

LIVED EXPERIENCES OF AFRICAN AMERICAN BREAST CANCER SURVIVORS

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

SCHOOL OF HEALTH PROMOTION & KINESIOLOGY

TEXAS WOMAN'S UNIVERSITY

BY

KIM MOSS-LINNEAR, BA, MPA, CHES®

DENTON, TEXAS

MAY 2022

Copyright © 2022 by Kim Moss-Linnear

## DEDICATION

This dissertation is dedicated to my mother, Cletia Mae Moss; my siblings, Regina Moss-Miles (Ebony Petty and Sylrika Petty), Richard Carter, and Pamela Joyce Lewis; my brother-in-law, Robert L. Lewis; and my oldest sister, Linda Thompson. Thank you all for always believing in me and encouraging me to follow my dreams. To my dad, Thomas Cone, for teaching me the importance diplomacy and perseverance. Last but not least, I dedicate this dissertation to my husband Charles Linnear, and my children, Trevyn Lewis, Elizabeth Linnear, Jon-Thomas Linnear, and Shaun Linnear, for believing in me and supporting me unconditionally.

## ACKNOWLEDGEMENTS

My sincerest appreciation and acknowledgment to my chair and mentor Dr. Suzanna Rocco Dillon, thank for your grit, and sharing your fearless determination and drive with me. My committee Dr. Mandy Golman and Dr. Lin Moore, your support and encouragement kept me going over the last year. My honorary committee member Dr. Damon Cottrell for your time and encouragement. Special acknowledgment to Dr. Massey-Stokes, who shared her expertise with me early in my doctoral journey. I want to acknowledge the Bridge Breast Network and Barbara Cares; both were instrumental in the recruiting process for the study.

A special thank you to the sisterhood of breast cancer survivors who participated in this study and sharing your experiences. Lastly, I want to acknowledge my “village of supporters” friends, family, TWU cohort, and colleagues. Thank you for all the love, positive thoughts and prayers you poured into my life during my doctoral journey.

## ABSTRACT

KIM MOSS-LINNEAR

### LIVED EXPERIENCES OF AFRICAN AMERICAN BREAST CANCER SURVIVORS

MAY 2022

The purpose of this phenomenological study was to explore the lived experiences of female African American breast cancer survivors from breast cancer diagnosis through treatment. Currently, approximately one in eight women will receive a breast cancer diagnosis in their lifetime. In 2022, it is estimated that 287,850 women in the United States will be diagnosed with breast cancer for the first time, and more than 51,400 women in the United States will die due to breast cancer (American Cancer Society, 2022). Specific to Texas, approximately 18,000 women in Texas diagnosed with breast cancer annually with African American women in Texas experiencing higher rates of aggressive and harder-to-treat breast cancer, and lower survival rates (Shimelis et al., 2018; Texas Cancer Registry, 2020).

Guided by Kleinman's explanatory model of illness (Kleinman et al., 1978) and critical race theory, this study explored African American women's experiences with breast cancer and medical discrimination. This study used a qualitative phenomenological approach to answer the research questions and utilized the latest version of NVivo to organize and analyze the semi structured interview data. NVivo was used to explore themes and provide textural reflections of qualitative interview data (Saldaña, 2013; Swygart-Hobaugh, 2019). Interpreting and coding of the interview data followed a rigorous and well-established seven-step process proposed by Moustakas (1994).

Themes identified from the data were: (a) physical and emotional scars of breast cancer, (b) the role of faith in the healing process, (c) the village of supporters, and (d) the health care

system is not centered around Black women. This study shared the profound life lessons the breast cancer survivors learned over the course of their journey from diagnosis through treatment and into their current level of survivorship. Survivors shared the unpredictable impact of breast cancer treatment and the faith used to overcome their illness. Lastly, to avoid the effect of medical discrimination, survivors in the study used advice from their “village of supporters,” which included physicians, church members, family, friends, co-workers, and most importantly other survivors, to identify culturally appropriate health care to meet their individual needs.

## TABLE OF CONTENTS

|                                                 |      |
|-------------------------------------------------|------|
| DEDICATION .....                                | ii   |
| ACKNOWLEDGEMENTS .....                          | iii  |
| ABSTRACT .....                                  | iv   |
| TABLE OF CONTENTS .....                         | vi   |
| LIST OF TABLES .....                            | viii |
| LIST OF FIGURES .....                           | ix   |
| I. INTRODUCTION .....                           | 1    |
| Breast Cancer .....                             | 1    |
| Breast Cancer Prevalence .....                  | 2    |
| Breast Cancer Costs .....                       | 3    |
| Theoretical Foundation .....                    | 3    |
| Kleinman's Explanatory Model .....              | 4    |
| Critical Race Theory .....                      | 6    |
| Purpose of Study .....                          | 6    |
| Research Questions .....                        | 7    |
| Delimitations .....                             | 7    |
| Importance of the Study .....                   | 10   |
| II. LITERATURE REVIEW .....                     | 11   |
| Literature Search Strategy .....                | 11   |
| Inclusion Criteria and Exclusion Criteria ..... | 12   |
| Breast Cancer Symptomatology .....              | 12   |
| Breast Cancer Risk Factors .....                | 13   |
| Breast Cancer Screening .....                   | 15   |
| Breast Cancer Staging .....                     | 17   |
| Breast Cancer and African American Women .....  | 17   |
| Breast Cancer Health Inequities .....           | 19   |
| Theoretical Frameworks .....                    | 23   |
| Kleinman's Explanatory Model of Illness .....   | 23   |
| Critical Race Theory .....                      | 24   |
| Summary .....                                   | 26   |
| III. METHODOLOGY .....                          | 28   |
| Research Design .....                           | 28   |
| Epistemology .....                              | 30   |
| Participants .....                              | 30   |

|                                                                                                                                                                                                                |        |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|
| Data Collection .....                                                                                                                                                                                          | 40     |
| Researcher’s Role .....                                                                                                                                                                                        | 41     |
| Protection of Human Subjects .....                                                                                                                                                                             | 41     |
| Data Analysis .....                                                                                                                                                                                            | 42     |
| Trustworthiness of Findings .....                                                                                                                                                                              | 44     |
| <br>IV. RESULTS .....                                                                                                                                                                                          | <br>46 |
| Themes .....                                                                                                                                                                                                   | 53     |
| Physical and Emotional Scars of Breast Cancer Treatment.....                                                                                                                                                   | 53     |
| The Role of Faith in the Breast Cancer Healing Process .....                                                                                                                                                   | 57     |
| Village of Supporters .....                                                                                                                                                                                    | 59     |
| The System Is Not Centered Around the Needs Black of Women.....                                                                                                                                                | 62     |
| Conclusion .....                                                                                                                                                                                               | 66     |
| <br>V. DISCUSSION .....                                                                                                                                                                                        | <br>68 |
| Discussion of Research Questions .....                                                                                                                                                                         | 69     |
| Research Question 1: What Are the Lived Experiences of Female<br>African American Breast Cancer Survivors Specific to the Perception<br>of Their Illness From Breast Cancer Diagnosis Through Treatment? ..... | 69     |
| Research Question 2: What Are the Lived Experiences of Female<br>African American Breast Cancer Survivors Specific to Medical<br>Discrimination From Breast Cancer Diagnosis Through Treatment? .....          | 72     |
| Summary .....                                                                                                                                                                                                  | 73     |
| Implications for Practice .....                                                                                                                                                                                | 74     |
| Understanding Cultural Differences .....                                                                                                                                                                       | 74     |
| Providing Culturally Appropriate Care.....                                                                                                                                                                     | 76     |
| Limitations .....                                                                                                                                                                                              | 77     |
| Conclusions .....                                                                                                                                                                                              | 78     |
| Future Research .....                                                                                                                                                                                          | 78     |
| <br>APPENDICES                                                                                                                                                                                                 |        |
| A. Questions.....                                                                                                                                                                                              | 97     |
| B. Demographic Survey .....                                                                                                                                                                                    | 99     |
| C. IRB Approval .....                                                                                                                                                                                          | 101    |
| D. Demographic Characteristics of Participants .....                                                                                                                                                           | 102    |
| E. Study Participant Breast Cancer Characteristics .....                                                                                                                                                       | 105    |

## LIST OF TABLES

|                                                                                                                    |    |
|--------------------------------------------------------------------------------------------------------------------|----|
| 1. Age-Adjusted Annual Breast Cancer Hospitalization Discharges per 10,000<br>Women in Texas, All Ages, 2015 ..... | 3  |
| 2. Age-Adjusted Surveillance, Epidemiology, and End Results Breast Cancer<br>Incidence of Women, All Ages .....    | 14 |
| 3. Interview Questions and Research Questions .....                                                                | 48 |
| 4. Initial Pattern of Analysis of Data .....                                                                       | 49 |
| 5. Summary of Themes and Opening Participant Quotes .....                                                          | 52 |

## LIST OF FIGURES

|                                                                          |   |
|--------------------------------------------------------------------------|---|
| 1. Kleinman's Explanatory Model of Illness: Individual Perceptions ..... | 5 |
|--------------------------------------------------------------------------|---|

# CHAPTER I

## INTRODUCTION

### **Breast Cancer**

Breast cancer, defined as a form of diseased cells commonly displayed in a grouping or mass within the small glands of the breast, is one of the leading causes of death for women in the United States (American Cancer Society [ACS], 2022; Centers for Disease Control and Prevention [CDC], 2020a). Breast cancer diagnosis is often through early screening methods, such as mammograms, breast ultrasound, magnetic breast imaging, clinical breast exams, and breast self-awareness exams. Mammograms, X-ray monitors for women's breasts, are the most common and often the most efficient way to help providers identify abnormal cells in the initial stages, allowing for early detection, appropriate follow-up, and timely treatment, as needed. Prevention is vital to reducing late-stage breast cancer diagnosis and mortality rates. Approximately one in eight women will receive a breast cancer diagnosis in their lifetime. An estimated 287,850 women in the United States will be diagnosed with breast cancer for the first time in 2022, and more than 51,400 women in the United States will die this year due to breast cancer (ACS, 2022; Siegel et al., 2021).

In Texas, breast cancer is the second leading cause of cancer deaths among women (Texas Cancer Registry [TCR], 2020). Approximately 18,000 women in Texas are diagnosed with breast cancer annually. The incidence rate of noninvasive in situ (Stage 0) breast cancer is highest among African American women in Texas. Malignant luminal HR-positive, invasive types of breast cancer diagnoses tend to be highest among Caucasian women, followed by African American women. African American women in Texas experience higher rates of

malignant triple-negative breast cancer HR-negative, which is often more aggressive and harder to treat, with low survival rates (Shimelis et al., 2018; TCR, 2020).

Across the United States, the number of African American women dying from breast cancer continues to increase, even as overall breast cancer mortality rates among Caucasian women decrease (Susan G. Komen [SGK], 2018). The mortality rate among African American women is roughly 40% higher than Caucasian women, with 29.2 deaths per 100,000 people reported for African American women and 20.6 deaths per 100,000 for Caucasian women (Richardson et al., 2016). Multiple factors contribute to the sustained increase in breast cancer death rates among African American women, including delays in follow-up, more aggressive and treatment-resistant types of breast cancer, late-stage diagnosis, treatment disparities, and institutional issues/system policies (Gehlert et al., 2021; Ray et al., 2018; SGK, 2018; Williams et al., 2016). Thus, it is essential to improve breast cancer outcomes for African Americans and address breast cancer disparities to decrease breast cancer mortality rates among this population (SGK, 2021b).

### **Breast Cancer Prevalence**

Breast cancer is most prevalent among women age 40 years and older (ACS, 2021). Researchers estimate approximately a quarter of a million women are diagnosed with breast cancer in the United States every year (White et al., 2020). The incidence rate of a woman in the United States to develop breast cancer during her life is about 12.8% (ACS, 2019). The prevalence of breast cancer can vary based on age and socioeconomic status (National Cancer Institute [NCI], 2020), often due to routine breast cancer screenings (CDC, 2020b). According to Yedjou et al. (2017), mortality rates are highest among African American, Hispanic, and Native American women compared to Caucasian women. The survival rate of African American women

is approximately 78% compared to Caucasian women at 90%. Also, rates for late-stage breast cancer are higher among African American women (8%) than Caucasian women (5%).

### **Breast Cancer Costs**

Cancer treatment is costly, both physically and financially. In the United States, cancer patients face higher health care costs than patients without cancer (Park & Look, 2019). Lung, breast, and colon cancer lead the country in cancer deaths (ACS, 2018). TCR (2018) published reports showed hospitalization costs for breast cancer in Texas increasing to over \$252 million over the last 5 years.

**Table 1**

*Age-Adjusted Annual Breast Cancer Hospitalization Discharges per 10,000 Women in Texas, All Ages, 2015*

| Demographics | Discharges | Age-adjusted discharge rate | 95% confidence interval |       |
|--------------|------------|-----------------------------|-------------------------|-------|
|              |            |                             | Lower                   | Upper |
| White        | 3,593      | 2.5                         | 2.4                     | 2.6   |
| Black        | 528        | 3.1                         | 3.1                     | 2.9   |
| Hispanic     | 746        | 1.7                         | 1.7                     | 1.6   |
| Other        | 209        | 2.5                         | 2.5                     | 2.1   |
| Total        | 3,593      | 2.5                         | 2.4                     | 2.6   |

*Note.* This table shows a high rate of African American women being hospitalized in Texas when compared to Caucasian women and Hispanic hospitalizations. The total cost of hospital charges was approximately \$252,493,925 (TCR, 2018).

### **Theoretical Foundation**

This study used a phenomenological approach to explore the lived experiences of African American women with breast cancer. The basis for employing phenomenology stemmed from the philosophical foundation and focused on individuals' reality and interconnectedness to social and cultural experiences (Hooker, 2015). The underpinning theoretical framework included

Kleinman's explanatory model of illness and critical race theory (CRT). The following section presents how both frameworks served to support the current research study.

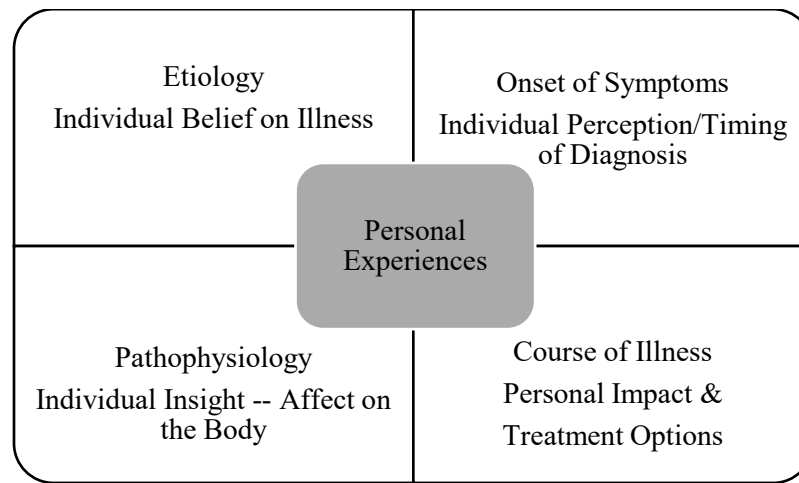
### **Kleinman's Explanatory Model**

The underpinning theoretical framework for this study was Kleinman's explanatory model of illness. The emergence of explanatory models during the 1970s allowed scholars to study medical experiences to differentiate a patient's disease from a patient's lived experiences with a particular illness (Laws, 2016). Kleinman et al. (1978) developed the explanatory model to provide a foundation for exploring patient experiences with health care access and patient satisfaction and provide clinicians with a cultural framework for treating patients. Kleinman's explanatory model of illness was developed to help health care providers recognize the social and cultural factors affecting patients and the impact these factors may have on treatment and recovery (Dinos et al., 2017). The use of Kleinman's explanatory model elicited robust feedback from African American breast cancer survivors, providing detailed accounts from their perspectives (see Ashcraft, 2013). The explanatory model is a culturally based way to investigate the participants' lived experiences with breast cancer.

Figure 1 shows the lived experience and personal observations based on individuals' perceptions of their illness. The constructs were useful to guide breast cancer survivor interviews, eliciting the women's perceptions of the five key elements of illness and analyzing how participants perceived their illness (see Laws, 2016). The interviews included questions specific to African American breast cancer survivors and their views of the disease, the onset of breast cancer symptoms, pathophysiology, the course and impact of breast cancer, and insight on the treatment options presented by their providers (see Kleinman & Benson, 2006).

**Figure 1**

*Kleinman's Explanatory Model of Illness: Individual Perceptions*



From “Culture, Illness, and Care: Clinical Lessons From Anthropologic and Cross-Cultural Research,” by A. Kleinman, L. Eisenberg, & B. Good, 1978, *Annals of Internal Medicine*, 88(2), 251–258. <https://doi.org/10.7326/0003-4819-88-2-251>

The hermeneutic phenomenological method to health education research was an appropriate design for this study. Wilson and Hutchinson (1991) offered a seminal method to Heidegger’s hermeneutic phenomenological approach, highlighting individuals’ medical experiences. The basis for employing phenomenology is its philosophical foundation and focus on individuals’ reality and interconnectedness to social and cultural experiences (Hooker, 2015). A phenomenological approach allowed the researcher to explore the associations among African American female breast cancer survivors and health care services (Gorichanaz, 2017). The phenomenological design provided a foundation for the researcher to uncover multiple aspects of the participants’ experiences and knowledge and learn from their interpretations (Neubauer et al., 2019).

## **Critical Race Theory**

Exploring African American women's experiences with breast cancer and medical health inequities occurred in line with CRT. Ladson-Billings presented CRT as a way to address the effects of race on educational disparities (Ford & Airhihenbuwa, 2018). CRT provides a systematic approach for scholars to understand and address racism in multiple areas of society. CRT underscored the exploration of breast cancer inequities and expanded the research outside of education (Cross, 2018). Moreover, the use of CRT in health education and promotion will assist public health researchers in examining long-standing public health policies. CRT epistemology stresses the experiential applications and is useful to examine the potential impact of race on health inequities within health care systems (Butler et al., 2018). In this study, CRT provided a framework to explore latent medical discrimination and organizational health disparities experienced by African American women when receiving breast cancer medical services (Ford & Airhihenbuwa, 2018; Ford & Jeffers, 2019).

## **Purpose of Study**

The purpose of this phenomenological study was to explore the lived experiences of female African American breast cancer survivors from breast cancer diagnosis through treatment. African American women diagnosed with breast cancer often face extensive and costly treatment options with meager survivor rates due to late-stage breast cancer (SGK, 2021b). Breast cancer health inequities, such as the unequal decline of breast cancer mortality nationally among African American women and Caucasian women (Newman & Kaljee, 2017), are of great personal interest to the researcher and were the impetus for this study.

Medical discrimination can include health care policies, practices, accessibility, and quality (Groos et al., 2018). Traditionally, the measurement of health outcomes is by individual

characteristics, with social constructs, individual experiences, and community aspects often neglected (Golden & Earp, 2012). Through the lens of CRT, the researcher investigated medical disparities among African American women ages 35 to 75 years to determine if medical discrimination contributed to breast cancer survivors' perceptions of health outcomes (see Quach et al., 2012).

### **Research Questions**

A phenomenological design was the approach used to address two research questions:

Research Question 1: What are the lived experiences of female African American breast cancer survivors specific to the perception of their illness from breast cancer diagnosis through treatment?

Research Question 2: What are the lived experiences of female African American breast cancer survivors specific to medical discrimination from breast cancer diagnosis through treatment?

### **Delimitations**

The delimitations for this study were as follows:

1. The interview participants were African American female breast cancer survivors ages 35 to 75 years who attended cancer support centers or participated in support groups or networks in Texas.
2. Participants must have received a breast cancer diagnosis of Stage 0 to Stage IV.
3. Participants must have identified as an African American female who was a breast cancer survivor in acute or extended survivorship and be between 6 months and 10 years postdiagnosis.

## **Limitations**

The limitations of this study were follows:

1. The findings of this study may not be transferable to all breast cancer survivors.
2. Data collection was from participant self-reports, which could be subject to recall bias, response bias, and social desirability.
3. Data collection occurred during the COVID-19 pandemic; thus, study outcomes could have been impacted by additional stressors.

## **Definition of Terms**

The following definitions of terms were appropriate for the purposes of this study.

*Breast cancer:* A form of diseased cells commonly displayed in grouping or mass within a woman's breast (ACS, 2019).

