


2023

## Descriptions of Breast Self-Care from Inner-City African American and Hispanic Women Seeking Care in a Comprehensive Breast Care center

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Title: Descriptions of Breast Self-Care from Inner-City African American and Hispanic Women Seeking Care in a Comprehensive Breast Care center

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Dissertation submitted  
To the school of Nursing  
at West Virginia University

in partial fulfillment of the requirements for the degree of

Doctor of Philosophy in Nursing

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Morgantown, West Virginia  
March 30, 2023

Keywords: breast self-care, breast self-awareness, clinical breast exam, screening mammogram, African America women, Hispanic women

## Abstract

Descriptions of Breast Self-Care from Inner-City African American and Hispanic Women Seeking Care in a Comprehensive Breast Care center  
Salamata Yoda

**Background:** A plethora of inquiries has irrefutably revealed a decline in the death rates of breast cancer in some ethnic populations due to timely diagnoses, and enhancement in treatment measures. However, not all women have gained equal access to these innovations in healthcare. Certainly, as a repercussion of the noted disparity, the overall breast cancer prevalence among African American and Hispanic women has steadily escalated. Although no single test can detect all breast cancers early, practicing breast self-care consisting of breast self-awareness (BSA) in combination with other screening methods such as clinical breast exam (CBE), mammogram screening, and a suitable follow up after a screening mammogram can upsurge the likelihood of early detection of the disease.

**Purpose:** The purpose of this inquiry was (1) to use Orem's theory of self-care to explore how breast self-care is described by inner New York City African American and Hispanic women seeking care in a comprehensive breast care center. (2) To use the findings as a guide for needs assessment in terms of *breast self-care agency*, *breast self-care deficit*, and *nursing system* based on the principle that disease prevention is fundamental to good health practices.

**Method:** A directed content analysis approach guided by Orem's self-care theory concepts of self-care agency, self-care deficit, and nursing system was used to direct the participant descriptions of their breast self-care, and to lead the analysis of those descriptions. Twelve African American and Hispanic women were recruited during a breast cancer awareness event. Semi-structured interviews were used to gather their stories. The stories were tape-recorded, transcribed verbatim, reconstructed, and confirmed via member check. Data analysis included various stages using specific descriptors, condensed meaning units, subthemes, and themes.

**Results:** Three themes emerged from predetermined categories within the concepts. *Self-care agency: is the power to manage breast self-care through the mutual influence of knowing and doing, in the context of one's culture. Self-care deficits were not identified: When asked about challenges and any discouragements to breast self-care, participants describe being capable of doing what they needed to do. The nursing system: supported breast self-care through healthcare providers, resources, and mammography follow-up.*

**Conclusions:** Findings from the study were consistent with the suggestions of Orem's Self-care nursing theory. When care is delivered in a comprehensive breast center, self-care agency is enhanced, self-care deficits are lessened, and nursing system is an interdisciplinary team. The results revealed and confirmed the usefulness of the framework. The study findings provide theoretical, practical, and policy implications for all healthcare providers who are caring for women. collaborative efforts should be made to assist healthcare centers with a functional nursing system which can provide women with the necessary support and care for breast self-care practices.

## **Dedication**

As a first-generation college graduate, I dedicate this work to my dear husband, my beloved children, my siblings, and to my deceased parents; especially to my mother who though never having been to school knew the power of education and never stopped encouraging me to pursue my schooling till she took her last breath.

## **Acknowledgement**

First and foremost, I am extremely grateful to “Allah” for allowing me to start and complete my PhD in sound and good health. This degree epitomizes many years of hard work, commitment, challenges, tears, and triumphs it took to accomplish this journey. Motivation pushed me to undertake this journey. Determination helped me not to give up no matter the difficulties. Perseverance helped me to achieve my goals. All the glory is ascribed to Allah!

Words cannot express my gratitude to my professor and chair of my committee Dr. Carpenter for his invaluable guidance, advice, continuous support, patience, and feedback at every stage of the research project. I am forever grateful to Dr. Smith whose love for Nursing theory is contagious and transcendent; thank you for your care and guidance. I am sincerely appreciative of Dr. Sheaves who provided me with constructive feedback that improved my study. I am deeply indebted to Dr. Robinson, who encouraged me to pursue higher education.

Additionally, this endeavor would not have been possible without the generous support from the Jonas Nursing and Veterans Healthcare, who financed my research.

I am very grateful to my classmates and cohort members for their feedback sessions, and moral support. Many thanks should also go to all the participants from Bronxcare Health Center, who impacted me, took part in the study, and enabled this research to be possible.

Finally, I would like to express my gratitude to my family and friends who have contributed one way or another to this achievement. A heartfelt thank you to my beloved spouse Moustapha, and children who have supported me and had to put up with my stresses and grumbles for the past years of study! Your unwavering support and belief in me have kept my spirits high during this process. Without your tremendous understanding, love, and encouragement, it would have been impossible for me to complete my study. Your prayers are greatly appreciated now and always!

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## Chapter 1: Introduction

Breast self-care has steadily decreased breast cancer mortality among a majority of women (Monticciolo et al., 2020; Peairs et al., 2017; Talley et al., 2017). However, taking into consideration the significant gaps in breast cancer screening utilization and breast cancer mortality, the same cannot be said about ethnic minority women from African American and Hispanic origins (ACS Cancer Statistics, 2021; Berry et al., 2005; Talley et al., 2017; Yedjou et al., 2017). The death rates due to breast cancer have dropped in some ethnic populations due to timely diagnoses and enhancement in treatment measures. However, not all women have gained equal access to these innovations in healthcare. There is evidence demonstrating that the overall breast cancer prevalence among African American and Hispanic women has steadily escalated (ACS Cancer Statistics, 2022; Berry et al., 2005; Talley et al., 2017; Yedjou et al., 2017).

In New York City (NYC), a multi-ethnic population, most people (58%) residing in its inner city of the Bronx live in high poverty. There are high unemployment rates, low median income, and a high number of uninsured people. Henceforth, it is important to investigate how African American and Hispanic women in a medically marginalized community living in the Bronx describe breast self-care. Chapter 1 presents the problem of *breast self-care* observed among African American and Hispanic women, the prevalence and impact of the problem, its significance, and how it relates to the knowledge base of nursing. The purpose, research question, methodology, and theoretical rationale, which are the major constituents of the study are subsequently examined in this chapter.

### Background of the Problem

The definition of *breast self-care* involves a woman's overall breast health, the activities she undertakes to care for, and to maintain her breasts in a healthy state. For proper *breast self-*

*care* to be practical, the woman needs to have the power to engage in self-care agency. This requires being knowledgeable about making healthy decisions about breast care (Orem, 2001, p. 253-256). Whereas no single test can detect all breast cancers early, practicing breast self-awareness (BSA) in combination with other screening methods such as clinical breast exam (CBE) and screening mammogram can upsurge the likelihood of early detection of the disease.

### **Statement of the Problem**

While documented improvement in breast self-care exists with the majority of female populations, not much is known about marginalized populations such as African American and Hispanic females living in New York City (NYC). In fact, one out of four women in New York City, aged 40 and older is not regularly screened for breast cancer; consequently, in NYC alone, there are approximately 6,278 new breast cancer cases each year, and more than 1,000 breast cancer-related deaths every year. Subsequently, there are 1876.2 newly diagnosed breast cancer cases among African American women, which causes more than 351 breast cancer-related deaths yearly. Likewise, there are about 1263.2 new breast cancer cases among Hispanic women leading to more than 182.2 breast cancer-related deaths every year (NYS Cancer Registry, 2019; New York State Department of Health, 2021). Hence, the problem addressed in this study is *breast self-care* among African American and Hispanic females.

### **Prevalence of the problem**

As one of the most prevailing types of female cancers, breast cancer is the second foremost cause of cancer-related deaths among women in New York State (NYS) (American Cancer Society, 2022; NYS Cancer Registry, 2019). It is predicted that in 2022, about 30% of newly diagnosed cancers in women will be breast cancers (American Cancer Society, 2022). Actually, New York State has one of the highest breast cancer rates in the country (NYS Cancer

Registry, 2019). Specific to New York State as opposed to New York City, over 16,400 women are diagnosed with breast cancer each year and about 2,644 lives are lost every year to breast cancer in New York State alone (NYS Cancer Registry, 2019). The overall cancer incidence among African American and Hispanic women has continued to rise (ACS Cancer Statistics, 2019; Yedjou et al., 2017). Across racial and ethnic groups in the U.S., African American women have 28.9 deaths per 100,000 women and the utmost breast cancer mortality rate, 40% higher than any other ethnic groups (ACS Cancer Statistics, 2019). According to the American Cancer Society, in 2018, the incidence of up-to-date mammography screening was 60% in Hispanic women 45 years of age or older as opposed to 64% in non-Hispanic Caucasian women. The breast cancer prevalence rate surged by about 0.5% per year in Hispanic women from 2009 to 2018 (Cancer Facts & Figures for Hispanic/Latino People 2021-2023). Hispanic/Latina American women have lower mammogram screening rates, are more disposed to present late-stage breast cancer diagnosis and have lower survival rates than Caucasian women (Castañeda et al., 2014; Hedeem & White, 2001; Mojica et al., 2007).

### **Impact of the problem**

If being a woman is a risk factor for getting breast cancer, then indeed, all women are naturally at risk of getting breast cancer. Yet Caucasian women are more likely to get breast cancer than women of other races. When paralleled with Caucasian or African American women, Hispanic women are less likely to get breast cancer. Although they have a lower prevalence of breast cancer when compared with their Caucasian counterparts; African American and Hispanic females have increased late-stage diagnosis and mortality due to breast cancer (New York State Department of Health, 2021). Countless studies have revealed that minority females are more prone than majority females to undergo delays in screening and treatment for breast cancer,

leading to delayed diagnosis of breast cancer, and eventually death (Bentley et al., 1998; Warner et al., 2012; Castañeda et al., 2014; Hedeem & White, 2001; Mojica et al., 2007; Reeder-Hayes et al., 2019).

### **Significance of the Study**

The problem of *breast self-care* among African American and Hispanic women is tied to the concepts of health, healing, and well-being (Smith, 2019, p. 10). Smith describes the concept of health, healing, and well-being as dynamic, transformative, and manifest in living and dying (Smith, 2019, p. 10). In this study, *breast self-care* is related to well-being through a focus on Orem's self-care concepts of self-care deficit, self-care agency, and nursing system. In particular, self-care agency is defined by Orem as: "the complex acquired capability to meet one's continuing requirements for care of self that regulates life processes, maintains, or promotes integrity of human structure and functioning and human development, and promotes well-being" (Orem, 2001, p. 254). It can be concluded that engaging in breast self-care promotes well-being. The findings of this study may reveal how African American and Hispanic women participate in breast self-care agency, thus contributing to the body of knowledge of nursing.

### **Purpose**

The purpose of this qualitative study is to explore how *breast self-care* is described by inner New York City African American and Hispanic women seeking care in a comprehensive breast care center. Orem's theory of self-care will be used to guide the study.

### **Research question**

How do New York City African American and Hispanic women seeking care in a comprehensive breast care center describe *breast self-care*?

## **Methodology**

To address the problem of how African American and Hispanic women in a medically marginalized community describe breast self-care, based on Orem's (2001) concepts of practice, a qualitative descriptive design will be used. Qualitative research methodology is a distinctive method of naturalistic inquiry, particularly suitable in providing a rich and deeper understanding of complex phenomena by giving voice to those whose opinions are seldom heard (Morse, 2007).

For this study, a directed content analysis approach will be used. The purpose of a directed approach to content analysis is to validate or extend conceptually a theoretical framework or theory (Hsieh & Shannon, 2005). For this study, the concepts of self-care agency, self-care deficit, and nursing system will be used to direct the participant descriptions of their breast self-care, and to lead the analysis of those descriptions. Directed content analysis will guide the gathering of descriptions and analysis.

## **Theoretical Rationale**

Orem's concepts of practice will be used as the theoretical framework for this study. Theory is an elemental part of a research process, and it is essential to use theory as a framework to provide perspective and guidance to the research study. Nursing theories and research provide a necessary groundwork and purposefully serve the goals of nursing practice (Fitzpatrick et Wallace, 2006). Orem suggested that descriptive studies may be used to investigate the self-care practices related to particular self-care requisites including universal, developmental, health-deviation or to the total self-care system (Orem, 2001). Henceforth, Orem's approach is considered an appropriate theoretical framework for the present study.

Orem's nursing theory of self-care is composed of three inter-related concepts. These concepts are self-care agency, self-care deficit, and nursing system (Orem, 2001, p. 141). *Self-care* is defined by Orem as: "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (Orem, 2001, p. 43). The theory of self-care refers to care that is performed by oneself for oneself when one has reached a state of maturity that is allowing for consistent, controlled, effective, and purposeful action (Orem, 2001, p. 149). It incorporates three self-care requisites comprising universal self-care requisites, developmental self-care requisites, and health deviation self-care requisites. The concepts of self-care are established on the principle that all individuals are capable of self-care (Orem, 2001, p. 143). Orem believes self-care is intentionally performed, regularly in time and in agreement with the regulatory obligations of individuals (Orem, 2001, p. 143). Self-care is comprised of the concepts of self-care agency, self-care deficit, and nursing system.

### **Self-care agency**

Self-care agency is "defined as the complex acquired ability of mature and maturing persons to know and meet their continuing requirements for deliberate, purposive action, and to regulate their own human functioning and development" (Orem, 2001, p. 254). Self-care agency as it relates to *breast self-care* refers to a woman's ability to deliberately engage in activities intended to promote and maintain her overall breast health perpetually. The activities she engages in to care for and preserve her breasts in a healthy state is breast self-care agency.

### **Self-care deficit**

Self-care deficit is defined by Orem as: "the relationship between self-care agency and therapeutic self-care demands of individuals in which capabilities for self-care, because of existent limitations, are not equal to meeting some or all of the components of their therapeutic

self-care demands” (Orem, 2001, p. 282). The concept of self-care deficit is essentially the elemental constituent of the theory, and is grounded on the principle that individuals are unable to meet their own basic needs; consequently, necessitating nursing intervention (Orem, 2001, p. 146). The aptitude to engage in self-care can be influenced by basic conditioning factors which are age, developmental state, life experience, health state, socio-cultural orientation, health care system factors, family system factors, patterns of living, environmental factors, and resource adequacy and availability. The ability to meet the therapeutic self-care demands is acquired and is different for all individuals (Orem, 2001, p. 147). The emerging deficit in meeting self-care is correlated to limitations or hindrances that prevent individuals from meeting their requirements for health, well-being, growth, and development. The concept of self-care deficit encompasses five methods of helping to include acting for and doing for others, guiding others, supporting another, providing an environment that promotes personal development and meets future demands, and teaching another (Orem, 2001, p. 146-147).

Self-care deficit as it relates to *breast self-care* refers to a woman’s inability to deliberately engage in activities intended to promote and maintain her overall breast health. Causes of the deficit may be related to difficulties or obstacles that prevent African American and Hispanic women from fulfilling their requirements for health, well-being, growth, and development.

### **Nursing system**

Nursing system as described by Orem is comprised of concepts and sequences of deliberate practical actions performed at times in coordination with actions of patients to develop self-care (Orem, 2001, p. 363). The nursing system as it relates to *breast self-care* will be centered around interventions related to women’s breast self-care needs (Orem, 2001, p. 148).

