently, the ACS, although it opposed the original USPSTF decision in 2009, changed its own guidelines and increased its recommended screening age from age 40 to 45 in 2015. Citing the same concerns as the USPSTF, the ACS stated that after careful examination of the burden of disease among women ages 40-54, it was determined that the risk of harm from false positive findings due to biopsies and unnecessary services, was greater than the risk of cancer in women ages 40-44 (ACS, 2015). ACS determined that the balance of risk to reward becomes more favorable at age 45. Both the USPSTF's and ACS' recommendations were silent on the disparity that could result due to this decision (Amirikia, et al., 2011). The National Comprehensive Cancer Network and American Congress of Obstetricians and Gynecologists (ACOG), however, continue to advocate for screening at age 40 (2015). ACOG stated that they interpreted the data and the weight assigned to the harms versus the benefits differently than ACS and USPSTF (2015).

These changing and inconsistent guidelines could cause confusion for all women, regardless of race. Although the USPSTF and ACS encourage individualized, informed decision making about when to start screening, women typically may not know if they are at increased risk for breast cancer. The breast cancer screening guidelines are a substantive issue as it is an area of controversy that affects the lives of thousands of women each year (Gersten, 2010). The guidelines set the standards for what procedures would be covered by insurance companies, and at what rate (USPSTF, 2016). So, while not overtly stated, it should be noted that by not screening women at age 40, insurance companies save money as they do not have to cover that procedure.

It also sets the standard by which women think about their own health. This issue crosses both the social and economic spectrums in its planning, decision making, and implementation processes. Hence, setting guidelines based on longevity, which has the objective of decreasing the years of potential life lost and maximizing life, rather than efficiency, would be the preferred model, especially for African American women (Amirikia, et al., 2011). This change in guidelines supports the argument that disparities exist because of policies and circumstances that are outside the control of the individual. Table 2.3 outlines the articles used to discuss the issues raised by the screening guidelines and recommendations.

Table 2.3

Articles Analyzing Screening Guidelines

Organization	Year	Screening Guideline
Amirikia et al.	2009	African American women were more likely to be diagnosed with breast cancer younger than age 45, and that cancers were general diagnosed in later stages than their White counterparts
ACS	2015	Screening for Women at Average Risk beginning at age 45; Ages 40-44 should talk to their physician
NCCN	2015	Annual Mammograms Recommended for Women Beginning at Age 40
USPSTF	2016	Biennial Breast Cancer Screening Starting at age 50
ACOG	2011	Annual Mammograms Recommended for Women Beginning at Age 40

Racism and Discrimination

Anecdotal evidence of racism in the health care system has long existed.

Fortunately, numerous studies have evidenced the association between perceived racism

and poor health outcomes (Griggs, Sorbero, Stark, Heininger, & Dick, 2003; Smedley, Stith, & Nelson, 2003; Taylor et al., 2007). The IOM report *Unequal Treatment* highlighted the extent to which people of color do not receive the same type of care as their White counterparts. Even when factors, such as insurance status and income, are controlled for, Black people tend to receive a lower quality of healthcare, including less access to specialty services and lower usage rates of high technology diagnostic and therapeutic procedures than White people, (Smedley et al., 2002).

Using Jones's (2000) theoretic framework for understanding racism, there are three levels of racism which are defined as: institutionalized racism, personally-mediated racism and internalized racism. *Institutionalized racism* focuses on systemic conditions such as access to health insurance and healthcare facilities; *personally-mediated racism* is defined as prejudice and discrimination toward someone of another race, and internalized racism is the acceptance by individuals of stigmatized races of negative messages about their abilities and intrinsic worth (Jones, 2000). *Unequal Treatment* documents how these issues of racism and discrimination lead to health disparities. Breast cancer is one of those diseases that has a positive association with perceived racism (Taylor et al. 2007).

The Black Women's Health Study, was an ongoing prospective cohort study conducted between 1997 and 2003 (Taylor et al., 2007). It was designed to examine risk factors for major illnesses in African American women. Study participants were asked to complete surveys about their experiences with discrimination in two categories, everyday discrimination (being treated as dishonest) and major discrimination (unfair treatment - job, housing, and police) (Taylor et al., 2007). Of the 59,000 respondents to the survey, 593 were identified as having been diagnosed with breast cancer. The researchers found

that women under age 50, who reported frequent everyday discrimination, were at higher risk for breast cancer than those who reported infrequent experiences. Consequently, as women experienced major discrimination in one or more areas, researchers showed that their risk for breast cancer increased. This study demonstrated the positive relationship between perceived experiences of racism and increased incidence of breast cancer among African American women younger than age 50 (Taylor et al., 2007).

Furthermore, other studies have identified systematic differences in the administration of chemotherapy with lower doses being given to African American women compared to White women (Griggs et al., 2003). Through a multivariate regression model, 489 cases of breast cancer treated between 1985 and 1997, across 10 treatment sites, in two geographical regions were reviewed. The administered doses and dose intensity were compared to standard regimens. The mean unadjusted dose proportion was lower for African Americans than it was for Whites. Seventy-two percent of the White women received a dose proportion of 0.80 or greater compared with only 61% of the African American women (Griggs et al., 2003).

Racism and discrimination toward African Americans has a long and distinct history in this country. Even with advances in socioeconomic status, access to care, and technology, the legacy and destructive nature of racism and discrimination is ever present (Jones, 2000). These studies underscore how racism plays a role in the disparate health outcomes of African American women with breast cancer. There is evidence that social and environmental events can have an effect at the individual's cellular and genetic level (Gehlert et al., 2008). Gehlert et al. looked at the model of downward causation and posited that the isolation and depression that is caused by social deprivation in turn

causes changes in gene expression which ultimately result in the TNBC diagnosis. As emphasized in *Unequal Treatment*: “The sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals, and patients” (Smedley et al., 2002, p.18).

Description of Data and Databases

This section describes the research methods and measures used in the literature reviewed above. The methods used for all studies referenced above were quantitative, retrospective studies using data from multiple local, state, and national databases. The existence of statewide cancer registries and national databases provides readily accessible data for comparison analysis. Table 2.4 outlines some of the databases and datasets used for each study.

Researchers used a variety of databases. Akinyemiju et al. (2015) and DeSantis et al. (2015) collected data through the Surveillance, Epidemiology and End Results (SEER) database which is a product of the National Cancer Institute. This database has been collecting information on cancer diagnosis since 1973. This makes it a go to source for any researcher doing retrospective studies as it allows researchers to analyze data over decades. This database can be examined by race for African Americans and Caucasians individually, as well as, all races combined going back to 1973. It also captures incidence trends, probabilities of developing cancer and specific causes related to survival rates.

Additionally, researchers used data from the North American Association of Central Cancer Registries (NAACCR). Established in 1987, it develops and promotes uniform data standards for cancer registries (NAACCR, 2016). Researchers who used

this database sometimes chose to exclude certain states if they did not meet the rigorous criteria for this registry. DeSantis (2016) excluded Arkansas, Minnesota, and Nevada because they failed to meet the NAACCR for one year or more between the time period from 2008-2012. DeSantis also excluded 15 states that did not have complete information for HER2 status which was added in 2010.

More recent studies that analyzed breast cancer subtypes used data from 2008-2012 and restricted it to women diagnosed in 2010 or later. Prior to 2010, HER2 status was not required by cancer registries. Akinyemiju et al. (2015) used data from SEER for women who were diagnosed in 2010 only, and limited their data to 18 population-based datasets in certain regions. This data set accounted for 28% of the population. Their dataset identified 47,586 women with breast cancer diagnosed in 2010 of which 12% had TNBC. In addition, they used census tract data from the National Cancer Institute SES index which is a measure of SES based on income, poverty, unemployment, occupational class, education, and house value.

Researchers used various models to measuring SES. Many used census tract data to get their measurements. Sineshaw et al. (2015) used a measure of SES derived from U.S. census tract data. Sineshaw et al. (2015) were able to categorize individuals based on insurance status grouping those with private insurance as high SES, those on Medicaid as low SES, those in the middle as moderate SES and others as unknown if insurance status data was unidentifiable. Unlike other researchers, Sineshaw et al. (2015) did not use SEER for their datasets. Instead they used data from the National Cancer Data Base (NCDB) which is jointly supported by the American Cancer Society and the American College of Surgeons. NCDB has been collecting data on ER and PR status since 2004 and

added HER2 in 2010, similar to SEER. Sineshaw et al. (2015) used data for 2010 and 2011 from NCDB in order to measure breast cancer subtypes over time.

Conversely, researchers used the same measure to determine normal weight, overweight, and obesity. Each researcher defined BMI using the standard method of dividing an individual's weight in kilograms (kg) by the square of the height in meters (m²). BMI less than 25kg/m² was considered normal or underweight. BMI of 25kg/m² - 29.9kg/m² was overweight, and BMI greater than 30kg/m² was obese (Cheng et al., 2015; Dawood et al., 2012; Mowad et al., 2013; Vona-Davis et al., 2008). Using this standard measure made it simple to compare data across studies.

Amirikia et al. (2011) used the SEER database to collect data from the California Cancer Registry to perform her study of young women with TNBC in order to address the USPSTF cancer screening guidelines. They analyzed age-specific invasive breast cancer data from 1998-2006 to determine the distribution of TNBC across three racial/ethnic groups. Although TNBC was not required to be reported until 2010, researchers were able to capture that information prior to 2010 from local databases. Cancer registries capture most aspects of cancer diagnosis including survival rates, mortality rates, demographic information for the population, and features of the disease. As the science evolves, the registry evolves to include information pertinent to the successful tracking and evaluation of cancer distribution across the population.

Identified Gaps

The state of the science explaining the high mortality rates of African American women from breast cancer is multifactorial and complex. While researchers have tried to explain the various aspects that contribute to increased death, it is still inconclusive as to

what factors are most attributable to the cause. Differing aspects of the social determinants of health (race, policy, access to care, and SES) all play a role in the high mortality rates of African American women with TNBC. Table 2.7 outlines the various factors discussed throughout the literature and denotes whether the factor contributes to increased disparities to care and/or increased mortality. However, the extent to which each of these contributes to the mortality rate is undetermined.

Table 2.4

Contributing Factors to Disparities in Care and Increased Mortality

Factors	Contributes to disparities in care	Contributes to increased mortality
Access to care: limited access to screening or treatment services	X	X
Screening guidelines: guidelines not accounting for the earlier age at which TNBC is present	X	X
Health insurance type/status: Medicaid/Private Insurance/no insurance determines what type of facility and level of care	X	X
Obesity: modifiable risk factor linked to higher prevalence of breast cancer, except for TNBC		X
Genetics: predisposition for women of African ancestry		X
Socioeconomic Status (SES): linked to higher prevalence of breast cancer, except for TNBC	X	X
Breast cancer subtype (TNBC): aggressive form of breast cancer with limited treatment options		X

SDOH posits that the social and physical environment in which people live is more important to determining health outcomes, than their genetics or health behaviors (CDC, 2014). However, a clear, causal link has not been made between SES and incidence of TNBC (Adams et al., 2012, Akinyemiju et al., 2015; Sineshaw et al., 2014; Vainshtein, 2008;). High breast cancer incidence tends to follow high SES. However, researchers have concluded that the TNBC subtype seems to be independent of SES, and is more prevalent in African American women regardless of SES. Yet, it does tend to be more common in women of low SES.

