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Perceptions and Behaviors of Caribbean and South American Women of Color Living in the United States Towards Breast Cancer

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Abstract

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MPH, Walden University, 2010

BS, Clayton State University, 2006

AS, Georgia Perimeter College, 2004

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

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Abstract

Breast cancer is a global public health issue, and even though the incidence and mortality rates for this disease have declined, a substantial gap in mortality rates between U.S. women of color and European American women remains. Strategies have been initiated to decrease this gap, but they have not addressed the special needs of women of color residing in the United States, who tend to be diagnosed only after they have developed late-stage breast cancer. The purpose of this phenomenological study was to understand the perceptions and behaviors of 20 first-generation Caribbean and South American-born women of color living in Atlanta, Georgia, related to breast cancer awareness, screening, treatment, and follow-up care. Qualitative data analysis was used to identify themes that included, but were not limited to, the role of genes in breast cancer, lifestyle influences and risk of breast cancer, environmental factors, positive perceptions of foods and their impact on breast health, the role of culture on health care decisions, fear of harm from radiation exposure, familial relationships, understanding why they sought screening and/or treatment, and familial health histories and increased risk of breast cancer. The participants' cues to take action were influenced by knowledge, health insurance coverage, confidence, educational attainment, age, income, family support, and self-motivation. Culture, race, or ethnicity had little to no effect on whether the women received breast cancer screening or mammography. The findings could facilitate social change by educating Caribbean and South American women of color in the United States about breast cancer and the need for screening, to reduce the incidence of breast cancer and the mortality rates among the target population and improving their quality of life.

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Dedication

This dissertation is dedicated to Ms. Patricia Caster, my mother, and Mrs. Minnie Caster, my beloved grandmother, for establishing in me a strong foundation and constantly reminding me that anything is possible with God. They have been a constant and loving present in my life, and I will always be indebted to them.

I also would like to dedicate this dissertation to my loving husband, Keith; my children, Keith Jr., Kevin, Kareem, Kristina, and Karen; my daughter-in-law, Tanesha; my granddaughters, London, Skyler and Justine; and my nephews, Mark, Marlon, and Marvin, for their utmost support and encouragement throughout this journey. For encouraging me when I wanted to quit, I will forever be thankful and grateful to them for helping me to make this possible. I love you all so much!

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Chapter 1: Introduction to the Study

Breast cancer is the most commonly diagnosed form of cancer in women and the second leading cause of mortality and morbidity in women in Western countries (Masi & Gehlert, 2009). Although gains have been made in research and preventive care, research has shown that U.S. women of color continue to have a higher breast cancer mortality rate than European American women, despite the fact that European American women have a higher incidence rate (Centers for Disease Control and Prevention [CDC], 2012; Hennis, Hambleton, Wu, Leske, & Nemesure, 2009). Taioli, Attong-Rogers, Layne, Roach, and Ragin (2010) stated that breast cancer survival depends on many factors, including place of birth, residence, and race, and that Caribbean women's survival rates are even worse than those of women of color born in the United States, which Taioli et al. suggested are the result of environmental, behavioral, and biological factors. In this study, I used the term *women of color* to identify women of African American descent; women from the Caribbean (African, East Indian, and Mixed descent); and women from South America. According to Wade (2011), this term was coined by activists to bond all non-White people and to form a coalition against racism. I identified the women in this study from the Caribbean and South America as women of color based upon their African or Indian heritage.

Significant gains have been made in the prevention, detection, and treatment of breast cancer in the United States, but disparities continue. The reasons women of color have lower incidence rates but higher mortality rates than their European American counterparts are complex. Meade, Menard, Thervil, and Rivera (2009) stated that there is insufficient, culturally specific breast cancer prevention education for immigrants living in the United States. Although Caribbean and South American women of color might have lower incidence rates of breast cancer than American women of color, they have higher mortality rates because of miscommunication of health care navigation and a limited understanding of English, late presentation because of limited access to care, citizenship status, socioeconomic status (SES), or a combination of all of these factors (Meade et al., 2009).