## Summary

This is a study of *breast self-care*. It is based on Orem's Self-Care theory that includes the concepts of self-care agency, self-care deficit, and nursing system. *Breast self-care* continues to be lower than recommended among African American and Hispanic women despite significant improvement in healthcare services. Through the lens of a qualitative descriptive directed content analysis using Orem's concepts of practice, this study is based on the research question: How do New York City African American and Hispanic women seeking care in a comprehensive breast care center describe breast self-care? Gathering descriptions of *breast self-care* offers insight into how *breast self-care* is lived and valued among these women.



## Chapter 2: Review of the Literature

Although breast cancer is currently the second principal cause of cancer-related death of women in the United States at an average lifetime risk of 13%, (The American Cancer Society, 2021), there are still substantial barriers to appropriate utilization of mammography screening among African American and Hispanic women. Existing data suggest that survival rates for African American and Hispanic women with breast cancer diagnoses are significantly lower than those for Caucasian women. The non-adherence to *breast self-care* is a factor in breast cancer mortality. Notwithstanding the established advantages of screening for breast cancer, these services remain underused, thus there is a need for effective, individualized patient communication and education about the importance of *breast self-care*. The purpose of this chapter is to present a synthesis of the literature review by examining articles pertaining to *breast self-care*. Based on Orem's theory of self-care agency, self-care deficit, and nursing system, a review of the literature was conducted to include the topics of: activities of *breast self-care*, self-care frameworks, factors related to breast care, and interventions for *breast self-care*.

### Activities of Breast Self-Care

*Breast self-care* is a combined approach to caring for the breasts and it consists of four specific activities intended to promote breast health. These activities include breast self-awareness (BSA), clinical breast examination (CBE), adherence to screening mammogram, as well as a suitable follow up after screening mammogram. Primarily, the first activity consists of BSA, which is described as a woman's awareness of the normal appearance and feel of her breasts. Women should be advised about the significance of being attentive to breast changes (ACOG, 2017; ACS Cancer Statistics, 2022). As a part of breast cancer screening, countless healthcare providers deem it valuable for a woman to be familiar with her own breasts, so she

can recognize what is normal from abnormal. Self-care agency related to BSA includes the woman's ability to seek the health education required to know about the signs and symptoms of breast cancer, and to have the ability to promptly inform her healthcare provider of any abnormality that may arise in her breasts including a mass, new onset of nipple discharge, and redness in the breasts. BSA is unlike breast self-examination (systematic examination of the breasts on a routine basis), which is no longer recommended due to a risk of harm from false-positive test results and a lack of evidence of the benefit associated with it (ACOG, 2017; Orem, 2001, p. 253-256). BSA should be performed mostly out of habit; the woman needs to have the power to deliberately engage in knowledge seeking behavior related to her breast health (Orem, 2001, p. 253-256). By looking at and feeling her breasts regularly, a woman can notice anything that seems peculiar. BSA can increase a woman's chances of finding breast cancer at an early stage; thus, improving her chances of survival.

A significant number of women reported the first sign of their breast cancer was a new breast mass they discovered on their own (Coates et al., 2001; Newcomer et al., 2002; Roth et al., 2011). As it happens, symptom-based breast cancer detection usually occurs when the woman notices the symptom during her usual daily undertakings such as bathing or dressing (ACS Cancer Statistics, 2022; Siu, 2016; US Preventive Services Task Force, 2009). Furthermore, these findings reiterate the reasons why a woman should be acquainted with her breasts and to promptly report any changes to her health care provider. While breast cancer may not be preventable, BSA can lead to early detection of breast cancer when treatments are likely to be more successful. Early detection can help improve a woman's health outcome if she develops the disease (ACS Cancer Statistics, 2022). When combined with regular screening mammogram and a CBE performed at yearly assessments, BSA plays a significant role in early

detection as it can help a woman notice any changes and get medical advice as early as possible (Provencher et al., 2016).

While research has not shown a clear benefit of BSA, the incidental findings of breast cancer based on reported self-detection stipulate a strong rationale for BSA in the detection of breast cancer. Nearly 50% of cases of breast cancer in women 50 years and older and 71% of cases of breast cancer in women younger than 50 years were discovered by women themselves (Coates et al., 2001; Newcomer et al., 2002). As a matter of fact, 43% of the 361 breast cancer survivors who participated in the 2003 National Health Interview Survey reported self-detection of their cancer themselves (Roth et al., 2011).

Likewise, of the 921 women in the cohort of low-income women who received breast cancer care through California's Breast and Cervical Cancer Treatment Program, 64% self-detected their breast cancer; these findings furthermore indicate the significant role of breast cancer self-detection in the diagnosis of breast cancer (Coates et al., 2001; Newcomer et al., 2002; Roth et al., 2011; Christie et al., 2010). Moreover, bearing in mind the non-adherence to screening mammogram and CBE among African American and Hispanic women, BSA is therefore an important diagnostic method in early detection of breast cancer. Consequently, it is vital to raise awareness of this responsibility in women so health outcomes can be improved (Calbayram and Guven, 2021).

The second activity entails having a CBE, which is a physical breast examination performed by a trained health care professional. Self-care related to CBE consists of the woman's aptitude to request or to remind her healthcare provider of her need to have her breast examined by a trained clinician. While the American Cancer Society (ACS) does not recommend CBE, the U.S. Preventive Services Task Force reported that there was inadequate

evidence to assess the benefits and harms of the CBE. In contrary, the American College of Obstetrics and Gynecologists and the National Comprehensive Cancer Network still advocate for CBE at intervals of 1-3 years for asymptomatic, average-risk women aged 25-39 years and annually for asymptomatic, average-risk women aged 40 years and older (Mango et al., 2018; Siu, 2016; US Preventive Services Task Force, 2009). A study conducted by Provencher et al. (2016) revealed that a substantial number of cancers would have been unnoticed if CBE had not been performed. In fact, of the 6333 malignancies detected by Provencher et al. (2016), 36.5% were diagnosed solely by mammography, while 54.8% were diagnosed by mammography and CBE, and 8.7% were diagnosed exclusively by CBE. Invasive tumors diagnosed by CBE alone were more often triple-negative, HER2-positive, node-positive, and greater in size than those identified by mammography alone ( $p < 0.05$ ) (Provencher et al., 2016). Compared with breast cancers revealed by mammography alone, those detected by CBE had more aggressive characteristics.

Subsequently, indicating that CBE is a very low-cost test that could ameliorate the detection of breast cancer (Provencher et al., 2016). Though the American Cancer Society does not endorse the performance of regular CBE as part of a routine breast cancer screening approach, this does not prohibit the performance of these exams. In fact, in certain circumstances, mostly involving women at higher-than-average risk, health care providers may rather suggest the performance of CBE, together with counseling about the woman's risk factors and possibility of early detection (ACS Cancer Statistics, 2022).

The third activity includes screening mammogram, which is an efficient preventive screening as it identifies signs of breast cancer by detecting and tracking alterations in a woman's breast tissue. *Breast self-care* related to screening mammogram consists of the

woman's ability to adhere to the yearly screening mammogram. Every woman is at risk for breast cancer, however when to begin getting mammograms and how frequent it is needed can differ from one woman to another. It is important for a woman to know her own personal family history, and inquiry of relatives about that history can help in guiding whether she should be under a closer screening schedule (ACS Cancer Statistics, 2022).

Although, most medical organizations including the American Cancer Society (ACS), the American College of Obstetricians and Gynecologists (ACOG), the U.S Preventive Services Task Force (USPSTF), the National Comprehensive Cancer Network (NCCN), the American College of Radiology (ACR), and the Society of Breast Imaging (SBI) unanimously recommend screening mammogram, there are different recommendations as to when a woman should get her first mammogram. The ACOG, the ACS, the NCCN, the ACR, and SBI have advised yearly screening mammogram commencing at age 40 for females with a normal risk of developing breast cancer (ACR, 2019). The ACS endorses that a woman may be able to begin getting mammograms if she desires to do so between the ages of 40 and 44. Average risk women should have their first mammogram by the age of 45. For high-risk women, experts usually advise scheduling mammograms beginning at age 40 or earlier (ACS Cancer Statistics, 2022; Mango et al., 2018; Oeffinger et al., 2015). The USPSTF instead recommends biennial mammography screening at age 50 and screening mammogram on women younger than 50 should be based on individual decision (ACS Cancer Statistics, 2022; Mango et al., 2018). The ACS does not recommend relying solely on any of the breast cancer screening methods (ACS Cancer Statistics, 2022).

Therefore, the use of the combined approach including BSA, CBE, screening mammogram, and a proper follow up after the mammogram offers women the greatest opportunity for reducing the breast cancer death rate through early detection.

Numerous systematic reviews and meta-analyses have indicated how screening mammogram has consistently reduced breast cancer mortality by approximately 40% since 1990 and most of this improvement is attributed to early detection (Monticciolo et al., 2020; Peairs et al., 2017; Talley et al., 2017). Despite its limitations, mammography continues to be the single most effective screening test to reduce breast cancer mortality and the only screening test for breast cancer supported by the United States Preventive Services Task Force, the American Cancer Society, and the American College of Radiology (Lehman et al., 2017; Monticciolo et al., 2020; Oeffinger et al., 2015).

Although the national efforts by the Center for Disease Control and Prevention and the Breast and Cervical Cancer Early Detection Program were effective in increasing breast cancer screening rates, there are still substantial disparities in breast cancer screening utilization and breast cancer mortality among African American and Hispanic women (Talley et al., 2017). While the mortality rates have plummeted in some ethnic populations due to both improvements in treatment and earlier detection, not all women have evenly benefited from these advances.

Furthermore, the populations in the Bronx are largely African American and Hispanic with low education, 80% have less than college degree, almost 60% speak little English (NYS census bureau, 2019). The elevated number of individuals lacking health insurance, residing in the urban community of the Bronx confront multiple barriers in their quest to seek medical help including *breast self-care*; thus, resulting in lower rates of breast cancer prevention, lower survival, and eventually, increased mortality (New York State Department of Health, 2021).

The fourth activity consists of a suitable follow up after a screening mammogram. Mammogram results are reported as BIRADS (Breast Imaging-Reporting and Data System), a classification system proposed by the American College of Radiology (ACR) (D'Orsi, and Bassett 2018; Magny et al., 2021). Not all abnormal findings are considered cancerous. *Breast self-care* related to follow up after a screening mammogram consists of the woman's ability to comply with the recommended follow up according to the findings. BI-RADS 0 mammograms are classified as inconclusive findings; thus, requiring additional breast imaging based on the findings. Mammograms with BI-RADS 1 to BI-RADS 2 results are considered negative to benign findings. Hence, those imaging can be followed up on in a year. Though BI-RADS 3 results are considered probably benign findings, a short-term imaging follow up is required. While BI-RADS 4 and BIRADS 5 mammograms are considered suspicious and highly suspicious findings, both requiring tissue sampling/breast biopsy. The last category is BI-RADS 6, and is used for pathology proven malignancy (D'Orsi, and Bassett 2018; Magny et al., 2021).

In a study measuring time from initial abnormal mammogram or symptom to breast cancer diagnosis, the staging of the cancer was classified using AJCC 8<sup>th</sup> Edition criteria (American Joint Committee on Cancer's Manual for Staging of Cancer). Among symptomatic women, median time to diagnosis ranged from 36 days among Caucasian to 53.6 for African Americans. Among women with abnormal mammograms, median time to diagnosis ranged from 21 days among Caucasians to 29 for African Americans. African Americans had the highest proportion (26 %) of Stage III or IV tumors (Warner et al., 2012). Similarly, a study conducted by Press et al. (2008) discovered that the median number of days to diagnostic follow-up after an abnormal mammogram was greater for African American (20 days) and Hispanic (21 days) women compared with non-Hispanic white (14 days) women ( $p < 0.001$ ) (Press et al., 2008).

Having access to diagnostic studies and high-quality treatment is essential to improve breast cancer survival. African American females are more prone than Caucasian females to undergo postponements in therapy or not receive appropriate treatment for breast cancer due to the lack of follow-up on the patients' part, and inadequate access to quality care. Interruptions in care and unsuitable treatment can consequently lead to larger tumors and poorer outcomes. An appropriate follow-up of abnormal mammography results and a prompt treatment after the diagnosis could ameliorate the health outcomes of all women with breast cancer. Access to quality care is a significant aspect in reducing inequalities in breast cancer survival ( Press et al., 2008; Warner et al., 2012).

### **Self-Care Frameworks**

Although the 18 articles found in the initial literature review were related to breast cancer screening, none of the studies used Dorothy Orem's self-care deficit theory (SCDT) as their theoretical framework. Since the SCDT is the main theoretical framework of the current investigation, a second literature review was deemed necessary to establish the theoretical congruence. Of the 59 articles generated from the second search; only 2 studies were conducted on breast cancer patients using SCDT as a conceptual framework (Dejange et associates 2018; Heinze & Williams, 2015). Still, the 2 articles were not related to breast cancer screening; instead, they were both emphasized on self-care of patients who already had breast cancer or who were surviving breast cancer (Dejange et associates 2018; Heinze & Williams, 2015). Indeed, self-care after breast cancer diagnosis is greatly different from self-care for early detection of breast cancer. Despite, the increasing utilization of Orem's general theory of nursing to guide practice, education, and research, it was certainly not used to promote *breast self-care* including mammogram screening among marginalized female populations (Hartweg, 1990). The



need for the current study, which explores description of *breast self-care* among African American and Hispanic women using Orem's self-care deficit theory of nursing is therefore justified.

Heinze and Williams (2015), purposefully described the self-care strategies used to alleviate symptoms reported by breast cancer survivors. Self-care approaches most reported by women were related to diet, nutrition, and lifestyle modifications; the least common category was related to herbal, vitamins, and complementary therapies. The self-care strategies used in the studies highlighted selfcare of patients who already had breast cancer or were surviving breast cancer. The reported self-care approaches used to alleviate symptoms of breast cancer were found to be mostly effective by breast cancer survivors (Heinze & Williams, 2015).

Dejange et associates (2018) concluded a clinical trial involving 70 women with breast cancer. This study sought to determine the effect of a self-care training program based on Orem's model on the anxiety of women with cancer undergoing chemotherapy. It was revealed in the study that self-care-based education for patients and attention to self-care needs of patients with breast cancer can decrease their anxiety. Additionally, the results indicated a noteworthy difference between the two groups in terms of pre- and post-anxiety changes ( $P < 0.001$ ). Orem's self-care model-based training program was found to lessen anxiety among patients with breast cancer and aided as a self-care model for nursing care interventions in these patients. It was also established that patients can significantly control their anxiety symptoms with increased awareness and self-efficacy. Comparably, Lien et al. (2010) also disclosed that nursing education was effective in controlling anxiety and promoting self-care of women with breast cancer undergoing chemotherapy.

Although Orem's theory of self-care was not exclusively used as a theoretical framework in the studies included in the literature review, the importance of self-care was mentioned in the literature. The powers of motivation, decision-making, and knowledge necessary to perform self-care actions, which are attributes of self-care, were mentioned throughout the literature (Altpeter et al., 2005; Bullock & McGraw, 2006; Chang et al., 1996; Curry, 1994; Ell et al., 2002; Gotay & Wilson, 1998; Mickey, Durski, Worden, & Danigelis, 1995; Pérez-Stable et al., 1996).