Obesity is a modifiable lifestyle risk factor that may contribute to breast cancer. Nonetheless, the research is not conclusive about whether or not that risk factor is distributed equally across breast cancer subtypes. As evidenced in the studies above, no associated link between race, obesity, and TNBC incidence could be identified (Cheng et al., 2015; Dawood et al., 2012; Mowad et al., 2013). This anomaly is leading researchers to believe that there may be a racial or genetic marker that causes African American women to be more susceptible to TNBC.

The lack of evidence to support SDOH as a cause of higher mortality, favors researchers who have been investigating a link between TNBC and African ancestry. Researchers have been trying to understand the role that genetics play in the prevalence of African American women with TNBC by comparing populations in sub-Saharan Africa and the U.S. (Newman, 2014). The evidence demonstrates that the prevalence of TNBC in African women is mirrored in African American women in the U.S. (Newman, 2014). TNBC has proved itself to be an aggressive form of breast cancer, with limited treatment options and poor prognosis (Irvin & Carey, 2008). If the evidence proves that it

is inherent in women of African ancestry, then it could be argued that the mortality rates will remain high as the only treatment option currently available for TNBC is chemotherapy and radiation (Irvin & Carey, 2008). Although, it is not clear why the disparity only started to appear in the 1980s, more studies must be done to understand the link between ancestral genetics and increased risk for TNBC. Research in this field has been limited and more studies of African populations may uncover a more definitive link that could explain the historical gap, as well.

While it is understood that TNBC is most commonly found in women younger than age 40, it is still critical to review the recommendations for screening guidelines. The absence of discussion by the USPSTF and ACS about the disparity that exists for African American women could have an adverse outcome on that population. While the research on screening guidelines is not fully supported because the disparity still existed prior to 2009 when the guidelines were lower, future studies should address recommendations for screening African American women who are more likely to be diagnosed with a more aggressive form of breast cancer at earlier ages. As African Americans are only 12%-13% of the U.S. population, it is not likely that the disparity will be uncovered when examining breast cancer at the population level (Amirikia et al. 2009). Current recommendations are based on population-based data.

SDOH also takes into account the lack of access to quality, affordable, and effective health care as a contributor to poor health outcomes and higher mortality. This includes the lack of access to early detection and treatment of the disease once it is diagnosed. As noted, the disparities gap began to widen in the 1980s when the recommended screening age was lower for the general population. However, as

technology advanced, the mortality rate for White women began to decrease while the rate for African American women increased. Technological advances in screening, like mammography, and treatment, like Tamoxifen, were not readily available to African American women (Hunt et al., 2013). Still, technological advances in screening do not address why African American women have a higher incidence of the TNBC subtype. And, technological advances in treatment do not help women with TNBC because TNBC is not responsive to adjuvant therapies. Future studies should exam new therapies for TNBC and an association with improved mortality.

Chapter Summary

Determining the reason for breast cancer disparities has proven to be fertile ground for researchers. Numerous studies have been conducted to identify the underlying cause for these disparities. Continued research to understand what role the SDOH play in the high incidence and mortality rates for African American women is needed. Genetics, the predisposition to certain diseases due to biology, or other aspects of SDOH are all viable concepts that may uncover some answers as to why TNBC disproportionately affects African American women.

In conducting this literature review, only quantitative studies were found. Qualitative studies exploring the lived experience of African American women with TNBC were not identified. While researchers have pointed to social circumstances and various aspects of life as the reason that African American women have higher mortality rates, the field would be enhanced by a study to understand the lived experience of women who are survivors of this disease.

Chapter 3: Research Design Methodology

Introduction

Thirty-two years after the Department of Health and Human Services' release of the Report of the Secretary's Task Force on African American and Minority Health in 1985, the nation is still grappling with the issue of racial health disparities. The report elucidated the prevalence and impact of health inequities suffered by African Americans and other ethnic groups compared to their White counterparts. Based on recent data of mortality rates of African American women with breast cancer, it is apparent that health inequities continue to exist (ACS, 2016).

Research Context

In 2008, cancer became the leading cause of death in Monroe County, NY across all racial/ethnic groups (Epidemiology of Cancer in Monroe County, 2012). Monroe County has one of the highest breast cancer screening rates with 84% of women ages 50 and older reporting having a mammogram within the past 2 years (Monroe County DOH, 2012; Behavioral Risk Factor Surveillance System, 2012). Unfortunately, Monroe County also has among the highest incidence rates of breast cancer across the state with an average of 660.6 cases and 104 deaths, annually (NYS Cancer Registry and Cancer Statistics [NYS CRCS], 2010-2014). When examining the data by race, the national pattern of higher mortality rates for African American women compared to White women can also be seen locally. African American women have a mortality rate of 22.9 compared to White women at 19.1 per 100,000 (NYS CRCS, 2010-2014).

While it is not known why African American women die at higher rates, the various factors that could contribute to this disparity have been outlined in Chapters 1 and 2. As previously stated, those factors include social determinants, such as breast cancer screening policy and guidelines (Amirikia et al., 2010), poverty and social conditions (Akinyemiju et al., 2015), and lifestyle choices that impact a woman's access to care, prior to, or in the early stages of the disease when it is most treatable. This has also been witnessed locally, and is highlighted in eight of the most economically disadvantaged zip codes in the city of Rochester (Finger Lakes Health Systems Agency [FLHSA], 2014): 14605, 14606, 14608, 14609, 14611, 14613, 14619, and 14621.

These eight zip codes share a unique set of conditions, including an overrepresentation of African American residents, disproportionate percentage of residents with a low educational level, high concentration of poverty, and low socioeconomic status (FLHSA, 2014). Approximately 63% of African Americans living in the nine county Finger Lakes region (Orleans, Genesee, Wyoming, Monroe, Wayne, Livingston, Ontario, Yates, and Seneca) reside in these eight zip codes (FLHSA, 2014). Additionally, in these zip codes: 54% of Monroe County's convenience stores, that do not provide healthy food options like fresh fruits and vegetables, are located; 33% of African Americans live in poverty; one-third of African American adults have less than a high school diploma; and African Americans suffer from multiple, preventable chronic diseases and have a 300% higher premature death rate than their White counterparts (FLHSA, 2014). Finally, the mortality rate of women dying from breast cancer in these zip codes was 55.9 compared to 49.5 for the rest of the county (NYS Vital Statistics 2013).

These eight zip codes are marred by the conditions that are outlined in the SDOH. These zip codes have been identified by the African American Health Coalition (AAHC) as target areas in need of immediate community and policy interventions (FLHSA, 2014) because of their high rates of health disparities and the low life expectancy. It is for these reasons that these zip codes in the city of Rochester served as the subject area for this research project.

Research Approach

Interpretive description, a phenomenological, qualitative research approach was used for this study. This research approach was not used to make sweeping generalizations about the population, or to make broad changes in public opinion, policy, or practice. It was utilized to give meaning to the cancer survivors' experiences (Thorne, et al., 1997).

Interpretive description is an inductive analytical research approach that draws from the qualitative methodologies of grounded theory, ethnography, and phenomenology, but goes beyond those disciplinary confines and creates a new way of interpreting and translating clinical phenomena for applied implications (Thorne, Reimer Kirkham, O'Flynn-Magee, 2004). It respects the prescriptiveness of the traditional methodological designs but understands that excellence in qualitative research requires the researcher to engage with the subject and have the intellectual capacity for inductive reasoning while interviewing. While interpretive description has emerged from other approaches, it is well suited to meet the needs of applied health care fields because it seeks to understand the shared experience of the subjects, as well as, their individual differences (Thome, Kirkham, & O'Flynn-Magee, 2004).

Interpretive description is designed for smaller scale qualitative studies using interviews, observations, and documentation as its data collection methods. It is widely used in the field of health care by nurses (Thorne et al., 2004). Its purpose is to capture themes and patterns in clinical phenomena and translate them into a description that could inform clinical practice (Thorne et al., 2004). It is a pragmatic approach that requires a logical framework rather than conventional procedures. It draws on qualitative principles that understand that: (a) reality is complex, contextual, constructed, and subjective; and (b) the researcher and subject are inseparable and interact to influence each other (Thorne et al., 2004). Therefore, it does not require the researcher to bracket preconceived notions as it assumes the researcher has theoretical knowledge that forms the basis for the research. It relies heavily on the researcher's process of intellectual inquiry which gives room "to see patterns, follow intuitions, and retrace a line of logical reasoning among and between pieces of data" (Thorne et al., 2004). However, it encourages the researcher to be skeptical of the obvious emerging themes and code broadly rather than precisely so that the researcher can be open to the infinite number of ways the data conveys the essence of the phenomena.

Interpretive description allows the researcher flexibility and creativity in their research design while maintaining coherence, accountability, and integrity within the research study (Thorne et al., 2004). Knowledge gleaned from each interview informed the next interview. Questions were added, revised or deleted according to the discoveries made from the research subjects' stories.

Research Participants

The sample was comprised of survivors of TNBC who live or work in neighborhoods in the city of Rochester with a high concentration of poverty, particularly the following zip codes: 14605, 14606, 14608, 14609, 14611, 14613, 14619, and 14621. Various sampling techniques were used to identify the target population.

First, nonprobabilistic, purposeful sampling was used to identify TNBC survivors. Purposeful sampling is used in qualitative research as a means of identifying and selecting specific populations related to the phenomenon being studied (Palinkas et al., 2015). Within this sampling methodology, both homogenous and snowballing techniques were used (Palinkas et al., 2015).

In order to understand how African American women experienced their breast cancer journey in light of SDOH factors, participants represented a homogenous group of women who: (a) identified as African American, (b) survived a diagnosis of TNBC, and (c) lived or worked in one of the eight aforementioned zip codes. This sampling method allowed participants to be selected through organizations that offered support to breast cancer survivors. These support groups met monthly and discussed topics that ranged from new diagnosis to survivorship for African American women living with breast cancer.

With permission from the executive director or group leader of these organizations, the researcher attended one of the support group meetings to introduce the study to the members. Email solicitations were also sent to distribution list alerting women to the study and asking that they self-identify if they were interested in participating. The email contained the main criterion for inclusion into the study which

was that the women must be African American survivors of TNBC. The researcher did not have access to the survivor database, nor the names of the women that received the email message until they responded affirmatively to the email solicitation.

As women self-identified for the study, the researcher was given their names and contact information as women of interest. Each interested woman was contacted by phone to inform them about the study in detail. Any concerns were discussed at the time and all questions were answered during the phone conversation.

Snowball sampling was also used to solicit referrals from women who knew other survivors of TNBC (Palinkas et al., 2015). Snowballing is a form of sampling that can enrich sampling clusters, and allow the researcher to access new participants and groups when other avenues have been exhausted (Noy, 2008). Breast cancer survivors tend to know other women who have been diagnosed with the disease and can serve as a referral base for identifying women who may not currently attend a support group. Once participants had been identified through the multiple recruitment strategies, they were consented and interviewed.