*Breast cancer acute survivorship:* Starts at diagnosis and lasts through the end of initial treatment. Cancer treatment is the focus (Cancer.net, 2019a).

*Breast cancer early detection and diagnostic screening:* The confirmation of breast cancer occurs through a series of screening tests by a physician. Tests can include mammograms, diagnostic mammograms, breast ultrasounds, magnetic resonance imaging, and biopsy (CDC, 2020c). In this study, the information provided by the participant will establish a diagnosis.

*Breast cancer extended survivorship:* Starts at the end of initial treatment and goes through the months following treatment. The effects of cancer and treatment are the focus (Cancer.net, 2019b).

*Breast cancer permanent survivorship:* Determined when years have passed since cancer treatment ended and there is a lower likelihood of cancer coming back. Long-term effects of cancer and treatment are the focus (Cancer.net, 2019b).

*Breast cancer stage:* Breast cancer staging indicates how far into the chest wall the cancer has spread. The stage varies based on the amount of cancer detected in the body (ACS, 2021a).

*Breast cancer Stage 0:* Ductal carcinoma in situ is noninvasive and there is no evidence of the cancer cells growing outside the detected area of the breast (Breast Cancer.org, 2020a).

*Breast cancer Stage I:* The cancer is affecting normal cells surrounding the breast tissue and involves multiple categories (Breast Cancer.org, 2020b).

*Breast cancer Stage II:* The breast cancer is generally invasive and involves multiple categories (Breast Cancer.org, 2020c).

*Breast cancer Stage III:* The next stage of invasive breast cancer that involves multiple categories (Breast Cancer.org, 2020d).

*Breast cancer Stage IV:* A diagnosis indicating cancer cells have spread outside the breast and lymph nodes to other areas in the body (ACS, 2021a).

*Health inequities:* Differences in health that are preventable and unnecessary, often considered discriminating and undeserved (SGK, 2021c).

*Lived experience:* An exploration of personal experiences and understanding from the perspectives of study participants (Laws, 2016).

*Medical discrimination:* Refers to institutions with historical inequities reinforcing policies and practices linked to outdated procedures that perpetuate poor health outcomes among African Americans (Bailey et al., 2017).

*Woman:* An individual of female/feminine gender (she/her/hers) between the ages of 35 and 75 years.

### **Importance of the Study**

Little is known about the personal experiences of African American women's survivors after primary treatment for breast cancer (Lindberg et al., 2015). Researchers have examined selected breast cancer topics, including exploring breast cancer mortality and disparities (Babatunde et al., 2020). However, qualitative research specifically focused on female African American breast cancer survivors' lived experiences from breast cancer diagnosis through treatment with the illness and the effect of medical services received is limited (Mullins et al., 2019). A robust depiction of female African American breast cancer lived experiences was necessary to inform the literature.

Through interviews with African American women diagnosed with breast cancer, the study provided an in-depth understanding of these experiences (see Campesino et al., 2012). This study contributed to health education practices and research. Additionally, the findings could provide clinical providers and health care organizations with knowledge to promote access to quality care and address practices that discriminate against African American breast cancer patients (White et al., 2020). Also, the findings indicated the importance of integrating health educators into interdisciplinary health care teams and educating clinicians on the increased disparities of medical discrimination among African American female breast cancer survivors (Quach et al., 2012). A review of historical factors related to medical discrimination will present the need for breast cancer treatment and potential associations between delayed services and breast cancer outcomes (Nelson & Kaminsky, 2020). Systemic change is necessary to increase breast cancer treatment services among African American women (Quach et al., 2012).

## CHAPTER II

### LITERATURE REVIEW

The purpose of this phenomenological study was to examine the lived experiences of female African American breast cancer survivors from breast cancer diagnosis through treatment. This chapter presents an overview of the literature showing the need to understand African American women's perspectives and lived experiences with breast cancer. There is a review of the research fundamental to African American women's breast cancer health outcomes. The six sections of the chapter are (a) breast cancer symptomatology, (b) breast cancer risk factors, (c) breast cancer screening, (d) breast cancer staging, (e) breast cancer and African American women, and (f) breast cancer inequities. CRT served as the framework to support the exploration of health inequities and gain knowledge through individuals having lived experiences with the phenomenon (Ford & Airhihenbuwa, 2010). In assessing the minimal research on the lived experiences of African American female breast cancer survivors, the researcher elicited perceptions from African American women of their experiences with breast cancer treatment and medical services (Campesino et al., 2012).

#### **Literature Search Strategy**

A systematic literature search began with Academic Search Complete, Access Medicine, APA PsycInfo, EBSCOhost Databases, Library of Medicine, Medline, Nursing & Allied Health Database, ProQuest, PubMed, Scopus, and the Texas Woman's University Health Sciences Librarian. Identifying relevant research meeting specific inclusion criteria entailed using the following keywords: *African American women, Black women, breast cancer, breast cancer screening, breast neoplasms, breast cancer mortality rates, cancer, late-stage diagnosis, survivorship, lived experiences, health care, minority health, race, racism, systemic racism,*

*medical discrimination, cultural race theory, Kleinman's explanatory model of illness, social determinants of health, health disparities, and health inequity, and phenomenology.* Additional sources of information were the websites of breast cancer-related agencies, including BreastCancer.org, Cancer.net, ACS, National Cancer Institute, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, Texas Department of Health and Human Services, TCR, National Breast Cancer Foundation, SGK, and National Coalition for Cancer Survivorship.

### **Inclusion Criteria and Exclusion Criteria**

The inclusion criteria for the literature review were (a) published in English; (b) published in peer-reviewed journals from 2003 (the year of the Institute of Medicine [IOM] report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*; IOM, 2003) through 2021; (c) full text; (d) focused on African American women with breast cancer; (e) qualitative approach to measure and/or improve lived experiences of African American women; and (f) discussions specific to perceptions of African American women with regard to health disparities, health inequities, and medical discrimination. Seminal works published before 2003 and supporting the study theories and providing foundational philosophies and concepts were essential to establish pioneering research. The exclusion criteria were (a) studies involving men with breast cancer, (b) articles not published in English, and (c) unpublished theses and dissertations.

### **Breast Cancer Symptomatology**

The ACS (2019) described breast cancer as cancer beginning in the breast. Breast cancer is most common among women, with men representing only 1% of diagnosed cases. Breast cancer most frequently starts in the milk glands of the breast as cells form together into an

uninhibited mass or lump. Breast cancer symptomatology is different for every woman. Breast cancer, like other diseases, is often unpredictable and lacks a clear indication that something is wrong. Often, women do not notice breast changes until consulting with their doctor (NCI, 2018). Warning signs include breast pain, swelling, dimpling, flakiness of the skin, discharge from the nipple, and change in the shape or size of the breast (CDC, 2020c). Further, the journey women take to a breast cancer diagnosis can be lengthy. Using data from a large national primary care database, Koo et al. (2017) identified the three most predominant signs for women with breast cancer as breast lumps, skin alterations on the breast, and breast ulcerations.

From 1990 to 2017, breast cancer occurrences increased by 123% worldwide (Li et al., 2019). Long-term predictions indicate there will be roughly two million new breast cancer diagnoses annually worldwide (Fred Hutch Breast Cancer Global Initiative, 2020). In the United States, one in eight women will receive a breast cancer diagnosis, and approximately 3% will die from it. In 2022, there will be more than 287,850 new cases of breast cancer diagnosed, with an estimated 51,400 dying from the disease (ACS, 2022; Siegel et al., 2021). Despite these alarming numbers, breast cancer mortality rates are declining; however, the decrease has not occurred equally (SGK, 2021a). Mortality rates for African American women in the United States are roughly 40% higher than Caucasian women (SGK, 2021c). The mortality rate disparity is related to aggressive cancers and late-stage diagnoses, often leading to extended treatment and poor survival rates among African American women (Williams et al., 2016).

### **Breast Cancer Risk Factors**

Despite multiple types of breast cancer, there are only two types of risk factors: modifiable and nonmodifiable. Modifiable risk factors impacting breast cancer are those that women can change, such as lack of physical activity, obesity, alcohol consumption, and hormone

therapy (CDC, 2020c). Nonmodifiable risk factors include gender, age, family history, generative history, dense breasts, and history of cancer-related diseases. Studies of breast cancer incidence rates from 1975 to 2017 showed African American women have a slightly higher risk of breast cancer incidence when calculated by age over the 40-year period compared to Caucasian women (NCI, 2021; SGK, 2021b). The average age for breast cancer among African American women is 58 compared to 68 among Caucasian women (Newman & Kaljee, 2017). Unfortunately, African American women are more likely to be diagnosed with aggressive forms of breast cancer at age 45 or younger and more likely to die from the disease (Churpek et al., 2015).

**Table 2**

*Age-Adjusted Surveillance, Epidemiology, and End Results Breast Cancer Incidence of Women, All Ages*

| Years of diagnosis | All races | Caucasian | African American |
|--------------------|-----------|-----------|------------------|
| 1975–2017          | 25.20     | 24.97     | 25.57            |

From *Age-Adjusted SEER Incidence Rates by Year, Race and Age*, by National Cancer Institute, 2021. [https://seer.cancer.gov/csr/1975\\_2017/](https://seer.cancer.gov/csr/1975_2017/)

As shown in Table 2, in a large national study, Shiyanbola et al. (2017) examined data from the breast cancer surveillance consortium and the collaborative breast cancer study for women with a family history of breast cancer from the 1980s to 2000. The study showed that women with a family history of breast cancer were roughly 13% more likely to be diagnosed with breast cancer than women with no family history. Interestingly, Shiyanbola et al. (2017) also noted an increase of 70% in the women reporting a family history of breast cancer during

this time frame. This growth overlaps with the increase of breast cancer mammography screenings from 1980 to 2000.

Dense breast tissue is another nonmodifiable risk factor, with women who have excessive connective tissue in the breast at a higher risk for breast cancer (CDC, 2020c). Approximately 43% of women in the United States have dense breast tissue (Kyanko et al., 2020). The risk factors for high breast density include race and ethnicity, genetics, reproductive history, environmental circumstances, and diet (Nazari & Mukherjee, 2018). Nazari and Mukherjee (2018) found that women with high breast density were twice as likely to develop breast cancer during their lifetime than women without dense tissue. On average, African American women have higher breast density than Caucasian women (Wright et al., 2019). The standard mammogram may not detect breast cancer in women with dense breasts, placing them at risk for late-stage diagnosis (Nazari & Mukherjee, 2018; Wright et al., 2019).

### **Breast Cancer Screening**

The three main screening methods for checking a woman's breast for cancer before becoming symptomatic are breast image screenings, clinical breast exams, and breast self-awareness exams (CDC, 2020a). A mammogram is one imaging technique used to X-ray a woman's breast; women with dense breasts often have an ultrasound as another means of prevention screening (ACS, 2021a). The detection of suspicious lumps is often through clinical breast examination. ACS recommends annual screening for women ages 45 to 54 and biennial screening for women age 55 and older (ACS, 2021). Women between 40 and 44 years could receive screening based on family history and breast cancer risk. Keating and Pace (2018) found a reduced risk of breast cancer for women aged 40 and younger than those 60 and older.

Striking differences exist in breast cancer incidence, prevalence, and mortality rates within racial and ethnic minority and low-income populations compared to the U.S. population as a whole. Trends in late-stage breast cancer incidence and mortality are highly indicative of the disparities. Although survival rates among African American women have increased, breast cancer mortality remains 40% higher for this population than Caucasian women (SGK, 2021a). As evidenced by the trends, early and frequent breast cancer prevention screening is vital for African American women to improve breast health outcomes (SGK, 2021b).

In 1990, the Breast and Cervical Cancer Mortality Prevention Act created the National Breast and Cervical Cancer Early Detection Program (NBCCEDP; CDC, 2020a). As authorized by Congress, NBCCEDP offers communities and clinicians a service delivery program to increase breast cancer knowledge and systematically expand breast cancer screening across the United States (Lee et al., 2014). NBCCEDP is a community-based program providing breast mammography screening, clinical diagnostics, and treatment to uninsured and underinsured women, thus removing barriers for women living below the poverty level (Myles et al., 2015). The program has increased mammography screening rates and decreased wait time between abnormal findings and diagnosis (White et al., 2020). The national program connects state cancer registries across the United States to breast and cervical cancer data, supporting reporting standards for breast cancer stage at diagnosis. The cancer registry statistics inform cancer treatment research and are vital predictors of breast cancer morbidity and persistence rates (CDC, 2020a). Further, the services have been influential among special populations, specifically states with high mortality among African American women, in reducing breast cancer screening barriers and providing breast health education services (White et al., 2020).

## **Breast Cancer Staging**

Following breast cancer screening and diagnosis, providers examine cancer cells to determine if they have spread or remain confined to the breast (NCI, 2020). Breast cancer survival is related to the staging and size of the tumor, lymph node status, and whether the cancer has spread to other parts of the body or metastasized (Breast Cancer.org, 2020). Doctors use the tumor, nodes, and metastases system of staging to determine the magnitude of the cancer and treatment recommendations (SGK, 2021a).

In 2018, there was a restructuring of breast cancer staging methods to be more inclusive of social determinants and geographic locations (Hortobagyi et al., 2018). Using large data sets from states with increased breast cancer mortality, researchers examined breast cancer staging according to age, race, income, and geographic location (Williams & Thompson, 2017). Williams and Thompson (2017) defined early-stage breast cancer as Stages 0, I, and II and late-stage breast cancer as Stages III and IV. Data analysis showed that African Americans had higher rates of late-stage breast cancer (39%) than Caucasian women (30%). The findings are significant and highlight the need for continuous inclusion of race in the staging process, particularly because the survival rate is substantially lower with advanced-stage diagnoses (SGK, 2021a).

## **Breast Cancer and African American Women**

Breast cancer disproportionately affects African American women. These women are among those most vulnerable to misdiagnosis, delayed services, and failed treatment due to inequities in health care systems (Nelson & Kaminsky, 2020; SGK, 2018). For example, Nelson and Kaminsky (2020) showed how structural racism can lead to African Americans experiencing medical inequities based on how health systems operate. Noonan et al. (2016) highlighted breast

cancer disparities among African American women, demonstrating that misdiagnosis can lead to treatment delays and insufficient medical care.

Racism and discrimination are not health problems by themselves, but rather contribute to and exacerbate health problems of African American women living in the United States (Noonan et al., 2016). Historically, African Americans achieve poor health outcomes based on discrimination related to health care services (Castle et al., 2018). Clayton et al. (2014) predicted that by 2050, the majority of women in the United States would be women of color. Racism and discrimination against women of color affect patient–doctor communication and African American women’s perception of health care provider response to health issues during clinical visits. Perceived racism and medical discrimination often lead women to skip primary care treatment and routine health care screenings (Nelson & Kaminsky, 2020). Minorities may also forgo treatment for chronic diseases, such as diabetes and hypertension, due to medical mistrust and perceptions of their primary care provider (Arnett et al., 2016). Often, minority women in the United States decline early detection screenings for breast, cervical, and colorectal cancer (Adams et al., 2017).

Perceptions of racism and discrimination could increase late-stage breast cancer diagnosis and increase mortality rates among African American women (Sutton et al., 2019). The emotional impact of medical discrimination and the stress-related risk factors affecting African American women’s health outcomes indicate a gap in the research associated with medical discrimination and the role of systemic racism (Nelson & Kaminsky, 2020). The institutional conditions of intentional or unintentional system policies and practices that perpetuate medical discrimination among African American women seeking breast cancer treatment services require a deeper exploration of the lived experiences told by African American women.

Health care inequalities present a momentous threat to African American women battling breast cancer (e.g., Nelson & Kaminsky, 2020; Williams & Thompson, 2017; Yedjou et al., 2017). For example, African American women in low-income neighborhoods who rely on Medicaid and Medicare most often live in medically underserved areas with minimal breast imaging services. Women living in these clusters typically end up in the emergency department when they find a lump, subsequently returning to communities with no social supports to help them navigate breast care.

Declining breast cancer mortality rates are not equal across race and ethnicity (SGK, 2018). African American women experience increased breast cancer mortality compared to Caucasian women (NCI, 2021). African American women also receive more breast cancer diagnoses before the age of 40 (SGK, 2021b). Factors associated with higher mortality rates among African American women are related to more aggressive and invasive tumors diagnosed at a later stage (Daly & Olopade, 2015). Low-income African American women living in urban areas may experience even more disparity depending on their neighborhood and access to health care services (Mishra et al., 2012). The imbalance of breast cancer mortality rates among African American women who live in poverty and have limited access to health care resources is further influenced by health disparities that significantly impact a woman's breast health outcomes (Karimi et al., 2018).

### **Breast Cancer Health Inequities**

Health inequities are differences in health that are unjust or most often avoidable (SGK, 2021c). Researchers from Texas performed a detailed review of breast cancer mortality based on geographical location, race, and ethnic group to determine the impact of the environment on breast cancer mortality rates (Pruitt et al., 2015). Using data from the TCR, Pruitt et al. (2015)

conducted an in-depth assessment of Texas neighborhoods concentrated on women living in urban areas. The researchers evaluated breast cancer patients from 1995 to 2009. Their study aligned with *the Unequal Treatment, Confronting Racial and Ethnic Disparities in Health Care* report released by IOM in 2003. The report showed remarkable differences in health care services across a wide range of illnesses, leading public health leaders to actively address health disparities and researchers to address breast cancer disparities impacting African American women. According to the seminal report, African American women with breast cancer were less likely to receive treatment, such as therapy recovery services, after mastectomy.

Pruitt et al. (2015) examined potential links between health disparities in breast cancer related to residential Texas neighborhoods among African American, Hispanic, and Caucasian women. Pruitt et al. defined racial segregation as the distance related to groups living separately from other groups, which can cause racial disparities. The authors also discussed the influence of early prevention and breast health awareness on health care service delivery. The findings indicated that Texas's health disparities were related to segregation and residential location. Further, the effects of segregation operate at the individual level, limiting access to health care, and at the community level, affecting exposure to environmental conditions and behaviors that could contribute to poor breast health outcomes.

### ***Health Care and Health***

Access to quality health care services is essential to African American women seeking breast cancer prevention and screening (SGK, 2018). The rate of uninsured African Americans in 2019 was roughly 15% compared to 11% Caucasian Americans (CDC, 2020b). Economic stability drivers impact access to quality care, including affordable insurance and a patient's ability to pay for coverage (Artiga & Hinton, 2018). For example, patients who are unemployed

or rely on Medicaid and Medicare might be unable to participate in timely cancer prevention screenings (Karimi et al., 2018). Health care delivery is essential to alleviating barriers to breast health services for African American women (SGK, 2018). The methods of information delivery can be crucial to a patient's health outcomes. Using community health workers or lay health educators to disseminate information assists in supporting patients' health care access needs and connecting with ancillary services (Page-Reeves et al., 2016).

Access to technology has become extremely important to health care services. The recent COVID-19 pandemic closed medical facilities, minimized inpatient care visits, and limited access to emergency departments (CDC, 2020a). Telehealth is one way for physicians to deliver quality patient care when in-person services are not readily available. However, if patients do not have access to reliable technology, telehealth, and other online health care services, they could be at risk for poor health outcomes (CDC, 2020b).

### ***Social and Community Context***

Support systems are an important part of patient care and can minimize health inequities within the health care system (Wallace, 2015). Support systems for breast cancer services include assistance with transportation, access to timely prevention screenings, or removing administrative barriers within clinical settings that could impede participation in vital breast cancer screenings (Mishra et al., 2012). Restrictive identification policies pose barriers to prevention services and crucial health care resources (LeBrón et al., 2018). One example of the detrimental effects of these policies is the water crisis in Flint, Michigan. Flint had lead contamination in the public water supply (Ruckart et al., 2019). During the initial phase of the crisis, residents had to show identification to receive government-issued bottled water (LeBrón et al., 2018). Restrictive policies such as this affect those most at-risk for adverse health outcomes

(SGK, 2021c). Individuals impacted in Flint included older adults, homeless individuals, and undocumented immigrants (LeBrón et al., 2018).