### **Factors Related to Breast Self-Care**

Numerous factors impede adherence to *breast self-care*. Factors such as education, awareness, motivation, empowerment, age, apprehension, satisfaction/discomfort felt during mammography, cultural background, faith/religion/spirituality, socioeconomic status, healthcare providers' influences and accessibility to care, can all favorably or unfavorably impact a woman's adherence to mammography screening. Literature will be reviewed on the topics of: risk, age, apprehension, culture, spirituality, socioeconomic status, healthcare providers, and accessibility.

### **Risk**

The study conducted by Facione (2002) investigating the influence of heuristic reasoning on women's perceived risk for developing breast cancer indicated that most women perceived their risk of breast cancer to be lower than that of other women (3:1) (Facione, 2002). These findings validated the expected bias toward optimism, and this was not related to the personality trait of optimism. Women following mammography recommendations exhibited greater assurance that their risk was low, insinuating that cancer awareness and education reduced unnecessary conviction. Women with a known history of nonthreatening breast disease and

women with a family history of breast cancer, or both overemphasized their threats. All these results suggest that heuristic thinking is being used to estimate personal cancer risk instead of relative risk. As a result, some women may delay breast cancer screening or postpone the evaluation of breast symptoms that may indicate breast cancer (Facione, 2002). Clinicians should expect women to be optimistic about their personal risk of developing breast cancer; therefore, assisting women to have an in-depth understanding of their relative risk is an essential part of a health promotion visit (Facione, 2002).

### **Age**

The prevalence of breast cancer for all women rises with age and is highest among Caucasian women; nevertheless, mortality rates are highest among older African American women. Moreover, Altpeter et al. (2005) found that past mammography screening was a predictor of the intention to get a mammogram. Whereas age was found to be an influential factor in a symptomatic woman's decision to not seek care and instead to watch the evolution and changes of a particular lump in her breast (Altpeter et al., 2005).

### **Apprehension**

The patient's feeling or fear of discomfort with *breast self-care* is a significant factor associated with non-participation. There is a possibility of the mammographic equipment to cause heightened apprehension and pain must be recognized as it could be a great source of impediment and consequently, preventing women from adhering to recommended breast cancer screening guidelines (Altpeter et al., 2005; Poulos & Llewellyn, 2005). Yet, factors such as never having a mammogram, breast cancer fear and worry were persuasive in a symptomatic woman's intents to watch her breast lump for changes (Altpeter et al., 2005; Poulos & Llewellyn, 2005).

## Culture

Currently, one out of four women in New York City aged 40 and older is not regularly screened for breast cancer. Consequently, in the city of New York alone, there are about 6,278 new breast cancer cases each year resulting in 1876.2 newly diagnosed breast cancer cases among African American women and about 1263.2 new breast cancer cases among Hispanic women. This scarcity in mammogram screening adherence causes more than 1,000 breast cancer-related deaths every year occasioning more than 351 breast cancer-related deaths yearly among African American women and more than 182.2 breast cancer-related deaths every year among Hispanic women (NYC Cancer Registry, 2019; New York City Department of Health, 2021). While the goal of mammography screening is to decrease breast cancer morbidity and mortality, screening rates are most likely to linger on the lower side, unless the problem of non-adherence to mammography screening observed among African American and Hispanic females is not actually addressed; thus, placing thousands of ethnic minority women at preventable risks of a late-stage diagnosis of breast cancer and eventually death. Henceforth, the problem addressed in this study is *breast self-care* among African American and Hispanic women.

Considering discomfort from a holistic perspective of the mammography experience obtained from women themselves, Poulos & Llewellyn (2005) developed a framework which provided much information on the positive and negative features of radiographer behavior during mammography that can be addressed through mammography education. Women described their feelings of vulnerability which arose from being undressed for the procedure, being pushed, or handled into unpleasant position, leading to increased feelings of powerlessness. This experience of helplessness points to changes needed in mammographic practice to provide women more

autonomy in the process by encouraging them to be more involved in the procedure rather than just collaborating (Poulos & Llewellyn, 2005).

Comparably, to evaluate the effect of verbal information given prior to the examination on women's expectations of discomfort and on actual discomfort experienced, an investigation by Shrestha & Poulos (2001) suggested a considerable difference between the two groups in the relationship between levels of discomfort felt and levels of expectations ( $p = 0.007$ ). Discomfort experienced during mammography is a factor related to non-participation of women in breast screening programs. Women's expectations of discomfort have been found to be correlated to the actual experiences of discomfort reported (Shrestha & Poulos 2001).

Although it was disclosed that seated and standing mammography produced images of comparable excellence and patients were equally satisfied with the procedures, a gerontologic approach is still required when caring for elderly patients (Evans, 2000). Particular attention and care are needed as most older patients have the tendency to fear falling, and they may experience dizziness, vertigo, and a shift in their center of gravity from the hips to the upper torso. To manage these age-related alterations and provide screening mammography for the elderly, some amendments to the imaging procedure are compulsory to achieve patients' satisfaction and consideration (Evans, 2000).

In a study conducted by Wagner (2004) to identify how the mammography industry addresses patient needs and satisfaction through consumer satisfaction, it was found that more than 50% of the healthcare institutions tried to address patient's satisfaction to some extent. The dissatisfaction described by women differed among several analyses due to the difference in instruments used to measure this dissatisfaction. Conversely, to facilitate genuine and valuable organizational amendment, the findings of the surveys indicated the need for institutions to

cautiously review reliability and validity criteria of satisfaction instruments as they may be requiring some conformities (Wagner, 2004). Since patients' satisfaction was the focus of this study, it would have been very informative and helpful for mammography departments to better understand what factors of a mammography exam impacted patients' satisfaction levels (Wagner, 2004).

According to the study conducted by Altpeter and associates (2005), analyses by race and age revealed that older African American women, compared with their Caucasian counterparts appeared as the greatest at-risk group for being the least informed about breast cancer and breast cancer risks, the least prone to identify themselves as being at risk of breast cancer, the least expected to talk about breast cancer risks or mammography with their healthcare providers, the least apt to have completed breast cancer screening, the most tending to report the viewpoints that cancer is spread through air and that co-existing health conditions and therapies can also trigger cancer, and most expected to vocalize convincing religious views about the principal role of God in curing cancer (Altpeter et al., 2005; Erwin et al., 1999).

The findings also indicated older African American women were inclined to practicing health care and the suggestions of their health care providers. Although more than one-half of the women conveyed that they would rather delay than take initiatives to see a provider if they were concerned about a health issue, older African American women were the most prone of all age groups to report they would go to see a physician and that a provider's recommendation was the main justification for them to get a mammogram. Moreover, older African American women were also more inclining to report the intention to take initiatives in the specific situation of discovering a breast lump, whether that action would be to get a mammogram or watch the lump for changes. These findings can help healthcare providers tailor more culturally sensitive breast

health interventions and have suggestions for the elaboration of other efforts to eradicate health disparities (Altpeter et al., 2005; Erwin et al., 1999).

The findings of a study examining the effectiveness of the Witness Project, a culturally sensitive cancer education program that trains cancer survivors to inspire and encourage early detection, as well as, to expand self-breast awareness and mammogram screening in a rural, underserved, African American women community indicated a significant increase ( $P < .0001$ ) in the practice of breast self-awareness and mammography among the Witness Project participants ( $P < .005$ ) compared with the women in the control counties (Altpeter et al., 2005; Erwin et al., 1999). This result provides support for rigorous, community-based, culturally sensitive educational programming incorporating the spiritual environment of the faith community and can certainly influence breast cancer screening behaviors among rural, underserved African American women (Altpeter et al., 2005; Erwin et al., 1999).

In addition, comparable to the use of culturally sensitive programs by lay health advisors (natural helpers) from the community to upsurge cancer screening in minority populations, this investigation also endorsed social connections such as those within the church. These social networks may be the medium for promotion of breast cancer screening, and early cancer detection (Altpeter et al., 2005; Erwin et al., 1999). Cultural sensitivity is a challenging realm to describe. The Witness Project considers the nature of the message to be delivered, to the messenger, to the kind of pamphlets and learning resources used, and to other institutions and faith groups included in the communities' world views and opinions as associated to their religious beliefs, influence, principles, moralities, positions, and obligations (Altpeter et al., 2005; Erwin et al., 1999).

## **Spirituality**

Since not much is known about how Islamic beliefs and civilizations impact followers' breast cancer screening practices, Underwood and collaborators (1999) sought to gain an understanding of the level to which Islamic beliefs and customs impact followers' healthcare practices. It was revealed that the religious beliefs and customs of the Muslim women partaking in the focus group considerably influenced their participation in breast cancer screening. Notwithstanding their knowledge of the benefits of regular breast cancer screening, the women reported they choose not to participate in available breast cancer screening programs, given that they were not structured in a manner that was consistent with the beliefs and customs of Islam. Considering that Muslim women are encouraged to veil and dress themselves modestly, they are discouraged from being alone together with another man unless they are related by birth or by marriage, it was therefore alleged that unless coordinated in agreement with Islamic beliefs and practices, Muslim women may not be comfortable partaking in recommended cancer screening programs, and as a result they may evade or select not to join unless they are particularly concerned about their breast health or the breast health of another person (Underwood, Shaikha, & Bakr, 1999). Indeed, purity, humility, and decency in comportment, appearance, outfit, and communication are expected of all Muslim women. (Underwood et al., 1999). Therefore, of specific relevance is to develop breast cancer screening approaches tailored to the principles and customs of Muslim women (Underwood et al., 1999).

Likewise, Altpeter et colleagues' study revealed that those religious beliefs about God's role in curing cancer were persuasive in symptomatic African American women's intents to watch the evolution of their breast lumps instead of seeking immediate care (Altpeter et al.,



2005). African American women were most prone to declare believable spiritual opinions about the primary role of God in curing cancer (Altpeter et al., 2005).

### **Socioeconomic status**

An investigation by Moudatsou and colleagues (2014) examined the associations of individual-level social capital with breast self-care screening and the knowledge for the existence of relevant screening tests. The findings revealed that considering the social context of the population may contribute to early detection of breast cancers (Moudatsou et al., 2014). It was comparable findings for individual social capital factors (participation in the community, value of life, tolerance of diversity), though with different associations with the outcomes of interest.

While knowledge was essentially linked with cognitive social capital dimensions (tolerance of diversity), adherence to screening recommendations was linked with both cognitive and structural social capital dimensions (value of life and participation in the community respectively) (Moudatsou et al., 2014). This concurs with the literature indicating that diverse social capital magnitudes have diverse aftermaths on health outcomes, acclaiming numerous paths by which the social context impacts health (Moudatsou et al., 2014). The findings imply that social capital facilitates screening adherence possibly by enabling the dissemination of information and by providing a moral responsibility to the adult female to invest in her future health. The ethical feature of social capital may prompt people to act in a preventive way both as a means of decreasing social loneliness, conforming with social norms and as a means that shields the effects of demanding life events (Moudatsou et al., 2014).

Hence, a woman's adherence or non-adherence to screening guidelines are not only associated to her distinctive health characteristics, but, also to her social and cultural circumstances. The examination of socioeconomic status often uncovers disparities in access to

resources. Social capital might facilitate the accessibility to pertinent information leading to the wake of conscience and subsequently to the adherence to breast cancer screening recommendations (Moudatsou et al., 2014).

### **Healthcare providers**

The role of healthcare providers as sources of information is to encourage women to adhere to their yearly breast care screening recommendations. In an analysis conducted by Metsch et al. (1998) assessing the relationship between the source of information and utilization of mammography revealed the most cited source of information was the media (90.2%). In a logistic regression, having had a checkup in the past year was the strongest predictor of having had a recent mammogram as opposed to a distant one (OR 4.17; 95% CI 2.92–5.95). Women who named their physician as an important source of information about health and prevention were also more likely to have had a recent breast examination (OR 1.85; 95% CI 1.27–2.69) (Metsch et al., 1998).

Health care providers help to inspire women to adhere to their yearly mammogram screening. This is factual even after considering the patient's age and utilization of the healthcare system for preventive care in general. The findings indicate the importance of clinicians' awareness of the national guidelines for breast cancer screening, of the risks and benefits of screening measures, and of the implications of normal and abnormal breast imaging findings. In addition, clinicians must understand the significance of proper follow up by taking advantage of reminder systems to prompt patients, eventually minimizing delays in treatment, and by implementing workplace regulations and approaches that support preventive care (Metsch et al., 1998). Providers may be more prone to screen when they hear of community awareness programs directed toward the medically underserved, participating in continuing education

programs on screening and counseling techniques, reorganizing office practices to include reminder systems and auxiliary staff, becoming accustomed with affordable and accessible screening and treatment services in their community, receiving reimbursement for patient education, and receiving training in new risk management approaches to reduce their legal liability (Gulitz, Hernandez, & Kent, 1998).

Gulitz, Hernandez, & Kent's (1998) investigation on why providers miss the opportunity to screen older women for cancer and to find potential strategies to increase utilization of breast cancer screening revealed four emergent themes of patient, provider, office, and access barriers which lead to under-utilization of screening. Patient and provider barriers indicated human factors or causes why both groups may be hesitant to partake in screening. Office and access barriers illustrated systems factors that obstruct the screening process for both groups. Primary care providers may miss the opportunity to perform or recommend screening for underserved groups of older women because of their perceptions of these human and systems factors (Gulitz, Hernandez, & Kent, 1998).

Blair (1998) examined whether family practice physicians and residents were screening older women for breast as recommended by the American Cancer Society. It was found that breast cancer screening was proposed roughly to 70% of the sample, with only about one third of the older women receiving mammography or clinical breast examination. The percentages of patients who received these tests were considerably lower. Some solutions to remedy these obstacles included improving the resident's exposure to the current recommendations, increasing geriatric content in the training program, and initiating a reminder system (Blair, 1998). Moreover, the use of mid-level providers may expand the preventive services offered to older women as well as edify and empower these women to become accountable for their own

healthcare. Jointly, physicians and midlevel providers can become patient advocates through political activism, encouraging legislation that guarantees payment for screening tests.

Ultimately, primary care providers can become involved in research that investigates the healthcare concerns of older women (Altpeter et al., 2005; Blair 1998).

### **Accessibility**

Numerous systematic reviews and meta-analyses have demonstrated that mammography screening has reliably decreased breast cancer mortality by at least 38% since 1990 (Monticciolo et al., 2020; Peairs et al., 2017; Talley et al., 2017). Much of this variation is ascribed to early detection with mammography. Thus, having access to diagnostic studies and high-quality treatment is essential to improve breast cancer survival (Miller et al., 2017; Monticciolo et al., 2020; Peairs et al., 2017; Talley et al., 2017). Greater disproportion in mortality rates is reported among minority women (Monticciolo et al., 2020). Data indicate a lower compliance rate with breast cancer screening recommendations in African American and Hispanic females, which may be leading to the disparity in late-stage diagnosis and cancer mortality in these populations (Monticciolo et al., 2020; Talley et al., 2017).

A study conducted by Mandelblat and associates (1996) examining the implementation of a breast and cervical cancer screening program in a public hospital emergency department revealed that emergency department cancer screening was achievable and led to a high rate of cancer detection. Based on screening history, medical status, and age, 1,850 (32%) of the 5,830 women seen in the ER during the 23-month study period were eligible for both mammography and CBE (Mandelblat et al., 1996). Of these women, 116 (6%) completed mammography and CBE. Among screened women, 10 (9%) and 20 (3%), respectively, had results that were suspicious or positive for breast or cervical cancer. This study demonstrated that provision of

preventive services, such as cancer screening in the ED has the potential to reach populations that may not have regular access to primary care services. Thus, this study facilitated access to care, and led to breast cancer diagnosis (Mandelblat et al., 1996).