Instruments Used in Data Collection

The purpose of the data collection process for this study was to obtain rich, descriptive data from face-to-face interviews, observations, and field notes. The interpretive description design was used to describe the lived experience of the survivors as they recalled their breast cancer journey (Thorne et al., 2004). Conducting interviews was an essential means of gathering data about the phenomena and allowing the participant to share their perspective (Creswell, 2014). The interview process permitted the researcher to ask open-ended questions, and let the researcher collect detailed

information from the participants which aided in ascribing meaning to the phenomena (Creswell, 2014). Hence, interviews were the primary source of data collection for this study.

The participants were solicited for the study by outreach through breast cancer survivors' networks and support groups, snowballing, and self-selection after hearing about the study by word of mouth. Upon expressing interest in participating in the study, the interview date was set via email or over the phone. Prior to starting each interview, the participants received all information about the study including, time commitment, eligibility criteria, voluntary consent, and the timeline for study completion. All interview questions, demographic sheets, and questionnaires were reviewed by a team of researchers, professionals, and survivors to ensure clarity and ease of understanding prior to beginning interviews with the participants. Participants were also given the opportunity to ask questions and share concerns. After written consent was obtained, the interview was conducted.

The researcher conducted face-to-face interviews with individual TNBC survivors to understand their experiences. The initial interview with the participants took place in their homes, or a private location of the interviewees choosing. First phase interviews were taken approximately 45 - 75 minutes. These interviews included a review of the study and consenting of the participants. Additionally, this interview was designed to garner the most data. All interviews were recorded with the permission of the interviewee, and transcribed by a professional transcriptionist. Notes were identified only by the participants' pseudonym.

The researcher also captured notes and recorded observations about the participants' appearance, expressions, and mannerisms, as well as, their homes or the location they chose for the interview. The researcher also captured thoughts, observations, and perceptions throughout the process (Creswell, 2014).

During the initial interview, the researcher asked open-ended questions to get a sense of the participant's breast cancer experience. The initial question to the interviewee asked about their experience. From the researcher's prior knowledge, it was understood that this was a common question posed to survivors that they were accustomed to answering. The breast cancer survivors tended to respond well to this question and it yielded rich, thick data. Subsequent questions probed for clarity and detail around the initial screening and follow-up procedures, such as: what prompted the screening; how long did it take to get follow-up services; what were they told about their diagnosis; who supported them through the breast cancer process; and, what were their feelings throughout this journey. The interviewer also asked similar probing questions about treatment: how did they decide their course of treatment; how long did it take to get to treatment; and, what was their support network? Finally, interviewees were asked if they thought their experience differed in any way from other women.

Toward the end of the interview, the women were given a list of factors from the social determinants of health. They were asked if they believed any of the factors played a role in their experience, and if so, to circle the factor(s). The factors listed included: race, education, age, income status, health insurance status, socio-economic status, and language. The women were asked to discuss how any of these factors played a role. Discussion of these factors occurred during the interview process. Nonetheless by

providing the list, it allowed the participants to confirm their initial statements, rethink their answers, or reject the factors.

Finally, using the Qualtrics database, the researcher used a pre-existing template to design a short demographic information sheet to gather data about the participants. Questions included: gender, age range, income level, job type, education level, marital/partner status, sexual preference, place of birth, racial identification, regional identification, family make-up, and insurance status. This form was used at the end of the interview. Six interviews were conducted for this study. The various data collecting methods gave the researcher multiple ways to validate the findings including member check so that the researcher could verify thoroughness and clarity of thoughts

Procedures for Data Collection and Analysis

Analysis of interpretive description research calls for a critical analysis of the current knowledge of the subject and a concurrent and iterative process during data collection and analysis (Thorne et al., 2004). The critical analysis of the subject is outlined in Chapter 4: Results. Interpretive description allows for the iterative, ongoing process of data analysis in order to guide the data collection process. The concurrent and iterative process of data collection and analysis began with the first interview and continued throughout the study. As data were gathered and audio recordings of each interview were reviewed, the data were continually analyzed in an effort to inform future interviews. Creswell and Maietta (2002) state that data analysis is a “zigzag” process where the researcher collects and analyzes data throughout the entirety of the study. Information garnered from each interview informed the questions asked during

subsequent interviews. This approach allowed for the direction of the study to evolve as new knowledge was ascertained (Thorne et al., 2004).

Data analysis began with a review of the research questions. Interpretive description reasons that the initial research questions may have been created on the basis of limited information (Thorne et al., 2004). Fortunately, this was not the case. The following 11 questions guided the interviews:

1. Tell me about how your breast cancer was detected.
2. What prompted the mammogram?
3. Tell me about the follow-up process once the abnormality was identified.
4. What were you told about your diagnosis?
5. How did you decide your course of treatment?
6. What was your overall level of satisfaction from screening through treatment?
7. How were you feeling throughout this journey?
8. Did you feel supported?
9. How were you supported through this process?
10. Do you think your experience differed in any way from other women?
11. Do you feel that your race or income level made a difference in your care?

Questions were added, edited, or adjusted as needed according to the ongoing data analysis from previous interviews.

Observations were also critical to the data analysis process. It gave the researcher the opportunity to witness data about the study as it pertained to information about social supports, community comfort, racial identity, and accessibility to care. Field notes were

used to capture the physical environment, neighborhood, and racial identification of the participants. Observational data was analyzed alongside the interview transcripts, and were reviewed in an iterative process to inform the study.

Data was organized by demographic information, observational field notes, and interview materials. Coding was used to frame the initial research construct. The process of coding allowed the researcher the ability to combine data for themes and ideas. However, interpretive description warns against the excessive use of codes “as the exhaustive effort this typically entails can detract from the mind’s inherent capacity to see patterns, follow intuitions, and retrace a line of logical reasoning among and between pieces of data,” (Thorne et al., 2004).

The researcher immersed herself in the data in order to generate new meanings and insights. Intellectual inquiry guided the researcher’s exploration into the breadth and meaning of the data by asking questions like: how does this fit?; why was this said?; and, what has been learned? The transcribed interviews were analyzed for thematic codes. Initial coding identified recurring terms, descriptions, and feelings described by the participants or observed by the researcher, and documented in the transcripts and field notes.

The initial codes were analyzed across interviews to generate the second level of codes. Further analysis through focused coding organized and consolidated the recurrences into higher order conceptual themes (Creswell 2014). Higher order themes were identified and categorized according to the previously identified tenets of SDOH. Through this process key findings emerged regarding strength, the physician / patient relationship, self-advocacy, and support. These themes were ordered into a narrative that

conveyed the essence of the experiences. Quotes from the survivors were used to highlight the themes and illuminate the story that was developed as a product of this study. These themes are explored in Chapter 4.

Interpretive description supports the long held qualitative methodological concept that it is the researcher's responsibility to grasp the data, create the meaning, posit the relationships, and recontextualize the data into findings (Morse, 1994). Interpretive description does not rely on the particularities of the steps taken to conduct the research, but on the knowledge and rationale of the researcher to interpret the data. It recognizes that while the explicit guidelines used for conducting the research may provide suggestions for future researchers, the findings may not be duplicated because it is the researcher who determines what data are relevant and how they are portrayed (Thorne et al., 2004).

Credibility

How well the researcher articulated the findings is the essential element in determining credibility or "interpretive authority" (Thorne et al., 1997). Credibility was derived from the transparency in the analytical. To ensure credibility, a brief summary of each participant was drafted to confirm they were identified and characterized accurately. Member checks were conducted with participants as they reviewed the study findings and confirmed the interpretations. Conclusions were tested with participants, as well.

Triangulation was used to improve the credibility of the findings and interpretations. Method triangulation was reached through the use of multiple data collection methods including interviews, demographic information, notes, and observations (Polit & Beck, 2012). Themes were also cross-referenced with existing data

and studies. Findings were reviewed with experts in cancer research and public health who have knowledge of the subject. Comprehensive discussions were conducted to analyze the data based on what the experts already believed about the topic and what new knowledge was gleaned from the research.

Data Storage and Security

Data was collected and stored digitally on a laptop which was attached to a server with login and logout requirements. The laptop was password protected and could not be lawfully accessed without the owner's knowledge. As previously stated, all interview transcriptions were de-identified to maintain confidentiality of data and assigned code names represented by gem stones known only to the researcher. Transcripts were loaded, stored and analyzed in an Excel spreadsheet. Only participant pseudonyms appeared on data collection materials. All field notes were retained by the researcher and stored securely in a locked drawer when not in use. Audiotapes and research documents will be destroyed in compliance with IRB guidelines.

Summary

The lack of qualitative research about African American women with TNBC necessitated the use of the interpretive description research design. Interpretive description is a design that enables people, with similar experiences, to give voice to their stories in a holistic way while respecting the individuality of each person (Thorne, Con, McGuinness, McPherson, & Harris, 2016). Interpretive description demonstrates the importance of the lived experience and allows the exploration of new concepts so that they can be better understood (Thorne et al., 2016). By interviewing TNBC survivors in these neighborhoods, the researcher was able to give meaning to their experiences and

describe the role poverty and race played in their ability to access affordable, quality healthcare.

Conducting research in this way is a valuable addition to the field as it informs clinical practice and future research by elucidating the social determinants of health through the perspective of the women who experience its tenets most closely.

Chapter 4: Results

Introduction

The purpose of this study was to understand the lived experience of African American female survivors of triple negative breast cancer (TNBC) to determine if any of the key tenets of the social determinants of health influenced their screening through treatment decisions or care. This study explored the women's beliefs on factors including: race, socioeconomic status, age, education level or health insurance status affecting their ability to access and/or receive quality healthcare during screening, diagnosis and/or treatment.

Using the interpretive descriptive qualitative research design, this study gives voice to the survivors' experiences throughout breast cancer journey and offers insights into their state-of-mind, decision making process and recommendations for improved care. The following questions guided the research:

1. What are the African American women's experiences with triple negative breast cancer from screening through treatment?
2. Do African American women believe race played a role in their screening and treatment options?
3. Do African American women believe social conditions played a role in their screening and treatment options?

This chapter presents the results of six interviews that were conducted from February 2017 to May 2017. It provides a brief description of each research participant to

allow the reader to know each woman individually. It outlines the methods used to collect and analyze the data including demographics, data collection procedure, and data analysis process. It is organized by major theme and excerpts from the interviews were used to highlight the participants' experience.

Participant Demographics and Description

Demographic information for each participant was collected using a questionnaire that included birth year, gender, race/ethnicity, income status, zip code, marital status, employment status, and household size. Participants' age at diagnosis ranged from 43-72 years old. Education levels ranged from high school diploma to masters level degree. Participants were either currently employed or retired, and earned incomes ranging from \$10,000 to more than \$100K annually. Participants' marital status varied across categories of married, separated, divorced or widowed. All participants were cisgender females of African descent identifying as Black, African American or Caribbean American. Two participants lived alone while the others lived with family members. All participants spoke English, and English was their primary language. Below is a chart of the demographic information.