Van Ravesteynet al. (2011) reported that this disparity might be the result of delays in the screening and treatment of women of color in the United States, whereas Freeman, Zonszein, Islam, Blank, and Strelnick (2011) noted that health care disparities are the result of SES, acculturation, immigration, and race or ethnicity. Factors such as access to care, financial burden, and limited resources, lack of social support, and cultural beliefs or perceptions also can be obstacles to receiving screening. Research has indicated that the majority of Guyanese women, for example, are diagnosed with Stage 3 or Stage 4 breast cancer (Guyana Ministry of Health, 2012) and that breast cancer is one of the most reported cancers in Guyana (Plummer, Persaud, & Layne, 2009). This information has been captured by a population-based cancer registry implemented in 2000 (Plummer et al., 2009). Data have been obtained from the national referral hospital and other public and private agencies (Plummer et al., 2009). However, these numbers might not have been correct because many individuals went to neighboring countries such as Trinidad and Tobago for medical care, so the numbers have not been reported or captured in Guyana’s system (Plummer et al., 2009).

Georgia is ranked 21st among the 50 U.S. states based upon its breast cancer incidence rate of 125.3/100,000 (CDC, 2012a). Between 2006 and 2010, the rate was 120.9/100,000 for women of color in Georgia, 124/100,000 for European American women, and 85.8/100,000 for Latina American women (American Cancer Society [ACS], 2013). There were no data regarding the different ethnic groups comprising African American or Latina American women. By comparison, Shirley et al. (2010) reported that in the Caribbean between 2000 and 2002, women from Jamaica had an incidence rate of 40.1/100,000, and women from Trinidad and Tobago had an approximate incidence rate of 30/100,000 (Joseph et al., 2013). Women from Barbados between the ages of 40 and 50 years experienced an incidence rate of 226.6/100,000 between 2002 and 2006 (Hennis et al., 2009).

Breast cancer has accounted for approximately 24/100,000 female deaths related to cancer in Trinidad and Tobago (Joseph et al., 2013). In 2008, breast cancer accounted for 22.8/100,000 female deaths in the Bahamas and 28.6/100,000 female deaths in St. Vincent and the Grenadines (Luciani, Cabanes, Prieto-Lara, & Gawryszewski, 2013). In South America, breast cancer accounted for 14.9/100,000 female deaths in Brazil in 2009, 15.1/100,000 in Venezuela, 18.5/100,000 in Paraguay, and 22.0/100,000 in Uruguay (Luciani et al., 2013). The ACS (2013) stated that between 2005 and 2009, women of color in the United States accounted for 31.6/100,000 breast cancer deaths, with Georgia accounting for approximately 29.7/100,000 deaths during the same year.

There have been documented differences in breast cancer screening and treatment protocols among women of color and European American women in the United States.

However, available data have been limited regarding the perceptions and behaviors of first-generation women of color from the Caribbean and South America living in the United States toward breast cancer and the reasons for diagnosis at a much later stage. I identified a need for research in this area to document and implement preventive measures for this population. In this study, I addressed the factors contributing to late screening, including knowledge of breast cancer, culture, and access to care.

Background

Approximately half a million women die of breast cancer every year. The World Health Organization (WHO, 2013) estimated that 522,000 women died in 2012 from breast cancer, with 58% of them living in developing countries. The International Agency for Research on Cancer (IARC, 2013) estimated that 508,000 deaths from breast cancer occurred in 2011. The ACS (2013) estimated that approximately 27,000 women of color living in the United States were diagnosed with breast cancer in 2011. During the 1980s, the incidence of breast cancer increased rapidly among women of color in the United States because of the increased use of mammography screening; this pattern has declined during the 2000s. According to the ACS, women of color in the United States have a 1:9 chance of developing breast cancer, whereas European American women have a 1:8 chance. The ACS also noted that between 2005 and 2009, women of color in the United States had breast cancer incidence rates of 118/100,000, versus 123/100,000 for European American women.