Similar systemic issues are barriers for African American women seeking breast cancer services (SGK, 2018). For example, population age standardization for breast cancer preventive care can perpetuate health inequities, as these endorsements are not a clear-cut measure to assess racial differences for the disease (Williams et al., 2016). Additionally, these types of population strategies can lead to underrepresentation in breast cancer mortality and increased breast health inequity for African American women. Addressing the lack of trust in health care systems and solutions requires health care systems to overhaul processes, policies, and institutional customs (CDC, 2020b). Health care systems should perform organizational assessments to evaluate effectiveness. They should also employ performance management tools to explore the root causes of systemic issues that impede sufficient resolution of health inequities.

### ***Built Environment***

An African American woman's built environment, or neighborhood, should not determine her access to breast cancer services (Karimi et al., 2018). Access to quality health care often has a direct impact on health, which, in turn, affects the increasing rate of African American women dying of breast cancer, even as overall death rates for women of other racial and ethnic groups decrease (SGK, 2018). African American women are among those at higher risk of developing breast cancer early (Babatunde et al., 2020), often diagnosed before age 40. SGK and other breast cancer organizations have advocated for African American women to receive breast exams before age 40 and have led the way in covering the cost for symptomatic women (SGK, 2018). In addition, African American women are often diagnosed at a later stage of breast cancer, which causes a financial burden and increases a woman's risk of dying from the

disease. Breast cancer screenings, early detection, and prevention improve population health by protecting a woman's quality of life and reducing mortality. Establishing communities with access to culturally appropriate medical services within their environment is essential to developing routine breast cancer practices (CDC, 2019).

### **Theoretical Frameworks**

A phenomenology approach guided this qualitative study, with Kleinman's explanatory model of illness providing a framework for the interview process. Also underpinning the foundation for the study was CRT, which served as a pathway to review medical discrimination as a potential result of systemic racism. This section provides an overview of Kleinman's explanatory model of illness and CRT.

#### **Kleinman's Explanatory Model of Illness**

Seminal work by Kleinman indicates the need to discontinue the model of "contemporary medical practice" and move to a modern health care design, allowing for nontraditional patient care methods and the exploration of how patients experience illness (Kleinman et al., 1978). The foundational work shows how clinicians might reimagine medical treatment as a dichotomy, linking clinical treatment, and patient-identified resources, such as family, religion, social support groups, and alternative treatments, to treat illness. Kleinman's model incorporates five topics: (a) etiology, (b) onset of symptoms, (c) pathophysiology, (d) course of illness/severity of prognosis, and (e) treatment. These components allow for the explanation of patients' perceptions, beliefs, and social ideologies.

In a study analyzing explanatory models of health and disease among Asian migrants in Chicago, Tirodkar et al. (2011) found the individuals' beliefs about health and well-being focused on spiritual aspects. When settlers relocated to urban Chicago, their care remained

rooted in the rural holistic approach, including diet and traditional practices to treat health and disease. In interviews with African American males, Ashcraft (2013) found the teens, when asked about their obesity, referred to their weight as “okay,” having no real relationship to who they were. Ashcraft shared how the teens’ explanations of their weight differed from mainstream views of slenderness as attractive, citing the African American culture’s different views of body size and social approvals. Gunn et al. (2019) used the explanatory model to assess breast cancer risk among women. Clinicians interviewed 30 women from varying racial and ethnic backgrounds and socioeconomic levels to assess perceptions of developing breast cancer. Gunn et al. worked with medical centers and academic medical groups in the United States affiliated with public health research and cancer outcomes. These studies indicate how Kleinman’s explanatory model allows public health researchers and clinical professionals to assess aspects of patients’ lives beyond their illness (Dinos et al., 2017). Overall, findings provided researchers insight on the social contrast between how the women manifested their risk compared to their actual risk of contracting breast cancer (Gunn et al., 2019). The model enables health care professionals to see the illness from the patient’s perspective and the holistic impact of the disease (Hsieh et al., 2016).

### **Critical Race Theory**

Public health research on CRT and the impact of racism on African Americans’ health outcomes is vital to reducing health disparities (Ford & Jeffers, 2019). CRT provides social behavior researchers with tools to confront racism and the systematic reinforcements used in health care organizations for decades (Freeman et al., 2017). CRT interventions are resources to measure racial disparities facing African Americans and Latino Americans using qualitative and quantitative research (Thomas et al., 2011). Seminal reports, focused on Black and minority

health released in 1985 by the U.S. Department of Health and Human Services, provide guidance to close the disparity gap (Thomas et al., 2011). A review of seminal reports is important to understand the generational challenges faced by African Americans, leading to increased mortality rates from cancer, heart disease, and other chronic diseases. The report led to funding for the Office of Minority Health and informed the focus of social determinants on health outcomes for all Americans (Thomas et al., 2011).

The IOM (2003) report showed how racism influences health services and impacts health treatment. Unfortunately, inequities revealed in the 2003 report remain within the health care systems (Wasserman et al., 2019). Public health experts have attempted to address the tremendous implications of medical discrimination (Smedley, 2012). CRT provides a structure for ongoing public health issues of systemic racism affecting health outcomes (Ford & Airhihenbuwa, 2018). The scope of CRT also supports broader factors detrimental to health outcomes, which include inequities in housing, jobs, and criminalization (Cross, 2018).

During spring 2014, local city officials transferred the Flint, Michigan water supply from Detroit to the Flint River (Masten et al., 2016). This switch proved to be incredibly damaging to the predominantly young and African American residents, as lead from the old Flint River pipes poisoned the water supply (Muhammad et al., 2018; Ruckart et al., 2019). The water crisis in Flint showed the impact of health inequities and how CRT can inform research. Muhammad et al. (2018) allowed Flint youth to reflect on city leaders' irresponsibility and provide their perspectives on the event and their future due to the catastrophe. The findings showed the lack of trust in public leaders to properly address and make amends for the water issues. Participants also expressed feelings of intentional sabotage of the city's water system because the community was majority African American and poor (Day et al., 2019). Overall, researchers were able to use

the fundamental methodology of CRT to support the youth's lived experiences and capture their insights of perceived discrimination based on experienced ecological stressors (Muhammad et al., 2018). Day et al. (2019) presented a systemic view of city officials' unconscious behaviors to disregard the lives of African Americans in the area based on past practices of open racism observed by city officials.

### **Summary**

Chapter 2 presented a review of the literature pertinent to the proposed study. Health care disparity is a national problem for African American women affected by breast cancer (Nelson & Kaminsky, 2020). African American women are among those most vulnerable to receive a breast cancer misdiagnosis, delayed services, and failed treatment due to inequities in health care systems (SGK, 2018). There are multiple barriers to accessing quality care, including geographical location and health insurance, which federal reports have documented for over 25 years (Smedley, 2012; Thomas et al., 2011). As such, there is an overwhelming need to address the disparate breast cancer mortality rates of African American women (SGK, 2021b). National organizations, including SGK, ACS, NBCCEDP, and many more, are committed to decreasing breast cancer mortality rates for African American women. However, it is necessary to address late-stage breast cancer diagnosis and subsequent adverse health outcomes, including mortality rates, among African American women in the United States (SGK, 2018). The abundance of breast health programs and collaborations currently informing African American women's health is noteworthy. Nevertheless, none have been successful in eliminating breast cancer health inequities related to systemic racism.

Based on the research review, no previous investigative scholars have applied Kleinman's explanatory model, phenomenology, and CRT to study medical discrimination

experienced by African American women and breast cancer. Understanding medical discrimination and using findings to treat breast cancer inequities are essential for addressing ongoing health outcomes that will continue to impede improvement in breast health consequences for African American women (Wallace, 2015). Addressing breast cancer disparities is challenging. As such, the present study focused on the lived experiences of African American breast cancer survivors. The study provided a platform to explore their beliefs about the disease and viewpoints surrounding medical discrimination, which affected access to care, breast cancer services, or treatment.

## CHAPTER III

### METHODOLOGY

The purpose of this phenomenological study was to examine the lived experiences of female African American breast cancer survivors from breast cancer diagnosis through treatment. There are striking differences in breast cancer incidence, prevalence, and mortality among racial and ethnic minorities compared to the U.S. population as a whole (CDC, 2020b). Trends in breast cancer incidence, late-stage breast cancer diagnosis, and differential access to health care services are indicative of the disparities (Yedjou et al., 2017). For example, in their exploration of racial disparities in breast cancer in the United States from 2010 to 2014, Richardson et al. (2016) found that breast cancer mortality rates among African American women were 41% higher than Caucasian women.

This trend continues at the state level, with Texas reporting similar disparities among African American women. The mortality rate of African American women remains high, even as screening mammography services increased to approximately 80% among African American women from 2012 to 2016 in Texas (TCR, 2020). African American women living in Texas urban areas with the highest density of racial/ethnic minorities continue to experience these disparities (Bambhroliya et al., 2012). These clusters of higher-than-average breast cancer death rates also show variances in the type of breast cancer treatment received compared to women residing outside these high-density clusters (Thomas et al., 2019).

#### **Research Design**

This study used a qualitative phenomenological approach to answer the research questions. Phenomenology is a traditional approach and provides a view of the world as individuals perceive it. The theoretical origins for phenomenology with expressive roots stem

from the philosophical roots of Husserl. The development of hermeneutic phenomenology, also known as interpretive or explanatory phenomenology, was based on the work of Heidegger and has been used by researchers (e.g., Neubauer et al., 2019) to explore lived experiences and capture public health issues within health professions. Hermeneutic phenomenology is a philosophy of being and offers participants an opportunity to dialogue conversationally and be an active part of the research process (Lauterbach, 2018). Hooker (2015) acknowledged the empathy inherent in phenomenology hermeneutics, recognizing compassion as a necessary element in health education research.

The researcher sought to understand how female African American breast cancer survivors perceive their experiences guided by the theoretical framework of Kleinman's explanatory model of illness while using CRT to evaluate medical discrimination. Kleinman's explanatory model of illness was appropriate to elicit robust feedback from participants about their breast cancer diagnosis, providing firsthand accounts of their experiences. Kleinman's theory suggested that the participants' experiences would be diverse and their conceptions of breast cancer and understanding of health care services related to their disease vastly different based on their unique social and cultural backgrounds (Tirodkar et al., 2011). A phenomenological design enabled a deeper dive into the lived experiences and explanations of the events African American women perceive as the causes of their illness, the health care services they received, and their individualized and phenomenological life experiences. This study's findings may be useful in improving awareness among health educators, physicians, and other medical providers (Neubauer et al., 2019).

## **Epistemology**

The process of qualitative analysis is to provide a connection for researchers to explore and examine phenomena with structure and guidance (Tracy, 2010). Epistemology provides qualitative researchers with foundationalist influences, such as rigor and data transformation (Burns et al., 2018; Tracy, 2010). Epistemology allows a scholar to synthesize the research questions with the facts and human aspects of the research (Burns et al., 2018). The epistemological approach was appropriate to explore the perceptions of African American female breast cancer survivors and their experiences with medical discrimination. A qualitative design was the means to explore the perceptions of African American female breast cancer survivors and their experiences with medical discrimination.

## **Participants**

There were 16 African American female breast cancer survivors who took part in semi-structured interviews for the study. Participants were recruited and interviews conducted until achieving data saturation. Participant selection occurred via purposive sampling procedures and snowballing (see Bonsu & Ncama, 2019; Woodley & Lockard, 2016) based on various inclusion and exclusion criteria to confirm that study participants were adults who met the stated delimitations. The inclusion criteria for this study were African American women 35 to 75 years of age who lived in Texas, spoke English, had a diagnosis of breast cancer detected from Stage 0 to Stage IV, and were in the acute to permanent survivorship stage between 6 months and 3 years postdiagnosis. Exclusion criteria included African American female breast cancer survivors and who lived outside the state of Texas.

The participant recruitment was through nonprofit breast cancer organizations that support breast cancer patients and survivors and provide services for patrons across Texas (i.e.,

Bridge Breast and SGK. After receiving Institutional Review Board (IRB) approval (see Appendix C), the researcher initially contacted representatives of nonprofit organizations in the state, asking them to share information about the study with the African American female breast cancer survivors their organization serves.

The participants' for this research were 16 women who met the study criteria of being African American women aged 35 to 75 years who lived in Texas, had received a diagnosis of breast cancer detected from Stage 0 to Stage IV, and were in a survivorship stage for between 6 months and 10 years postdiagnosis. To confirm race and ethnicity participants were asked to identify their race and ethnicity. In addition to asking the city of residence, the demographic survey also included zip code to confirm participants location in Texas. A complete analysis of participants' demographics is included in Appendix D presents an overview of the participants demographic survey data. The interviews occurred via video conferencing or face-to-face at a convenient location in compliance with the CDC's COVID-19 protocols.

The biographical information collected from the interview data on each participant provided insight into the lives of breast cancer survivors, including age, age at diagnosis, stage of breast cancer, type of breast cancer, the treatment chosen, current treatment, survivorship status, employment status, income, insurance status, and level of education. Participants' descriptions of the characteristics of their breast cancer survivorship provided insight into their lives. All 16 women completed the demographic survey, providing categorical data on age, geographical location in the state, race, highest level of education completed, employment status, insurance status, and income.

Participants' median age was 54 years, with most women resided in North Texas. All 16 women who participated in the study identified as African American. Approximately 25% of the

participants ( $n = 4$ ) lived in Fort Worth, 16% ( $n = 3$ ) lived in Arlington, and 13% ( $n = 2$ ) lived in Dallas. The remaining 7 participants (44%) lived in various communities throughout Texas. Most participants (38%;  $n = 6$ ) reported having earned a master's degree, 25% ( $n = 4$ ) reported having earned a bachelor's degree, 32% ( $n = 5$ ) indicated having completed some college studies, and 7% ( $n = 1$ ) reported high school education as their highest education earned. Among participants employed for wages, most (75%;  $n = 12$ ) reported annual earnings of \$50,000 to \$100,000. The remaining participants (25%;  $n = 4$ ) reported incomes of \$50,000 or less. Insurance and health plan information reported by participants documented that 75% ( $n = 12$ ) had employer-based on private insurance, 13% ( $n = 2$ ) had Medicare or Medicaid, and 13% ( $n = 2$ ) had no insurance. Descriptive summaries for each of the participants are presented hereafter to provide context to the research.

Survivor 1 Janna, age 51, participated in annual mammograms. Janna found her breast cancer during her yearly breast cancer exam, "I started participating in annual mammograms at the age of 40, and that is how I found my lump." Janna was diagnosed in November 2019 with Stage 0 estrogen-receptive positive breast cancer at age 49. The first person she told about her breast cancer was her husband. Janna's treatment included a mastectomy of the right breast. Janna reported having a master's degree and earning approximately \$100,000 a year. Janna reported having employer-based insurance from diagnosis through treatment, which covered most of her treatment costs. Janna is in extended breast cancer survivorship.

Survivor 2 Donna, age 44, had never had a mammogram prior to her breast cancer diagnosis. She found her breast cancer during a self-breast exam sharing, "I had done self-breast exams since my early twenties. I had a friend who died from breast cancer." In February 2020, Donna was diagnosed with Stage II, HER2-positive breast cancer (triple positive) breast cancer

at age 43 during the early start of the COVID-19 pandemic. The first person she told about her breast cancer was her co-worker. Donna's treatment included six rounds of chemotherapy followed by a lumpectomy, which included removing 13 cancerous lymph nodes, and 33 rounds of radiation post-surgery. After radiation, Donna had an additional surgery in January 2021 to remove her uterus, ovaries, and cervix in efforts to decrease her estrogen levels. Due to COVID-19 protocols, no family members could visit the hospital or accompany her to treatment. Donna also attended rehabilitation alone in May and June 2021, receiving immunotherapy during her rehabilitation treatment. Donna reported earning a bachelor's degree and approximately \$50,000 a year. Donna had employer-based insurance throughout her breast cancer journey, from diagnosis to treatment. However, insurance did not cover all of her surgeries and treatment. As a result, Donna's supporters started a GoFundMe page and raised \$10,000 to assist with her medical bills. At the time of the interview, Donna was awaiting additional surgeries. Donna is in acute breast cancer survivorship.

Survivor 3 Lee, age 73, had never had a mammogram before her diagnosis and found her lump herself, "I was just so scared because I had felt that knot in my breast, and I was scared, and I just... I kept crying, and I just kept believing that it was gonna leave." Lee was diagnosed in May 2018 at age 70 with Stage III triple-negative breast cancer, which doctors said "was almost Stage IV." The first person she told about her breast cancer was her best friend. Lee's treatment included six rounds of chemotherapy, radiation, and a mastectomy, which included the removal of several lymph nodes. Lee reported earning a high school diploma and being retired, with an annual income of about \$10,000 a year. She had Medicaid for insurance during diagnosis and throughout her treatment. Lee did not have enough insurance to cover her treatment and surgery

costs. Lee reported that her family was assisting with her medical bills. Lee is in extended breast cancer survivorship.

Survivor 4 Kora, age 48, had never had a mammogram before her diagnosis and found the lump during a self-breast exam, “I have always done self-breast exams, I had just turned 40, so I did a mammogram.” Kora was diagnosed with Stage III triple-negative breast cancer in September 2013 at age 40. The first person she told about her breast cancer was her supervisor at work. Kora’s treatment included surgery (a mastectomy) followed by chemotherapy and radiation. Kora reported having earned a master’s degree and was employed with an annual salary of approximately \$50,000 a year. Kora had employer-based insurance from diagnosis through treatment, which covered most of her treatment costs. Kora is in permanent breast cancer survivorship.

Survivor 5 Marlene, age 54, participated in annual mammograms; however, Marlene found her lump during her monthly self-breast exam, “I had my mammogram, I keep it around my birthday, which is in October, and I had my mammogram in October. I found the lump around March.” Marlene was 44 years old when she was diagnosed with Stage II estrogen-positive breast cancer. The first person she told was her mother. Marlene received a lumpectomy, followed by chemotherapy and radiation. Marlene reported having earned a bachelor’s degree and an annual salary of approximately \$50,000. Marlen had employer-based insurance from diagnosis through treatment, which covered most of her treatment costs. Marlene is in permanent breast cancer survivorship.

Survivor 6 Toni, age 65, participated in annual mammograms and has been diagnosed with breast cancer twice. Toni was first diagnosed with breast cancer in her 40s and found the lump by breast self-examination. In 2011, at age 55, she was diagnosed with breast cancer a

second time during a routine breast cancer exam. Toni, based on her previous diagnosis, did not receive a specific stage with the second diagnosis though her breast cancer was reported as triple-negative (i.e., estrogen, progesterone, and HER-2 negative). The first person she told about her breast cancer was her husband. Toni's treatment included a double mastectomy, the removal of 12 lymph nodes, chemotherapy, radiation, and reconstructive surgery. Toni reported having earned a master's degree, being retired, and making approximately \$100,000 a year. Toni had employer-based insurance from diagnosis through treatment, which covered most of her treatment costs. Toni is in permanent breast cancer survivorship.

Survivor 7 Aden, age 54, participated in annual mammograms due to a breast issue as a child, "When I was 11, I had extremely dense breast and had a big lump (benign) removed from my right chest and began participating in yearly mammograms the age of 12." Aden, because of her dense breast tissue required a series of two mammograms to confirm her breast cancer (October of 2018 and January 2019). Aden was diagnosed in 2019, at age 52, with Stage II aggressive HER2-positive breast cancer in both breasts with spread/invasion into several lymph nodes in her underarm. The first person she told about her breast cancer was her husband. Aden's treatment included chemotherapy and radiation followed by a double mastectomy, with additional chemotherapy after the mastectomy. Aden reported having a bachelor's degree but has lost her job and was unemployed at the time of the interview. Aden reported earning approximately \$20,000 a year. Aden had employer-based insurance from diagnosis through treatment, with minimal expenses covered by insurance. She reported making monthly payments for her medicine and surgery expenses. At the time of the interview, Aden was awaiting additional surgery (COVID-19-related delay). Aden is in acute breast cancer survivorship.

Survivor 8 Edith, age 75, reported receiving in annual mammograms and found her breast cancer during a yearly breast exam. Edith was diagnosed with Stage I, triple-negative breast cancer in October 2016 at the age 70. The first people she told about her breast cancer were her daughters. Edith's treatment included a mastectomy of the right breast with lymph nodes removed, followed by chemotherapy. Edith reported having earned a bachelor's degree and being in retirement at the time of the interview. She reported earning approximately \$30,000 a year. Edith had Medicare, AARP, and Aflac throughout her breast cancer journey, from diagnosis through treatment. Her insurance plans covered all her treatment and surgery. Edith is in extended breast cancer survivorship.