Table 4.1

Demographic characteristics

Name (Pseudonym)	Age	Income	Marital	Education	Racial Preference	Employment	Zip Code
Topaz	50s	\$100K+	Married	Bachelors	African American	Full-time	14611
Amethyst	40s	\$60K+	Separated	Masters	African American	Full-time	14608
Emerald	70s	\$60K+	Divorced	Associates	Black	Retired	14619
Diamond	70s	>\$20K	Widowed	High School	Caribbean American	Retired	14621
Ruby	Private	Private	Private	Private	Private	Private	Private
Citrine	70s	\$40K+	Divorced	Bachelors	Caribbean American	Retired	14608

Six participants were interviewed for this study. They were selected through support groups, snowballing, and word of mouth. All participants consented to one-to-one interviews which lasted between 45 and 90 minutes. All participants had completed treatment for TNBC prior to the interview, although two were still recovering from surgery or chemotherapy. All of the women lived or worked in one of the eight identified zip codes: 14605, 14606, 14608, 14609, 14611, 14613, 14619, and 14621. None of the women were visually overweight or obese. A few of them commented on the importance of living healthy lifestyles and being physically active. Their homes were well-kept and decorated with pictures, heirlooms, and items of cultural or familial pride. Participants were given pseudonyms represented by gemstones to maintain their confidentiality.

Topaz. I met Topaz one evening after work at a local restaurant near her home. We sat in a corner booth far removed from the other patrons. Topaz is a mild-mannered,

soft spoken woman who appeared ready to share her experience with me. She was open about her journey and answered all questions in detail without hesitation. Topaz did not need much prompting as she recounted her story. Throughout our conversation, Topaz expressed how this experience gave her peace and perspective. “I must admit going through that whole process I really developed peace and I learned how to sit and be still for a while.” (Topaz, p. 3) She shared that prior to her first diagnosis she was short-tempered and impatient. However, during our time together, I saw nothing but a positive, inspirational woman who was hopeful that her experience could help others.

Topaz lives and works in two of the eight identified zip codes in the City of Rochester. She has had two bouts with TNBC. She was first diagnosed in her late 40s and then again 5 years later in her early 50s. Topaz found both of her breast cancers as they were not immediately identified through the mammogram. In fact, three tumors were identified in the same breast over the 5-year period. Topaz spoke passionately about how her life changed through this process, and the importance of women living healthy lifestyles as a means to prevent cancer. She encourages all women to monitor their eating habits and remain physically active in order to maintain a healthy weight and reduce their risk for breast cancer.

Amethyst. Amethyst lives in an identified zip code in Rochester. I met her at her home shortly after she had been discharged from the hospital for an emergency mastectomy. She was seated in her comfy chair with a machine, known as a Wound VAC, connected to her breast area working to close an open wound from the surgery. I did not discover this information until partway through the conversation. Her mother was also present as she had arrived from out of town to take of her. They seemed to have a

close relationship as her mom prepared lunch while Amethyst and I sat in the living room talking. Her mother intentionally stayed out of the way; however, I could see she was a caring and attentive woman as she even reminded me to put quarters in the parking meter to avoid getting a ticket.

Amethyst was diagnosed in September 2016. She is the youngest participant of this study being diagnosed in her early 40s. She found her own breast cancer when she felt a lump in her breast. However, she delayed getting it diagnosed as she convinced herself it was something else. This was Amethyst's only diagnosis of breast cancer, but her second bout with cancer as she had Hodgkin's lymphoma as a teenager. After having gone through chemotherapy in her childhood, Amethyst was adamant about not doing chemotherapy again. Hence her procrastination in getting her breast cancer diagnosed because, "I was in no rush to get a diagnosis and have doctors cramming that recommendation down my throat" (p. 2)

As a substitute for chemotherapy, Amethyst researched other methods of healing and decided to use alternative therapies to beat this cancer. Amethyst, a knowledgeable and decisive woman, uses an array of herbs and supplements to manage her condition. She is also conscious of what she eats and understands how different foods may affect cancer's growth or spread. Amethyst's strength and determination led her to learn all she could about this disease and various complementary and alternative options for treatment. Amethyst would like women to know that they do not have to be beholden to traditional medicine and that there are other choices available.

Emerald. I met Emerald in her home on a Friday afternoon. She, and her granddaughter, greeted me at the front door. We sat in the dining room and talked about

her diagnosis, as well as, the experiences that made her the strong woman she is today. Emerald is a retired engineer in her early 70s. She is the oldest of eight children, and grew up quickly as she had to raise her seven siblings in her mother's absence. She continues to be a caregiver now taking care of her granddaughter who lives with her. Emerald has overcome many challenges throughout her life and credits many women in her past for molding her into a confident, resilient woman. "I stood on a lot of women's shoulders. A lot of them" (p. 30).

Emerald had no personal or familial history of cancer. She was diagnosed with breast cancer in 2012 in her late 60s after a suspicious spot appeared on her mammogram. However, because she had dense breast tissue, it took some time before the radiologist made a definitive diagnosis. Once she was diagnosed, Emerald chose to face her cancer journey primarily on her own. As she is the consummate caregiver and a fiercely independent woman, she chose not to involve anyone else and go it alone. Emerald is now a member of a local support group and chooses to share her story, strength and knowledge with newly diagnosed women to help them maintain their dignity and autonomy throughout their journey. She raises money to support breast cancer programs and mentors women who are new to the group. Emerald lives in an identified zip code in Rochester, and wants to share her story so that other women can be empowered through their experience, just like she was.

Diamond. I met Diamond at her home on a Sunday afternoon. She is a retired woman who lives with her daughter and grandchildren in one of the identified zip codes. She spends most of the year in Rochester helping her daughter raise her grandchildren, but departs for a warmer climate a few months out of the year. We talked in Diamond's

bedroom for privacy. Diamond is a pleasant and kind woman with a calming presence. She was diagnosed in October 2016 in her early 70s after her routine annual mammogram. She was still recovering from the side effects of chemotherapy at the time of our interview. Diamond's positive attitude, quiet strength, and family support were essential to her recovery.

Diamond relied heavily on the love and support of her daughter, extended family, and close friends to get through this experience. "My daughter would go with me every day for chemo and every day for radiation. My family would call. They would visit, which was a great success for me because I was able to recover quite nicely" (p. 3). Her daughter, who was Diamond's primary caregiver throughout her journey, was also part of the interview. Diamond's daughter accompanied her to all of her appointments, did research about TNBC, posed questions to the physicians, advocated for her when needed, and did everything she could to make sure Diamond made it through this experience in best possible way. "Okay, focus on what's to be done. What's next? What do I need to do? What does she need to do to get to a place where she is whole again?" (p. 14). Diamond hopes to share a few words of wisdom for other women who have to face this disease.

Ruby. I met Ruby after work on a Thursday evening in the conference room of a local organization. She is a very private woman and was hesitant to take part in the interviews. However, after hearing more about the study, she decided to participate. Ruby works in one of the identified zip codes. She lives with her husband and son in a suburb of Rochester. Although she didn't say, based on our conversation, I estimate that Ruby is in her late 40s. She is an articulate, composed, and professional woman. She was the

most reserved of the women and was measured in her words not wanting to give too much away. What Ruby thought was going to be a quick conversation ended up lasting over an hour.

We met at this particular place because it was a familiar and comfortable space for her as she has been a member of this organization since 2006 when she was first diagnosed with breast cancer. At that time, Ruby was in her early 30s. She had two more recurrences of breast cancer since then with the last one occurring in 2016. Each of Ruby's experiences was different. She had three separate cancers occurring between both of her breasts. Each cancer's identification, screening, and treatment were different. Her last diagnosis was confirmed as TNBC. It is unclear whether or not the first two diagnoses were TNBC as TNBC was not part of the lexicon at that time. However, Ruby does know that they were both estrogen receptor negative.

Through her three experiences Ruby has amassed a wealth of information and knowledge. She wants women to understand the importance of research and self-advocacy. Had she not advocated for herself during one of her experiences, she could have taken medication that had the potential to do her harm. Ruby wants women to glean whatever they can from her story so that they can have an experience with less fear, confusion and ambiguity. "I just heard the word to self-advocate. You really do have to mentor women not to just be the sick, poor person because, unfortunately, they [doctors] miss things, and it's too rushed. The system is too rushed. There's too much going on" (p. 21).

Citrine. I met Citrine in her home on a Thursday night. She is an independent woman who lives alone in one of the identified zip codes. She is a retired woman in her

mid-70s. Like Diamond, she spends most of her time here but returns to her home country during the winter months. We sat in her dining room and talked for approximately 40 minutes. Citrine is a spiritual woman who gets her strength from her deep faith in the Lord. It was her faith that allowed her to maintain a positive attitude throughout her journey, and did not let the cancer diagnosis depress her or distract her from her regular routine. "Yeah, I went to [my country] as usual, and do what I had to do, as usual."

Citrine was diagnosed in 2011 during her routine mammogram. She was in her late 60s at the time. As she recounted her story, her strong faith came through in every word. She was resolute in her belief that the Lord would be her support and healer. Because she knew the Lord was the healer, she relied on his grace and mercy to see her through. She attended her appointments and her treatments without family and friends, but with the Lord by her side. The physician asked "Is anybody with you?" And I first said no. Then I said "Oh yeah! Yeah, somebody is with me." And he looked at me. I said "Yeah, Jesus is with me" (p. 5). Citrine opted not to do chemotherapy. She had surgery and radiation. Citrine is a 6 year survivor of her cancer.

Each woman's journey was different, but they had some characteristics that were the same: strength, faith, and self-advocacy. These characteristics are discussed further in the thematic findings.

Thematic Findings

The purpose of this study was to understand the experience of women with TNBC to see if any of the key tenets of the social determinants of health influenced their screening through treatment decisions or care. At the end of each interview, the women

were asked if they felt race, educational level, age, income status, health insurance status, socio-economic status or language played a role in their screening through treatment options or in their level of care. While each participants' experience was unique, many similarities emerged. Those similarities were categorized into themes with the key themes highlighted below.

Policy and guidelines. Screening guidelines have been noted as a barrier for women because they can be confusing. Until 2009, the screening age for breast cancer started at age 40. However, with the recent changes to the guidelines, various organizations have established different guidelines ranging from age 40 to age 50 with intervals of 1 to 2 years. Yet, confusion of the guidelines was not an issue for these women. "But every year I went for my mammogram from the time I was 40. So it wasn't that I never went or I missed every year. I never missed on a mammogram." (Citrine, p. 9). However, starting in 2009 when the USPSTF changed the screening guidelines, various organizations have published different recommendations for when women should start getting screened. However, none of these women cited screening guidelines as a barrier. "Through my primary care. He said I should start getting my mammogram every year. Every year in October, I would go and get screened" (Diamond, p. 8). They were all aware of the screening guidelines and when screening was appropriate for them. "I've been getting mammograms since my 30s because I had cancer when I was a kid" (Amethyst, p. 29). Even in the event when someone did not get screened, it was due to their own priorities and not any social circumstances. "It's sad to say that I've been too busy to have a mammogram" (Ruby, p. 13).

This suggests that women in Rochester, regardless of where they live, are aware of the importance of annual screenings. This also aligns with data that show Monroe County has one of the highest breast cancer screening rates in the state with more than 80% of eligible women reporting that they received a mammogram at least once every two years (MCDOH, 2012).