In many regions of South America and the Caribbean, breast cancer incidence rates are the same as those in European countries. For example, in 2012, Brazil had an incidence rate of 59.46/100,000, Guyana had 50.37/100,000, Haiti had 106.86/100,000, and Argentina had 71.24/100,000 (IARC, 2012). For the same year, Russia had an incidence rate of 45.64/100,000, the United States had 92.93/100,000, Canada had 79.79/100,000, and Germany had 91.55/100,000 (IARC, 2012). The CDC (2013) found that although the breast cancer incidence rates among women of color in the United States were lower than those of European American women, their mortality rates were higher.

Shirley et al. (2010) stated that breast cancer has been the most common form of invasive cancer among Jamaican women for the past 30 years. Jamaica has the highest incidence rates (40/100,000) among the Caribbean countries, with women ages 70 to 79 years having the highest rate (20.9/100,000) and women ages 50 to 59 years having the next highest rate (19.7/100,000), followed by women ages 40 to 49 years (18.7/100,000; Shirley et al., 2010). Among the Guyanese population, Plummer et al. (2009) noted that cancer has been listed as one of the five leading causes of death in this population over the past 15 years, with breast, cervical, and prostate as the major cancers. Plummer et al. stated that further investigation is warranted for SES, dietary, and genetic influences on the observed patterns of incidence within this population. Since its inception in 2000, the National Cancer Registry in Guyana has recorded more than 2,000 cancer cases, a cumulative incidence rate of 301.3/100,000.

Mammography screening has been associated with yearly increased numbers of early-stage breast cancer diagnoses (Bleyer & Welch, 2012). Among U.S. women ages 40 years and older, breast cancer incidence rates have increased from 112/100,000 to

234/100,000 over 40 years (1976-2008; Bleyer & Welch, 2012). Between 2000 and 2009, U.S. women of color experienced a 0.7% yearly increase in breast cancer incidence rate because of the positive impact of mammography screening (Bleyer & Welch, 2012). However, the number of women diagnosed with late-stage breast cancer decreased from 102/100,000 to 94/100,000 during the same period, suggesting that mammography had been an effective tool in reducing the rates of advanced-stage cancer (Bleyer & Welch, 2012).

Although the overall health of the U.S. population has improved over the years, according to the U.S. Department of Health and Human Services (DHHS, 2009), a disproportionate number of U.S. citizens who are members of racial and ethnic minority groups continue to lack access to or fail to receive adequate preventive health services. As a result, African Americans, Hispanic Americans, American Indians, and Asian Americans are more likely than European Americans to experience poor health and die prematurely (DHHS, 2009).

Statement of the Problem

The high incidence of breast cancer among women of color in Georgia continues. Women of color in the United States have an overall incidence rate of 118.1/100,000 (DeSantis, Naishadham, & Jemal, 2013), whereas women of color in Georgia have an incidence rate of 120.9/100,000 (ACS, 2013). The mortality rate for women of color in Georgia between 2005 and 2009 was 29.7/100,000; the national rate was 31.6/100,000.

The problem is that culturally specific breast cancer prevention education for immigrants from the Caribbean and South America living in the United States has been lacking (Meade et al., 2009). To be more specific, there has been a gap in the literature regarding the breast health practices and perceptions among women of color from South America and the Caribbean living in the United States. In their study of the biological characteristics of breast cancer in the Caribbean, Bhikoo, Srinivasa, Yu, Moss, and Hill (2011) stated that the lack of breast cancer information from this region prevented them from conducting a full assessment. There also has been scant literature regarding women of color from the Caribbean and South America who enter the U.S. health system for mammograms and subsequently require more diagnostic tests and possible treatment because of abnormal findings. My literature search identified a gap in knowledge about the perceptions and health-seeking behaviors of women of color from the Caribbean and South America, information that is needed to create effective and culturally sensitive education. I sought to identify the behaviors and perceptions of women of color from South America and the Caribbean living in Atlanta, Georgia, regarding breast cancer awareness, screening, treatment, and follow-up care after abnormal screenings.