Survivor 9 Cinthia, age 57, participated in annual mammograms and began routine mammograms early in adulthood, "Because my mother had been diagnosed with breast cancer at 36, I began getting mammograms very early." In 2019, Cinthia was diagnosed with Stage I triple-negative breast cancer, which was found during her early breast exam. The first person she told was her husband. Cinthia's treatment included a double mastectomy, lymph nodes removal, and chemotherapy. Cinthia held a bachelor's degree and earned approximately \$100,000 a year. Cinthia had employer-based insurance from diagnosis through treatment, which covered her treatment cost. Cinthia is in acute breast cancer survivorship.

Survivor 10 Sherry, age 60, participated in annual mammograms but reported finding her breast lump just before her yearly mammogram appointment, "My mother had died from breast cancer, so I get my mammogram religiously." Sherry, who is BRCA negative, was diagnosed in January 2013 with Stage I, estrogen-receptive positive breast cancer at age 52. The first person she told about her breast cancer was her sister. Sherry's treatment included a lumpectomy followed by radiation. Sherry had completed some college studies and earned approximately

\$50,000 a year. Sherry had employer-based insurance from diagnosis through treatment. Sherry's insurance did not cover all of her medical expenses, which required her to make copays and pay out-of-pocket for some medical expenses. She is in permanent breast cancer survivorship.

Survivor 11 Tamal, age 40, had never had a mammogram prior to her diagnosis. Tamal reported finding her lump by accident, "It was over a span of a couple of weeks I actually noticed a lump. I went to work and showed my co-work, and she said, 'you need to go to the doctor.'" Tamal was diagnosed in September of 2018 with Stage II estrogen-receptive positive breast cancer at age 37. The first person she told about her breast cancer was her co-worker. Tamal's treatment involved chemotherapy followed by a double mastectomy. Tamal reported having completed some college studies, being employed, and earning approximately \$40,000 a year. She had employer-based insurance from diagnosis through treatment. Unfortunately, her insurance did not cover all of her treatment. At the time of the interview, Tamal reported making payments on her treatments and out-of-pocket costs. Tamal is in extended breast cancer survivorship.

Survivor 12 Dafne, age 39, had never had a mammogram and found her breast cancer shortly after giving birth to her son, "I was having problems with my breast after I finished breastfeeding my son, so my OB-GYN ordered a mammogram." Dafne spent 7 months waiting for her insurance company to approve a mammogram because of her age. In August 2015, at age 33, Dafne was diagnosed with Stage I estrogen-receptive positive breast cancer. The first person she told about her breast cancer was her mother. Dafne's treatment included a lumpectomy followed by radiation. Dafne reported holding a master's degree, being employed and earning approximately \$100,000 a year. Dafne had employer-based insurance, from diagnosis through

treatment, which covered most of her treatment costs. Dafne is in extended breast cancer survivorship.

Survivor 13 Jewel, age 56, participated in annual mammograms and found her breast cancer during her yearly mammogram, “I have always gotten a mammogram, my mother had breast cancer, and I have family members that have suffered from different forms of cancer. I believe it is in my DNA.” Though Jewel indicated her felt that breast cancer was “in her DNA” she had not, and did not plan to get BRCA testing. Jewel was diagnosed in 2017, at age 52, with Stage II estrogen-receptive positive breast cancer. The first person she told about her breast cancer was her sister. Jewel’s treatment included a mastectomy of the right breast and chemotherapy. Jewel reported having completed some college studies, being unemployed at the time of the interview, and earning approximately \$20,000 a year. She had employer-based insurance from diagnosis through treatment, which covered part of her treatment cost. Jewel reported being responsible for copays and out-of-pocket charges. At the time of the interview, Jewel did not have health insurance. Jewel is in extended breast cancer survivorship.

Survivor 14 Naye, age 50, participated in annual mammograms and found her breast cancer during her yearly mammogram,

I was at home with my daughter during COVID. She was virtual learning at home. It wasn’t a bad time, and we had groceries, we had toilet paper, paper towels. We were stocked up and decided to go ahead with my annual appointments.

Naye was diagnosed in October 2020, at age 49, with Stage I, estrogen-receptive positive breast cancer. The first person she told about her breast cancer was her sister. Naye’s treatment included a double mastectomy. At the time of the interview Naye reported COVID-19-related delays in her having her post-mastectomy reconstructive surgery. Naye held a master’s degree,

was employed, and earned approximately \$75,000 a year. She had employer-based insurance throughout her breast cancer, from diagnosis through treatment, though it did not cover all of her surgeries and treatment expenses. Naye was responsible for copays and out-of-pocket costs. Naye is in acute breast cancer survivorship.

Survivor 15 Leah, age 52, participated in annual mammograms and found her breast cancer during her yearly mammogram, “My mother is a survivor, we’ve had genetic testing, and it is not genetics. We had other females on my mom’s side of the family that had been diagnosed, one deceased at the age of 48, I believe.” Leah was diagnosed in November 2017, at age 48, with Stage II estrogen-receptive positive breast cancer. The first person she told about her breast cancer was her mother. Leah’s treatment included a mastectomy of the right breast, lymph nodes removal, and chemotherapy. Leah held a bachelor’s degree and earned approximately \$30,000 a year. Leah had employer-paid insurance from diagnosis through treatment. Leah’s insurance initially covered most of her treatment and surgery costs; however, her employer changed plans during her treatment requiring Leah to pay for copays and more out-of-pocket costs. Leah is in extended breast cancer survivorship.

Survivor 16 LeVale, age 46, participated in annual mammograms but found her breast doing a breast self-exam, “I had my yearly exam earlier in the year and was at home watching TV, and my hand brushed up against my breast, and I thought—Hmm. Wonder what that is?” LeVale was diagnosed in December 2018, at age 44, with Stage II triple-negative breast cancer. The first person she told was her husband. LeVale’s treatment included chemotherapy followed by a double mastectomy. She reported having completed some college studies and earning approximately \$100,000 a year. LeVale had employer-based insurance from diagnosis through

treatment, which covered all her treatment costs. LeVale is in extended breast cancer survivorship.

### **Data Collection**

The researcher used primary data collected through semi-structured, one-on-one interviews that were 60- to 120-minutes in duration (see Appendix A). Before the interviews, the researcher obtained informed consent and asked the participants to complete a demographic survey (see Appendix B) to indicate social determinants, such as household income, insurance status, education level, employment, and zip code to validate city location within Texas.

Interview settings were face-to-face or via Zoom video conferencing to accommodate the participants due to the COVID-19 pandemic and CDC protocols. The interview dates and times were scheduled at the participant's convenience during 4- to 6-week period. The researcher scheduled a private meeting for each interview, with the link and password emailed to the participant. For additional security, each Zoom meeting had a waiting room and the screen sharing function was disabled. Recordings of the Zoom audio only were saved to the researcher's computer (not the cloud) and imported into NVivo for analysis; audio files were deleted immediately after completing research analysis and transcription. The researcher advised participants of the audio recording for the purpose of accuracy in data collection.

### **Interviews with Breast Cancer Survivors**

During the interviews, the women received encouragement to talk freely and share their stories and experiences. Open-ended questions assisted participants in telling their stories. When necessary, probing questions were used and allowed the researcher to obtain deeper meaning and clarification. The participants were to inform the researcher if they felt upset or uncomfortable and wished to discontinue the interview. All interview audio recordings were password protected

and transcribed verbatim. The transcripts showed pseudonyms rather than participant names. To deeply understand the lived experiences each transcript of the interview was analyzed and member checking was conducted as needed with participants to ensure accuracy of the qualitative data.

### **Researcher's Journal**

While interviewing the participants, the researcher maintained written descriptions of every interview. Immediately following each individual interview, the researcher wrote in her journal to record notes. Each journal entry included the (a) date, time, and place of the interview; (b) nonverbal responses, including tone of voice, gestures, or reactions to questions; and (c) specific words, expressions, and idioms used (Sunstein & Chiseri-Strater, 2011). Data collection spanned approximately 6 weeks from mid-July to mid-September of 2021.

### **Researcher's Role**

The researcher was an African American female from Texas. The researcher's race and background provided her the opportunity to work with African American breast cancer survivors. Further the researcher has an advanced degree and has worked in breast cancer social behavior research for the past 10 years. To address predispositions and preconceptions, the researcher recorded personal feelings, biases, and insights to separate personal experiences, interpret the interviews from a new perspective. Additionally, the researcher recorded notes in her journal and expressed personal feelings, which were often reflective of what researchers have learned through each interview (Creswell & Creswell, 2018).

### **Protection of Human Subjects**

The researcher adhered to all ethical standards, beginning with seeking approval from the Texas Woman's University IRB. The participants received informed consent documentation

before interviews, clearly explaining the study and their rights. Participants were able to ask and receive answers to their questions about the study prior to participation. There was minimal risk to participants, primarily limited to psychological discomfort associated with answering some of the questions related to their experiences with breast cancer and medical discrimination. The researcher worked with breast cancer support center resources staff across Texas to recruit participants, who received a \$20 gift card as compensation for their time.

### **Data Analysis**

Analysis of the data for the current study occurred using a phenomenological research approach. Creswell and Creswell (2018) defined phenomenological research as a “qualitative strategy in which the researcher identifies the essence of human experiences about a phenomenon as described by participants in a study” (p. 249). For this research study, interviews were conducted and transcribed in English. Each interview transcript and the researcher’s journal underwent independent review and coding using computer-assisted qualitative data analysis software (CAQDAS; Maher et al., 2018). The latest version of NVivo enabled the organization of the semi structured interview data. The software has received consistent use by researchers to explore themes and provide textural reflections of qualitative interview data (Saldaña, 2013; Swygart-Hobaugh, 2019). Interpreting and coding the interview data followed a rigorous and well-established seven-step process proposed by Moustakas (1994): (a) labeling and grouping data by applicable experiences/data organization (e.g., horizontalization), (b) identifying relevant expressions and reducing/eliminating unrelated expressions to establish invariant constituents, (c) assembling and thematizing invariant constituents considered as core themes from participant experiences, (d) conducting final determination of invariant constituents, (e) formatting a personalized textual description for each participant (using verbatim examples of interview

transcripts), (f) developing participants' personalized description based on the textual description and inspired differences, and (g) designing a textural-structural description of the connotations of the experiences for each participant, incorporating relevant themes and eliminating duplicate and unclear expressions. Based on the personalized textural-structural descriptions, there was an overall description of meanings and experiences created representing the participants (Moustakas, 1994).

Data analysis through this delineated process allowed the researcher to understand the lived experiences of female African American breast cancer survivors from breast cancer diagnosis through treatment, including any perceived medical discrimination experienced during that treatment (e.g., Bedside manner, feeling ignored, made to feel inferior by medical providers). Researchers (e.g., Ranskin et al., 2018) have highlighted the importance of rigorous data analysis in health education and social behavior research. The analysis process is critical as it provides structure for the data that researchers see, hear, and experience to inform their decision-making and the determination of final themes. For the current study, the researcher's role was to determine major themes from the lived experiences and perceptions of the participants (Babbie, 2016). As such, data analysis included the examination of interview transcripts as well as the researcher's journal. It is necessary to expand the data collection and go beyond just the interviews to increase credibility and capture what interviews may miss (Creswell & Creswell, 2018). Additionally, the researcher was involved in the interview process with the participants to better understand and evaluate each interview transcript while determining patterns and themes (Saldaña, 2013).

## **Trustworthiness of Findings**

To support the trustworthiness of the study, the researcher provided a reliable interpretation of the participants' collective well-being and individual viewpoints (Bonsu & Ncama, 2019; Tracy, 2010). To confirm trustworthiness, the researcher employed conventional principles to demonstrate internal validity, external validity, reliability, and objectivity (Shenton, 2004). The ethics for value in social behavior research is constantly changing. Therefore, establishing trustworthiness in qualitative research is imperative to social research studies (Tracy, 2010). In this study, the researcher used three measures of trustworthiness to determine the dependability of the study: credibility, transferability, and confirmability (Morse, 2015). Utilizing these steadfast criteria allows reviewers to understand the lived experiences of female African American breast cancer survivors.

To establish credibility, researchers must show that their study explores the proposed results of the study (Shenton, 2004). In this study, the methods used to increase the credibility of the findings were triangulation, peer debriefing, and member checking. Using triangulation, the researcher aligned data from different sources (i.e., interviews, researcher journal, and member checking) to provide a comprehensive review of the findings (Morse, 2015; Shenton, 2004). Peer debriefing entailed seeking guidance from experts in the field of health studies to review the data and challenge researcher preconceptions (Morse, 2015). The peer debriefer was an expert in the field with at least 5 years of postgraduate experience in public health assessment and evaluation.

Member checking is one of the most valuable research methods supporting study findings (Shenton, 2004). Member checking allowed for the verification of information expressed during the participant interviews (Morse, 2015). For member checking, participants responded to clarifying statements during and at the end of the interviews to ensure accuracy of the content

(Shenton, 2004). Participants were encouraged to change, clarify, or elaborate on their responses to ensure accurate interpretations.

Additional methods used by the researcher to ensure trustworthiness included transferability and confirmability. A detailed description of the participants' lived experiences was essential for transferability. Including the interview responses in the findings allowed readers to transfer elements of the research to their experiences (Morse, 2015; Tracy, 2010). Shenton (2004) defined confirmability as "the qualitative investigator's comparable concern to objectivity" (p. 72). In this study, each interview was transcribed, analyzed, and triangulated with the researcher's journal notes to decrease researcher bias (Shenton, 2004) and increase confirmability. NVivo was the tool used for data analysis. The NVivo digital mapping process incorporates bracketing concepts by coding themes found in the data collection process (Maher et al., 2018). The digital coding process kept the researcher from including personal assumptions and emotions in data analysis, which reduced the transmission of researcher interest in the study (Swygart-Hobaugh, 2019; Tufford & Newman, 2010).

The researcher is actively involved in the breast cancer community in Texas through local, state, and national organizations. This involvement indicates the importance of providing credible health education and promotion of breast cancer education. The researcher has studied as a certified health educator in Texas and participated in breast cancer prevention, survivorship, and treatment programs since 2009 at the University of North Texas Health Science Center, SGK, ACS, and Bridge Breast Network.

## CHAPTER IV

### RESULTS

The purpose of this phenomenological study was to explore the lived experiences of female African American breast cancer survivors from breast cancer diagnosis through treatment. This chapter presents the perspectives and impacts of breast cancer among African American women and the viewpoint of breast cancer survivorship. The findings for this qualitative study are presented as they connect to the following research questions:

1. What are the lived experiences of female African American breast cancer survivors specific to the perception of their illness from breast cancer diagnosis through treatment?
2. What are the lived experiences of female African American breast cancer survivors specific to medical discrimination from breast cancer diagnosis through treatment?

Kleinman's explanatory model of illness (Kleinman & Benson, 2006) served as a guide for the interview questions to explore participants' perceptions based on the five fundamental elements of etiology, the onset of illness—symptomatology, pathophysiology, course of illness/severity of prognosis, and treatment. Table 3 demonstrates how these components were addressed through the interview guide, which allowed for the exploration of survivors' perceptions, beliefs, and social ideologies. The researcher utilized CRT to understand how female African American breast cancer survivors perceived medical services and evaluate medical discrimination.

Table 4 shows the initial patterns of analysis and how the research data was organized. The information gathered from initial patterns of analysis of data from the interview responses were used to explore participants' perceptions based on the five fundamental elements of

Kleinman's explanatory model of illness. Within the initial data patterns shared by participants in response to Research Question 1, nonmodifiable factors were identified by study participants and included family history, dense breast, breast calcification, hormones, and environment.

Participant responses to Research Question 1 were also related to modifiable risk factors.

Participants shared that sedentary lifestyle, work-life stressors, and lack of physical activity may have contributed to their breast cancer diagnosis. Additionally, participants reported long-term exposure to prescription drugs such as steroids and oral contraceptives, and their overall reproductive history as potential factors contributing to their breast cancer diagnosis when responding to questions specific to Research Question 1. Initial data patterns in participant's responses to Research Question 2 included their interactions with medical experts and how they believed providers made them feel when seeking medical care. Participants shared examples of providers ignoring medical request and making participants feel inferior when seeking medical services as contributing to health discrepancies when they sought breast cancer services.

**Table 3***Interview Questions and Research Questions*

| Research Question 1                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Research Question 2                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Interview questions</p> <p>To establish etiology:</p> <p>What do you believe caused your breast cancer?</p> <p>Who was the first person you told about your diagnosis?</p> <p>To establish onset of symptoms:</p> <p>What life events led to your diagnosis of breast cancer?</p> <p>At what stage was the breast cancer diagnosed? What type of breast cancer were you diagnosed with?</p> <p>To establish pathophysiology:</p> <p>What does breast cancer do to you, and how does it affect your body?</p> <p>Describe your experience with breast cancer.</p> <p>To establish course of illness:</p> <p>Describe the course of your breast cancer and how it has changed your life.</p> <p>What has been the impact of breast cancer on your personal life (e.g., family, friends, socially)?</p> <p>To establish treatment:</p> <p>Tell me about the treatment options that were available to you and why you made that decision.</p> <p>Tell me about activities that helped you during your diagnosis and treatment.</p> <p>What type of insurance did you have when you were diagnosed? Were you satisfied with your insurance and the coverage you received? Did your cost of insurance for services impact your treatment decision-making?</p> | <p>Interview questions</p> <p>While receiving treatment for breast cancer, did you ever experience medical discrimination with a medical practitioner? Or were you made to feel inferior when receiving medical care services?</p> <p>Did you feel understood by your doctor? Why?</p> <p>Have you ever experienced discrimination, been prevented from doing something, or been hassled or made to feel inferior because of your race, ethnicity, or color?</p> |

After a review of the initial patterns of analysis and further breakdown of the data, recurrent themes were constructed from the data (i.e., interview with survivors, review of researcher journal, peer debrief). The four themes that were generated from the thematic analysis of the perspective of African American breast cancer survivors were (a) physical and emotional scars of breast cancer treatment, (b) the role of faith in the healing process, (c) village of supporters, and (d) the system is not centered around the needs of Black women. These themes are supported by the study participants perceptions the further illustrate the lived experiences of the African American female breast cancer survivors. Table 5 provides a summary of the thematic analyses and initial quotes from study participants. Those stories and pointed depictions are discussed copiously within this chapter.