National breast cancer campaigns such as Susan G. Komen for the Cure, the American Cancer Society's Making Strides in Breast Cancer Walk, and October Breast Cancer Awareness Month activities have helped to raise the level of consciousness and education about breast cancer. New legislation, like the Affordable Care Act and New York State's Get Screened. No Excuses. campaign, makes it easier for women to get screened for breast cancer by removing cost sharing, mandating hospitals to provide screenings outside of the normal 9-5 business hours, and ensuring that breast cancer screening and diagnostic imaging services are paid in full by insurance. However, large disparities continue to exist in the health care system and trend across other chronic diseases and cancer types as outlined in Chapter 1. Fortunately, in the case of breast cancer, Monroe County has done better than most. However, this may be an exception, not the rule.

TNBC. All of the research participants were survivors of TNBC. However, since TNBC is a fairly new discovery, it was not surprising to learn that the women were not familiar with this form of breast cancer. As Topaz stated:

We both met with him and he described the type of cancer that I had. He said that it was a triple negative and that it was fast growing, very aggressive so they needed to start taking action immediately. I didn't really understand when he first

told me a triple negative. I was like triple negative, what is that? I didn't know that there were different types of breast cancer. I just thought breast cancer was breast cancer. (Topaz, p. 2)

They were equally unaware of the progression of the disease and its aggressive nature. “He explained to me that stage one is the lowest but with the type of cancer I had it was very aggressive and fast growing so they had to treat it quickly” (Topaz, p. 2). To compensate for their lack of awareness, the women learned about TNBC from their physicians, as well as, engaging in their own research on the Internet. There was a mix of opinions about the level of specificity and the amount of information they received from their physician s regarding the aggressive nature of TNBC. This ranged from in depth detail to very little. “He was great because he even like drew a diagram and just showed me everything about the breast and the tumor. He was really, really good” (Topaz, p. 11). “I don't believe that even when I was diagnosed with triple negative this time, that I was made aware enough that this is somewhat of a really different kind of cancer. I was just told triple negative and that was from my oncologist” (Ruby, p. 20).

However, even when the physician explained the disease, and in some cases used visual aids, a full understanding of the disease did not take place during the physician’s consultation. In some cases, the name itself, TNBC, led to confusion. “I found out through my research that the triple negative, it was worse than what I understood it to be. You know, going in, the triple negative that sounds good. Okay, it would be even better to take care of because it’s negative” (Diamond’s daughter, p. 13). Women needed time to go home, process the information, and do some research of their own.

Once the diagnosis was understood, the gravity of this form of breast cancer, as it is explained in the literature, may still not have been fully appreciated.

So he said he would like me to see the oncologist because she might think I have to get chemo. So he had two names for me - the radiologist and the oncologist. So I went to her, the oncologist first. And she couldn't convince me why I needed to do chemo. And I was asking her all kinds of questions. I said for this little thing? (Citrine, p. 3)

Yet, the aggressive nature of TNBC was realized when the diagnosis was not made early enough.

[In] October everything was fine. When I went back in April, the cancer had broke through and grown like a weed. And like he said, if I had to wait till a couple more months for an ultrasound, or whatever, or mammogram, it would have been too late. That's how fast it grew. (Emerald, p. 2)

The fact that the women did not have a full understanding of the disease, may have worked in their favor because the women did not view this as a devastating diagnosis. "Because even the radiologist didn't say, oh you have this and have to get that, and it was nothing that nobody made a fuss about" (Citrine, p. 4). Had they fully grasped the gravity of the situation, they may have experienced an added level of stress that could have altered their attitudes and behaviors throughout their journey. A full understanding of the devastating effects of TNBC could have diminished their sense of autonomy and/or ability to make their own decisions.

As Turkman described in her dissertation of exploring the psychosocial needs of African American women with TNBC, found that "women perceived their TNBC

experience as separate and different from the more common subtypes of breast cancer,” and “this knowledge, particularly the lack of treatment options, profoundly affected their sense of security and confidence in their future” (2014, p. 39). So, the question remains as to how much information physicians should give each woman about her breast cancer. Future discussion remains for determining what the appropriate amount of information to give is, and when is the appropriate time to give it.

I think it's that thing where they don't want to scare the patient and, again, you can go online and in that case it's at your pace. You decide if you want to keep reading and scare yourself, or whether you're not going to be scared, but you're going to use the information. (Ruby, p. 20)

SDOH: social conditions do not matter. Contemporary literature, as outlined in Chapter 2, leads us to believe that social conditions such as lack of insurance, access to information or physicians, and knowledge of screening guidelines are barriers to screening for women in urban environments. However, these were not identified as obstacles for any of the women in this study. The essential question for this study was to determine if women faced any barriers to their care due to SES or race. When asked specifically about race being a factor, the women struggled to identify a situation where they felt their race played a role. Ruby recounted an incident she had with her oncologist who refused to send her for a blood test. “If you ask me if I think race ever played a part in any of my whole journey, that would be the only time that maybe, but it's such a big maybe, I don't even know because it's a bizarre occurrence and I can't explain why he did that,” (p. 20). Overall, the women said that they did not feel as though race was a factor. “I didn't feel it. Oh no, maybe there is some bias somewhere, but I am not aware of it. I

didn't feel it" (Diamond's daughter, p. 17); "I didn't get that feeling either" (Diamond, p. 17). The overwhelming response was that they did not perceive any factors of SDOH to be barriers during their breast cancer experience; however, they could see how it would be an issue for others. "My answers are all no [regarding the SDOH factors]. But, I could see, it's quite obvious, that these are factors for other people" (Amethyst, p. 34). Age, language, and income were not cited as barriers, nor were they points of discussion during the interviews.

Health insurance. Health insurance did not reveal itself to be a barrier. Five of the women reported that they had good health insurance and paid a minimal amount, if anything, for services.

[I had] fantastic health insurance and I never worried once. Yeah, I felt really fortunate for that. I don't think even for the surgery I did [pay]. I kept waiting for chemotherapy co-pay bills to show up, but no, I did not pay co-pays for chemo. I don't think I paid a co-pay for the surgery. I had two surgeries and, yeah, it was all covered. (Ruby, p. 9)

One of the five women even stated that she had such good health insurance, she received reimbursements for going to her appointments. "[Insurance] is wonderful I tell you. They would give me money for going to my treatments, chemo, radiation, they would send me checks. I'm like, oh my gosh, this is a wonderful policy" (Topaz, p. 12). While the sixth woman did share concerns about medical expenses because she had a high deductible insurance plan, she had made a deliberate decision to pursue alternative therapies which she knew would not be covered by insurance. "Insurance will cover a prescription, they won't cover herbs" (Amethyst, p. 27). Although Amethyst felt

insurance should cover her alternative therapy, insurance was not a barrier to her care as she consciously decided to forego conventional medicine in favor of natural remedies.

If insurance covered it, it would be great. . . . [my supplements] have to be between seven, probably somewhere around \$700 a month. That's still way cheaper. Let's say I could do that for a whole year, it's still way cheaper than a chemotherapy session which could cost \$25,000 on average. (Amethyst, p.28)

Access. Access to information also did not emerge as a barrier for these women.

All of the women discussed having access to information and the ability to do research about their diagnosis.

I read the papers they gave me because I'm just that way inclined. I was that kind of informed patient. I was also consulting Dr. Google, that's what my physician calls him. I was supplementing the information they gave me with information there and then getting questions from there that I could ask them. (Ruby, p. 8)

As conventional research dictates, access to the Internet or information is usually cited as a barrier to care in communities with high concentrations of poverty. However, that was not the case for these women. "I would go on the Internet a lot after I was diagnosed. I would really try to educate myself more about the triple negative" (Topaz, p. 20). And research was not just for the diagnosis; they were determined to understand as much as possible about their situation. "Afterwards, we did research. Why we have cancer? What was going on? And chemo, anything. All this was new to me" (Diamond, p. 3). One of the women, because she was adamant about not doing chemotherapy, also researched alternative treatments. "I started researching herbs and alternative methods. I added Qigong and I did additional research and found out there were specific yoga

interventions that had been studied and peer reviewed” (Amethyst, p. 5). They felt confident in their ability to read and comprehend the information they received from the Internet. “I’m fortunate that I know how to research and read and be an advocate for myself” (Amethyst, p. 11)

While research states that screening guidelines, insurance status and access to information are factors in women’s health options and choices, this population of women did not have that experience. Remarkably, unexpected themes emerged that are a cause for discussion. Women shared similar feelings about the physician / patient relationship, importance of having a positive attitude, and perceptions of support groups. Each of these areas is explored in further detail below.

The strength of a woman. Although SDOH proved itself not to be explanatory for these women, one theme emerged as a topic for discussion in all interviews. This overarching theme is captured as “strength of a woman” and revealed itself in the way these women chose to handle their diagnosis. The image of Black women as being strong and resilient in the face of adversity has been a hallmark of the literature for years (Shorter-Gooden, 2004). In her work on the resistance strategies of African American women coping with racism and sexism, Shorter-Gooden described three internal ways in which Black women deal with these life stressors: (a) standing on the shoulders of their ancestors and those who paved the way, (b) valuing themselves and maintaining a positive self-image, and (c) relying on their faith and spiritual beliefs (2004). Some of these strategies were displayed through the women’s stories in how they dealt with the stressor of having TNBC. “I stood on a lot of women’s shoulders. A lot of them” (Emerald, p. 30).

The women's strength was evident in their convictions, their faith, and their will to survive this disease. This diagnosis was just something that happened in their lives; it was not something that was defining their lives. "So I'm very strong. Sometimes I think I'm too strong for my own good sometimes, you know? And I think that helped me, too" (Emerald, p. 8). They were clear and definitive about what they would do, what they would not do, and what they had to do. And, once they made those decisions, they were resolute. "You have to have your wits about you and do your research, and ask questions, and read up, and make the right appointments. Just tackle it, that's the next thing to do" (Ruby, p. 6). Strength showed itself repeatedly in how they managed their care and coped with the effects of this devastating disease. "Just the way that I handled it, I was much stronger than I anticipated. I was very strong" (Topaz, p. 5). What's humbling is that these women were not consciously being strong, they just were. "When people tell me that you're so strong and I'm, my first response is, huh? Really? I'm just living my life" (Amethyst, p. 11). The strength of a woman emerged with two subthemes, just as highlighted in the literature: faith and attitude.

Attitude. In order to get through this diagnosis, it was clear that their positive demeanor and outlook on their situation was pivotal to the success of their treatments. "You know, I took a positive outlook on everything. I said, "That too shall pass." That is what I used to keep saying, "That too shall pass" (Diamond, p. 10). All of the participants shared that keeping a positive attitude through this experience is what kept them going.

I just kind of wish that they . . . if they had to go through cancer, they would go through the way I went through. They said "Miss, I can't believe you going

through cancer, you supposed to be sad. Why I'm supposed to be sad? Why am I supposed to be sad, though? (Emerald, p. 30)

It was obvious that having a good attitude meant that they looked good and felt good about themselves. "I didn't act sick, or didn't look sick" (Citrine, p. 5). In some cases, this was to the extent that people did not believe they were dealing with cancer. "They're looking at me like. 'but you look so good!'. Like I was a faker, you know" (Amethyst, p. 17).