Having a consistent source of care and an assigned healthcare provider from whom one can receive healthcare recommendations are the strongest predictors of screening use (Coughlin, 2019; Guo et al., 2019; Oeffinger et al., 2015; Ogunsiji et al., 2017; Patel et al., 2014; Wang et al., 2008; Zamorano-Leon et al., 2020). Though, many minorities and low-income women, who have the highest mortality rates from breast cancer have not been reached by traditional cancer screening programs because they lack regular access to health care and rely on emergency departments for their primary care. Emergency departments have served as locations for a variety of prevention activities directed to high-risk groups, including programs to screen for breast cancer (Coughlin, 2019; Guo et al., 2019; Oeffinger et al., 2015; Ogunsiji et al., 2017; Patel et al., 2014; Wang et al., 2018; Zamorano-Leon et al., 2020).

The major transformation of health care in the United States during the last 20 years has greatly impacted access to healthcare services. Notably among those changes are the Patient Protection and Affordable Care Act (ACA), the Electronic Medical Records (EMR), and the impact of COVID-19.

Actually, the 2010 Patient Protection and Affordable Care Act (ACA) was a comprehensive national health care reform which allowed substantial numbers of people to obtain health insurance coverage and facilitate health care accessibility in the United States (Tsapatsaris et al., 2021). The ACA Medicaid expansion plan has impacted health insurance coverage and improve timely health care access for previously uninsured women; thus, facilitated access to breast cancer screening. When paralleled to Caucasian women, African

American and Hispanic women aged 50–74 (who are targeted by the USPSTF mammography screening guidelines) experienced a slight shift toward stage I breast cancer at diagnosis with the ACA's preventive services provision (Silva et al., 2017). Although the shift in stage I cancers was marginal, it was considered a potentially noteworthy public health impact as it ameliorated the prognosis for thousands of women and further reduced the need for invasive treatments such as chemotherapy. Furthermore, the slight decrease minimally mitigated the racial disparity in breast cancer stage at diagnosis for a substantial number of women (Silva et al., 2017).

Despite its limitations, the Electronic medical records (EMR) technology provides to health care providers information in formats that were not feasible with paper charts. As one of the key revolutions of healthcare, the EMR ameliorated achievement of chronic disease management, preventive care, and health screening objectives by providing treatment targets or reminders to providers when certain screening recommendations are due or outdated. The EMR expedited requests and tasks delegation to various team members, as well as facilitation of appointment booking, which can also be done remotely by patients who might have the ability to do so. Another advantage of the EMR is improving communication with patients through the use of patient portals and personal health records, which more effectively engage patients in managing their own care. Preferably, the EMR should be on a single platform nationwide to facilitate inter-operability and portability horizontally and vertically across the referral chain (Honavar, 2020).

While the EMR has weakened personalized face-to-face patient care and the significant provider-patient interaction, it has overall improved quality of care, patient outcomes, and safety through enhanced management, lessening in medication errors, management of prescriptions,

reduction in needless investigations, and improved communication and interactions among providers, patients, and the interdisciplinary team (Honavar, 2020).

Although the COVID-19 pandemic has undesirably affected healthcare accessibility globally, urban regions of the United States such as New York City where African American and Hispanic women are more highly concentrated was the pandemic focal point. Furthermore, public hospitals in metropolitan pandemic epicenters such as New York City aid as healthcare safety nets for medically underserved populations. The financial expenses of treating COVID-19 associated illnesses have inexplicably affected safety net healthcare facilities where cancer care is provided to a greater number of African American and Hispanic patients (Tsapatsaris et al., 2021). This unprecedented constraints in healthcare access are likely to exacerbate the previously existing disparity in accessibility to care, cancer detection, treatment, and survival among African Americans and Hispanic women. In fact, about 285,000 breast exams were missed between March 15 and June 16, 2020 (Ashoor et al., 2021; Tsapatsaris et al., 2021).

With the COVID-19 pandemic, the total number of cancer screening tests received by women through the CDC's National Breast and Cervical Cancer Early Detection Program dropped by 87% for breast cancer during April 2020 as compared with the previous 5-year means for that month (CDC, 2021). Extended interruptions in screening related to the COVID-19 pandemic may lead to late-stage diagnoses of breast cancer, poor health outcomes, and an increase in cancer disparities among women already experiencing health inequalities. Bearing in mind that breast cancer is a highly prevalent and curable type of cancer, timely access to diagnosis and treatment may have a better outcome, mostly among patient groups with previously poor health care access, such as African American and Hispanic women. However, as safety standards are in place and the COVID-19 vaccine has become accessible, mammogram

screening rates are picking up and are rising at many facilities (Alagoz et al., 2021; Tsapatsaris et al., 2021). Health-care providers must modify their efforts to support prevention programs and reach out to underserved populations such as African American and Hispanic women living in the Bronx (NYC).

Factors including disorganized structural healthcare systems negatively affected the satisfaction and health outcomes of patients with breast cancer based on care efficacy and assistance received during their treatment course. Obstacles experienced by participants while attempting to access healthcare services included challenges in scheduling appointments, collaborating with the healthcare team, accessing necessary information, and navigating the healthcare system, as well as, unaffordability of resources to meet healthcare necessities (Gullatte et al., 2010; Rauscher et al., 2012; Webber et al., 2017).

Taken together, facility factors accounted for 43% of the diagnostic delay ( $p < .0001$ ) (Goldman et al., 2013; Molina et al., 2015). Health system-related factors (e.g., referral pathways) contributed to substantial delays in presenting and diagnosing breast cancer (Espina et al., 2017). Among English-speaking Latinas, undergoing an annual physical exam was the strongest predictor of breast cancer screening. Women who did not undergo a mammogram during the previous year were less likely to be insured, have a clinical breast exam at their last checkup, have their breasts examined by their doctor at least once annually, or have undergone a mammogram previously.

Furthermore, delayed seeking of medical attention was associated with misinformation regarding the requirement of a consistent health care provider, a source of health coverage, and recent preventive care ( $P < 0.005$ ) (Rauscher et al., 2010). Moreover, the proportion of women who underwent imaging and biopsy within 11 and 3 months, respectively, varied across facilities



(interquartile range: 85.5%–96.5% for imaging and 79.4%–87.3% for biopsy) (Oliveira et al., 2011). Uninsured ethnic minority women who could not obtain adequate healthcare services were at an increased risk of late-stage breast cancer diagnosis (Castañeda et al., 2014; Espina et al., 2017; Oliveira et al., 2011). Moreover, taking into consideration the wide-ranging racial and ethnic disparities in breast cancer survival, as well as dissimilarities in healthcare delivery, eliminating inequities in healthcare accessibility, early detection, and improved treatment strategies are healthcare necessities (Monticciolo et al., 2020; Peairs et al., 2017; Talley et al., 2017).

### **Interventions for Breast Self-Care**

Interventions supporting *breast self-care* included combined community outreach projects, health education, counseling, and systems navigation, which were delivered by teams consisting of a peer counselor, social workers, community-based, and culturally sensitive educational programs. These programs will be described below.

#### **The Atlanta Project**

To assist in minimizing the deleterious health outcomes of breast cancer through early prevention initiatives, undertakings such as the Atlanta Project, one of six community demonstration projects in breast and cervical cancer control and detection in the United States, is reinforced by the American Cancer Society (ACS). These projects implemented in Atlanta, Harlem, Miami, Oakland, West Virginia, and Wisconsin examined whether cancer screening among different underprivileged populations resulted in reduced morbidity and mortality related to breast and cervical cancer. Of the 3852 women screened in the Atlanta project, 12 breast cancers were identified and treated. More than 60 community outreach education programs about breast cancer screening have been offered from January 1992 through December 1993. Most

reassuringly, more than 3000 additional women older than 40 years have been brought into the primary care system who beforehand did not have a source of healthcare. At the conclusion of the project, a repeat survey was commenced to report whether any noteworthy improvement has arisen as an outcome of the intervention. The repeat inquiry indicated that 82.3% (odds ratio = 1.50 [0.99-2.27]; chi-square = 4.02; P = 0.045) of the women randomly surveyed were being screened for cancer of the breast, a significant increase compared with the baseline screening rate (Curry, 1994).

Likewise, there has been an upsurge in women's awareness of breast cancer as an effect of the intervention's outreach and in reach activities and their provider's focus on screening during their clinic visit. A significant improvement was also noted in the number of clinical breast examination performed by clinicians as well as education about self-breast examination, 76.2% of the time (odds ratio = 1.77 [1.22-2.55]; chi-square = 9.60; P = .0019) (Curry, 1994). The project attempted to provide women with experiences and prospects to understand the benefits of self-care and to assist them in acquiring the services they need within the health system in their community; thus, empowering women to become accountable for their health and health maintenance. Moreover, the project also educated healthcare providers and expose professionals to the worth of empowering their patients to care for themselves (Curry, 1994).

### **Screening Older Minority Women (SOMW) Project**

The Screening Older Minority Women (SOMW) was a three-year project, intended to upsurge the use of cancer screening tests, such as breast exams and mammograms among African American and Latina women aged 50 and older. Since older women of color tend to use fewer cancer screening services (Clayton & Byrd, 1993) and are more likely to rely on members of informal networks for social support (Bullock, 2004), the behavior change intervention was

adapted to engage social networks and community connections. Of the 238 younger women, 82.8% completed the 12-month interview; 66.9% of the older women completed the 12-month follow-up interview. Guidelines identified to help researchers and practitioners in planning and implementing community health promotion intervention with women of color included developing and implementing collaborative goals; creating a participatory exchange of resources to support the goals, systematically incorporating intergenerational activities into the intervention, and helping community participants develop skills that create sustainability when possible (Bullock & McGraw, 2006).

### **Adherence Follow-up Program (SAFe)**

The pilot study of the Screening Adherence Follow-up Program (SAFe) consisted of a greatly organized, theory- and evidence-based intervention delivered by a team comprising a peer counselor and a social worker (Ell et al., 2002). A scripted baseline telephone interview identified probable obstacles to follow-up adherence and each participant was offered counseling interventions. After the assessment, participants were appointed to different services based on their degree of risk for nonadherence. Participants with major mental health signs, psychosocial stressors, or who had received a diagnosis of cancer were promptly referred to the team social worker for additional evaluation and management. Reinforcing telephone follow-up calls were done at 6 and 12 months. In fact, the study results indicated auspicious findings as 71% of SAFe participants were Hispanic, 18% were Black, and 11% were from other ethnic backgrounds. Adherence rates through diagnostic resolution and the initiation of treatment for women who had received a diagnosis of cancer were 93% and 90%, respectively, at the two study sites. Rates of adherence among women who could not be situated or who declined the study consent were significantly lower (72% and 69%, respectively) (Ell et al., 2002). The rate of timely adherence

was also greater among the women served. Patient satisfaction with SAFe was mostly high as SAFe lowered barriers to diagnostic follow-up and promoted adherence to and initiation of treatment among disadvantaged women with abnormal mammogram findings (Ell et al., 2002).

Similarly, a study conducted by Gotay & Wilson (1998) to examine the effectiveness of screening interventions based on social support for breast cancer in low-income, African American, and Hispanic, revealed that women who had encouragement from others, social networks, and social ties were more likely to conform with mammography, or CBE ( $P < 0.01$ ), and were more likely to know about self-breast awareness ( $P < 0.0001$ ) (Burnett, Steakley, & Tefft, 1995; Mickey, Durski, Worden, & Danigelis, 1995; Kang, 1994, as cited in Gotay & Wilson, 1998).

### **Save our Sisters Project**

Various studies have established consistent relationships between participation in programs based on social support and enhanced screening. Hence, indicating the significance of social support intervention among African Americans and Hispanics women. Correspondingly, as described by Eng and colleagues, the Save our Sisters Project, a social network strategy for reaching rural black women used "natural helpers" as lay health educators for older African American women (Eng, 1993; Eng & Smith, 1995, as cited in Gotay & Wilson, 1998).

### **Por La Vida" (For Life), "Consejeras"**

Likewise, through the program "Por La Vida" (For Life), Navarro and coworkers recruited "consejeras," Hispanic American women in San Diego to promote breast cancer screening within their social networks (Navarro et al., 1995, as cited in Gotay & Wilson, 1998).

**Witness Project**

Equally, the Witness Project designed by Erwin and colleagues took advantage of churches and community organizations to encourage screening among African American women in rural Arkansas. This program used African American women breast cancer survivors through a team of "witness role models" to speak to the participants about their personal experiences, teach self-breast awareness, emphasize the worth of early diagnosis, timely, and suitable treatment (Erwin et al., 1996, as cited in Gotay & Wilson, 1998).

**Compañeros en la Salud (Partners in Health)**

Through the program "Compañeros en la Salud" (Partners in Health) in Phoenix, Arizona, Castro, and colleagues used the church to promote screening, referrals, and breast-self-awareness training to Hispanic American women by involving "Promotoras," or peer health educators who are considered natural leaders by members of their community (Castro et al., 1995, as cited in Gotay & Wilson, 1998).

**Programa A Su Salud (Program for Your Health)**

Several programs in Hispanic American communities such as "Programa A Su Salud" (Program for Your Health), by Ramirez and coworkers; "En Acción Contra el Cancer" by Perez-Stable and associates have used a combination of mass media (print, radio, and television), community Bulletins/other print materials, and social networks to promote cancer screening. While the outreach campaigns pointed at reinforcing health professional education about cancer screening, they were also directed at lay health educators from the community who distribute materials and refer women in a target region for screening. (Pérez-Stable et al., 1996; Ramirez et al., 1995, as cited in Gotay & Wilson, 1998).

### **Nonprofessional navigator program in Harlem**

The study conducted by Freeman and colleagues (1995) revealed the success of a nonprofessional navigator program in Harlem (with 88% completion of recommended biopsy, compared with 57% of patients who did not receive the navigator assistance) used to aid low-income African American and Hispanic patients in negotiating the complex healthcare system. The navigator served as a "pro-active patient advocate" pinpointing, and foreseeing the obstacles faced by the patient (Freeman, Muth, & Kerner, 1995, as cited in Gotay & Wilson, 1998).

### **Summary**

Based on Orem's theory of self-care agency, self-care deficit, and nursing system, a review of the literature was conducted to include the topics of: activities of *breast self-care*, self-care frameworks, factors related to breast care, and interventions for *breast self-care*. Although there were several studies using Orem's framework, no descriptive studies on how women describe *breast self-care* using Orem's framework were found. Furthermore, there were no studies on how different ethnic groups describe *breast self-care*. This study will be designed to uncover how African American and Hispanic women describe *breast self-care*.

## Chapter 3: Method

The purpose of this chapter is to describe the methods used for the current study and the research problem in this study of *breast self-care* among African American and Hispanic females. Chapter 3 presents the sample selection, the measures, the procedures for data collection, the plans for managing/analyzing the data, the suggested measures for human rights, and human rights and ethical considerations (IRB). Moreover, the methods to assure the study rigor/trustworthiness, and the study limitations are described in the succeeding pages.