**Table 4**

*Initial Pattern of Analysis of Data*

| Pattern of analysis                             | Research data                                                                                                                                                                                                                                                             |
|-------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Research Question 1                             |                                                                                                                                                                                                                                                                           |
| Etiology—<br>susceptibility to<br>breast cancer | Family history/genetics<br>Dense breast<br>Calcification<br>Fibrocystic breast<br>Breast cancer screening<br>Hormones<br>Environment                                                                                                                                      |
| Onset of illness—<br>symptomatology             | Sedentary lifestyle<br>Stress at work/work environment (100+ hours a week)<br>Environment<br>Graduate school<br>Family/busy life<br>Newly married; newborn/young children<br>Caring for elderly parent<br>Death of parents<br>Family matriarch; go to caregiver for other |

Table 4 Continued

| Pattern of Analysis                                                         | Research Data                                                                                                                                                                                                                                                                                                      |
|-----------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Research Question 1 continued                                               |                                                                                                                                                                                                                                                                                                                    |
| Pathophysiology on individual results otherwise associated with the disease | Loss of friends<br>Loss of family<br>Insecurity<br>Marriage problems (divorced)<br>Mental health<br>Depression<br>Post-traumatic stress syndrome [PTSD]: fear of cancer returning<br>Physiological aspects of removing breast(s)                                                                                   |
| Course of illness/severity of prognosis—effect of breast cancer             | Menopause<br>Delays in family planning/childbirth<br>Loss of memory<br>Polyps on uterus<br>Loss of femineity/hormone imbalance<br>Neuropathy<br>Chronic disease: loss of vision, bone disease, heart disease<br>long-term use of prescription medications<br>Infection from surgery<br>Arthritis/severe joint pain |
| Coping/support systems                                                      | God/faith/spiritual belief/praise<br>Journaling<br>Keep fighting/keep moving<br>Continued to work<br>Do not stress/sweat the small stuff<br>Do not put things off<br>Family<br>Husband<br>Friends/network of breast cancer survivors<br>Doctor                                                                     |

Table 4 continued

| Pattern of analysis              | Research data                                                                                                                                                                                                                                                                                                                                                                                                                                |
|----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Research Question 2              |                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| Perceived medical discrimination | <p>Medical practitioner behavior</p> <p>Bedside manner</p> <p>Did not share all options</p> <p>Made to feel inferior</p> <p>Doctor did not listen-</p> <p>Ignored questions about treatment and care</p> <p>Ignored request to end tamoxifen/oral medicines</p> <p>Implicit bias</p> <p>Brochures/pamphlets; checking into the hospital did not include me</p> <p>Healthcare professional/multiple</p> <p>Health care practices/policies</p> |

**Table 5***Summary of Themes and Opening Participant Quotes*

| Thematic findings                                          | Participant quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Physical and emotional scars of breast cancer treatment    | <p>I personally regret not getting a double mastectomy. I just wanted to save my breast and have some sense of femininity. It just all happened so fast, I did not really have time to take it all in. (Survivor 1 Janna)</p> <p>I just wanted to know I was doing the right thing. I was so afraid getting treated, but I know it was the right thing to do. (Survivor 4 Kora)</p>                                                                                                               |
| The role of faith in the healing process                   | <p>I know watching my mom and how she prayed through her cancer really helped me. I knew my faith would carry me through this thing. (Survivor 3 Lee)</p> <p>I could honestly tell you there's no way in the world that I could have went through this without God. (Survivor 16 LeVale)</p>                                                                                                                                                                                                      |
| Village of supporters                                      | <p>What surprises me from my supporters is that as I started to talk to women newly diagnosed, they would say, "Okay, this is going to happen to you. This is how you deal with the nausea." The support they give you how to survive the process are invaluable. (Survivor 9 Cinthia)</p> <p>I told my bible study group I had breast cancer and asked them to be my community of supporters. It was important to me for my family to have space to just heal and be. (Survivor 2 Donna)</p>     |
| The system is not centered around the needs of Black women | <p>For me, I was fighting age, and being an African American woman, I felt like the system just did not know what to do with me. I was what to do with 34 years old. I felt very small. (Survivor 12 Dafne)</p> <p>I have always liked doctors that were not White, so I would always get a doctor...not White. So I would say, in order not to have the discrimination, in my opinion, be diligent and find maybe a doctor that's not Caucasian. Maybe. That's my opinion. (Survivor 7 Aden)</p> |

## Themes

### Physical and Emotional Scars of Breast Cancer Treatment

The first theme, physical and emotional scars of breast cancer treatment, addresses Research Question 1 and demonstrated how the treatment received by the breast cancer survivors left them with long-term physical and emotional scars. The scars of breast cancer treatment were both emotional and physical. Participants primarily identified these scars with treatment from surgery (i.e., lumpectomy, mastectomy, double mastectomy), radiation, and chemotherapy. When the women in the study reflected on initial treatment, they also identified the biopsy as their first step in the treatment process. When the survivors shared their experiences of physical and emotional scars, the description shared described how the physical scars and emotional scars of breast cancer treatment were intertwined. Also, the physical scars often impacted/triggered resurgence of the emotional scars. Some women in the study shared the treatment left them with feelings of PTSD. The women first described the emotional strain of determining which surgical treatment to choose (i.e., mastectomy, double mastectomy, or lumpectomy). Among the breast cancer survivors in this study, 25% ( $n = 4$ ) decided on a lumpectomy, 38% ( $n = 6$ ) opted for a mastectomy to remove one breast, and 38% ( $n = 6$ ) underwent a double mastectomy. The women in the study described treatment decisions tangled with thoughts of fear and preservation for their breasts. For example, several participants struggled during their early diagnosis to determine what surgical treatment was best for them (e.g., lumpectomy, single mastectomy, double mastectomy). The women in the study believed the underlying concern was “fear.” Specifically fear of doing the right thing. Tamal recalled how she challenged was after she heard her surgical treatment options:

So, between the three, they told me the chances and some of the percentages related to the surgeries and the breast cancer returning. I made the choice to do the double mastectomy. It wasn't till after the surgery, and I made that choice... I knew what a double mastectomy was.

Often, when the women made the decision to have a double mastectomy, it was the more aggressive treatment option. The decision for some of the participants was based on anxiety and fear around the breast cancer coming back later in another breast. For example, Naye said she had breast cancer in one breast, and she decided to have a double mastectomy because she was worried if she chose a single mastectomy, the breast cancer would come back in the other breast. Naye shared, "God forbid, later on, the breast cancer return in my right breast. I just didn't want to go through that." Naye also shared her continuously thinking about her breast cancer coming back. Naye said, "It's like PTSD. I finally had to go to a counselor to help me deal with feeling like my breast cancer might come back." Several of the women in the study felt like Naye. Choosing an aggressive treatment gave her and other women in the study a sense of peace. Several survivors, including Cinthia and LeVale, shared these sentiments. Cinthia, was diagnosed with cancer in one breast, said, "I chose a double mastectomy. I never wanted to go through it again. So I went very radical, and I'm very happy that I did. Very happy." Similarly, LeVale shared:

Yeah. I did the double mastectomy, although they told me you know like, this doesn't decrease your chances of it coming back, but just my peace of mind, I need to know that I tried to do everything that I could to prevent it.

The majority of the women in this study chose aggressive treatments that left them scarred physically, but their decisions provided them with a sense of emotional solace. The relief

was not based on the perception that the breast cancer would not come back. Instead, for most of the participants, it was the comfort of knowing they had done everything they could to fight their breast cancer.

The physical scars of breast cancer treatment included scars from surgeries, radiation, and long-term abnormalities related to chemotherapy. The scars from breast cancer surgeries included wounds from lumpectomies, mastectomies, and double mastectomies. Even after the participant's breast cancer reconstruction surgeries to restore their breasts, the women recalled scars seen and unseen related to their breast cancer treatment. Aden, who had a double mastectomy recalled:

I'm not the same as I was before because of physically having a double mastectomy, and I have not yet had my reconstruction. And so, I just— I don't know. Maybe I'm a little different, and I'm just glad to be alive. You know? I mean, I guess I'm not vain, is what I probably want to say. I'm not vain. I don't care about not having breasts. Well, I would like to have my breast, and I did yesterday, as a matter of fact, say, I'm like, 'Oh, I miss my hair, and I miss my chest, my breast.' But still, all things considered, I'm here, you know?

Similarly, Toni was diagnosed with breast cancer twice shared:

It left scars. I have lymphedema now on my left side, as a result of them taking out my 12 lymph nodes. I have osteopenia. I found out several years later that before they did my chemo or radiation, they didn't do an echocardiogram. All my heart valves were damaged, so I'm on heart medication for cardiomyopathy, and I a hysterectomy and a double mastectomy with reconstruction.

While other women may not have the enduring internal and external scars described by Toni, many women in the study shared how they live each day with the residual side-effects from chemotherapy (e.g., osteopenia, lymphedema, neuropathy). Jewel, shared about her side effects from chemotherapy:

I'm always in pain because I ended up with rheumatoid arthritis, and so it's very aggressive. It is very aggressive. And then I got nerve issues. I ended up with trigeminal neuralgia, which is a killer of pain in the face. I cannot express myself emotionally. It flares up, so I have to be careful. It affects everything on the right side of my face, including my ear.

While sharing their experiences with the physical scars of breast cancer, the women expressed feelings of frustration over their treatment decisions. Several of the women repeatedly shared about how they wished they had received more information about their treatment options at the time, and shared feeling disappointed about their treatment decisions, particularly surgical decisions. Dafne, shared her emotional frustrations with her physical and mental scars resulting from breast cancer treatment. Dafne stated:

It's an emotional thing, every time. You never get numb to it. It's always emotional. They took a significant amount of my breast off, but it's lopsided. It's so much smaller than my right breast. Of course, it disfigured my body, and I'm really insecure about it. I'm really insecure about it. And sometimes I think about that I did a partial lumpectomy because I wanted to save my breast, but I really didn't save my breast. I could've just got rid of it and got another breast because it looks freakish. It really looks freakish.

Overall, the women describe the physical and emotional scars of breast cancer as something they have to confront and deal with every day, even after being breast cancer-free (had no evidence of disease).

### **The Role of Faith in the Breast Cancer Healing Process**

The second theme, the role of faith in the healing process, answers Research Question 1. In this theme, the African American breast cancer survivors discussed the importance of faith in their overall breast cancer experiences. Several survivors addressed the role of the faith and how essential their spiritual health was in their breast cancer journey. Additionally, many of the participants discussed the church's role and how knowing the "saints" (i.e., church members) were praying for them brought them peace through treatment and helped them believe they would be cured. The majority of the women in this study shared the importance of faith in their healing process and how their spiritual well-being impacted their healing process. Most of the survivors in this study 63% ( $n = 10$ ) revealed that their relationship with God and their overall faith were vital to their outlook as a survivor. Additionally, all women in the study 100% ( $n = 16$ ) shared that their faith was always part of their coping philosophy. Echoing the sentiments of many of the survivors, Marlene shared:

At first, it's fear. Then for me, it was, "Okay, build with my faith, because if you say you believe in this God that can heal you, then now's the time to show it." So it was just... I just think the world is already so doom-and-gloom, so I'm not going to walk around doom-and-gloom. I look at it as God gave me another chance.

The women in the study expressed how as wives, sisters, aunts, mothers, and grandmothers, they are the matriarchs in their families, so when they became ill, the family

began to stress and worry. As such, the survivors' strong faith was not just for their healing but also for their families. For example, Janna shared:

My faith gave me the courage to share my journey. My faith helped me talk with my family and friends so they could understand what I was feeling, you know, what I was going through. They needed to be a part of it, and God helped me figure out how to get past the fear to open up.

Similarly, Leah shared how she was able to become more transparent with her husband about her breast cancer because of her faith. As indicated in her remarks, she relied on her faith:

My mother is a breast cancer survivor. My mom said, "We don't do fear." She's like, "Remove that." Then she said, "Let go and let God lean on your faith." And I said, "Okay." And I was done. That was the end of fear.

LeVale, like Leah, mentioned how she relied heavily on faith to get her through the lasting effects of breast cancer:

I can say that first of all, I have to keep my faith, and I know that only God has gotten me through it all. I know that when I look back on the things that I did throughout my treatment, the places I went throughout my treatment, the hospital stays I had throughout my treatment, I could honestly tell you there's no way in the world that I could have went through that. It was nobody but God. Nobody could see me through it because it was rough.

Like LeVale, Aden shared her sentiments about her faith, which was further challenged due to her breast cancer diagnosis occurring just before the COVID-19 pandemic. At the time of the interview, she was still awaiting breast reconstruction surgery due to COVID-19 hospital

surgery limitations. Nevertheless, Aden was bold and took charge of her journey with her faith front and center:

I just believed that I was okay. I chose life. That's what I told people. "I chose life." I didn't choose to sit up and be in pity and everything. It's like, "I know I'm gonna live." My faith is paramount. I believed I was healed. You can't walk in pitying yourself because you are here for a reason.

Clearly, the role of faith is essential for the African American women who participated in this study. The women relied heavily on their feelings of faith, spiritual well-being, and belief in God to see them through the rough road that lay ahead of them after hearing they had breast cancer.

### **Village of Supporters**

The third theme village of supporters also sought to answer Research Question 1. The women in the study spoke repeatedly about their support team. The survivors described their supporters as their village or community. Several women in the study were connected to breast cancer survivors who provided medical referrals to breast cancer surgeons and oncologists and helped them identify the medical providers they believed would prioritize their needs as a female African American breast cancer patient. The survivors in this study frequently referenced the importance of their "village" or "community" of supporters in their breast cancer journey. At least 82% of the survivors ( $n = 13$ ) had expansive breast cancer support systems with support from family, friends, church members, co-workers as well as other African American breast cancer survivors. The participants expressed the significance of their support system being inclusive of others who had been through breast cancer and how valuable it was to connect with other breast cancer survivors with whom they could relate and share similar experiences. The survivors in this study stated that their support systems were an essential part of their breast

cancer journey. Most of the women in the study had a village of supporters that included their immediate family and a community of friends, co-workers, and church members. The village of supports provided the survivors in the study with nonstop help during their breast cancer battles. For example, most of the women in this study had multifaceted support systems that provided daily needs, such as transportation to doctor appointments, meal preparation, and assistance with childcare. The survivors in the study also relied on their village of supporters for medical referrals to physician groups and oncologists known for providing culturally knowledgeable care. Survivor 2 Donna, shared how she formed her village of supporters and how important they were in helping her battle breast cancer during the COVID-19 pandemic:

So I really realized that I was kind of trailblazing this path because nobody had been in a pandemic before. I told my bible study group I had breast cancer and asked them to be my community of supporters. So my mom, aunts, uncles, and even my husband and boys would not have to do it all. It was important to me for my family to have space to just heal and be. They said okay and created a meal train, and left groceries and notes at the door for us. My bible group formed a GoFundMe me page. I was like no, I don't want to do that. They did it anyway and raised \$10,000.

Aden, like Donna, started her breast cancer journey during the pandemic. Aden recalled her experiences with her support group, stating:

I will say this—being connected to other breast cancer survivors, having a good, strong church, it's people who are praying for me. They will send me gift cards and notes. People just encouraging me, texting me. People don't understand how important getting get well cards and notes. How that really encourages you through the journey.

Another notable support group for the women in this study was an extensive village of breast cancer survivors and breast cancer medical providers. For example, Leah shared how having support from her mother, who battled breast cancer in 2009, was a big help to her:

My mom was amazing. She helped me a lot to understand what I was about to go through. I also had a close friend who was a breast cancer survivor, and she helped me to identify the right treatment and medical providers for me.

LeVale had a similar experience and shared how her best friend, who was a breast surgeon, was vital in her breast cancer journey from the start. LeVale recalled,

When I had my biopsy, the radiologist knew my friend very well. He knew she was a breast surgeon. Later, when I was selecting my oncologist, my friend helped me and my husband select an oncologist. Having her as support in my journey was crucial.

Marlene shared a comparable story and how her village included medical professionals:

A lot of my friends at the time of my diagnosis were physicians. I had a fantastic support group. They referred me to hospitals and medical services. As a matter of fact the majority of my medical team was African American, including my oncologist, physician, and even surgeon.

It is clear from the experiences shared that the breast cancer survivors in this study relied heavily on their village of supporters. They shared the importance of (a) social support groups, particularly amid the COVID-19 pandemic; (b) supportive survivors; and (c) staying connected with their community of supporters during their breast cancer journey. Moreover, the survivors in the study highlighted how their community of supporters connected them to medical services and other indispensable breast cancer services, particularly services provided by culturally aware service providers.

## **The System Is Not Centered Around the Needs of Black Women**

The last theme generated from the study is that the system is not centered around the needs of Black women relates to Research Question 2, revealing the perceptions African American women have towards medical discrimination. When the breast cancer survivors in this study were asked about their perceptions of healthcare systems and whether they had experienced medical discrimination, less than half of the survivors in the study shared having experiences with medical discrimination, approximately 38% ( $n = 6$ ). However, all the survivors shared they perceived the health care system was not centered around the needs of Black women based on their experiences as breast cancer survivors. For example, Donna stated:

Fortunately, I don't feel like I was discriminated against. I did notice other things, like the documentation or just...the forms that they gave me, the pamphlets that you read. I don't see people like me, you know...implicit bias. Just little things like that [showing] you're not represented. You [referring to PI]...myself, as a Black woman, was not included in these discussions.

Additionally, the women shared stories that indicated implicit bias and a lack of cultural sensitivity by some health care providers. Kora, discussed similar experiences and recalled the following:

I had to go every week to see [my first oncologist]. The oncologist proceeded to examine me...to make sure, you know, just to see what was going on. And at this point, I had radiation and chemo treatments, and he just looked at my breast like he was seeing me for the first time and said, "What did you have? Did you have a mastectomy?" It was like in disgust. It made me feel like— It made me feel so small because I was like, "You don't remember me of all people?" I mean, nobody in his office looked like me. It was just

White women. So for me to come in here and for you to can't even remember what kind of treatment I had or—and I see you every week, right? I don't know what it was. I have no idea what it was. I don't know if he just didn't care. I don't know. It just blew me away because here I am in the thick of breast cancer treatment, and then you ask me a question that you should have known it was not. You know I didn't have a mastectomy. I never went back to him.

Other women in the study described what they believed to be more deliberate (i.e., overt acts of discrimination) actions by health care providers. For example, Jewel believed she experienced medical discrimination when her insurance status changed (she became uninsured). However, she was unsure if it was related to her race or insurance status. Regardless, she believed the system was not centered on her needs as a Black woman. Jewel shared:

I feel like my doctor does not want to run tests on me because I am underinsured or Black or something. She always says things like, “Well, let's try another, cheaper option.” I explained that I will pay out of pocket for the best treatment, but she just refused. I finally went to my OB-GYN for help, and she ordered me what I needed, and I paid for it.

In another example, Tamal recalled the exchange with her nurse practitioner and how discriminatory that experience felt to her:

I noticed a knot on my breast, it was poking out like it was swollen, but it wasn't red or painful. It was like, you know like you fall and bump your head and you get a knot. I showed my friend at work and she was like, “Girl, go get that checked out.” And I laughed because I had just turned 40, and I said I ain't never had no mammogram. But she insisted. So, I made the appointment. The nurse practitioner examined my breast and my lump. And I remember her words to me. She said, kind of like nonchalant, she was

like... “Oh. Well, I don’t think there’s anything wrong. I don’t really think you need to have a mammogram at this point. But if you want, I will go ahead and order you one; but I don’t really think it’s necessary.” And she was like, “Well, I tell you what. Let’s just wait and see what happened, and then we’ll revisit this issue if it don’t change, if it don’t go away.” I said to myself, Lord, please let me get this mammogram. I just said, “ma’am please I need this mammogram, so I can get this lump checked out.

This experience was so emotional for Tamal, she cried as she recalled the office visit. Tamal believed if she had not insisted on getting a referral, her Stage II breast cancer might have killed her. Overall, Tamal shared she felt the nurse practitioner did not take her seriously because she was young and Black or both. She knew her response was coming from a place of emotions, but she also shared how she did not know why the nurse practitioner took such an offhanded approach to her situation.

A similar story was shared by Dafne, who, as previously noted, received her breast cancer diagnosis at the age of 33. Dafne shared how she struggled to get her provider and insurance company to refer her for a mammogram, including waiting 7 months for approval from her insurance to get a mammogram. Dafne explained how her experiences with the health care system were not ideal in the beginning. She recalled:

So, after I was able to get my mammogram and biopsy accepted by my insurance, I found out I had breast cancer as my doctor is on her way to the US Open in London boarding her plane. She told me that my pathology reported came back and I had DCIS and she told me that she was going to follow-up with me in two weeks. I said, “What do you mean?” She said, “They did find cancer. It’s estrogen positive, progesterone positive. We found it in the left breast.” She then said she would be out of the office for two weeks and then

she would contact me when she got back. To add more confusion to the situation, I was at work and just in complete shock.

Dafne further discussed that she was not able to really process her diagnosis or ask questions. She was very disappointed in how her doctor chose to share her breast cancer diagnosis.

Other women in the study believed they may not have experienced medical discrimination. They deliberately chose African American physicians because they perceived that the system was not centered around the needs of Black women (based on prior pre-cancer experiences with the medical system). Furthermore, the women in the study with this belief shared how they often connected with their village of supporters who were breast cancer survivors for medical referrals to doctors who knew how to relate to their specific personal attributes. For example, the women shared how if they were a “straight shooter” (i.e., a no-nonsense personality type), they wanted a “straight shooter” for a doctor. Other survivors sought out doctors who were receptive to being asked questions and spent time with their patients because they wanted medical care without feeling rushed or having their doctor become frustrated in addressing their needs. It was imperative to the study survivors not to complicate their breast cancer journey with possible discrimination. This was undoubtedly identified by Aden, who shared:

I have always liked doctors that were not White, so I would always get a doctor...not White. And I always wanted the doctors who were doctors of internal medicine because they treat the whole person, not just the symptom. So I would say, in order not to have the discrimination in my opinion, you should be diligent and find maybe a doctor that's not Caucasian, maybe, that's my opinion.

Additionally, as previously shared by Marlene, she relied on her village of supporters to connect her to doctors they knew and who were African American.