However, the strength to stay positive through a negative time must come from somewhere. And, while they drew strength from various sources, their knowledgeable, their families, or their networks, they all had one thing in common, their faith.

My faith was so strong that telling me that word wasn't a death sentence for me. I said 'Lord, why not me? If everybody else could have something, why not me? But I know you are the healer and I have the faith in you. So I know you are gonna take care of me.' And I went about my business. (Citrine, p. 2)

Faith. The power of faith was consoling and comforting for the women. "My faith is heavy, heavy, heavy. It's heavy. And I knew all the time that God is not in buildings. He's everywhere at the same time. He's omnipotent with all power. It ain't over till He says it's over" (Emerald, p. 14). It brought them out of despair. "I got so low one time that I actually feel like I heard God talk to me. It really jarred me out of that depth of despair because it's not up to you" (Ruby, p. 13). And, it allowed them to continue to live their lives and follow their regular routines. "Well, first they'd be surprised that I'm still working" (Amethyst, p. 17). They never let the diagnosis hold them back or keep them down.

I just kept taking it one day at a time and doing what I could on those days that I felt good. I never did let it get to me. I never was mad or angry. I said well maybe this is something that's going to help me learn more about myself, and it did.

(Topaz, p. 5)

They talked about the ability to continue with their daily activities: mowing the lawn, going on vacation, cooking and going to church.

But me and my God and you know, he takes care of me. And he really took care of me. Because I was cutting my grass, and I see my yard is long and all, I cut grass. I do all my stuff myself. (Citrine, p. 10)

The extension of the church and church family was just as critical.

I have a very strong faith and my church was very supportive too. Very supportive. That's probably why I just reacted the way I did because of my faith through this whole thing when I was diagnosed the first time and the second time.

(Topaz, p. 18)

The power of prayer from the congregation was a source of strength and healing.

I found a church near me and started attending and actually asked all these new people that I didn't know for prayer. It was a good experience because they welcomed me and so that saw me through the tail end of my chemotherapy.

(Ruby, p. 13)

“Soon as I got diagnosed I asked my church to put me on the prayer list” (Amethyst, p. 16). And, prayer doesn’t only have to come from the church. “I cried, and then I called my primary care and he told me to come right away to his office. ...he even prayed with me at the end of that visit” (Diamond, p. 2).

The strength that these women drew from their attitudes and faith is aligned with the literature which discusses strategies for how African American women deal with life's stressors. Faith is an internal resource that research has shown helps African American women overcome trials and tribulations (Shorter-Gooden, 2014).

The Physician / Patient Relationship

A breast cancer diagnosis may be one of the most difficult health issues a woman may have to deal with in her life. It not only affects her, but her family, friends, colleagues and many others around her. As the woman is processing the diagnosis and the toll that the cancer will have on her life, her body, and her appearance, one thing she does not want to be concerned about is her health care team. "They were all very nice. They treated me with respect. The doctor would listen to hear what I had to say. ... They were very concerned, I must say" (Diamond, p. 7).

Research has shown that the significance of the physician / patient relationship is critical to optimal patient health (Peabody, 2014). The importance of these relationships was evident with the women in this study. "The doctors were always there for me, they answered all my questions, they gave me the literature" (Topaz, p. 11). All of the women expressed confidence and resolve in their ability to choose their physician, get other opinions, or change physicians, if necessary. "I was able to choose new doctors as I saw fit" (Ruby, p. 5). They were empowered to seek multiple opinions about their diagnosis. "I had an appointment for my third opinion because, in the meantime, I had lost faith in the one [doctor] I had chosen" (Amethyst, p. 9).

This form of empowerment is of particular importance because women going through a breast cancer diagnosis interface with a number of physicians including: the

primary care physician (PCP) who may have provided guidance and referrals to the cancer specialist; the radiologist who identified the cancer through screening; the surgical oncologist or breast surgeon who removed the tumor; the medical oncologist who monitored and managed their overall care and may have administered chemotherapy; the radiation oncologist who administered the radiation treatments; and the plastic surgeon who may have reconstructed their breast. With each physician, the women had to develop a new relationship and this could be a source of stress as they have to navigate this system.

I'll always say this, that it's a very incomprehensive way basically everything just seems kind of fractured and broken up when you need to do more than one kind of treatment. For the surgery, it's a whole separate thing where you're trying to find the surgeons and talk to people and organize that. Then if you need chemotherapy it just doesn't bleed into the next thing really. It's now a whole other thing where you have to now find your oncologist. (Ruby, p. 6)

However, once they do navigate the system, women want to have a care team that they can trust and rely on during this vulnerable time, “Because as I say, I thank God for the doctors I have. It was caught in time, and as I say, thank my radiologist for the time she took, and she really set up a program with me” (Citrine, p. 9).

In general, the women discussed the good relationships they had with their primary care physicians (PCP) and the level of care they received from their health teams. “I can't say enough about them. I had really good doctors” (Topaz, p. 11). For the most part, the women enjoyed a trusting relationship with their primary care physicians. “I had trust in my doctors . . . I know I had a good doctor. And I knew he was gonna do

the right thing for me” (Emerald, p. 22). They also shared that these relationships played a significant role in helping them manage this process. “I’m fortunate, I’m super fortunate that my primary care doctor actually came around. That made a huge difference in my . . . my mindset” (Amethyst, p. 11).

However, at some point, with each of the women, there was a physician / patient relationship that did not go, as well. “He just refused. It was such an unusual way. This doctor was just a terrible, terrible person” (Ruby, p. 15). They each reported at least one negative experience with a physician who was dismissive or did not listen to their concerns about side effects of treatment, and this tended to be with one of the cancer specialists. “A lot of things that I was telling them, they were saying no that’s not common. That’s not one of the side effects” (Topaz, p. 4). Or, in some cases, made them feel as though they were delusional. “And I said, you know, I’m burning my nipple on the opposite side. Oh, that’s in your mind” (Emerald, p. 11). At other times, they simply did not believe the physician even heard them.

So they weren’t really hearing me. No matter what I was saying, their ultimate goal was to get me to understand that they were here to kill the tumor, irrespective of whatever impact that had on my body and my psyche. (Amethyst, 6)

Yet, the inner strength of these women did not allow them to sit silently and be dismissed or invalidated. At some point during the journey, each woman talked about the fact that they had to take a stand and advocate for themselves.

Self-advocacy

As defined by Molina et al. (2015), advocacy is the “ability to seek, evaluate, and use information to promote one’s health.” “I found that I was really having to advocate

for myself” (Ruby, p. 21). The power to advocate for themselves allowed them to speak up and refuse treatments in times of discomfort, “I told my oncologist that I'm going to be stopping the chemo treatment. They tried to persuade me but I was set in my way as I am, and I told her no” (Diamond, p. 2); uncertainty, “I'm saying no because I'm not going to take the medication unless I'm certain that it is estrogen positive” (Ruby, p. 14); fatigue, “I don't want another surgery. I said oh my gosh, I just can't go through that right now. I said I really cannot” (Topaz, p. 14); or lack of trust, “I lost faith because she, after seeing me multiple times, having access to my chart and literally looking at my boobs, she wasn't sure where to. . . her actions indicated to me that there may be some confusion about which areas were cancer and which areas weren't” (Amethyst, p. 9).

These women were not passive about their health.

I do remember specifically advocating for myself, asking questions, trying to bring the doctor's mind back to something he said two visits ago that somehow has fallen by the wayside, and watching him say, ‘Oh, yeah, I said that, didn't I?’

Me wondering oh my God, what if I didn't remind you? (Ruby, p. 20)

Furthermore, their actions were significant because research has shown that while patients may want to engage in collaborative relationships with their care team, they are reluctant to do so because they do not feel confident or adequately equipped to do so. Yet these women not only engaged, they had the wherewithal to make their own decisions about their health.

Support

Through their journey, the women talked about the support they received from family, friends, church, and coworkers. Having support, whether they used it or not, was

reassuring to them. Hence the surprise at finding out that most women did not go to a support group. And, in fact, had a negative perception of them. “You see, some of them support groups make you sicker than anything. You go there and you hear the stuff, and you're like oh my God” (Citrine, p. 9).

Support groups. Prior to beginning this study, it was anticipated that cancer support organizations would be the primary source for participant recruitment. A large breast cancer organization, with a database of over 4,500 survivors, was contacted in order to identify potential participants. Surprisingly, this organization only yielded one-third of the participant pool. Although the women in this study all confessed to receiving information about cancer support organizations either from their physicians or by finding it during their own research, most admitted to never pursuing the information any further. “I have never been to any. I was just going through my own stuff. That was enough. I got support [from my family], that I must say” (Diamond, p. 9). What was unknown to me was the perception that some women had toward these organizations. Of the women in the study, two-thirds of them believed that attending a support group would worsen their experience, dampen their spirits, or extract too much of their energy.

In Rochester, there are two primary support groups for women with breast cancer, one which has a majority White population (80%), and the other specifically for African American women. These groups provide opportunities for peer mentoring, presentations and workshops facilitated by experts in the field, exercise classes, cooking information and recipes, meditation, and yoga programs, outings/parties, and book clubs, with support groups being a small part of what also happens there.

We don't talk about cancer all the time. We talk about food; we might talk about clothes. We might talk about kids; we might talk about husband; we might talk about family. But it's the outreach to us, you know, everybody's on the same journey. (Emerald, p. 18)

Yet the perception of these organizations was mixed with women questioning the importance and relevance of these groups. Half of the participants never made any contact with these organizations because they believed that people who were involved with these organizations would have negative energy that would corrupt their positive feelings about their experience.

It probably would've been depressing and people would probably be complaining, not complaining but angry or something then I would've had the attitude, 'You know what? It's not worth being angry. Take one day at a time, life goes on.' They might not want to hear me say that but I was over all this. I'm over that. I'm not angry so my whole personality is not like that. I don't even want to entertain that and I don't want you to say you should be angry. No I'm not angry. I'm not angry. (Topaz, p. 18)

Conversely, one participant did attend both organizations. At one organization she took advantage of the learning seminars but shied away from the support group. At the other, she attended the support group and was disappointed and uncomfortable with the experience.

They did something that wasn't comfortable for me when everybody went around introducing themselves. My name is. . . ; I had this kind of cancer, and this was my intervention. When I went I still wasn't telling people that I even had cancer, let

alone all the details of it and what I wanted to do. So I wasn't comfortable with that. (Amethyst, p. 18)

Of the two remaining women, each are members of one of the support organizations and they are both promoters for their organization. However, as they are both long-time survivors, they function as mentors and advocates for women, as opposed to individuals seeking support. This makes their perspective a little different because they are operating from a space of knowledge and wisdom with the ability to offer support to women who need it. “You really do have to mentor women not to just be the sick, poor person because, unfortunately, they miss things and it's too rushed. You have to advocate for yourself. I cannot stress that enough” (Ruby, p. 21).