### Method

#### Research design

The research problem guided the selection of the method and Orem's self-care theory was selected as the appropriate framework for the study (Hsieh & Shannon, 2005; Orem, 2001). The research question is: "How do New York City African American and Hispanic women seeking care in a comprehensive breast care center describe breast self-care?" To obtain an in-depth understanding of the phenomenon of *breast self-care*, a qualitative descriptive approach using a directed content analysis will be used in this study. Content analysis is a research method used to interpret meaning from the content of text (Hsieh & Shannon, 2005). Qualitative research is a distinctive method of naturalistic inquiry, particularly suitable in providing a rich and deeper understanding of complex phenomena and tracking unique or unexpected events by giving voice to those whose opinions are seldom heard (Morse, 2007). While there are three different approaches to content analysis, conventional, directed, or summative, this study will focus on the directed approach in which analysis starts with a theory as guidance (Hsieh & Shannon, 2005).

## **Theoretical Framework**

This study is based on Orem's recommendation to use descriptive studies to investigate the self-care practices related to particular self-care requisites. (Orem, 2001). The purpose of a directed approach to content analysis is to validate or extend a theory (Hsieh & Shannon, 2005). Therefore, a directed approach to content analysis will be used in the current research (Hsieh & Shannon, 2005; Orem, 2001). Through a deductive approach, existing theory or research can help focus the research question. It can offer descriptions of concepts of interest (Hsieh & Shannon, 2005).

## **Sample Selection and Setting**

A purposive sampling strategy will be used to recruit participants for the current investigation. Lincoln and Guba suggested that the determination of a study sample size be guided by the criterion of informational redundancy, indicating that, sampling can be terminated when no new information is elicited by sampling more units. Likewise, it has been previously endorsed that qualitative studies require a minimum sample size of at least 12 to reach data saturation (Lincoln & Guba, 1985). Thus, a sample size of 12 is expected to be adequate for the qualitative analysis of this investigation.

Written permission will be obtained from BronxCare Health System, the facility where participant recruitment will take place. Recruitment will be done via fliers distributed at BronxCare Health System.

## **Enrollment**

The principal investigator (PI) will provide contact information to potential participants on the recruitment flyers encouraging them to call if they desire to participate in the study. Once, the phone calls are received from the participants, the PI will review eligible participants to



isolate known obstacles to partaking in the study. African American and Hispanic women who meet the inclusion criteria will be selected and re-contacted via telephone to confirm enrollment in the study and simultaneously schedule interviews.

**Inclusion criteria:** The population of interest is noninstitutionalized adult African American and Hispanic women  $\geq 40$  years, alert, and oriented, regardless of their ability to speak English or not. In the United States, breast cancer screening recommendations are issued by different medical organizations. However, the organizations do not all concur on when to begin screening mammograms and how regularly to repeat them. In fact, most organizations encourage women to meet with their healthcare providers to discuss what's right for their individual situation. The most current guidelines according to the U.S. Preventive Services Task Force recommend that women ages 50 to 74 years old should have a screening mammogram every two years. Women ages 40–49 years old are encouraged to talk to their health care providers about when and how frequently they should have screening mammograms. A woman considered at a high risk for breast cancer, as determined by a health care provider, may need to begin screening earlier (NYS Department of Health, 2021).

**Exclusion criteria:** Men, women younger than 40 years of age, transgender individuals, institutionalized female population, women of unknown race, individuals with a lack of cognitive ability to respond to the interview questions, and pregnant women.

### **Semi-Structured Interview Guide**

Research question guiding this interview is: How do New York City African American and Hispanic women seeking care in a comprehensive breast care center describe breast self-care?

The interview guide used in this study was framed based on Orem's Self-Care Theory. This is a nursing theory composed of three interconnected concepts: self-care agency, self-care deficit, and nursing system (Orem, 2001, p. 141). The duration of the interview is 30-60 minutes. The interview is written in French, English, and Spanish. The PI is fluent in French and English. A Spanish translator will be used for Spanish speaking participants. See Appendix A for the semi-structured interview script.

***Self-care:*** Self-care agency is defined by Orem as: “the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being” (Orem, 2001, p. 43). Orem identified three self-care requisites comprising universal self-care requisites, developmental self-care requisites, and health deviation self-care requisites (Orem, 2001, p.143). The interview questions for self-care agency follow:

- ***Self-care agency. (Orem, 2001, p. 43).***

- 1) *What does taking care of your breasts mean to you?*

- 2) *I would like to talk with you about knowing your breasts.*

- a. *Talk to me about how you know your breasts?*

- b. *What does knowing your breasts mean to you?*

- 3) *What about your culture, influences how you take care of your breasts?*

- a. *[Note to Self: Listen for family and community]*

- 4) *What activities do you perform to take care of your breasts?*

- 5) *Tell me how you are actively involved in taking care of your breasts?*

***Self-care deficit.*** Self-care deficit is defined by Dorothy Orem as: “the relationship between self-care agency and therapeutic self-care demands of individuals in which capabilities for self-care, because of existent limitations, are not equal to meeting some or all of the

components of their therapeutic self-care demands” (Orem, 2001, p. 282). As proposed by Orem, a deficit in meeting self-care could be related to difficulties or obstacles that prevent individuals from fulfilling requirements for health, well-being, growth, and development. The preventing factors may include resource unavailability or inadequacy, age, developmental state, life experience, health state, socio-cultural orientation, health care system factors, family system factors, patterns of living, environmental factors (Orem, 2001, p. 147). The interview questions for self-care deficit follow:

1) *What, if any, challenges have you encountered when taking care of your breasts.*

a. *[Note to Self: Listen for challenges about insurance, travel, and culture]*

2) *What, if anything, discourages you from taking care of your breast.*

**Nursing system:** Nursing systems as described by Orem includes the concept of self-care deficit. Nursing system establishes the structure and the content of nursing practice. It articulates the nurse property of nursing agency with the patient properties of therapeutic self-care demand (Orem, 2001, p. 147).

The interview questions asked in this section are related to the supportive-educative system in which the individual can perform with assistance or need to learn how to perform required methods for therapeutic self-care. The nurse role in this section is to provide the necessary education and support the individual in achieving therapeutic self-care. The interview questions for nursing system follow:

1) *How does the nurse assist you with taking care of your breast?*

2) *Tell me about the healthcare resources you have to take care of your breast?*

3) *What concerns do you have about getting care for your breasts?*

4) *If you had a mammogram, what follow up care did you receive?*

## **Procedures for Data Collection**

Permission will be obtained from the participants for all interviews to be audiotape-recorded and transcribed verbatim for greater accuracy. Explanation will be provided about how the recordings will be used, stored, and eventually destroyed according to the IRB guidelines (Roberts & Hyatt, 2019). An appropriate physical environment will be created for the interviews. Prior to the interview, demographic data will be collected from each participant (see Appendix B). The data will be collected by the PI through semi-structured, one-on-one in-depth interviews with all participants at the most convenient location according to each participant's preference, either in her home or in the PI's office located at BronxCare Health System. Probes might be used after an open-ended question, for more precision or exploration of participants' description of self-care agency. Data will be in the form of words, stories, and experiences that will be analyzed into a formal structure (Sandelowski, 2000, 2010). The interview itself, and the observation of the participants are all essential parts of the interview process. Body language, nonverbal cues, and voice intonation are also valuable signs to take note of from the participants.

Furthermore, the data collection process will be guided by the criterion of informational redundancy, implying that, data collection will continue until the saturation point, at which no new or relevant information is obtained by sampling more units (Lincoln & Guba, 1985). Data collection in the qualitative research is essentially based on data saturation. Since numbers are not important in ensuring adequate samples, the aim of qualitative sampling is about the depth of the data. Data will be collected until the analysis no longer indicate anything new or different about the samples. Each interview will take roughly 30–60 minutes. As interpretive validity is the accurate description that participants give to the phenomena in question, Sandelowski (2000, 2010) reported the need for precise description from the participants.

Interpretive validity will be attained by having subjects describe their experiences and interpreting those responses while remaining as close as possible to the data (Sullivan-Bolyai et al., 2005).

### **Data Analysis**

Orem's self-care theory will guide the discussion of findings and coding will begin after data collection. The data will be transcribed verbatim and analyzed by the directed content analysis method. To analyze the text using content analysis, the text will be coded, or broken down into adaptable code categories. The transcripts will be read numerous times and the significance of the data will be discussed to obtain a deep description of breast self-care among New York City African American and Hispanic women seeking care in a comprehensive breast care center. The data will be analyzed and categorized using Orem's self-care theory, with the concepts including self-care agency, self-care deficit, and nursing system (Orem, 2001, p. 141).

Subsequently, data that cannot be coded will be identified and analyzed to determine if they represent a new category or a subcategory of an existing code. Newly identified categories will either provide a conflicting view of *breast self-care* or might further refine, extend, and enrich Orem's Self-Care Theory (Orem, 2001, p. 141). Background and qualifications of the researchers involved in the study will be provided. Peer scrutiny of the research project will be performed. Direct quotations from the research participants will be presented throughout the data collected during the interviews. Frequent debriefing sessions will be performed. Investigators' triangulation, which relates to the use of more than one data analyst will be used to confirm and enhance the credibility of the findings (Shenton, 2004). See Appendix C for Analysis Plan. An audit trail and coding checks will be performed to show the transparency of the study. See Appendix D for Example Audit Trail. Two experts in nursing research and women's health

who are not part of the research team will be asked to investigate separately the interviews and raw data, as well as the interpretation derived from them to ensure the study's findings are the result of the experiences and ideas of the participants, rather than characteristics and preferences of the PI. To enable a future researcher to repeat the work, detailed report will be provided about the study settings, participants, and study processes. Moreover, coding and re-coding approaches will be performed after two weeks of prior coding (Shenton, 2004).

### **Human Rights (subjects' protection) and Ethical Considerations (IRB)**

Approval was obtained from the WVU Institutional Review Board (IRB). Each participant will be given a thorough description about the study, the reasons why it is being conducted, why they are being invited to take part, the possible benefits, risks, and burdens which may result from their personal participation in the study. The informed consent form will be written in language easily understood by each participant (French, English, and Spanish).

All research will adhere to the Bronxcare health System and WVU Institutional Review Board (IRB) policies including adherence to the Health Insurance Portability and Accountability Act. Participant privacy and confidentiality will be supported by adhering to the three main principles of the Belmont report and the corresponding IRB requirements for conducting research that involve human subjects (Roberts & Hyatt, 2019). Following the first principle of the Belmont report, respect for persons, the participants will be given the ability to fully exercise their autonomy. The participant will have the right to voluntary consent to take part in the study. The informed consent will consist of the participant knowing the possible risks and benefits of partaking in the study. The participants' privacy and confidentiality will be maintained throughout the study, and they will have the right to withdraw from participating in the study without any consequences. The second principle of the Belmont report, beneficence, will consist

of maintaining privacy and confidentiality to help protect the participants from potential harms, including psychological harm such as embarrassment, distress, invasion of privacy or a breach of confidentiality. Subsequently, the third principle of the Belmont report, justice, will ensure that participants who may benefit from the study are not excluded.

Since the study involves African American and Hispanic women (minority and immigrant women) who may have language difficulties, ethical dilemmas related to communication barriers and privacy will be addressed. As privacy is in the eye of the participant, data collection, consisting of individual interview, will take place based on participant availability, and in the environment where the participants will feel comfortable to disclose their information in this manner. Cultural sensitivity will be a central aspect of the study because some cultures are more reserved than others.

To minimize the risks of infringement to confidentiality, adherence to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) guidelines and anonymity will be maintained throughout the research processes by retaining research data without any identifiers so that participants' participation is completely anonymous, and the data collected will not be linked to the research participants (Roberts & Hyatt, 2019). Furthermore, consent forms and paper copies of participants' data will be stored in the PI's locked file cabinet in a locked office, and on a password protected computer.

### **Risks/benefits**

All participants will be provided with a detailed description of the study, the possible benefits, risks, and burdens which may result from participation in the study. Each participant will be informed that she may withdraw from the study at any time for any reason. Each

participant will be informed that her healthcare in the Bronx Care Health System will not be impacted by her decision to participate or not to participate in the proposed study.

No risk of physical, social, or psychological harm is expected. The participant may experience negative emotional reactions to questions posed. In the event of negative emotional reactions, the participant will be referred to the social worker of Bronx Care Health System for closer follow-up.

Since participants' recruitment will be done at BronxCare Health System, the PI will not recruit her patients; rather, clinic personnel will recruit those potential participants through flyers posted in the clinic area. This measure will abate the threats to coercion and ethical concerns. Study participants will be monetarily remunerated for their participation; each participant will receive a \$25.00 gift card for participating in the study.

### **Methods to Assure Rigor**

Principles to assure rigor will be adhered to in the process of collection and analysis of participant descriptions. These principles are credibility, transferability, dependability, and confirmability. Credibility refers to how congruent the findings of the study are with reality. Transferability is achieved if the findings of a qualitative study are transferable to other similar settings. Dependability as the detailed reporting of the processes within the study so to facilitate a future researcher to replicate the work. Confirmability is applicable when the study findings are based on the analysis of the collected data and examined via an auditing process (Shenton, 2004).

### **Limitations of the Study**

Collecting data from a single borough, Bronx (NYC) might limit the transferability of the study. Further limitations include sampling women who are already inclined to attend a health



care facility as their experience may be vastly different from another woman of color living in the community and who does not come to the hospital for some reasons. It would be interesting to also have a sample of community women to compare whether there are differences in their perception of BSA. Bearing in mind the nation's history of unethical medical and research practices on ethnic minority populations, it might be challenging to get African American and Hispanic women to join the current study. Moreover, minorities, immigrants or refugees' women are considered vulnerable populations and could be at risk of compromised free will.

### **Summary**

To obtain an in-depth understanding of the phenomenon of *breast self-care*, and using Orem's Theory of Self Care, this study will use a qualitative descriptive approach using directed content analysis. The research question guiding this study is: How do NYC African American and Hispanic women seeking care in a comprehensive breast care center describe *breast self-care*? Data will be collected using semi-structured interviews based on Orem's theory. Trustworthiness of findings will be supported by adherence to established criteria for credibility, dependability, confirmability, and transferability.

## Chapter 4: Results

This chapter reports on the results of *Descriptions of Breast Self-Care from Inner-New York City African American and Hispanic Women seeking care in a comprehensive breast care center*. Participants were recruited from a large not-for-profit healthcare system in the Bronx, New York City. Participants were interviewed face-to-face using a semi-structured interview method framed based on Orem's Self-Care Theory. The research question guiding this study was, "How do New York City African American and Hispanic women seeking care in a comprehensive breast care center describe breast self-care?" The sections included in this chapter are participant demographics, the themes identified through the process of directed content analysis, and evidence to support the trustworthiness of the findings.

### Participant Demographics

Twelve African American and Hispanic women ages ranging from 40-80 participated in this study. Of the twelve participants, six identified as Hispanics or Latinas (ages: 46, 52, 55, 57, 63, 80), four identified as African Americans (ages: 41, 54, 62, 64), and two identified as Africans (ages: 40, 59). One of the interviews required the use of a Hispanic interpreter as the participant was not fluent in English. Two of the participants were French speakers and spoke English as well; some interpretation for clarification was done by the interviewer who also happened to be fluent in French. Of the twelve women, six (50%) reported working either in the public or private sectors as they are obtaining their health insurance through their jobs. The remaining 50% of the of the sample size did not disclose their employment status.

### Themes

The predetermined categories of self-care agency, self-care deficit, and nursing system were used as the organizing framework for presenting the findings from this study.

### *Self-Care Agency*

Table 1 describes the theme related to self-care agency, along with the meaning units from the participant descriptions that support the theme.