The comments generated in this theme expressed by the African American women in this study demonstrate that they did not believe the system was centered on including their needs. The women revealed how important medical referrals were to their journey and the role other medical providers have in helping remove barriers to medical discrimination. Most notable, the women established if they felt discriminated against, they discontinued services with the medical provider and identified a medical provider with their best interest to aid in their fight against breast cancer.

### **Conclusion**

This chapter included the results of the phenomenological research study of female African American breast cancer survivors aged 35 to 75 years. Their experiences related to their illness were guided by Kleinman's explanatory model of illness and their perceptions of medical discrimination. Also documented in this chapter are the initial data patterns analysis, which led to four re-occurring themes results clearly outlining the experiences and perceptions shared by the women in the study. Within those initial patterns, the study participants shared their beliefs

Each of the themes generated in the study provided a glimpse into the life of an African American breast cancer survivor. The first theme generated focused on the physical and emotional scars of breast cancer treatment. Next, the women in the study explained the challenges they faced while battling breast cancer.

Furthermore, study participants shared how even after overcoming the physical aspects of breast cancer treatment, the emotional scars lingered. These scars included fear of breast cancer returning, anxiety about the treatment they choose, and wondering what residual illnesses might

develop as a result of their treatment. The theme of the role of faith in the healing process resonated across all the survivors. The women shared how faith, church, and prayer were essential to believing they would defeat breast cancer. The village of supporters was a part of those “saints” praying and providing hope to the women in the study as they battled breast cancer. However, the women recalled often, this village of supporters was much more than pray warriors. Most often, this was a well-connected village of resources specifically focused on removing barriers to medical care services and providing emotional support to help care for the well-being of the survivors. The final theme generated, the system is not centered around the needs of Black women, demonstrated challenges the participants in the study faced at times seeking medical care. However, the women recalled how they persevered despite these encounters to move their battle with breast cancer toward a win for themselves and their village of supporters.

## CHAPTER V

### DISCUSSION

The purpose of this phenomenological study was to examine the lived experiences of female African American breast cancer survivors from diagnosis through treatment. This investigation was grounded in the seminal work of Kleinman et al. (1978) and deliberately guided by his explanatory model of health (Kleinman et al., 1978). Furthermore, the application of CRT components focused on public health enabled the exploration of systemic processes and procedures, often inadvertently reinforcing racial disparities among African American women when seeking standard health care (Ford & Jeffers, 2019; Thomas et al., 2011). Viewed through these lenses, the findings contribute to the literature on breast cancer survivorship from the female African American perspective.

This study explored the lived experiences of female African American breast cancer patients living in Texas, their perceptions of breast cancer, and lived experiences related to medical discrimination. Purposeful and snowball sampling were the approaches used to recruit participants. All participants completed a demographic survey and participated in interviews. The research was predominately centered around the core tenets of Kleinman's explanatory model and the threats to breast cancer survivors' treatment due to health care system inequities, such as delayed services and misdiagnoses (Nelson & Kaminsky, 2020; SGK, 2018). The research incorporated Kleinman's five components of etiology, the onset of symptoms, pathophysiology, course of illness/severity of prognosis, treatment (Kleinman et al., 1978), and the perceptions of medical discrimination (Dinos et al., 2017; Freeman et al., 2017). This chapter discusses those findings based on the research questions, implications for practice, limitations, conclusion, and suggestions for future research.

## **Discussion of Research Questions**

### **Research Question 1: What Are the Lived Experiences of Female African American Breast Cancer Survivors Specific to the Perception of Their Illness From Breast Cancer Diagnosis Through Treatment?**

Providing data to answer Research Question 1, African American women described their lived experiences as breast cancer survivors. All the survivors in this study presented their breast cancer experience as a life-altering process, teaching them how to appreciate their time and celebrate life. In addition to these experiences, the participants provided details on symptoms leading up to diagnosis, treatment details, lifestyle and supportive activities during treatment, and how breast cancer affected their lives according to their position on the survivorship spectrum.

Participants described various symptoms during their interviews. The perceptions shared by African American women concerning breast cancer survivors focused on symptomology, risk factors, screening, stage of breast cancer, treatment, and breast cancer survivorship networks. Additionally, almost all survivors felt strongly about the importance of social support systems to help navigate health care services. Williams et al. (2016) stated support groups are essential to breast cancer survivors' emotional and spiritual health.

The survivors in the study frequently reported not having any initial symptoms and finding their breast cancer during an annual mammogram or breast self-examination. Study participants reporting signs of breast irregularities described warning signs as rapidly growing lumps that were uncomfortable but not always painful. However, breast cancer symptomatology was different for each of the participants in the study. The experiences are consistent with the literature. Breast cancer, like other diseases, is often unpredictable and lacks a clear indication that something is wrong. Furthermore, often women do not notice breast changes until consulting

with their doctor (NCI, 2018). Warning signs include breast pain, swelling, dimpling, flakiness of the skin, nipple discharge, and change in the shape or size of the breast (CDC, 2020c).

The women in the study identified modifiable risk factors, such as sedentary lifestyle, obesity, and lack of physical activity, as potential contributors to their breast cancer diagnosis. Modifiable risk factors impacting breast cancer are those that women can change, such as lack of physical movement, being overweight, and menopause medication (CDC, 2020c). Participants also reported long-term use of medications, including steroids and oral contraceptives, and overall reproductive history as potential contributors to their diagnoses. According to the CDC (2020c), these are considered risks factors related to breast cancer history.

In addition, breast cancer screening recommendations are crucial for preventing late-stage breast cancer diagnosis (ACS, 2021a). Overall, there are striking differences in breast cancer incidence, prevalence, and mortality rates among racial and ethnic minorities compared to the minority U.S. population (SGK, 2021a). For example, although survival rates among African American women have increased, breast cancer mortality remains 40% higher for this population than for Caucasian women.

Finding breast cancer early detection is essential to the survival of breast cancer patients (SGK, 2021a). Several women in this study described their breast cancer as “aggressive” or “fast-growing.” The women in the study who discovered their breast cancer through self-breast exams recalled how quickly their breasts symptoms progressed from their initial observation to their actual diagnosis. These observations were consistent with the literature, such as Richardson et al. (2016) who reported that African American women tend to have more aggressive breast cancers than Caucasian women.

Further, breast cancer survivors in this study diagnosed as Stage I or Stage II often chose more aggressive procedures (e.g., single mastectomy or double mastectomy), instead of a lumpectomy, to minimize the reoccurrence of their breast cancer. For example, study participants who chose aggressive surgery reported additional analysis of their breast cancer tissue showing cancer-producing cells beyond their original diagnosis. Left untreated after surgery, the women were concerned they may have received a future diagnosis of late-stage breast cancer. The additional treatment approaches for those newly diagnosed were most likely due to restructuring breast cancer staging methods to be more inclusive of social determinants and geographic locations (Hortobagyi et al., 2018). Williams and Thompson (2017) examined breast cancer staging according to age, race, income, and geographic location using large data sets from states with increased breast cancer mortality. Williams and Thompson defined early-stage breast cancer as Stages 0, I, and II and late-stage breast cancer as Stages III and IV. Data analysis showed that African Americans had higher rates of late-stage breast cancer (39%) than Caucasian women (30%; SGK, 2021a).

Additional discussion by the participants focused on treatment and networking with survivors to find the best care. Traditionally, African American women are disproportionately affected by breast cancer through misdiagnosis, delayed services, and inadequate breast cancer treatment due to health care system inequities (Nelson & Kaminsky, 2020; SGK, 2018). Aware of this concern, the women in this study sought out and relied on referrals and recommendations from breast cancer survivor networks to identify practitioners. The participants relied on their village of supporters to forego potential perceived barriers associated with medical discrimination, provide physician referrals, treatment recommendations, and serve as a continuous resource throughout their breast cancer journey. Adam and Koranteng (2020) stated

that social support from family, friends, and caregivers often helped with the emotional support among breast cancer patients. Social support networks for breast cancer survivors often include access to information and removing administrative barriers within health care systems that could impede participation in vital breast cancer screenings (Mishra et al., 2012).

**Research Question 2: What Are the Lived Experiences of Female African American Breast Cancer Survivors Specific to Medical Discrimination From Breast Cancer Diagnosis Through Treatment?**

For Research Question 2, the researcher asked female African American breast cancer survivors to describe their lived experiences with medical discrimination. Participants emphasized the limitations created by barriers in health care systems and the impact the limitations may have on health outcomes for African American women (Karimi et al., 2018; SGK, 2018). Women in the study who did not perceive experiencing medical discrimination recognized the significance of health disparities for African American women. The study participants reported how their family members and friends had experienced health inequities and suffered adverse care due to medical discrimination. The observation by the women is consistent with information from the literature, which notes health care system barriers, such as access to breast cancer, are factors in finding and treating breast cancer early (SGK, 2018). In addition, the participants were keenly aware of the risks they faced as African American women, who are at higher risk of developing breast cancer early (Babatunde et al., 2020). Most often, the women in the study diagnosed with breast cancer before age 40 experienced medical discrimination related to ageism as a younger patient seeking services and an African American woman with an early diagnosis. Researchers with the SGK Foundation have documented that diagnosis and treatment for women under 40 are challenged with timely care due to their age

(SGK, 2018). These delays may contribute to late-stage breast cancer diagnosis, causing further financial burden and increasing the risk of dying from the disease (SGK, 2018).

The breast cancer survivors in the current study revealed specific coping tactics they used to address potential medical discrimination. These strategies included creating a network of breast cancer physicians, developing relationships with clinical experts on breast cancer treatment, and navigating health care processes and procedures to achieve desired outcomes. Participants identified health care systems as often providing limited access to care for African American women that required them to seek other providers to receive appropriate treatment, which is consistent with the work of Freeman et al. (2017). For example, one survivor's oncologist refused to order an MRI based on the belief that she would not be able to pay for services. The survivor also shared she believed it was because she was Black. As a result, the survivor turned to her gynecologist for the MRI. This survivor's experiences are consistent with the seminal observations of public health experts in the groundbreaking IOM report, *Unequal Treatment*, which exposed how racism influenced health services and impacted health care treatment (IOM, 2003). Additionally, the findings from the current study are supported by Nelson and Kaminsky's (2020) work, which provided historical data on health inequities and how integrated implicit biases are a part of general practices in U.S. health care systems. In order for breast cancer patients and survivors to experience different treatment and outcomes, experts need to continue to address the prejudice and ongoing public health issues of systemic racism affecting health outcomes (Ford & Airhihenbuwa, 2018).

### **Summary**

The purpose of this phenomenological study was to examine the lived experiences of female African American breast cancer survivors from diagnosis through treatment. The study

used a qualitative research approach positioned around Kleinman's explanatory model of illness and CRT. The lead researcher analyzed the lived experiences of female African American breast cancer survivors and their perceptions of medical discrimination. The study findings exposed insight into breast cancer treatment's physical and emotional effects of breast cancer treatment, the importance of faith in the breast cancer healing process, and the unique relationship between the African American women's breast cancer survivors and their village of survivors. The researcher also explored breast cancer survivors' perceptions of medical discrimination and their belief that the health care system is not centered around the needs of African American women.

Furthermore, the current study exposed the need for more culturally competent services focused on physician and patient communication. As outlined in Kleinman's model, medical practices should employ culturally connected medical practices and processes to allow patients to build trust and create patient care methods that explore patients' needs. These techniques may include exploring a patient's cultural, social, and spiritual perceptions to treat diseases like breast cancer. For example, physicians may consider offering more extended office visits or providing chemotherapy in a culturally responsive format to meet patients' needs. Changes in health care systems focused on patient experiences will enable health care professionals to view breast cancer from the women's perspective and provide a holistic model for treating and managing the disease (Hsieh et al., 2016; Kleinman et al., 1978).

### **Implications for Practice**

#### **Understanding Cultural Differences**

African American women are the most vulnerable to misdiagnosis, delayed services, and failed treatment due to inequities in health care systems (Nelson & Kaminsky, 2020; SGK, 2018). Structural racism can lead to medical care inequality, and misdiagnosis can result in

treatment delays and inadequate care (Noonan et al., 2016). Breast cancer survivors could benefit from support activities led by health educators. As Kleinman's explanatory model suggests, clinicians need to rethink how health care services are delivered (Kleinman et al., 1978). To support cultural differences, public health educators and health care organizations should advocate for interdisciplinary care teams to connect breast cancer patients to culturally appropriate care (Kumra et al., 2020). Health care organizations that incorporate interdisciplinary care teams promote cultural humility and organizational accountability, which may minimize health biases among physicians and clinicians (Kumra et al., 2020; Nelson & Kaminsky, 2020). Additionally, community health programs focused on breast cancer prevention should incorporate community health educators to administer cultural assessments to increase cultural awareness within health promotion programs and services (Kumra et al., 2020; SGK, 2018).

The survivors in the current study indicated that health organizations and clinical providers were not meeting their medical needs; and, instead of the clinical providers, the breast cancer survivors relied on their village of supporters to secure culturally appropriate medical services. A potential solution to this issue could be for health care systems to perform organizational assessments to explore systemic practices that may encourage racial inequities and implicit biases. Health care organizations should consider overhauling their processes, policies, and institutional customs (CDC, 2020b). As a result, health care organizations may reduce health discrepancies and establish trust in health care systems.

There is a need for performance management tools to explore the root causes of systemic issues preventing the resolution of health inequities. Prioritizing organizational assessments to assess cultural competencies and interdisciplinary care teams is vital to recognizing and eliminating health care policies and practices that promote racial disparities. Unfortunately, these

assessments are often limited or not promoted by senior leadership throughout the organization. Awareness and assessment of patients' cultural identity and social determinants of health are crucial responsibilities for providers and health care organizations (National Commission for Health Education Credentialing [NCHEC], 2020). Health educators can offer written materials, verbal communication, instruction, and multimedia approaches tailored to patients' cultural awareness and identity to promote behavioral change in physicians, reduce barriers, and increase recommended health services (Garcia et al., 2010).

### **Providing Culturally Appropriate Care**

Health educators can provide support in clinical settings by offering tailored patient services. In *Healthy People 2030*, the U.S. Department of Health and Human Services (2021) identified the five areas of social determinants of health, demonstrating how social interactions with physicians and clinical practitioners can contribute to stress in at-risk populations and impact health outcomes. Health educators are trained to employ strategies to positively affect health outcomes and promote culturally appropriate care include educating physicians to support better clinical outcomes and more meaningful interactions. For example, breast cancer oncologists may consider incorporating health educators within the clinical setting to develop comprehensive patient education plans for improved adherence to clinical recommendations and positive patient outcomes (Gorrindo et al., 2014). Additionally, extending the functionality of health care teams would allow health educators to coordinate with physicians and promote collaborative health care teams. Shared efforts may increase the likelihood of breast cancer patients adhering to their health care management plans. As a result, patients could receive resources to more effectively navigate their breast cancer diagnosis, treatment, and survivorship care through the health care system (Ritsema et al., 2014).

## **Limitations**

This qualitative study had several limitations that may affect the applicability and of the study findings. First, most survivors in the current study received referrals from other survivors who were or had received breast cancer services and/or participated in support groups provided by Bridge Breast Network. As a result, some of the participants were acquainted with each other. Some of the women in the study, who were familiar with African American women working with other breast cancer agencies, may have provided different interview responses. As a result of these affiliations with specific health care agencies, the women's overall knowledge and awareness of breast cancer might be more advanced than other women diagnosed with the disease. Therefore, the findings from this study may not be transferable to other African American women diagnosed with breast cancer.

Second, the number of participants for this study was represented only one ethnicity (non-Hispanic Black/African American). Study findings might have varied with breast cancer survivors recruited from other ethnic and cultural backgrounds. It is worth noting, however, that the researcher believed using one ethnic group permitted a more comprehensive understanding of the lived experiences of the participants' interests.

Third, the use of video conferencing due to COVID-19 protocols could be another limitation of the study. Participants shared they were reluctant to engage in video conferences at home out of fears that family members working from home might overhear their conversation. These women chose to meet face-to-face instead of risking others hearing their stories. Another limitation of video conferencing is that software and internet interruptions could have forced a pause in interview communication, which could have resulted in a loss of data points or the participant's train of thought in responding.

## **Conclusions**

Throughout this study, many survivors were aware of the risk of inconsistencies in care among African American breast cancer survivors. As a result, the women created support networks to support African American women diagnosed with breast cancer to avoid medical discrimination. Additionally, based on the findings, it appeared that many participants were aware of African American women's increased risks of dying from breast cancer compared to Caucasian women based on nonmodifiable risk factors, such as dense breasts. The risk factors for high breast density include race and ethnicity, genetics, reproductive history, environmental circumstances, and diet (Nazari & Mukherjee, 2018). As such, the women in this study sought out and connected with breast cancer survivor groups to increase the probability of success after diagnosis. The most salient message from the study is that networking is an active and ongoing process among breast cancer patients and survivors. Networking includes consulting for treatment considerations, recommending physicians, and effectively and regularly communicating and assisting new breast cancer survivors.

## **Future Research**

Based on the results from this investigation, there are several areas of future research recommended:

1. Future studies should explore ways for health educators and health care providers to collaborate as social change agents by actively engaging in public policy strategies to improve patients' health care access.
2. Future studies should include a more deliberate exploration of African American breast cancer survivors and the mental health implications related to PTSD. Support systems are an essential part of patient care and can minimize health inequities within

the health care system. Support systems for breast cancer services include mental assistance with life-altering diseases, such as breast cancer, which create a frightening situation.

3. Future studies should include the factor of maternal breast cancer among African American breast cancer survivors who do not have a family history of breast cancer. A few of the participants' mothers had breast cancer, but the women did not test positive for hereditary BRCA genes.
4. Future studies should focus on the family support received by African American breast cancer survivors. For example, many survivors discussed the importance of family support throughout their battles. However, few researchers have focused on the lived experiences of the families of breast cancer survivors.

## REFERENCES

- Adam, A., & Koranteng, F. (2020). Availability, accessibility, and impact of social support on breast cancer treatment among breast cancer patients in Kumasi, Ghana: A qualitative study. *PloS ONE*, 15(4), Article e0231691. <https://doi.org/10.1371/journal.pone.0231691>
- Adams, L. B., Richmond, J., Corbie-Smith, G., & Powell, W. (2017). Medical mistrust and colorectal cancer screening among African Americans. *Journal of Community Health*, 42(5), 1044–1061. <https://doi.org/10.1007/s10900-017-0339-2>
- American Cancer Society. (2018). *7 things to know about getting a mammogram*. <https://www.cancer.org/cancer/breast-cancer/mammogram>
- American Cancer Society. (2019). *Breast cancer facts & figures 2019–2020*. <https://www.cancer.org/research/cancer-facts-statistics/breast-cancer-facts-figures.html>
- American Cancer Society. (2021). *American Cancer Society recommendations for the early detection of breast cancer*. <https://www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection/american-cancer-society-recommendations-for-the-early-detection-of-breast-cancer.html>
- American Cancer Society. (2022). *Type of breast cancer*. <https://www.cancer.org/cancer/breast-cancer/about/how-common-is-breast-cancer.html>
- Arnett, M., Thorpe, J., Gaskin, D., Bowie, J., & LaVeist, T. (2016). Race, medical mistrust, and segregation in primary care as usual source of care: Findings from the exploring health disparities in integrated communities study. *Journal of Urban Health*, 93(3), 456–467. <https://doi.org/10.1007/s11524-016-0054-9>

- Artiga, S., & Hinton, E. (2018, May 10). *Beyond health care: The role of social determinates in promoting health and health equity*. Kaiser Family Foundation.  
<https://www.kff.org/racial-equity-and-health-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/>
- Ashcraft, P. (2013). Explanatory models of obesity of inner-city African-American adolescent males. *Journal of Pediatric Nursing*, 28(5), 430–438.  
<https://doi.org/10.1016/j.pedn.2013.01.002>
- Babatunde, O., Eberth, J., Felder, T., Moran, R., Truman, S., Hebert, J., Zhang, J., & Adams, S. (2020). Social determinants of racial disparities in breast cancer mortality among Black and White women. *Journal of Racial and Ethnic Health Disparities*, 8, 147–156.  
<https://doi.org/10.1007/s40615-020-00766-y>
- Babbie, E. (2016). *The practice of social research*. CENGAGE Learning.
- Bailey, Z., Krieger, N., Agénor, M., Graves, J., Linos, N., & Bassett, M. (2017). Structural racism and health inequities in the USA: Evidence and interventions. *The Lancet*, 389(10077), 1453–1463. [https://doi.org/10.1016/S0140-6736\(17\)30569-X](https://doi.org/10.1016/S0140-6736(17)30569-X)
- Bambhroliya, A., Burau, K., & Sexton, K. (2012). Spatial analysis of county-level breast cancer mortality in Texas. *Journal of Environmental and Public Health*, 2012, Article 959343.  
<https://doi.org/10.1155/2012/959343>
- Bonsu, A., & Ncama, B. (2019). Recognizing and appraising symptoms of breast cancer as a reason for delayed presentation in Ghanaian women: A qualitative study. *PloS ONE*, 14(1), Article e0208773. <https://doi.org/10.1371/journal.pone.0208773>
- Breast Cancer.org. (2020a). *Breast cancer stages*.  
<https://www.breastcancer.org/symptoms/diagnosis/staging#stage0>

Breast Cancer.org. (2020b). *Breast cancer stages*.