This paradox about support groups was a surprising discovery in this study. Subsequently, I attended a meeting at one of the organizations and the executive director was aware of the negative perception and many attendees shared those beliefs. One attendee stated that she didn't want to attend a support group because she associates them with alcoholics and drug addicts. Hence, they have changed the name from support groups to networking groups. The executive director also commented that she knows that strong women are not looking for support; they are looking for information, comradery and distractions from the current situation. This could explain the difficulty in recruiting many participants through this channel.

Summary of Results

The aim of this study was twofold: first, to understand the lived experience of African American female survivors of triple negative breast cancer (TNBC), and second, to determine if any of the key tenets of the social determinants of health influenced their

screening through treatment decisions or care. Both aims were met. Through the interview process, the first aim was met and a full accounting of the women's journeys were recorded and summarized for each research participant. The second aim was answered through the women's accounts of their journey. They all stated unequivocally, that their screening through treatment options were not influenced by social conditions, but by relationships, research and/or prior experiences. The findings for the second aim are highlighted in the first theme, SDOH: Social conditions do not matter.

The experiences of this group of women went against the contemporary literature on African American women with TNBC. These women covered the economic, educational, age, and geographic spectrum; yet, they had fairly similar experiences. SDOH was not part of their experience. None of the women felt that they experienced racism or substandard care because of their age, race, SES, or any other factor. In this study, the SDOH framework did not account for the protective factors of strength, resilience, and faith inherent in each woman that allowed them to mitigate the damage this disease could have caused to their psyche and overall well-being.

These protective factors were revealed through the theme, strength of a woman. This theme encompassed sub-themes about faith and self-advocacy. Their depth of faith when dealing with adversity and the importance of the ability for self-advocacy was paramount for these women to successfully beat their diagnosis. Yet, the question remains, what would have been different if they were a different race, specifically White? Would the information given to each woman about TNBC have been deeper and more consistent across providers? Would their need to advocate and research have been as

great, or would more information have been provided to them in advance? These questions are discussed further in Chapter 5.

Chapter 5: Discussion

Introduction

The purpose of this study was to understand the lived experience of African American, female survivors of triple negative breast cancer (TNBC), and to determine if any of the key tenets of the social determinants of health, particularly race and place/social conditions, influenced their screening through treatment decisions or care. This study was conducted using an interpretive description approach of qualitative methodology which allowed the researcher to use an iterative process for collecting and analyzing data. Semi-structured interviews were conducted to capture the experiences of six women who live or work in one of eight target zip codes within the city of Rochester.

The first aim of the study was to understand the lived experience of African American female survivors of TNBC. This aim was met through the interview process. A full accounting of the women's journeys was recorded and summarized for each research participant in Chapter 4. The second aim was to determine if any of the key tenets of the social determinants of health (race, educational level, age, income status, health insurance status, socio-economic status or language) influenced their screening through treatment decisions or care. This was answered through the analysis of the women's accounts of their journey and their completion of the SDOH factor checklist. All women stated that their screening through treatment options were not influenced by race or social conditions. Personal factors and relationships emerged as the key influencers for their decision making.

Discussion of Findings

Six amazing women were interviewed for this study. Other than the fact that they were all African American women, this was a demographically diverse group of survivors. Their ages ranged from 43-75 years old. Their incomes ranged from less than \$20K to more than \$100K, their marital statuses covered all categories of married, separated, divorced, and widowed, and they all lived in different sections of the city. In addition to being demographically diverse, their demeanors differed from mild-mannered and easygoing, to assertive and straightforward. Cultural backgrounds and family upbringing also varied as the women had Caribbean, southern or northern heritage.

Finally, there were no observable, physical limitations that the women were challenged by. They did not appear to be overly obese or overweight, did not use any walking aids, and seemed to be in general good health. In fact, a few of the women discussed the importance of being healthy and exercising. “I guess that people exercise, healthy living, that is so important. I cannot stress how important, especially if you're overweight, you have got to do something. You have to. You have to,” (Topaz, p. 21). And, while many of them did not know each other, they shared a common experience in their triple negative breast cancer journey.

As outlined in Chapter 2, a plethora of quantitative research cited SDOH as a significant, contributing factor to poor health for people living and working in high poverty communities. Quantitative research has demonstrated that women who live or work in lower socioeconomic communities could experience barriers that inhibit their access to quality, affordable health care which could lead to higher mortality rates. The prevailing research question of this study was to determine if the experiences of women

living in communities described by the SDOH would mirror the results reported in the quantitative research. Would these women encounter barriers to screening due to confusing screening guidelines (Amirikia et al. 2009), or face challenges that would prevent them from getting timely follow up care from health care providers? Would they encounter inadequately staffed facilities, or would treatment be cost prohibitive because of lack of insurance (Adams et al., 2012)? Furthermore, would they be met with interpersonal or structural racism that would impede their care, (Jones, 2000)? The answer to this question was a unanimous and resounding, “no.” “My answers are all no [regarding the SDOH factor list]. But, I could see, it's quite obvious, that these are factors for other people,” (Amethyst, p. 34). The findings of this research study did not support that claim.

SDOH, as it related to the African American women in this study, did not appear to be a relevant issue. These six women, who represented a diverse group of women, experienced TNBC in similar ways. Regardless of income level, marital status, educational background or area in which they lived, they all had access to resources, credible knowledge about screening behaviors, the ability to access and receive care for their screenings, diagnosis and treatments, and the wherewithal to advocate for themselves.

This is a surprising finding because as conventional discussions of SDOH in Rochester suggest, the women would have encountered some barriers based on where they lived (FLHSA, 2014). This raises the question of whether or not the women in this study were a true representation of the women in those communities. If they were not, then future research should be done to recruit a more representative group of women. If

they were, these findings bode well for the level of breast cancer prevention and early detection education in Monroe County, which has long been recognized for its higher than average breast cancer screening rates for African American women (Monroe County DOH, 2012).

This could also speak to the level of awareness raised by New York State which has made the early detection of breast cancer through screenings a priority. NYS leads the nation in ensuring women, regardless of insurance status, have full access to breast cancer screenings at convenient times with no cost to them (NYS Senate Bill S8093, 2016). NYS is the only state that requires insurance companies to cover breast screening and diagnostic imaging for women without cost-sharing (NYS Senate Bill S8093, 2016).

This expansion of health care insurance goes beyond the provisions of the Affordable Care Act which guarantees no cost for preventive screening, but not diagnostic imaging (H.R.3590 - Patient Protection and Affordable Care Act, 2010). New York State also launched a 5-year campaign to increase breast cancer screening rates by 10% by 2021 (governor.ny.gov, 2016). Part of this campaign takes direct aim at providing access to technology that will disproportionately benefit women of color, providing more access to screening that will assist women in high poverty communities where facilities are not easily accessible, and implementing legislation that will provide funding to low-income women with financial barriers to screening (New York State Governor Andrew M. Cuomo, 2016).

However, it should not be concluded that health outcomes would be equivalent for other forms of cancer, or other chronic diseases, for that matter. As outlined in Chapter 1, the report of the African American Health Coalition revealed the devastating

health condition of people who live in the eight Monroe County zip codes with the highest concentration of poverty. African Americans in these zip codes suffer from multiple, preventable chronic diseases and have a 300% higher premature death rate than their White counterparts (FLHSA, 2014).

Furthermore, issues of racism in Rochester have been highlighted through the work of the Rochester Monroe Anti-Poverty Initiative (RMAPI, 2015). While individuals may not personally feel overt racism, examples of structural and institutional racism exist throughout health care and are a cause of health disparities and inequities (Smedley, 2002). Yet, it is common for people to not recognize racist acts perpetrated against themselves, but yet to perceive that it happens to others (Rojas-Sosa, 2016).

The women in this study were hard-pressed to identify instances of racism. Ruby recounted the incident she had with an oncologist who refused to send her for a blood test. “If you ask me if I think race ever played a part in any of my whole journey, that would be the only time that maybe, but it's such a big maybe, I don't even know because it's a bizarre occurrence and I can't explain why he did that,” (p. 20). Yet, Jones (2000) contends that even with advances in socioeconomic status and access to care the destructive nature of racism and discrimination is ever present.

Strength. African American women are known for their strength and resilience (Shorter-Gooden, 2004). The image of strength in the face of adversity has become a sense of pride and badge of honor in African American communities. However, due to the health conditions of the Black community (FLHSA, 2014), it is obvious that Black women must do more to take care of themselves and their health. Her strength may

sometimes be a hindrance to her good health as she may erroneously believe that she can handle more than she actually can.

As stated by many of the women, they chose to go through their journey alone without leaning on others (Amethyst, p. 7; Emerald, p. 8; Citrine, p. 5). This speaks to their innate strength that is discussed in the literature. However, they also shared the welcomed comfort and support they received from family and friends when they were not expecting it. Being the caregiver is what many Black women are known to be and have always been. For centuries, they have cared for others, then their own, and lastly, if at all, themselves. These women should not have to also shoulder the burden of cancer on their own. Black women must learn to accept and rely on the support and strength of others, be that from family, church, or women who have had the same experience. This may be found in support groups, as well.

Information. As discovered in the interviews, the need for information was great. All of the women reported conducting supplemental research to fill the gaps in information received from their provider. They needed to understand their cancer, and get as much information as possible. However, it is common that providers tend to underestimate how much information their patients need, when they need it, and in what format (Ong et al., 1995). Ong et al. reported that while doctors believe they are giving precise, thorough information, the patient's needs are not met because they are not receiving the type of information that is relevant to them. Hence, the women all sought out information on their own throughout the process.

This could be interpreted as the women not getting as much information as they needed, or that they wanted a secondary source of information to confirm what they were

hearing from the provider. As noted by Ruby, “unfortunately, they [doctors] miss things, and it's too rushed. The system is too rushed. There's too much going on.” If this is the case, there are implications for how providers disseminate information to their patients.

Self-advocacy. Self-advocacy emerged as a theme because at some point, with each of the women, they mention having a poor interaction with one of their cancer specialists. They encountered a situation where their physician did not listen to them, was dismissive of their concerns, or blatantly disregarded their request. It was at this time that they had to advocate for themselves to ensure they received the care and attention they wanted. However, as research has shown, self-advocacy is not common among cancer patients (Blumenthal-Barb, 2017).

Blumenthal-Barb’s study has shown patients tend to defer to the physician for fear of being perceived as difficult. This phenomenon is contextualized through culture and values stating that in studies of patient reluctance to be an active part of shared decision-making, the patients look to the physician as an authority figure and do not want to appear to be problematic. This occurs even in life-threatening or life altering situations when the patients should be active participants. However, even in life-threatening situations, patients tend to trust in their physician’s knowledge and experience and defer to their physician’s recommendations.

Additionally the reluctance to challenge physicians is also seen in populations with lower education levels as well as people who are unfamiliar with medical terminology. In a focus group study of patients discussing cancer screenings, researchers found that those who are unfamiliar with words, such as tumor, tended not to ask as many

questions, (Blumenthal-Barb, 2017). This makes it difficult for the physicians to determine the level of understanding that these patients had.

However the women in this study, regardless of education level, socioeconomic status, or cultural background all exercised their right and duty to be active participants in their care. They questioned their care team, challenged the physicians at times, and advocated for themselves when necessary. These women were not passive patients. They cared about themselves and their health, and insured that when their well-being was in question that they took responsibility to make sure they knew what was appropriate for them.