<b>Table 1.</b> Theme of Self-Care Agency and Associated Meaning Units		
Theme 1	Self-care agency is the power to manage breast self-care through the mutual influence of knowing and doing, in the context of one's culture.	<ul style="list-style-type: none"> <li>• An attentive presence on examining breasts</li> <li>• Protecting breasts through supportive measures</li> <li>• Being mindful of nutrition and exercise</li> <li>• Awareness of how breasts appear and feel</li> <li>• Influence of culture is personal, kept private, and not talked about.</li> </ul>

Self-care agency is defined by Orem as “the complex acquired ability of mature and maturing persons to know and meet their continuing requirements for deliberate, purposive action, and to regulate their own human functioning and development” (Orem, 2001, p. 254). Self-care agency as it relates to *breast self-care* refers to a woman's ability to deliberately engage in activities intended to promote and maintain her overall breast health perpetually. The activities she engages in to care for and preserve her breasts in a healthy state is breast self-care agency. When asked about breast self-care agency, participants described being attentive and protective of their breasts, and being mindful of their diet and nutrition. In addition, the culture

influenced *breast self-care* activities. The meaning units derived from their descriptions laid the foundation for the theme. These meaning units included an attentive presence on examining breasts, protecting breasts through supportive measures, being mindful of nutrition and exercise, awareness of how breasts appear and feel, influence of culture is personal, kept private, and not talked about. As a result, the following theme emerged from the category of self-care agency.

*Theme 1: Self-care agency is the power to manage breast self-care through the mutual influence of knowing and doing in the context of one's culture.*

When asked about activities of breast self-care, participants spoke of being very attentive to their breasts, and taking care in examining them. Participants stated:

- “Breast self-care means ... putting them in a good...comfortable bra.... checking your breast... and.... looking for [things] that shouldn't be there....”
- “Breast self-care is... not only [physically], but it's psychologically.... it's the fear to come up with breast cancer or any other cancer at all.... going to my doctors' appointments...and....telling my doctor right away if I feel any pain or anything...”

Participants also talked about protecting their breasts with supportive measures, and through attention to diet and exercise. Participant descriptions included:

- “.... don't put on a bra that's too tight...maintain the breast loose, comfortable...and not tightening the breasts....”
- “.... making sure I moisturize my skin.... [not letting] the dry crackles stand anywhere.... [not upsetting my breasts] .... not bumping into stuff...”
- “.... doing exercise....to maintain the breast firm.... eating healthy.... avoiding any kind of food that is not good for cancer... [not smoking] ...the carcinogens in the cigarette can affect any, and every part of your body, not just the breasts....”

- “... Not drinking coffee...as the denseness of the breast masses can increase with the consumption of caffeine... as long as I am taking care of my body...I am taking care of my breasts...”

Participants were also knowledgeable about how their breast look and feel. This was evident in the following participant comments:

- “There isn’t any disconnection from my breasts and myself... they are part of me...”
- “Being conscious about what I am doing...and having a good relationship with them.”
- “... knowing what’s normal from abnormal.... what to look out for.”
- “On some days, they demand that you talk to them.... during my cycle, if they are feeling heavy, very sad, or just very out of sort...swollen...just fatter and bruise; they are asking me to just touch them with affection.”

When asked about cultural influences on breast self-care, participants spoke of breast self-care being personal, kept private, and not talked about. This was indicated in the subsequent participant comments:

- “In my culture, we were not taught to take pride and to take care of yourself.”
- “They did not physically show you...they show you by you just watching them take care of themselves...”
- “The way we take care of it is personal...and private”
- “...My culture didn’t teach me anything... only when I came to America...My doctor is the one who always influences me to go get my mammogram.”
- “In my culture, it’s not very emphasized.... we are not reminded

enough...it's easy to forget and to become very dismissive.”

- “...Breast health, and anything related to that was always around cancer.”

### *Self-Care Deficit*

Table 2 describes the theme related to self-care deficit, along with the meaning units from the participant descriptions that support the theme.

<b>Table 2.</b> Themes of Self-Care Deficit and Associated Meaning Units		
Theme 2	Self-care deficits were not identified	<ul style="list-style-type: none"> <li>• Being capable of doing what needs to be done</li> <li>• Having a health plan for breast care</li> <li>• Easy access to transportation</li> </ul>

Self-care deficit is defined by Orem as: “the relationship between self-care agency and therapeutic self-care demands of individuals in which capabilities for self-care, because of existent limitations, are not equal to meeting some or all of the components of their therapeutic self-care demands” (Orem, 2001, p. 282). The aptitude to engage in self-care can be influenced by basic conditioning factors which are age, developmental state, life experience, health state, socio-cultural orientation, health care system factors, family system factors, patterns of living, environmental factors, and resource adequacy and availability (Orem, 2001, p. 146). Self-care deficit as it relates to *breast self-care* refers to a woman’s inability to deliberately engage in activities intended to promote and maintain her overall breast health. Causes of the deficit may be related to difficulties or obstacles that prevent African American and Hispanic women from fulfilling their requirements for health, well-being, growth, and development.

When asked about *breast self-care* deficits, participants described having the capability to

fulfill their breast care related needs, having access to a health plan including breast care, and transportation. The meaning units derived from their descriptions laid the foundation for the theme. These meaning units included being capable of doing what needs to be done, having a health plan for breast care, and easy access to transportation. As a result, the following theme emerged from the category of self-care deficit.

*Theme 2: Self-care deficits were not identified.*

When asked about challenges and any discouragements to *breast self-care*, participants describe being capable of doing what they needed to do. Comments included:

- “I have it easy, open doors to take care of my breasts. When you have a health plan that back you up.”
- “Nothing discourages me from taking care of my breast...”
- “...everything that I am doing for my breast health, I am capable of doing it....”
- “I haven’t encountered any challenges... because we live in New York.”

They also spoke about the health plan provided for them in the breast clinic. Comments included:

- “.... I have a job that has an insurance plan that pays for the routine checkups. I don’t have any issue getting into my appointments...”
- “...The insurance will prefer that You only go to the hospital when you have an emergency....”
- “I have been working for the last 40 years of my life and I have always had health insurance.”

Participants also talked about either having their own means of transportation or having access to public transportation. Participant descriptions included:

- “...I have a car; my husband drives me... transportation is not an issue for me...I always go to my appointment ...”
- “In NYC, you might have to get on the bus or the train depending, to go see a good doctor or specialty...”
- “.... They will tell you to come at a certain time and if you left, they would not give you the transportation fare .... you will have to go back home walking...”

### *Nursing System*

Table 3 describes the two themes related to nursing systems, along with the meaning units from the participant descriptions that support the theme.

<b>Table 3.</b> Themes of Nursing Systems and Associated Meaning Units		
Theme 3	The nursing system supports breast self-care through healthcare providers, resources, and mammography follow up.	<ul style="list-style-type: none"> <li>• Nurse provides information on exams</li> <li>• Some experience no assistance from the nurse</li> <li>• Resources include doctors, insurance, health plan, and reading materials</li> <li>• Most voiced no concerns at all about self-care</li> <li>• Mammogram concerns regarding procedure and possible results</li> <li>• Participants describe follow up as: an appointment, 1-year follow up, email,</li> </ul>



		or in the portal, sonogram, ultrasound, or biopsy
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Nursing system as described by Orem is comprised of concepts and sequences of deliberate practical actions performed at times in coordination with actions of patients to develop self-care (Orem, 2001, p. 363). The nursing system as it relates to *breast self-care* will be centered around interventions related to women's *breast self-care* needs (Orem, 2001, p. 148). When asked about nursing system, participants described having a health plan that includes access to healthcare providers, healthcare resources including information on breast exams, teaching, support, communication, appointments, and follow up care on test results. While most participants voiced no concerns at all about self-care, some apprehensions were related to mammographic procedures and possible follow up results. The meaning units derived from their descriptions laid the foundation for the theme. These meaning units included: the nurse provides information on exams, some experience no assistance from the nurse, resources include doctors, insurance, health plan, and reading materials, most voiced no concerns at all about self-care, mammogram concerns regarding procedure and possible results, participants describe follow up as: an appointment, 1-year follow up, email, or in the portal, sonogram, ultrasound, or biopsy. As a result, the following theme emerged from the category of nursing system.

*Theme 3: The nursing system supports breast self-care through healthcare providers, resources, and mammography follow up.*

When asked about how the nurse assists with breast self-care, participants describe how the nurse provides them with information, teaching, and support. Comments included:

- “I can always see or call my nurse, my doctor, my health insurance to ask for information about my breast....”
- “The nurse tells me how to examine my breast...by teaching the right way of checking myself.”
- “The nurse [provides] professional opinions.... pamphlets and information.”
- “Providing information, teaching, and support.”
- “The nurse understands, and puts herself in your situation... it’s a matter of being comfortable.”
- “The nurse assists me with the mammogram; ... and makes me feel reassured, even though it hurts.”
- “... having a sense of knowing that you are in a safe place, and that someone cares...”
- “Appreciate the concerns of nurses who are looking into what is happening and answering any questions.”

When asked about resources for breast self-care, participants describe establishing a health plan that includes healthcare providers, resources, and insurance. Comments included:

- “A health plan that back you up, and makes you feel comfortable, so you can go ahead .... Not worrying about the cost.”
- “I feel safe because I have been coming to the breast clinic for a couple of years.”
- “I have a good relationship with my primary doctor, and can speak about anything, no matter how small it is.”
- “My doctors do everything that needs to be done in my situation.”
- “I have the resources to be taken care of here; I get to see my doctors... and I feel satisfied with my health plan.”

- “If you have the resources to find out what’s going on in your body, you can do anything...”

When asked about concerns about breast self-care, most participants voiced no concerns at all about self-care, while others reported concerns regarding the lack of knowledge, mammographic procedures and possible follow up results. Comments included:

- “...I do have concerns about [coming up] with breast cancer...; actually, this is my first time to have a biopsy and I hope when I get my results tomorrow everything will be alright...”
- “...I don’t want to remove my breast; and that’s my biggest concern....”
- “...I am concerned about the lack of knowledge, people were advised to stay home because of COVID 19... when I had the mammogram after 3 years of not having it, I found out that I have between stage 2 and 3 breast cancer.... If I had done my mammogram earlier, it wouldn’t be that bad at all...”
- “... I totally hate having my breasts smashed in a machine ...I emotionally can’t physically take myself to this appointment where I am going to feel...like I am in a torture chamber.... why does it have to be so cruel.... I am 57, if I don’t have another mammogram in my life, who am I going to blame? The bad experience? The pain...?”

When asked about mammogram and follow up care, participants describe implementing follow up care with appointments, communication, and tests results. Comments included:

- “.... I know, intuitively, if nothing is wrong, I am not going to receive a call; I will receive a letter in the email.”
- “I always get an appointment to discuss the results in the breast clinic, with my GYN [gynecologist], or primary care doctor.”

- “I am asked to come back in 6 months because there is something that needs to be monitored”
- “Every time I get a mammogram, I always get an appointment to discuss the results in the breast clinic....”

### **Trustworthiness**

The criteria to assure rigor were adhered to in research design, method, and collection and analysis of participant descriptions. These principles are credibility, transferability, dependability, and confirmability.

Credibility attests to how congruent the findings of the study are with reality and the accuracy in concordance with the purpose and research question. Numerous provisions were made to ensure the credibility of the study findings. The deep-rooted method of directed content analysis was used to guide this inquiry. Moreover, the investigator has extensive clinical experience with the study population and has over seven years of experience in conducting medical interviews. Likewise, using the semi-structured interview script, the investigator conducted a practice tape recorded interview with a fellow experienced in qualitative research before starting the interview. The constructive feedback provided by the fellow aided in improving the efficacy and accuracy of the interview processes. Orem’s self-care theoretical framework was used to guide the collection of data. The data were transcribed verbatim and analyzed following the directed content analysis method. The texts were coded and broken down into categories. The transcripts were read numerous times and the significance of the data were discussed to obtain a clear and deep description of breast self-care among New York City African American and Hispanic women seeking care in a comprehensive breast care center. The data were analyzed and categorized using Orem’s self-care theory pre-determined concepts

including self-care agency, self-care deficit, and nursing system (Orem, 2001, p. 141). No new category or subcategory of an existing code was identified

A purposeful sampling was performed to include Hispanic (6), African American (4), and African (2) participants, and this proportionately reflects the populations served at the comprehensive breast care center. Participation was voluntary, and participants were told that they can share as little or as much as they would like. Participants were assured that their information is kept anonymous and protected and the data collected will not be linked to the research participants (Roberts & Hyatt, 2019). Each participant was informed that her healthcare in the Bronx Care Health System would not be impacted by her decision to participate or not to participate in the study. The interviews were scheduled based on the participant's availability and took place in the environment where the participant felt comfortable to disclose their information (via zoom or in person in the PI's office). Cultural sensitivity was a central aspect of the study because some cultures are more reserved than others. The reconstructed stories from the transcribed interviews were provided to the participants for a member check, allowing for each participant to verify the accuracy of their words and the opportunity to add, modify, or delete any of their data. All the participants confirmed their stories. All data were analyzed under the guidance of knowledgeable committee members in directed content analysis, hence providing peer scrutiny and further perspectives for accuracy of data analysis. Finally, the findings are supported by direct quotations from the participants.

Transferability is achieved if the findings of a qualitative study are transferable to other similar settings/populations. To enhance transferability of the study findings to similar settings/populations, or to enable a future researcher to repeat the work, detailed report of the methods and procedures were provided including the eligibility measures, recruitment

approaches, data collection, and analysis. Furthermore, a rich description is provided about the study settings, participants' background, demographics, and study processes.

Dependability attests to the ability to reproduce the similar study findings. To facilitate an in-depth understanding of the method and its effectiveness, a thorough description of the research design and implementation was provided. Moreover, an exhaustive description of the operational details of data gathering, including the interview script and study processes are presented. Lastly, reflective appraisal of the study via discussion, limitations, and a detailed audit trail provide evidence to support dependability of findings.

Confirmability is pertinent to objectivity, authenticating that the study findings are entirely the result of the study alone and not from the inclinations or descriptions of the investigator. This can be confirmed when the study findings are based on the analysis of the collected data and examined via an auditing process and in concordance with committee members experience of the methods being used in the study, not in the clinical expertise related to the study population, background, or purpose (Shenton, 2004). Extensive audit trails were maintained for each step in the data analysis process. Additionally, coding checks were continuously made to establish the confirmability of the findings and to show the transparency of the study. The committee members who are experts in nursing research were asked to examine separately the interviews and raw data, as well as the interpretation derived from them to ensure that the findings are the results of the experiences and ideas of the participants, rather than descriptions and predilections of the PI.

## **Synthesis**

In concordance with the direct content analysis methodology, the data were analyzed and categorized using Orem's self-care theoretical framework and its pre-determined concepts of

self-care agency, self-care deficit, and nursing system (Orem, 2001, p. 141). The three themes resulting from this study summarize how Inner-New York City African American and Hispanic Women seeking care in a comprehensive breast care center describe *Breast Self-Care*: (a) Self-care agency is the power to manage *breast self-care* through the mutual influence of knowing and doing, in the context of one's culture, (b) Self-care deficits were not identified, (c) The nursing system supports breast self-care through healthcare providers, resources, and mammography follow up.

## Chapter 5: Discussion

This study used a qualitative descriptive design to get descriptions of *breast self-care* from African American and Hispanic women seeking care in a comprehensive breast care center. Using a directed content analysis approach, descriptions of self-care agency, self-care deficit, and nursing system were analyzed. Three themes emerged. The findings of the study are meaningful in the search for ways to promote health, healing, and wellbeing for those seeking care in a comprehensive breast care center.