<https://www.breastcancer.org/symptoms/diagnosis/staging#stage1>

Breast Cancer.org. (2020c). *Breast cancer stages*.

<https://www.breastcancer.org/symptoms/diagnosis/staging#stage2>

Breast Cancer.org. (2020d). *Breast cancer stages*.

<https://www.breastcancer.org/symptoms/diagnosis/staging#stage3>

Burns, V., Macdonald, M. E., & Carnevale, F. (2018). Epistemological oppression and the road to awakening: A boot camp, a Twitter storm, and a call to action! *International Journal of Qualitative Methods*, 17(1), Article 1609406918763413. Advance online publication.

<https://doi.org/10.1177/1609406918763413>

Butler, J., Fryer, C., Garza, M., Quinn, S., & Thomas, S. (2018). Commentary: Critical race theory training to eliminate racial and ethnic health disparities. *Ethnicity & Disease*, 28(Suppl 1), 279–284. <https://doi.org/10.18865/ed.28.S1.279>

Campesino, M., Saenz, D. S., Choi, M., & Krouse, R. S. (2012). Perceived discrimination and ethnic identity among breast cancer survivors. *Oncology Nursing Forum*, 39(2), E91–E100. <https://doi.org/10.1188/12.ONF.E91-E100>

Cancer.net. (2019a). *Post-traumatic stress disorder and cancer*.

<https://www.cancer.net/survivorship/life-after-cancer/post-traumatic-stress-disorder-and-cancer>

Cancer.net. (2019b). *What is survivorship?* <https://www.cancer.net/survivorship/what-survivorship>

- Castle, B., Wendel, M., Kerr, J., Brooms, D., & Rollins, A. (2018). Public health's approach to systemic racism: A systematic literature review. *Journal of Racial and Ethnic Health Disparities*, 6, 27–36. <https://doi.org/10.1007/s40615-018-0494-x>
- Centers for Disease Control and Prevention. (2019). *National Breast and Cervical Cancer Early Detection Program: National report for program years 2003–2014*. U.S. Department of Health and Human Services. <https://www.cdc.gov/cancer/nbccedp/pdf/nbccedp-national-report-2003-2014-508.pdf>
- Centers for Disease Control and Prevention. (2020a). What is breast cancer screening? [https://www.cdc.gov/cancer/breast/basic\\_info/screening.htm](https://www.cdc.gov/cancer/breast/basic_info/screening.htm)
- Centers for Disease Control and Prevention. (2020b). *Social determinants of health*. <https://www.cdc.gov/socialdeterminants/data/>
- Centers for Disease Control and Prevention. (2020c). *What are the symptoms of breast cancer?* [https://www.cdc.gov/cancer/breast/basic\\_info/symptoms.htm](https://www.cdc.gov/cancer/breast/basic_info/symptoms.htm)
- Churpek, J., Walsh, T., Zheng, Y., Moton, Z., Thornton, A., Lee, M., Casadei, S., Watts, A., Neistadt, B., Churpek, M., Hou, D., Zvosec, C., Liu, F., Niu, Q., Marquez, R., Zhang, J., Fackenthal, J., King, M., & Olopade, O. (2015). Inherited predisposition to breast cancer among African American women. *Breast Cancer Research and Treatment*, 149, 31–39. <https://doi.org/10.1007/s10549-014-3195-0>
- Clayton, J. A., Brooks, C. E., & Kornstein, S. G. (2014). Toward more individualized medicine: Introducing the *Women of Color Health Data Book*, fourth edition. *Journal of Women's Health*, 24(10), 781–782. <https://doi.org/10.1089/jwh.2014.1508>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative and mixed methods approaches*. SAGE.

- Cross, R. (2018). Commentary: Can critical race theory enhance the field of public health? A student's perspective. *Ethnicity & Disease*, 28(1), 267–270.  
<https://doi.org/10.18865/ed.28.S1.267>
- Daly, B., & Olopade, O. (2015). A perfect storm: How tumor biology, genomics, and health care delivery patterns collide to create a racial survival disparity in breast cancer and proposed interventions for change. *CA: A Cancer Journal for Clinicians*, 65(3), 221–238.  
<https://doi.org/10.3322/caac.21271>
- Day, A., O'Shay-Wallace, S., Seeger, M., & McElmurry, S. (2019). Informational sources, social media use, and race in Flint, Michigan's water crisis. *Communication Studies*, 70(3), 352–376. <https://doi.org/10.1080/10510974.2019.1567566>
- Dinos, S., Ascoli, M., Owiti, J., & Bhui, K. (2017). Assessing explanatory models and health beliefs: An essential but overlooked competency for clinicians. *BJPsych Advances*, 23(2), 106–114. <https://doi.org/10.1192/apt.bp.114.013680>
- Ford, C. L., & Jeffers, K. S. (2019). *Critical race theory's antiracism approaches: Moving from the ivory tower to the front lines of public health*. American Public Health Association.  
<https://doi.org/10.2105/9780875533049ch16>
- Ford, C., & Airhihenbuwa, C. (2010). The public health critical race methodology: Praxis for antiracism research. *American Journal of Public Health*, 100(Suppl 1), S30–S35.  
<https://doi.org/10.2105/AJPH.2009.171058>
- Ford, C., & Airhihenbuwa, C. (2018). Commentary: Just what is critical race theory and what's it doing in a progressive field like public health? *Ethnicity & Disease*, 28(Suppl 1), 223–230. <https://doi.org/10.18865/ed.28.S1.223>

- Fred Hutch Breast Cancer Global Initiative. (2020). *Implementation strategy for improving breast cancer care globally*.
- Freeman, R., Gwadz, M., Silverman, E., Kutnick, A., Leonard, N., Ritchie, A., Reed, J., & Martinez, B. (2017). Critical race theory as a tool for understanding poor engagement along the HIV care continuum among African American/Black and Hispanic persons living with HIV in the United States: A qualitative exploration. *International Journal of Equity Health*, 16, Article 54. <https://doi.org/10.1186/s12939-017-0549-3>
- Garcia, S. F., Hahn, E. A., & Jacobs, E. A. (2010). Addressing low literacy and health literacy in clinical oncology practice. *The Journal of Supportive Oncology*, 8(2), 64–69. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3127453/>
- Gehlert, S., Kavanaugh-Lynch, M. H., & Fernandez Poole, S. (2021). Searching beyond the lamppost to reduce breast cancer disparities. *International Journal of Environmental Research and Public Health*, 18(3), Article 1186. <https://doi.org/10.3390/ijerph18031186>
- Golden, S., & Earp, J. (2012). Social ecological approaches to individuals and their contexts: Twenty years of health education & behavior health promotion interventions. *Health Education & Behavior*, 39(3), 364–372. <https://doi.org/10.1177/1090198111418634>
- Gorichanaz, T. (2017). Auto-hermeneutics: A phenomenological approach to information experience. *Library & Information Science Research*, 39(1), 1–7. <https://doi.org/10.1016/j.lisr.2017.01.001>
- Gorrindo, P., Peltz, A., Ladner, T. R., Miller, B. M., Miller, R. F., & Fowler, M. J. (2014). Medical students as health educators at a student-run free clinic: Improving the clinical outcomes of diabetic patients. *Academic Medicine*, 89(4), 625–631. <https://doi.org/10.1097/ACM.0000000000000164>

- Groos, M., Wallace, M., Hardeman, R., & Theall, K. P. (2018). Measuring inequity: A systematic review of methods used to quantify structural racism. *Journal of Health Disparities Research and Practice*, 11(2), 190–205.  
<https://digitalscholarship.unlv.edu/jhdrp/vol11/iss2/13>
- Gunn, C. M., Bokhour, B., Parker, V. A., Parker, P. A., Blakeslee, S., Bandos, H., & Holmberg, C. (2019). Exploring explanatory models of risk in breast cancer risk counseling discussions: NSABP/NRG Oncology Decision-Making Project 1. *Cancer Nursing*, 42(1), 3–11. <https://doi.org/10.1097/NCC.0000000000000517>
- Hooker, C. (2015). Understanding empathy: Why phenomenology and hermeneutics can help medical education and practice. *Medicine, Health Care and Philosophy*, 18, 541–552.  
<https://doi.org/10.1007/s11019-015-9631-z>
- Hortobagyi, G. N., Edge, S. B., & Giuliano, A. (2018). New and important changes in the TNM staging system for breast cancer. *ASCO Educational Book*, 38, 457–467.  
[https://doi.org/10.1200/edbk\\_201313](https://doi.org/10.1200/edbk_201313)
- Hsieh, J.-G., Hsu, M., & Wang, Y.-W. (2016). An anthropological approach to teach and evaluate cultural competence in medical students: The application of mini-ethnography in medical history taking. *Medical Education Online*, 21(1), Article 32561.  
<https://doi.org/10.3402/meo.v21.32561>
- Institute of Medicine. (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care*. The National Academies of Sciences, Engineering, Medicine.  
<https://doi.org/10.17226/10260>

- Karimi, S., Rafiey, H., Sajjadi, H., & Nejad, F. (2018). Identifying the social determinants of breast health behavior: A qualitative content analysis. *Asian Pacific Journal of Cancer Prevention*, 19(7), 1867–1877. <https://doi.org/10.22034/apjcp.2018.19.7.1867>
- Keating, N., & Pace, L. (2018). Breast cancer screening in 2018: Time for shared decision making. *JAMA Insights*, 319(17), 1814–1815. <https://doi.org/10.1001/jama.2018.3388>
- Kleinman, A., & Benson, P. (2006). Anthropology in the clinic: The problem of cultural competency and how to fix it. *PLoS Medicine*, 3(10), Article 30294. <https://doi.org/10.1371/journal.pmed.0030294>
- Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, 88(2), 251–258. <https://doi.org/10.7326/0003-4819-88-2-251>
- Koo, M., Wagner, C., Abel, G., McPhail, S., Rubin, G., & Lyratzopoulos, G. (2017). Typical and atypical presenting symptoms of breast cancer and their associations with diagnostic intervals: Evidence from a national audit of cancer diagnosis. *Cancer Epidemiology*, 48, 140–146. <https://doi.org/10.1016/j.canep.2017.04.010>
- Kumra, T., Hsu, Y. J., Cheng, T. L., Marsteller, J. A., McGuire, M., & Cooper, L. A. (2020). The association between cultural competence and teamwork climate in a network of primary care practices. *Health Care Management Review*, 45(2), 106–116. <https://doi.org/10.1097/HMR.0000000000000205>
- Kyanko, K., Hoag, J., Busch, S., Aminawung, J., Xu, X., Richman, I., & Gross, C. (2020). Dense breast notification laws, education, and women’s awareness and knowledge of breast density: A nationally representative survey. *Journal of General Internal Medicine*, 35(7), 1940–1945. <https://doi.org/10.1007/s11606-019-05590-7>

- Lauterbach, A. A. (2018). Hermeneutic phenomenological interviewing: Going beyond semi-structured formats to help participants revisit experience. *The Qualitative Report*, 23(11), 2883–2898. <https://nsuworks.nova.edu/tqr/vol23/iss11/16/>
- Laws, B. (2016). Explanatory models and illness experience of people living with HIV. *AIDS Behavior*, 20, 2119–2129. <https://doi.org/10.1007/s10461-016-1358-1>
- LeBrón, A., Lopez, W., Cowan, K., Novak, N., Temrowski, O., Ibarra-Frayre, M., & Delva, J. (2018). Restrictive ID policies: Implications for health equity. *Journal of Immigrant and Minority Health*, 20(2), 255–260. <https://doi.org/10.1007/s10903-017-0579-3>
- Lee, N., Wong, F., Jamison, P., Jones, S., Galaska, L., Brady, K., Wethers, B., & Stokes-Townsend, G. (2014). Implementation of the national breast and cervical cancer early detection program: The beginning. *Cancer*, 120(Suppl 16), 2540–2548. <https://doi.org/10.1002/cncr.28820>
- Li, N., Deng, Y., Zhou, L., Tian, T., Yang, S., Wu, Y., Zheng, Y., Zhai, Z., Hao, Q., Song, D., Zhang, D., Kang, H., & Dai, Z. (2019). Global burden of breast cancer and attributable risk factors in 195 countries and territories, from 1990 to 2017: Results from the Global Burden of Disease Study 2017. *Journal of Hematology & Oncology*, 12(140), 1–12. <https://doi.org/10.1186/s13045-019-0828-0>
- Lindberg, P., Koller, M., Steinger, B., Lorenz, W., Wyatt, J., Inwald, E., & Klinkhammer-Schalke, M. (2015). Breast cancer survivors' recollection of their illness and therapy seven years after enrolment into a randomised controlled clinical trial. *BMC Cancer*, 15(554) 1–13. <https://doi.org/10.1186/s12885-015-1573-6>

- Maher, C., Hadfield, M., Hutchings, M., & de Eyto, A. (2018). Ensuring rigor in qualitative data analysis: A design research approach to coding combining NVivo with traditional materials methods. *International Journal of Qualitative Methods*, (17), 1–13.  
<https://doi.org/10.1177/1609406918786362>
- Masten, S. J., Davies, S. H., & McElmurry, S. P. (2016). Flint water crisis: What happened and why? *Journal: American Water Works Association*, 108(12), 22–34.  
<https://doi.org/10.5942/jawwa.2016.108.0195>
- Mishra, S., DeForge, B., Barnet, B., Ntiri, S., & Grant, L. (2012). Social determinants of breast cancer screening in urban primary care practices: A community-engaged formative study. *Women's Health Issues*, 22(5), 29–38. <https://doi.org/10.1016/j.whi.2012.06.004>
- Morse, J. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, 25(9) 1212–1222.  
<https://doi.org/10.1177/1049732315588501>
- Moustakas, C. (1994). *Phenomenological research methods*. SAGE.
- Muhammad, M., De Loney, E., Brooks, C., Assari, S., Robinson, D., & Caldwell, C. (2018). “I think that’s all a lie... I think it’s genocide”: Applying a critical race praxis to youth perceptions of Flint water contamination. *Ethnicity & Disease*, 28(1), 241–246.  
<https://doi.org/10.18865/ed.28.S1.241>
- Mullins, M., Peres, L., Alberg, A., Bandera, E., Barnholtz-Sloan, J., Bondy, M., Funkhoser, E., Moorman, P., Peters, E., Terry, P., Schwartz, A., Lawson, A., Schildkraut, J., & Cote, M. (2019). Perceived discrimination, trust in physicians, and prolonged symptom duration before ovarian cancer diagnosis in the African American Cancer epidemiology study. *Cancer*, 125(24), 4442–4451. <https://doi.org/10.1002/cncr.32451>

- Myles, Z., Rice, K., Degroff, A., & Miller, J. (2015). A profile of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provider network: Results from the year NBCCEDP survey of program implementation. *Quality in Primary Care*, 23(6), 315–317. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4912227/>
- National Cancer Institute. (2018). *Cancer stat facts: Female breast cancer*. <https://seer.cancer.gov/statfacts/html/breast.html>
- National Cancer Institute. (2020). *PDQ cancer information summaries*. <https://www.ncbi.nlm.nih.gov/books/NBK65906/>
- National Cancer Institute. (2021). *Age-adjusted SEER incidence rates by year, race and age*. [https://seer.cancer.gov/csr/1975\\_2017/](https://seer.cancer.gov/csr/1975_2017/)
- National Commission for Health Education Credentialing. (2020). Health Education Responsibilities. <https://www.nchec.org/health-education-responsibilities>
- Nazari, S., & Mukherjee, P. (2018). An overview of mammographic density and its association with breast cancer. *Breast Cancer*, 25, 259–267. <https://doi.org/10.1007/s12282-018-0857-5>
- Nelson, B., & Kaminsky, D. (2020). How structural racism can kill cancer patients. *Cancer Cytopathology*, 128(2), 83–84. <https://doi.org/10.1002/cncy.22247>
- Neubauer, B., Witkop, C., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education*, 8, 90–97. <https://doi.org/10.1007/s40037-019-0509-2>
- Newman, L. A., & Kaljee, L. (2017). Health disparities and triple-negative breast cancer in African American women. *JAMA Surgery*, 152(5), 485–493. <https://doi.org/10.1001/jamasurg.2017.0005>

- Noonan, A., Velasco-Mondragon, H., & Wagner, F. (2016). Improving the health of African Americans in the USA: An overdue opportunity for social justice. *Public Health Review*, 37, Article 12. <https://doi.org/10.1186/s40985-016-0025-4>
- Page-Reeves, J., Kaufman, W., Bleecker, M., Norris, J., McCalmont, K., Ianakieva, V., Ianakieva, D., & Kaufman, A. (2016). Addressing social determinants of health in a clinic setting: The WellRx pilot in Albuquerque, New Mexico. *Journal of the American Board of Family Medicine*, 29(3), 414–418. <https://doi.org/10.3122/jabfm.2016.03.150272>
- Park, J., & Look, K. (2019). Health care expenditure burden of cancer care in the United States. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*, 56, Article 0046958019880696. <https://doi.org/10.1177/0046958019880696>
- Pruitt, S. L., Lee, S. J. C., Tiro, J. A., & Xuan, L. (2015). Residential racial segregation and mortality among Black, White, and Hispanic urban breast cancer patients in Texas, 1995 to 2009. *Cancer*, 121(11), 1845–1855. <https://doi.org/10.1002/cncr.29282>
- Quach, T., Nuru-Jeter, A., Morris, P., Allen, L., Shema, S., Winters, J., Le, G., & Gomez, S. (2012). Experiences and perceptions of medical discrimination among a multiethnic sample of breast cancer patients in the greater San Francisco Bay Area, California. *American Journal of Public Health*, 102(5), 1027–1034. <https://doi.org/10.2105/AJPH.2011.300554>
- Ranskin, I., Shelton, R., Comeau, D., Cooper, H., Griffith, D., & Kegler, M. (2018). A review of qualitative data analysis practices in health education and health behavior research. *Qualitative Inquiry in Health Education & Behavior*, 46(1), 32–39. <https://doi.org/10.1177/1090198118795019>

- Ray, E., Wheeler, S., & Reeder-Hayes, K. (2018). Race and place: Complex constructs in breast cancer care. *Translational Cancer Research*, 7(6), 1361–1365.  
<https://doi.org/10.21037/tcr.2018.09.11>
- Richardson, L., Henley, S., Miller, J., Massetti, G., & Thomas, C. (2016). Patterns and trends in age-specific Black-White differences in breast cancer incidence and mortality – United States, 1999–2014. *MMWR Morbidity and Mortality Weekly Report*, 65(40) 1093–1098.  
<https://doi.org/10.15585/mmwr.mm6540a1>
- Ritsema, T. S., Bingenheimer, J. B., Scholting, P., & Cawley, J. F. (2014). Differences in the delivery of health education to patients with chronic disease by provider type. *Public Health Research*, 11(130175), 2005–2009. <https://doi.org/10.5888/pcd11.130175>
- Ruckart, P., Ettinger, A., Hanna-Attisha, M., Jones, N., Davis, S., & Breysse, P. (2019). The Flint water crisis: A coordinated public health emergency response and recovery initiative. *Journal of Public Health Management and Practice*, 25(1), S84–S90.  
<https://doi.org/10.1097/PHH.0000000000000871>
- Saldaña, J. (2013). *The coding manual for qualitative researchers*. SAGE.
- Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63–75. <https://doi.org/10.3233/EFI-2004-22201>
- Shimelis, H., LaDuca, H., Chunling, H., Hart, S., Na, J., Thomas, A., Akinhanmi, M., Moore, R., Brauch, H., Cox, A., Eccles, D., Ewart-Toland, A., Fasching, P., Fostira, F., Garber, J., Godwin, A., Konstantopoulou, I., Nevanlinna, H., Sharma, P.,... Couch, F. (2018). Triple-negative breast cancer risk genes identified by multigene hereditary cancer panel testing. *JNCI: Journal of the National Cancer Institute*, 110(8), 855–862.  
<https://doi.org/10.1093/jnci/djy106>