Faith. Faith was another theme that emerged as an anchor for these women. As mentioned previously, they experienced their cancer diagnosis as an event that happened in their lives and not something that would determine their lives. They had a positive attitude throughout their journey. Topaz mentioned finding peace in her life through this diagnosis, Citrine talked about knowing that she would be OK because she believed in the Lord and he would see her through, and Amethyst talked about the power of prayer. These women leaned on their faith to get them through this difficult journey. As best said by Citrine, “my faith was so strong that telling me that word wasn't a death sentence for me.”

Reliance on faith has been discussed in the literature (Lynn & Levine, 2014). In their study, Lynn and Levine examined African American women with breast cancer to understand how they coped with their diagnosis. They found that religious and spiritual practices were an integral part of the women's coping strategies. The women in their study talked about the importance of attending religious services, being part of the church

community and having people pray for them, as well as the comfort they found through prayers and the encouragement through reading biblical scriptures. This study also showed that the faith that Black women have reflects in a better quality of life that they enjoy even when going through a serious diagnosis like breast cancer.

Implications and Recommendations

Bias toward African Americans has a long and distinct history in this country. There have been multiple studies that evinced the association between perceived racism and poor health outcomes. Taylor et al. (2007) found that women under age 50, who reported frequent everyday discrimination, were at higher risk for breast cancer than those who reported infrequent experiences. Other studies have identified systematic differences in how chemotherapy was administered to African American women compared to White women (Griggs et al., 2003). These studies are evidence of how bias plays a role in the disparate health outcomes of African Americans in this country. The findings from this study have implications for researchers, physician practices, and patients.

Researchers. Quantitative researchers have identified areas of structural racism and implicit bias in their findings, as discussed above. Structural racism is embedded in the structures and policies that shape the lives of Americans. It also underscores the link between race and place as African Americans, disproportionately, tend to live in low socioeconomic environments. Conventional wisdom dictates that living in low SES environments increases the likelihood of poor health outcomes. However, quantitative research may not take into account protective factors such as faith, support, and inner strength that serve to mitigate challenging social factors. In this study, the women did not

succumb to the conditions of their environment or their disease because they relied heavily on their faith, inner strength, wisdom, and self-advocacy skills to help them fight against forces that could have impeded their care.

Public health researchers focus on risk factors and may not consider protective factors that allow people to resist or overcome those risk factors. Researchers should consider using measures of protective factors in their studies that could give a fuller understanding of participants' experiences. There are several tools that could be used to measure spirituality and resiliency when coping with diseases. This would allow for a holistic view of study participants and better predictors for health outcomes.

Physician practice. Although the women in this study reported that racism did not play a role in their care, the larger societal and structural forces must not be overlooked. While physicians may not be aware of their biases, it is evident from the previously cited research that biases do exist and are present in patient care. Health care professionals should consider taking steps to become more aware of their implicit biases. There are various trainings available that discuss areas of cultural humility, implicit bias, and structural racism. Physicians could seek out and participate in cultural awareness training that speaks to the role that racism and implicit bias play in the health care field. Additional barriers could be placed if women feel that racism or bias was seeping into their care. Engaging in honest conversations about race and racism, and working to dismantle policies and symbols of racism and oppression in the health care field, could help with building trusting relationships with their patients.

Ensuring good educational training is equally important because it was clear that the women wanted more information about their disease in a format they could

understand. Research has shown that while patients may want to engage in shared decision making with their care team, they are reluctant to do so because they may not feel confident or adequately equipped to participate in a collaborative discussion with their physician about their health needs (Frosch et al., 2012). Physicians must be inclusive of their patients thoughts and ideas to ensure shared decision making.

Additionally, the women talked about the amount of information and resources they received from their physicians regarding their TNBC, and stated that it was not enough. They also reported there was no consistency with what information was given, when the information was given, and by whom. Hence, health care providers may consider creating a process that will aid in the smooth, concise, and comprehensive flow of information to their patients. Teams should consider:

- who would be best to convey needed information to the patients (physicians, nurses, social workers, etc.),
- at what point during treatment it would best be conveyed (consultation, follow-up, special appointment, or a combination of times),
- what information should be conveyed based on the patients' needs and wants, and,
- in what format the information be conveyed (face-to-face, reputable resource list, brochures, and pamphlets, email/text messages, etc.).

Making more information available to their patients, in a way that they will understand, will help patients feel equipped and knowledgeable to participate in shared decision making. Information should also be provided in a manner that is inclusive of different races and languages.

Additionally, the women all shared that they had good, trusting relationships with their PCPs. This may have been the first physician they talked to about their diagnosis, confided in, and trusted with their sensitive information. Unfortunately, other than giving a referral to a surgeon, the PCP is not typically involved in the patients' cancer journey. That tends to fall under the purview of the cancer team of oncologists and surgeons. However, there may be a larger role that the PCP can play with their breast cancer patients.

As the ACA forces health care providers to move toward a medical home model, it gives way for the PCPs to be more involved in their patients' care as part of the cancer team. While the PCP is not an expert in cancer, nor is he/she expected to be, there is a critical role that they could play. The PCPs involvement would be more of a collaborative approach with the patient to: reinforce information received from the cancer team; ask questions to ensure the patient understands medical directions, assist the patient in reviewing instructions and formulating questions, and encourage the women to follow up on instructions received from their cancer team. PCPs could consider instituting a process of following up with each patient after their initial visit with their cancer team. The PCP would not be expected to be a cancer expert, but to be a trusted source, and sounding board for the patient during times of uncertainty.

This would be a new role for the PCP as they are currently not involved after the cancer diagnosis. They may not receive reports of the patients progress through their treatment, or be kept abreast of any issues or concerns. Moreover, the PCP may not be incentivized to participate in this way, as there is no reimbursement mechanism for the PCP to bill for consultative or advisory services during the patients' cancer treatment.

Yet, it is the PCP with whom each woman remembered having the positive, trusting relationship. Therefore, a new reimbursement structure may need to be developed to allow physicians to allocate time to their patients who are dealing with a cancer diagnosis.

Patients. Research has revealed that African American women are strong, independent and resilient through the most trying times. However, this strength could also become an unintended barrier to their well-being. Women going through a diagnosis as serious as cancer should learn to accept help. Many of the women chose to go through their journey alone, even though they did not have to. Amethyst stated that she did not see the point in involving other people. However, in retrospect, she admitted that she should have taken someone with her to her first appointment. No matter how strong a person is, it can be helpful to have another person available to take notes, think of questions, and help advocate, if needed. For the most part, that type of assistance will come from family or friends. However, there are times when it may come from strangers.

Although support groups were not embraced by most of the women because they perceived them as being filled with negativity and depressing conversations, it is an alternative that breast cancer patients may want to consider. According to Emerald, support groups offer more than depressing conversations and angry outbursts. They offer advice, distractions from the present circumstance, referrals for better care, and laughter in place of grief. They also offer advocacy, unity, and purpose for those who want to do more to fight their disease. From Emerald's and Ruby's point of view, there is a lot of positivity and information that comes from support groups. Therefore, women with a

breast cancer diagnosis may want to allow themselves time to learn more about these groups. They may be surprised to find that they could tap into another source of strength.

Limitations

The contemporary, quantitative research shows that TNBC is more likely to occur in young women under the age of 40 years of age. However, the women identified for this study were all diagnosed with TNBC over age 40. The lack of recruiting women, ages 39 and younger, to this study could be viewed as a limitation. Life experiences, knowledge and circumstances may have differed for younger women in contrast to older, more established women. Young women may have endured additional challenges associated with attending or finishing college, experiencing their first brush of independence without parental constraints, establishing a career, starting or raising a family, or dreaming about what their future holds. As screening guidelines do not target women below the age of 40, a cancer diagnosis for someone just starting their adult life could be a devastating incident. Future research may warrant inclusion of this particular population as the likelihood of TNBC occurring in women of this age group is significantly higher.

Additionally, this study aimed to discover if social conditions were a factor for women living in high poverty communities. However, the women in this study may not be representative of most women in those neighborhoods. The income level of most women in this study was not that of women in poverty. Although, the participants lived and/or worked within the eight zip codes area, five out of six of the women an income range that was at 350% or higher of the 2017 Federal Poverty Level set at \$12,060. Yet the average income for an African American household in Rochester is \$27,078.

As these women had higher than average incomes, they were not burdened with some inconveniences that lower income women may have encountered. For example, they all had reliable transportation that allowed them to easily access care. They all had personal computers in their homes and the ability to do research which allowed them to access information about their TNBC diagnosis freely. They all had health insurance so that finances did not pose a barrier to their care. Had they been of a lower SES, their ability to navigate barriers may have been impaired and given rise to challenges in screening through treatment options.

Future Studies

This research study helps to fill a gap in the literature that does not address the lived experience of Black women who live or work in low socioeconomic environments and have this aggressive form of breast cancer. Although the study participants reflected a diverse spectrum of income, marital status, educational level it was a small sample size was small and cannot be used to generalize for all African American women with TNBC. Yet, this study lays the foundation for future research in multiple areas.

Since the participants were all of the same race, this study did not allow for a comparative analysis of experiences against women of other races. While it was beyond the scope of this study to compare the experience of African American women to that of White women, future studies may choose to include women of various races and ethnicities to determine if there are significant differences in the way women are treated by their physicians, the timeliness of appointments, the amount of information that is received, and the level of advocacy that is required to ensure proper care.

Additionally, per the NYS Vital Statistics (2013) the mortality rate of women dying from breast cancer in these zip codes was 55.9 compared to 49.5 per 100,000 for the rest of the county. Future research may include the families of women who lost their battle with TNBC. Insight from the family on how the decedent experienced their journey could give new understanding to this topic.

Researchers may also want to study the feasibility of PCPs playing a new and extended role in the care of their patients with breast cancer. It would be essential to weigh the benefits and challenges of a new practice model for practitioners to understand how they could implement a new method of care for their breast cancer patients.

Finally, researchers may want to expand upon this study by including African American women aged younger than 40, and those with lower income levels. According to the research, TNBC is more likely to be found in younger women under age 40. In addition, women in lower SES may have more barriers to access for screenings and treatment. Ensuring a study population was inclusive of these two groups will further enhance the field of knowledge.

Conclusion

This was a qualitative study of six African American women who were diagnosed with TNBC and lived or worked in eight specific zip codes in the city of Rochester. Qualitative research is not meant to be generalizable but to describe the phenomenon of the lived experiences of the participants (Leung, 2015). The findings from this study serve to complement the existing quantitative research. The detailed accounts of each woman add a depth of knowledge about how African American women experience TNBC that should not be ignored. As outlined in Chapter 2, qualitative research that

highlighted the lived experience of African American women with TNBC was nonexistent. Yet, this study gives a look into the lives of these women, that is often ignored in quantitative research.

While SDOH is important for assessing risk factors, it does not tell the whole story. Although it is clear that issues of race and place matter, they were not barriers for any of the women in this study. Protective factors of strength, resilience and faith may mitigate social conditions and allow women to thrive even in the worst circumstances. This knowledge should be used to enhance the field and can be transferred to future research.

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