This completed study serves to fill a recognized gap in the literature of how those receiving care in a comprehensive breast care center in inner city New York City can be supported in *breast self-care*. The study further advances knowledge on the topic by describing in the words of these women breast self-care agency, self-care deficit, and nursing system.

The major topics of this chapter include discussion of study findings. The headings are as follows: the study research question and purpose, integration of the findings with Orem's theory of self-care, findings related to the literature, contribution to the knowledge base of nursing, implications of the findings for further research, implications of the findings for nursing practice, implications of the findings for policy, limitations, and conclusion.

The purpose of this qualitative study was to explore how *breast self-care* is described by inner New York City African American and Hispanic women seeking care in a comprehensive breast care center. Orem's theory of self-care was used to guide the study. The Research question was as follows: How do New York City African American and Hispanic women seeking care in a comprehensive breast care center describe *breast self-care*? Through a purposive sampling strategy, twelve African American and Hispanic women who met the inclusion criteria were recruited to take part in the current investigation.



## Findings

The findings of this study are the themes that were derived from descriptions of New York City African American and Hispanic women. The themes are on self-care agency, self-care deficit, and nursing system.

### Self-care agency

Self-care agency is the power to manage *breast self-care* through the mutual influence of knowing and doing in the context of one's culture. This theme was generated from women seeking care in a comprehensive breast care center. While this study acknowledges the importance of attentive presence on examining breast, protecting breasts through supportive measures, being mindful of nutrition/exercise, and being aware of how breasts appear and feel, it shows how the influence of culture can be personal, kept private, and not talked about.

### Self-care deficit

The theme generated on self-care deficit for women seeking care in a comprehensive breast care center was that no self-care deficits were identified. Self-care deficit was not identified because the findings revealed the participants who took part in the current research were capable of doing what they need to do for their breast health, they had a health plan for breast care, and transportation available. Most participants conveyed no concerns and others reported that nothing discourages them from taking care of their breasts. Although the participants did not identify any major deficit that could prevent them from getting their breast care, most of the participants admitted to how *breast self-care* or awareness was not a central focus of education in their culture. The majority of the participants who took part in the study were able to demonstrate their ability to meet their therapeutic self-care demands which although acquired, may be different for all individuals (Orem, 2001, p. 147).

## **Nursing system**

The theme generated from nursing system is that the nursing system supports *breast self-care* through health care providers, resources, and mammography follow up. For women seeking care in a comprehensive breast care center, the nursing system supported *breast self-care* with a health plan that provides teaching, support, and follow up resources. The study supported Orem's theory by indicating that establishing a health plan that includes healthcare providers, resources, insurance, providing information, teaching, support, implementing follow up care with appointments, communication, and tests improved participants' aptitude to follow through with their breast care (Orem, 2001, p. 148-363).

Overall, the findings of the current investigation indicated that if women are provided with a good supportive nursing system offering adequate healthcare resources, a reliable health plan, access to providers, the needed education, communication, individualized support (as the needs for each participant may be different), and a functional system to ensure effective follow up care, they will be more likely to have self-care agency (which is demonstrated by the women's ability to deliberately engage in activities intended to promote and maintain their overall breast health) and they will be less likely have any self-care deficit (Orem, 2001, p. 146-254). The findings of the study demonstrated coherence with Orem's self-care theory and provided a very good approach to *breast self-care*. Although breast cancer may not be avoidable, Orem's self-care theory was a useful approach to studying this research question as the activities of *breast self-care*, which is a combined approach to caring for the breasts and consisting of breast self-awareness (BSA), clinical breast examination (CBE), adherence to screening mammogram, as well as a suitable follow up after screening mammogram are all intended to promote and maintain the breasts in a healthy state. Appropriate *breast self-care* can lead to early

detection of breast cancer which in turn can improve health outcome as breast cancer treatments are likely to be more effective when the disease is diagnosed early (ACS Cancer Statistics, 2022; Provencher et al., 2016).

The findings of this research revealed a large majority of the participants had a very good healthcare support system as demonstrated with the theme generated from Orem self-care concept of Nursing system: For women seeking care in a comprehensive breast care center: The nursing system supports *breast self-care* with a health plan that provides teaching, support, and follow up resources. These women were practicing breast self-awareness (BSA) in combination with other screening methods including clinical breast exam (CBE) and screening mammogram. Most of the participant statements provided evidence that they were knowledgeable about making healthy decisions about breast care and they had the power to engage in self-care agency (Orem, 2001, p. 253-256).

### **Findings Related to the Literature**

Previous inquiries have mostly examined breast cancer patients using Orem's self-care theory from the perspective of disease management intent only. Correspondingly, the clinical trial conducted by Dejange et colleagues (2018) evaluated the effect of Orem's self-care model training program on improving the anxiety of 70 women with breast cancer. The findings revealed a noteworthy difference between the control group and the intervention group in terms of pre- and post-anxiety changes ( $P < 0.001$ ) (Dejange et al., 2018). A lower post-intervention anxiety level was observed in the intervention group as compared to the control group. Orem's self-care model-based training program was found to reduce anxiety among patients with breast cancer and was used as a self-care model for nursing care interventions in these patients. The analysis demonstrated that patients can noticeably control their anxiety symptoms with increased

awareness and self-efficacy (Dejange et al., 2018). Lien et associates (2010) also obtained similar findings as their study revealed that nursing education was successful in controlling anxiety and promoting self-care of women with breast cancer undergoing chemotherapy.

A study conducted by Afrasiabifar et al. (2018) evaluating the effect of a self-care program using Orem's self-care model on the life quality in women with breast cancer undergoing chemotherapy revealed no noteworthy differences in the mean self-care scores of the experimental and control groups before the educational intervention. However, after the intervention, a noteworthy difference was found between the two groups in terms of mean self-care. Thus, confirming the effectiveness of Orem-based educational intervention on self-care in the patient's undergoing chemotherapy (Afrasiabifar et al., 2018).

All the above-mentioned inquiries were conducted on women who had breast cancer and were undergoing chemotherapy. While breast cancer may not be preventable, *Breast self-care* as a combined approach to caring for the breasts and consisting of four specific activities intended to promote breast health [breast self-awareness (BSA), clinical breast examination (CBE), adherence to screening mammogram, as well as a suitable follow up after screening mammogram] can lead to early detection of breast cancer when therapies are likely to be more effective. Based on these principles, the current study thus departed from the approach taken by other studies by using Orem's self-care theory to obtain a description of *breast self-care* among African American and Hispanic women. Disease prevention as early detection can save lives and can help improve a woman's health outcome if she develops the disease (ACS Cancer Statistics, 2022).

The findings of the present investigation aligned well with the results of various studies conducted on different populations and assessing different interventions. Masoudi et al. (2009)

evaluated the effect of self-care program education based on Orem's theory on mental aspect of quality of life in 70 patients with multiple sclerosis. A statistically significant difference was observed between the control and experimental groups when comparing their performance before and after treatment with eight educational sessions about self-care based on Orem's theory (Masoudi et al., 2009). This analysis was conducted on patients with multiple sclerosis whereas the current study assessed *breast self-care* behaviors among African American and Hispanic women.

Heinze & Williams (2015) evaluated symptom alleviation and self-care among breast cancer survivors after treatment completion. The self-care method category most stated by the participants in the literature review was diet/nutrition/lifestyle. The findings of the current study share similar findings with Heinze & Williams' (2015) publications as the participants from the existing study also spoke to these categories (diet/nutrition/lifestyle) as their self-care methods. The self-care method category least indicated was herbs/vitamins/complementary therapy. The participants mainly reported that the self-care methods were perceived as efficient (Heinze & Williams, 2015).

Although the studies from the literature review were not related to breast cancer screening, the emphasis was on improving patient symptoms using self-care strategies. Self-care to assist in disease management is certainly more demanding than the need for self-care to assist in disease prevention as validated by the World Health Organization's definition which principally target healthy people: "Self-care in health refers to activities, individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by lay people on their own

behalf, either separately or in participative collaboration with professionals” (World Health Organization 1984). In fact, the need for self-care when battling breast cancer or a chronic debilitating condition is emphatically more challenging than self-care when trying to prevent a late-stage diagnosis of breast cancer. Chronic disease care is a challenging matter for patients’ well-being and an encumbrance for global healthcare, as it involves one of the primary costs of healthcare systems (Alqahtani et al., 2022; World Health Organization., 2019). The literature review did not yield any study using Orem’s self-care theory to promote *breast self-care* in African American and Hispanic women. Thus, supporting the need for this study, which again explored the description of *breast self-care* among African American and Hispanic women using Orem's self-care theory of nursing.

Although Orem’s theory of self-care was not exclusively used as a theoretical framework in the studies included in the literature review, the significance of self-care was revealed in the literature. The powers of motivation, decision-making, and knowledge necessary to perform self-care actions, which are all characteristics of self-care, were stated throughout the articles included in the literature review (Altpeter et al., 2005; Bullock & McGraw, 2006; Chang et al., 1996; Curry, 1994; Ell et al., 2002; Gotay & Wilson, 1998; Mickey, Durski, Worden, & Danigelis, 1995; Pérez-Stable et al., 1996).

Remarkably among the notable transformation of health care in the United States during the last 20 years are the Patient Protection and Affordable Care Act (ACA), the Electronic Medical Records (EMR), and the impact of COVID-19. Obviously, the literature review revealed that the ACA Medicaid expansion plan has increased health insurance coverage and improved timely health care access for previously uninsured women; thus, facilitated access to breast cancer screening and healthcare providers (Gulitz et al., 1998; Metsch et al., 1998; Silva et al.,

2017; Tsapatsaris et al., 2021). Similarly, the EMR enhanced achievement of preventive care, and health screening objectives by providing reminders to providers when certain screening recommendations are due or obsolete, expedited requests, simplified appointment booking, and improved communication with patients using patient portals and personal health records ((Altpeter et al., 2005; Erwin et al., 1999; Honavar, 2020; Gulitz et al., 1998; Metsch et al., 1998). These findings were established in the present inquiry as the participants reported having an efficient nursing system, which supports *breast self-care* through a health plan that includes access to healthcare providers, resources, insurance, information, support, follow up care on test results, and proper communication.

Inopportunately, with the COVID-19 pandemic, the total number of cancer screening tests received by women through the CDC's National Breast and Cervical Cancer Early Detection Program has declined by 87% for breast cancer during April 2020 as compared with the previous 5-year means for that month (CDC, 2021). Correspondingly, when asked about concerns about breast self-care, most participants voiced no concerns while one participant reported being concerned about the lack of knowledge and proper follow up. Her comments included: "*...I am concerned about the lack of knowledge, people were advised to stay home because of COVID 19... when I had the mammogram after 3 years of not having it, I found out that I have between stage 2 and 3 breast cancer.... If I had done my mammogram earlier, it wouldn't be that bad at all...*" The current study findings are concordant with the literature review, revealing that extended interruptions in screening due to the COVID-19 pandemic could lead to late-stage diagnoses of breast cancer, and poor health outcomes; thus, increasing cancer disparities among women already experiencing health inequalities (CDC, 2021). Cogitating that breast cancer is a highly prevalent and treatable type of cancer, timely access to diagnosis and treatment may have

a better health outcome, mostly among patient groups with previously poor health care access, such as African American and Hispanic women (Alagoz et al., 2021; Tsapatsaris et al., 2021).

Most participants voiced no concerns when asked about breast self-care, while some reported being concerned about the mammographic procedures. Comments included: “... *I totally hate having my breasts smashed in a machine ...I emotionally can't physically take myself to this appointment where I am going to feel...like I am in a torture chamber.... why does it have to be so cruel.... I am 57, if I don't have another mammogram in my life, who am I going to blame? The bad experience? The pain...?*” These findings are concurring with the literature review indicating that the heightened apprehension and pain caused by the mammographic equipment are significant factors associated with non-participation to recommended mammogram screening guidelines (Altpeter et al., 2005; Poulos & Llewellyn, 2005).

### **Significance**

The significance of this research inquiry resides in the fact that the problem of *breast self-care* is linked to the concepts of health, healing, and well-being. (Smith, 2019, p. 10). This investigation revealed how *breast self-care* practices by African American and Hispanic women promoted well-being through a focus on Orem's self-care concepts of self-care agency, self-care deficit, and nursing system (Orem, 2001, p. 254).

The theme generated from Self-Care Agency is that for women seeking care in a comprehensive breast care center, Self-care agency is the power to manage *breast self-care* through the mutual influence of knowing and doing, in the context of one's culture. Participants spoke to being attentive and protective of their breasts, being mindful of their diet, nutrition, and exercises. These attributes are all supportive of health, healing, and well-being as being responsible for one's action can aid primary care prevention and ill health.



The theme generated from Self-care deficit was that Self-care deficits were not identified. Most participants negated having any challenges or discouragements to *breast self-care*. Instead, they reported having the capability to fulfill their breast care related needs, having access to a health plan for breast care, and easy access to transportation. These factors show that although health, healing, and well-being may be perceived as better managed in the healthcare system, individuals are more likely to take care of themselves and to assume responsibility for their breast health if they are made aware through breast self-awareness and if they are empowered.

The theme generated from nursing system was that the nursing system supports breast self-care through healthcare providers, resources, and mammography follow up. Most participants described how the nurse provide them with information, teaching, and support. They reported having access to a health plan that includes healthcare providers, resources, insurance, follow up care with appointments, communication, and tests results. In the present study, the participants reported having the adequate nursing system to sustain their breast health needs. Thus, this theme supports health, healing, and well-being.

The findings of the current inquiry demonstrated that the three emerging themes are inter-related and revealed that when individuals are provided with adequate healthcare resources or nursing system, they are more likely to have breast self-care agency and therefore less likely to demonstrate self-care deficit. These findings reinforced the relevance of Orem's self-care theory in the field of nursing. The application of *breast self-care* to Orem's theory of self-care provided a new insight on how forthright nursing theories can be applied into practice by promoting disease prevention. Directly related to *breast self-care* with the purpose of breast cancer prevention, Orem's theory is worthy of mention as the model applicable to both illness and wellness. Orem's

theory of self-care is a valid and essential theory that can guide individuals in their quest for breast care, breast health, healing, and wellness.

### **Trustworthiness of Study Findings**

The criteria for evaluating trustworthiness of the findings include credibility, transferability, dependability, and confirmability (Shenton, 2004). Trustworthiness was addressed throughout study planning, implementation, and interpretation of findings. The criteria to assure rigor were adhered to in research design, method, and collection and analysis of participant descriptions include credibility, transferability, dependability, and confirmability.

#### **Credibility**

According to Shenton (2004), credibility refers to how congruent the findings of the study are with reality. Credibility was addressed throughout the study. The study is designed based on a directed approach to content analysis and the Self Care Theory is used as a theoretical framework. The relevance of the study to the nursing field is pertinent as understanding how NYC African American and Hispanic women seeking care in a comprehensive breast care center describe breast self-care is important in improving breast health among these populations. An expert's opinion on breast health was obtained and the research method was clearly defined. An interview guide was provided to allow participants to talk about relevant themes in their own words and at their own pace. Background and qualifications of the researchers involved in the study was provided. Peer scrutiny of the research project was performed. Direct quotations from the research participants were presented throughout the data collected during the interviews. Frequent debriefing sessions were performed throughout the study and data analysis. Examination of previous research findings was conducted and included in the literature review. Additionally, the steering dissertation committee verified and confirmed the researchers'

interpretation; emergent themes was examined based on their experience, areas of proficiency and understanding of the literature. Bracketing was used to set aside personal theories, research presuppositions, inherent knowledge, and assumptions as separate from what is observed in the research process (Creswell, 2007). Investigators' triangulation was used to confirm and enhance the credibility of the findings (Shenton, 2004).