- Shiyanbola, O., Arao, R., Miglioretti, D., Sprague, B., Hampton, J. M., Stout, N., Kerlikowske, K., Braithwaite, D., Buist, D., Egan, K., Newcomb, P., & Trentham-Dietz, A. (2017). Emerging trends in family history of breast cancer and associated risk. *Cancer Epidemiology Biomarkers & Prevention*, 26(12), 1753–1760.  
<https://doi.org/10.1158/1055-9965.epi-17-0531>
- Siegel, R., Miller, K., Fuchs, H., & Jemal, A. (2021). Cancer statistics, 2021. *CA: A Cancer Journal for Clinicians*, 71(1), 7–33. <https://doi.org/10.3322/caac.21654>
- Smedley, B. (2012). The lived experience of race and its health consequences. *American Journal of Public Health*, 102(5), 933–935. <https://doi.org/10.2105/AJPH.2011.300643>
- Sunstein, B. S., & Chiseri-Strater, E. (2011). *Fieldworking: Reading and writing research*. Bedford/St.Martin's.
- Susan G. Komen. (2018). *African-American health equity initiative: From education to impact*.  
<https://ww5.komen.org/AAHealthEquity/>
- Susan G. Komen. (2021a). *Breast cancer facts*. <https://www.komen.org/breast-cancer/facts-statistics/breast-cancer-statistics/>
- Susan G. Komen. (2021b). *Disparities in breast cancer outcomes for Black women in the U.S. are unacceptable*. <https://www.komen.org/about-komen/our-impact/breast-cancer/health-equities-initiative/>
- Susan G. Komen. (2021c, February 4). *Speak truth to power: Stand up, speak up*.  
[https://www.komen.org/wp-content/uploads/2021\\_STTP\\_Regional-TX.pdf](https://www.komen.org/wp-content/uploads/2021_STTP_Regional-TX.pdf)
- Sutton, A., He, J., Edmonds, M., & Sheppard, V. (2019). Medical mistrust in Black breast cancer patients: Acknowledging the roles of the trustor and the trustee. *Cancer Education*, 34(3), 600–607. <https://doi.org/10.1007/s13187-018-1347-3>

- Swygart-Hobaugh, M. (2019). Bringing method to the madness: An example of integrating social science qualitative research methods into NVivo data analysis software training. *IASSIST Quarterly*, 43(2), 1–16. <https://doi.org/10.29173/iq956>
- Texas Cancer Registry. (2018). *Female breast cancer in Texas*. <https://www.dshs.state.tx.us/tcr/data/breast-cancer.aspx>
- Texas Cancer Registry. (2020). *Breast cancer*. <https://www.dshs.state.tx.us/tcr/data/breast-cancer.aspx>
- Thomas, P., Class, C., Gandhi, T., Bambhroliya, A., Do, K., & Brewster, A. (2019). Demographic, clinical, and geographical factors associated with lack of receipt of physician recommended chemotherapy in women with breast cancer in Texas. *Cancer Causes & Control*, 30(4), 409–415. <https://doi.org/10.1007/s10552-019-01151-9>
- Thomas, S., Quinn, S., Butler, J., Fryer, C., & Garza, M. (2011). Toward a fourth generation of disparities research to achieve health equity. *Annual Review of Public Health*, 32, 399–416. <https://doi.org/10.1146/annurev-publhealth-031210-101136>
- Tirodkar, M., Baker, D. W., Makoul, G., Khurana, N., Paracha, M., & Kandula, N. (2011). Explanatory models of health and disease among South Asian immigrants in Chicago. *Journal of Immigrant and Minority Health*, 13(2), 385–394. <https://doi.org/10.1007/s10903-009-9304-1>
- Tracy, S. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837–851. <https://doi.org/10.1177/1077800410383121>
- Tufford, L., & Newman, P. (2010). Bracketing in qualitative research. *Qualitative Social Work*, 11(1), 80–93. <https://doi.org/10.1177/1473325010368316>

U.S. Department of Health & Human Services. (2021). *Healthy People 2030*.

<https://health.gov/healthypeople>

Wallace, S. (2015). Equity and social determinants of health among older adults. *Journal of the American Society on Aging*, 38(4), 6–11.

Wasserman, J., Palmer, R., Gomez, M., Berzon, R., Ibrahim, S., & Ayanian, J. (2019).

Advancing health services research to eliminate health care disparities. *American Journal of Public Health*, 109(S1), S64–S69. <https://doi.org/10.2105/AJPH.2018.304955>

White, M., Kavanaugh-Lynch, M., Davis-Patterson, S., & Buermeier, N. (2020). An expanded agenda for the primary prevention of breast cancer: Charting a course for the future. *International Journal of Environmental Research and Public Health*, 17(3), Article 714. <https://doi.org/10.3390/ijerph17030714>

Williams, D., Mohammed, S., & Shields, E. (2016). Understanding and effectively addressing breast cancer in African American women: Unpacking the social context. *Cancer*, 122(14), 2138–2149. <https://doi.org/10.1002/cncr.29935>

Williams, F., & Thompson, E. (2017). Disparities in breast cancer stage at diagnosis: Importance of race, poverty, and age. *Journal of Health Disparities Research and Practice*, 10(3), 34–45. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6326172/>

Wilson, H., & Hutchinson, S. (1991). Triangulation of qualitative methods: Heideggerian hermeneutics and grounded theory. *Qualitative Health Research*, 1(2), 263–276. <https://doi.org/10.1177/104973239100100206>

Woodley, X., & Lockard, M. (2016). Womanism and snowball sampling: Engaging marginalized populations in holistic research. *The Qualitative Report*, 21(2), 321–329. <https://nsuworks.nova.edu/tqr/vol21/iss2/9/>

- Wright, N., Akinyemiju, T., Subhedar, P., Rida, P., & Aneja, R. (2019). Targeting risk factors for reducing the racially disparate burden in breast cancer. *Frontiers in Bioscience*, *11*, 136–160. <https://doi.org/10.2741/s531>
- Yedjou, C., Tchounwou, P., Payton, M., Miele, L., Fonseca, D., Lowe, L., & Alo, R. (2017). Assessing the racial and ethnic disparities in breast cancer mortality in the United States. *International Journal of Environmental Research and Public Health*, *14*(486), 1–14. <https://doi.org/10.3390/ijerph14050486>

## APPENDIX A

### INTERVIEW QUESTIONS

The following questions served as a guide for the semi-structured interviews. Interview questions were structured on social behavior studies focused on lived experiences of participants to inform social and culture aspects of illnesses (Ashcraft, 2013; Laws, 2016).

*To establish etiology:*

1. What do you believe caused your breast cancer?
2. Who was the first person you told about your diagnosis?

*To establish onset of symptoms:*

3. What life events led to your diagnosis of breast cancer?
4. At what stage was the breast cancer diagnosed? What type of breast cancer were you diagnosed with?

*To establish pathophysiology:*

5. What does breast cancer do to you, and how does it affect your body?
6. Describe your experience with breast cancer.

*To establish course of illness:*

7. Describe the course of your breast cancer and how it has changed your life.
8. What has been the impact of breast cancer on your personal life (e.g., family, friends, socially)?

*To establish treatment:*

9. Tell me about the treatment options that were available to you and why you made that decision.
10. Tell me about activities that helped you during your diagnosis and treatment.

11. What type of insurance did you have when you were diagnosed? Were you satisfied with your insurance and the coverage you receive? Did your cost of insurance for services impact your treatment decision making?

*To explore perceived medical discrimination:*

12. Did you feel understood by your doctor? Why? (select best response):
- a. Accept it as a fact of life?
  - b. Try to do something about it?
13. Have you ever experienced discrimination, been prevented from doing something, or been hassled or made to feel inferior because of your race, ethnicity, or color?
14. While receiving treatment for breast cancer, did you ever experience medical discrimination with a medical practitioner? Or were you made to feel inferior when receiving medical care services?

APPENDIX B  
DEMOGRAPHIC SURVEY

1. What is your age?
2. In what city in Texas do you live?
3. What is your ZIP code?
4. Which one of these groups would you say best represents your race? To the best of your ability, please choose at least one from the following choices:
  - ☐ Caucasian/White/Non-Hispanic
  - ☐ Black/African American/Non-Hispanic
  - ☐ Hispanic
  - ☐ Asian
  - ☐ Native Hawaiian or other
  - ☐ Pacific Islander
  - ☐ American Indian or Alaska Native
  - ☐ Other
5. What is the highest grade or year of school that you completed?
  - ☐ Never attended school or only attended kindergarten
  - ☐ Grades 1–8 (Elementary)
  - ☐ Grades 9–11 (Some high school)
  - ☐ Grade 12 or GED (High school graduate)
  - ☐ College 1–3 years (Some college or technical school)
  - ☐ Bachelor's degree (4 years of college)
  - ☐ Master's degree
  - ☐ Doctorate
6. Are you currently...?
  - ☐ Employed for wages
  - ☐ Self-employed
  - ☐ A homemaker
  - ☐ A student
  - ☐ Retired
  - ☐ Unable to work

7. Do you have any of the following insurance/health payment plans?

- ☐ Private or employer-based health insurance
- ☐ Medicare or Medicaid
- ☐ Affordable Care Act insurance
- ☐ Other
- ☐ No health insurance or payment plan

8. Last year, what was your total family income from all sources before taxes?

- ☐ Less than \$10,000
- ☐ More than \$10,000 but less than \$20,000
- ☐ More than \$20,000 but less than \$30,000
- ☐ More than \$30,000 but less than \$40,000
- ☐ More than \$40,000 but less than \$50,000
- ☐ More than \$50,000 but less than \$75,000
- ☐ More than \$75,000 but less than \$100,000
- ☐ More than \$100,000

APPENDIX C

IRB APPROVAL



**Texas Woman's University**  
**Institutional Review Board (IRB)**

[irb@twu.edu](mailto:irb@twu.edu)

<https://www.twu.edu/institutional-review-board-irb/>

July 20, 2021

Kim Moss-Linnear  
Health Promotion & Kinesiology

Re: Initial – IRB-FY2021-288 Lived Experiences of African American Breast Cancer Survivors

Dear Kim Moss-Linnear,

The above referenced study has been reviewed and approved using expedited review procedures on July 20, 2021 by the TWU IRB – Denton operating under FWA00000178. If you are using a signed informed consent form, the approved form has been stamped by the IRB and uploaded to the Attachments tab under the Study Details section. This stamped version of the consent must be used when enrolling subjects in your study.

Note that any modifications to this study must be submitted for IRB review prior to their implementation, including the submission of any agency approval letters, changes in research personnel, and any changes in study procedures or instruments. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All modification requests, incident reports, and requests to close the file must be submitted through Cayuse.

Approval for this study will expire on July 19, 2023. A reminder of the study expiration will be sent 45 days prior to the expiration. If the study is ongoing, you will be required to submit a renewal request. When the study is complete, a close request may be submitted to close the study file.

If you have any questions or need additional information, please email your IRB analyst at [irb@twu.edu](mailto:irb@twu.edu) or refer to the [IRB website](https://www.twu.edu/institutional-review-board-irb/).

Sincerely,

TWU IRB – Denton

## APPENDIX D

### DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

| Factors                                                            | <i>N</i> | <i>n</i> | %   |
|--------------------------------------------------------------------|----------|----------|-----|
| Total participants                                                 | 16       |          |     |
| Which one of these groups would you say best represents your race? |          |          |     |
| Caucasian/White/Non-Hispanic                                       |          | 0        | 0   |
| Black/African American/on-Hispanic                                 |          | 16       | 100 |
| Hispanic                                                           |          | 0        | 0   |
| Asian                                                              |          | 0        | 0   |
| Native Hawaiian or Other Pacific Islander                          |          | 0        | 0   |
| American Indian or Alaska Native                                   |          | 0        | 0   |
| What is your age?                                                  |          |          |     |
| 70–75                                                              |          | 2        | 13  |
| 60–69                                                              |          | 1        | 6   |
| 50–59                                                              |          | 8        | 50  |
| 40–49                                                              |          | 3        | 16  |
| 35–40                                                              |          | 2        | 13  |
| In what city in Texas do you live?                                 |          |          |     |
| Arlington                                                          |          | 3        | 16  |
| Burleson                                                           |          | 1        | 6   |
| Crowley                                                            |          | 1        | 6   |
| Dallas                                                             |          | 2        | 13  |
| DeSoto                                                             |          | 1        | 6   |
| Forney                                                             |          | 1        | 6   |
| Fort Worth                                                         |          | 4        | 25  |
| Glen Heights                                                       |          | 1        | 6   |
| Irving                                                             |          | 1        | 6   |
| Plano                                                              |          | 1        | 6   |

| Factors                                                         | <i>N</i> | <i>n</i> | %  |
|-----------------------------------------------------------------|----------|----------|----|
| What is your ZIP code?                                          | 16       |          |    |
| 75038                                                           |          | 1        | 6  |
| 75063                                                           |          | 1        | 6  |
| 75115                                                           |          | 1        | 6  |
| 75126                                                           |          | 2        | 13 |
| 75154                                                           |          | 1        | 6  |
| 75202                                                           |          | 1        | 6  |
| 76001                                                           |          | 1        | 6  |
| 76006                                                           |          | 1        | 6  |
| 76028                                                           |          | 1        | 6  |
| 76036                                                           |          | 1        | 6  |
| 76044                                                           |          | 1        | 6  |
| 76112                                                           |          | 2        | 13 |
| 76211                                                           |          | 1        | 6  |
| 76226                                                           |          | 1        | 6  |
| What is the highest grade or year of school that you completed? | 16       |          |    |
| Grade 12 or GED (high school graduate)                          |          | 1        | 6  |
| College 1–3 years (some college or technical school)            |          | 5        | 31 |
| Bachelor’s degree (4 years of college)                          |          | 6        | 38 |
| Master’s degree                                                 |          | 8        | 50 |
| Doctorate                                                       |          | 0        | 0  |
| Are you currently...?                                           | 16       |          |    |
| Employed for wages                                              |          | 12       | 75 |
| Self-employed                                                   |          | 0        | 0  |
| A homemaker                                                     |          | 0        | 0  |
| A student                                                       |          | 0        | 0  |
| Retired                                                         |          | 2        | 13 |
| Unemployed                                                      |          | 2        | 13 |

| Factors                                                          | <i>N</i> | <i>n</i> | %  |
|------------------------------------------------------------------|----------|----------|----|
| Do you have any of the following insurance/health payment plans? | 16       |          |    |
| Private or employer-based health insurance                       |          | 12       | 75 |
| Medicare or Medicaid                                             |          | 2        | 6  |
| Affordable Care Act insurance                                    |          | 0        | 0  |
| No health insurance or payment plan                              |          | 2        | 6  |
| Last year, what was your total family income?                    | 16       |          |    |
| \$10,000–20,000                                                  |          | 1        | 6  |
| \$20,000–30,000                                                  |          | 1        | 6  |
| \$30,000–40,000                                                  |          | 1        | 6  |
| \$40,000–50,000                                                  |          | 1        | 6  |
| \$50,000–75,000                                                  |          | 6        | 38 |
| \$75,000–100,000                                                 |          | 6        | 38 |

# APPENDIX E

## STUDY PARTICIPANT BREAST CANCER CHARACTERISTICS

| Survivor/<br>participant<br>name                   | Age at<br>diagnosis | Breast<br>cancer<br>stage/<br>type                    | Dense<br>breast | Participated<br>in annual<br>mammo-<br>gram prior<br>to diagnosis | Found<br>breast<br>cancer-<br>self-<br>breast<br>exam<br>(SBE)<br>or<br>mammo-<br>gram<br>(MGM) | Family<br>history<br>of<br>breast<br>cancer | BRCA<br>tested | Reported<br>breast<br>cancer as<br>aggressive |
|----------------------------------------------------|---------------------|-------------------------------------------------------|-----------------|-------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|---------------------------------------------|----------------|-----------------------------------------------|
| Survivor 1<br>Janna                                | 49                  | Stage 0<br>Estrogen<br>Positive                       | Yes             | Yes                                                               | MGM                                                                                             | No                                          | Yes            | No                                            |
| Survivor 2<br>Donna                                | 40                  | Stage II<br>HER2-<br>Estrorogen<br>Triple<br>Positive | No              | No                                                                | SBE                                                                                             | No                                          | Yes            | Yes                                           |
| Survivor 3<br>Lee (mother<br>had breast<br>cancer) | 70                  | Stage III<br>Triple<br>Negative                       | No              | No                                                                | SBE                                                                                             | Yes                                         | No             | Yes                                           |
| Survivor 4<br>Kora                                 | 40                  | Stage III<br>Triple<br>Negative                       | No              | No                                                                | SBE                                                                                             | No                                          | No             | Yes                                           |
| Survivor 5<br>Marlene                              | 54                  | Stage II<br>Estrogen<br>Positive                      | Yes             | Yes                                                               | SBE                                                                                             | No                                          | No             | No                                            |
| Survivor 6<br>Toni (breast<br>cancer<br>twice)     | 55                  | Stage III-<br>Triple<br>Negative                      | Yes             | Yes                                                               | MGRM                                                                                            | No                                          | No             | Yes                                           |
| Survivor 7<br>Aden                                 | 52                  | Stage II<br>HER<br>Positive<br>in both<br>breast      | Yes             | Yes                                                               | MGM                                                                                             | No                                          | No             | Yes                                           |
| Survivor 8<br>Edith                                | 70                  | Stage I<br>Triple<br>Negative                         | Yes             | Yes                                                               | MGM                                                                                             | Yes                                         | Yes            | Yes                                           |

| Survivor/<br>participant<br>name                                   | Age at<br>diagnosis | Breast<br>cancer<br>stage/<br>type | Dense<br>breast | Participated<br>in annual<br>mammo-<br>gram prior<br>to diagnosis | Found<br>breast<br>cancer-<br>self-<br>breast<br>exam<br>(SBE)<br>or<br>mammo-<br>gram<br>(MGM) | Family<br>history<br>of<br>breast<br>cancer | BRCA<br>tested | Reported<br>breast<br>cancer as<br>aggressive |
|--------------------------------------------------------------------|---------------------|------------------------------------|-----------------|-------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|---------------------------------------------|----------------|-----------------------------------------------|
| Survivor 9<br>Cinthia<br>(mother had<br>breast<br>cancer)          | 55                  | Stage I<br>Triple<br>Negative      | Yes             | Yes                                                               | MGM                                                                                             | Yes                                         | Yes            | Yes                                           |
| Survivor 10<br>Sherry                                              | 52                  | Stage I<br>Estrogen<br>Positive    | Yes             | Yes                                                               | SBE                                                                                             | Yes                                         | Yes            | No                                            |
| Survivor 11<br>Tamal                                               | 37                  | Stage II<br>Estrogen<br>Positive   | Yes             | No                                                                | SBE                                                                                             | No                                          | No             | No                                            |
| Survivor 12<br>Dafne<br>(grand-<br>mother had<br>breast<br>cancer) | 33                  | Stage I<br>Estrogen<br>Positive    | No              | No                                                                | MGM                                                                                             | Yes                                         | Yes            | No                                            |
| Survivor 13<br>Jewel<br>(mother had<br>breast<br>cancer)           | 52                  | Stage II<br>Estrogen<br>Positive   | Yes             | Yes                                                               | MGM                                                                                             | Yes                                         | No             | No                                            |
| Survivor 14<br>Naye                                                | 49                  | Stage I<br>Estrogen<br>Positive    | No              | Yes                                                               | SBE                                                                                             | No                                          | No             | No                                            |
| Survivor 15<br>Leah<br>(mother had<br>breast<br>cancer)            | 48                  | Stage II<br>Estrogen<br>Positive   | No              | Yes                                                               | MGM                                                                                             | Yes                                         | Yes            | Yes                                           |
| Survivor 16<br>LeVale                                              | 44                  | Stage II<br>Triple<br>Negative     | Yes             | Yes                                                               | SBE                                                                                             | No                                          | No             | Yes                                           |