### **Transferability**

According to Yilmaz (2013), transferability is achieved if the findings of a qualitative study are transferable to other similar settings. The rigor of transferability was addressed in various instances. The literature review was systematically conducted and included more than 18 articles which are considered sufficient. Thick descriptions of the phenomenon under investigation, the study settings, and participants were provided. A semi-structured interview guide was used, and the interviews was conducted by the PI who took notes of her observations during the interviews. Due to the purposive sampling, attempts were made to minimize selection bias by distributing flyers during a breast cancer awareness event; the first 12 women who called to take part in the study and met the inclusion criteria were recruited (Yilmaz, 2013).

### **Dependability**

Shenton (2004) referred to dependability as the detailed reporting of the processes within the study so to facilitate a future researcher to replicate the work. Dependability of the study was revealed through numerous processes. The research question is adequately substantiated and rings true with US data suggestion of ethnic differences in breast cancer mortality. Description of the researchers' roles and research procedures was provided. An audit trail and coding checks was performed for transparency of the study. To enable a future researcher to repeat the work, detailed report was provided about the study settings, participants, and study processes. To

address the matters of dependability and confirmability, the data analysis was verified by two experts in qualitative study design who are part of the dissertation committee. Moreover, coding and re-coding approaches were performed after two weeks of prior coding (Shenton, 2004).

### **Confirmability**

According to Yilmaz (2013), confirmability is applicable when the study findings are based on the analysis of the collected data and examined via an auditing process. A thorough methodological description was done by the PI to allow the integrity of the study findings to be examined. An audit trail was used. Investigators' recognition of shortcomings in the study's method and their potential effects was established. Additionally, two expert researchers who are part of the dissertation committee and are familiar with qualitative study design separately investigated the interviews and raw data, as well as the interpretation derived from them to ensure that the study's findings are the result of the experiences and ideas of the participants, rather than characteristics and preferences of the PI. Member checks and peer scrutiny was performed. Investigators' triangulation was performed through the assistance of two expert researchers who are part of the dissertation committee and served as data analysts. Data source triangulation included the use of space (in person and zoom platform), time (the interviews were performed at different times according to the participants' preference and availability), and persons (Hispanic women, African, and African American women were involved in the study as participants) to strengthen conclusions about findings and to reduce the risk of false interpretations. Knowing that researchers' attitudes in qualitative research can influence design, data collection, and analysis, the assistance of the steering dissertation committee was used to confirm a balanced representation of the data, understanding of the study findings, and their implications for policy and practice (Yilmaz, 2013).

## Implications

This study has yielded findings that are coherent with the suggestions of Orem Self-care nursing theory. When care is delivered in a comprehensive breast center, self-care agency is enhanced, and self-care deficits are lowered, and nursing system is an interdisciplinary team. The results revealed and confirmed the usefulness of the framework. The study findings provide theoretical, practical, and policy implications for all healthcare providers who are caring for women. The following are hereby recommended:

### Policy

As it was demonstrated in the current study, when women are provided with an efficient nursing system, they will have breast self-care agency and will most likely not present any breast self-care deficit. Also, this study is in line with the Healthy People 2030 objectives of addressing disparities in breast cancer treatment (Healthy People, 2030). Hence, from a policy perspective, the results of the present study suggest that efforts should be made to develop policy supporting the development of comprehensive breast care centers for women. Participants in the study had a health plan that included access to healthcare providers, healthcare resources, information on breast exams, teaching, support, communication, and follow up care. A comprehensive breast care center can provide women with the necessary support and care for *breast self-care* practices.

### Practice

This analysis has yielded findings that can serve as a guide for needs assessment in terms of *breast self-care* agency, *breast self-care* deficit, and an adequate nursing system. While most of the studies reviewed addressed self-care during the disease process, the research suggests that self-care is substantial in preventing the disease (Shah & Guraya, 2017; Sitt et al., 2018; Yoda & Theeke, 2022). Hence, considering that disease prevention is essential to good health practices,

all women should be taught on the importance of *breast self-care* to prevent breast cancer, promote early detection, and minimize the risks of late-stage diagnosis of breast cancer. The present study aided in understanding the importance of breast cancer prevention by exploring how African American and Hispanic women seeking care in a comprehensive breast care center describe *breast self-care*. Most of the participants admitted to how *breast self-care* or awareness was not a central focus of education in their culture. Thus, another practice implication is for health care providers to reinforce breast self-care with all women they see in practice.

### **Theory Development**

When Orem's self-care theory was developed, **nursing system** was the concept used to describe the environment of care for the women. Moving forward, the environment of care has extended to include a range of health care providers in a collaborative model of care. Broadening the concept of **nursing system to health care system** that is interdisciplinary is a more contemporary view of this concept.

### **Research**

Orem's self-care approach is considered an appropriate theoretical framework for studying African American and Hispanic populations. Future research might consider studies using quantitative methodologies or chart reviews to uncover if the lack of deficit found in the current qualitative study correspond with the objective realities.

### **Limitations**

While the use of directed content analysis with a well-established theory to guide data collection and interpretation add strength to this study, it can also serve as a potential limitation. Using pre-existing theory poses the risk of predetermined bias on the part of the researcher, threatening objectivity and confirmability of the findings. The risk of bias was minimized by

performing peer scrutiny of the research project. Strategies such as trustworthiness, reflexivity, bracketing and intuiting were used to ensure that any pre-understanding was set aside, and a non-judgmental attitude was maintained throughout the study and data analysis. A detailed research plan was created, and the study findings were reviewed with the participants for accuracy and transparency. Coding and analysis of the data were performed with the assistance of two expert qualitative researchers who are part of the dissertation team (Hsieh & Shannon, 2005).

In addition, transferability of study findings is limited in qualitative research. Collecting data from a single borough, Bronx (NYC) might limit the transferability of the study findings. The participants of the present study are receiving care in a comprehensive breast care center; there is a possibility that their experiences may be greatly dissimilar to another woman of color from the community who does not attend any health care facility for some reasons. Future inquiries should include a sample of community women to compare whether there are differences in their perception of BSA.

### **Conclusion**

Gathering descriptions of breast self-care agency, self-care deficit, and nursing system offers insight into how *breast self-care* is lived and valued among African American and Hispanic women in inner New York City. These findings offer implications for future practice, research, and policy change to support these women, as well as to improve their health, healing, and well-being. Orem's self-care theory served as an appropriate and valuable theoretical framework for studying the problem of *breast-self-care*. Through the current study, it was once again revealed how Orem's contribution to not only the field of nursing, but to the overall health field is substantial in improving individuals' breast health outcomes.

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**Appendix A: Demographic Data**

Age: \_\_\_\_\_ Sex: \_\_\_\_\_

Race/Ethnicity: \_\_\_\_\_ Language \_\_\_\_\_

Employment Status: Public sector \_\_\_\_\_

Employment Status: Private sector \_\_\_\_\_

## Appendix B: Semi-Structured Interview Script

Research question guiding this interview is: How do New York City African American and Hispanic women seeking care in a comprehensive breast care center describe breast self-care?

The interview guide used in this study was framed based on Orem's Self-Care Theory. This is a nursing theory composed of three interconnected concepts: self-care agency, self-care deficit, and nursing system (Orem, 2001, p141). The duration of the interview is 30-60 minutes. The interview is written in French, English, and Spanish. The PI is fluent in French and English. A Spanish translator will be used for Spanish speaking participants.

***Self-care:*** Self-care agency is defined by Orem as: “the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being” (Orem, 2001, p43). Orem identified three self-care requisites comprising universal self-care requisites, developmental self-care requisites, and health deviation self-care requisites (Orem, 2001, p143). The interview questions for self-care agency follow:

- ***Self-care agency. (Orem, 2001, p43).***
  - 1) *What does taking care of your breasts mean to you?*
  - 2) *I would like to talk with you about knowing your breasts.*
    - c. *Talk to me about how you know your breasts?*
    - d. *What does knowing your breasts mean to you?*
  - 3) *What about your culture, influences how you take care of your breasts?*
    - a. *[Note to Self: Listen for family and community]*
  - 4) *What activities do you perform to take care of your breasts?*
  - 5) *Tell me how you are actively involved in taking care of your breasts?*

***Self-care deficit.*** Self-care deficit is defined by Dorothy Orem as: “the relationship between self-care agency and therapeutic self-care demands of individuals in which capabilities for self-care, because of existent limitations, are not equal to meeting some or all of the components of their therapeutic self-care demands” (Orem, 2001, p.282). As proposed by Orem, a deficit in meeting self-care could be related to difficulties or obstacles that prevent individuals from fulfilling requirements for health, well-being, growth, and development. The preventing factors may include resource unavailability or inadequacy, age, developmental state, life experience, health state, socio-cultural orientation, health care system factors, family system factors, patterns of living, environmental factors (Orem, 2001, p.147). The interview questions for self-care deficit follow:

1) *What, if any, challenges have you encountered when taking care of your breasts.*

a. *[Note to Self: Listen for challenges about insurance, travel, and culture]*

2) *What, if anything, discourages you from taking care of your breast.*

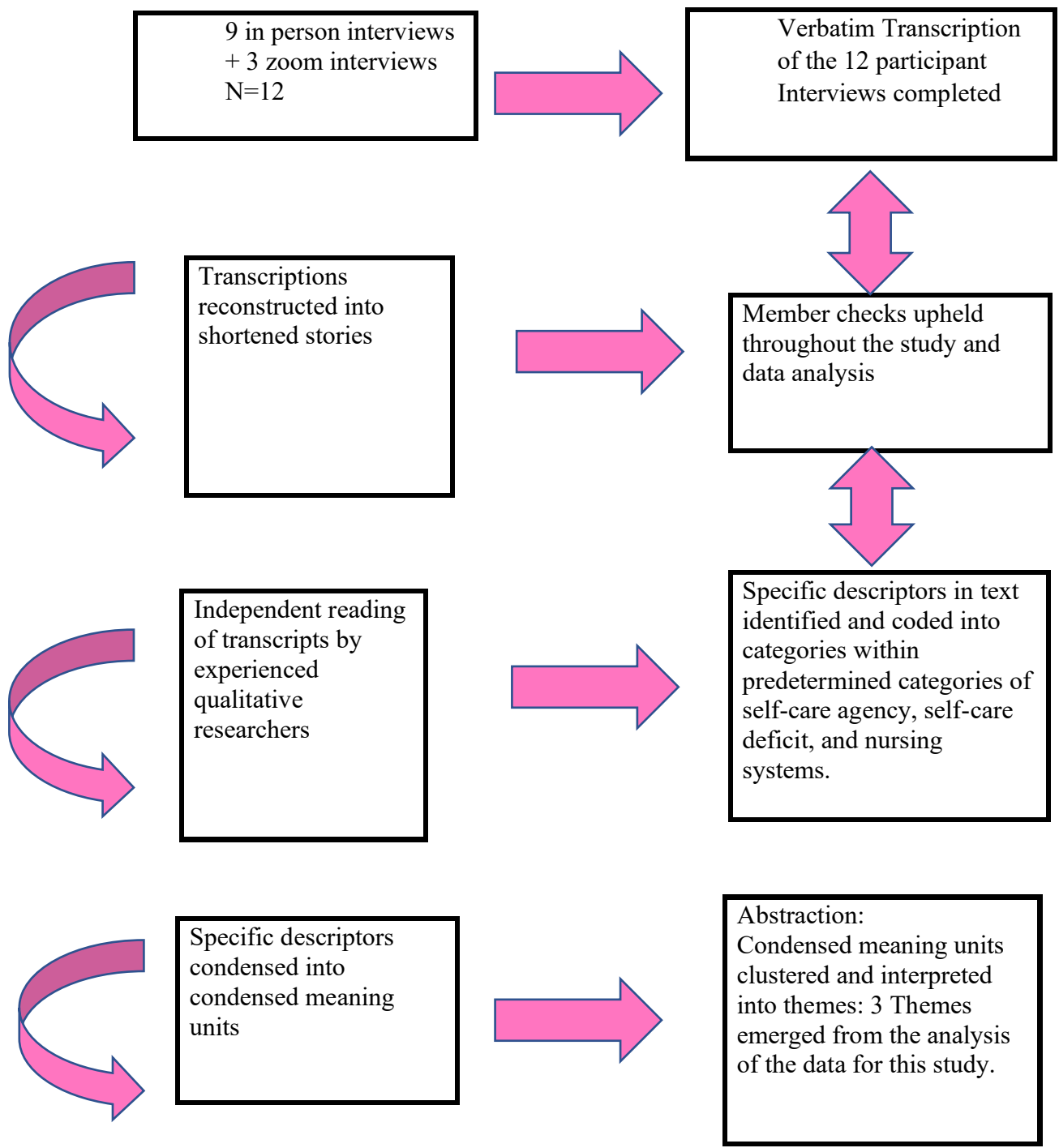
***Nursing systems:*** Nursing systems as described by Orem includes the concept of self-care deficit. Nursing system establishes the structure and the content of nursing practice. It articulates the nurse property of nursing agency with the patient properties of therapeutic self-care demand (Orem, 2001, p147).

The interview questions asked in this section are related to the supportive-educative system in which the individual can perform with assistance or need to learn how to perform required methods for therapeutic self-care. The nurse role in this section is to provide the necessary education and support the individual in achieving therapeutic self-care. The interview questions for nursing system follow:

1) *How does the nurse assist you with taking care of your breast?*

- 2) *Tell me about the healthcare resources you have to take care of your breast?*
- 3) *What concerns do you have about getting care for your breasts?*
- 4) *If you had a mammogram, what follow up care did you receive?*

### Appendix C: Analysis Plan



## Appendix D: Example Audit Trail

Specific Descriptors	Meaning Units (sub-themes)	Theme 1
<p><b>Self-Care Agency</b> <b>Activities of breast self-care</b></p> <ul style="list-style-type: none"> <li>• “Making sure .... no lumps or discharge.”</li> <li>• “I do the self-checkup... I track my cycle every month...”</li> <li>• “.... don’t put on a bra that’s too tight...maintain the breast loose, comfortable...and not tightening the breasts....”</li> <li>• “....my exercise routine, what I eat, all of it, what I drink, how I feel rested, as I long as I am taking care of my body...I am taking care of my breasts.... “</li> <li>• “.... if there was something different, I will know automatically.....”</li> <li>• “I know my breasts because I know how the size is, the feeling when I touch my breasts...if there is any abnormality.... some color or redness, changes of the skin of my breasts, something that I am not familiar with...”</li> <li>• “Yes, our culture influences how we take care of our breast; our breast is in a way what represent us, put in a category (as women); but how we take care of it is an individual situation.</li> <li>• “Nobody spoke to me about taking caring of my breast.</li> </ul>	<ul style="list-style-type: none"> <li>• An attentive presence on examining breast.</li> <li>• Protecting breasts through supportive measures.</li> <li>• Being mindful of nutrition and exercise.</li> <li>• Awareness of how breasts appears and feels.</li> <li>• Influence of culture is personal, kept private, and not talked about</li> </ul>	<p>Self-care agency is the power to manage breast self-care through the mutual influence of knowing and doing, in the context of one’s culture.</p>