Purpose of the Study

The purpose of this phenomenological study was to examine the perceptions and behaviors of first-generation women of color from South America and the Caribbean living in Atlanta, Georgia, regarding breast cancer awareness, screening, treatment, and follow-up care after abnormal screenings. The results will add to the current body of knowledge regarding the psychosocial factors of breast cancer among this target population. I described the individual participants’ characteristics and their relationships with their health care providers and health services. Factors motivating the participants to seek breast health care and follow-up treatment were investigated.

Research Questions

The study was guided by six research questions (RQs):

1. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the severity of breast cancer in this population?
2. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the barriers to receiving breast cancer screening or treatment?
3. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the benefits or hazards of breast cancer screening?
4. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about their susceptibility to breast cancer?
5. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about what would motivate them to seek breast cancer screening or treatment?
6. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about their confidence in taking care of their own breast health?

Conceptual Framework

The term *conceptual* or *theoretical framework* refers to the system of concepts, assumptions, beliefs, expectations, and theories that supports and informs research. It is the visual or written product that explains either in graphic or narrative format the key concepts, factors, or variables being studied and the relationships between and among them (Watts, 2011). The conceptual or theoretical framework can be viewed as an organized way of thinking about how and why a project takes place and about how its activities are understood.

I used the health belief model (HBM; Becker & Rosenstock, 1984) to explore the perceptions of the study sample. The HBM was developed to understand and explain why people fail to participate in preventive health programs (Crosby, DiClemente, & Salazar, 2006). The concepts of the HBM related to breast cancer awareness, screening, treatment, and follow-up protocols include (a) perceived severity of having breast cancer; (b) perceived susceptibility or vulnerability to breast cancer; (c) perceived benefits of being screened for breast cancer; (d) perceived barriers to being screened for breast cancer; (e) cues to action to seek screening for breast cancer; and (f) self-efficacy, or the confidence in their ability to take action (Crosby et al., 2006; Harvey & Lawson, 2009).

This model shows that individuals will likely take action to prevent disease or illness if they believe that they are vulnerable to health conditions and the serious consequences of not taking action (Harvey & Lawson, 2009). Individuals also will take action if precautionary behaviors to prevent disease or illness and the benefits of taking action outweigh the cost of not taking action (Bond & Nolan, 2011). I provide more information about the HBM in Chapter 2.

Nature of the Study

I conducted this phenomenological study to examine the perceptions and behaviors of first-generation women of color from South America and the Caribbean living in Atlanta, Georgia, regarding breast cancer awareness, screening, treatment, and follow-up care after abnormal screenings. I obtained my data from in-depth interviews. According to Creswell (2007), in-depth interviews allow phenomenological researchers to obtain information about the phenomena they are studying. By conducting in-depth interviews, I was afforded the opportunity to collect data about the participants' lived experiences related to breast cancer (Cohen, Manion, & Morrison, 2000).

I prepared identical open-ended questions for each interview. Although I provide more details about the methodology in Chapter 3, I determined the eligibility of the potential participants by asking them to complete a demographics questionnaire (see Appendix A). It was my intention to interview all of the eligible participants, but if their schedules did not give them the time to answer all 34 interview questions (see Appendix B), I prepared the questions in a questionnaire format and allowed those participants to submit written responses. As noted by Patton (2000), this method opened the way to ask probing questions. When analyzing the data, I identified themes gleaned from the participants' perceptions, behaviors, beliefs, and knowledge about breast cancer awareness, screening, treatment, and follow-up care after abnormal screenings.

Definitions of Terms

I adapted many of the definitions from the National Cancer Institute's (NCI, 2012) dictionary of cancer terms.

Attitude: A learned way of evaluating things and comprises different components, such as emotional, which is how an individual feels toward something or someone; cognitive, which relates to thoughts and beliefs about the subject; and behavioral, which is how the attitude affects behavior (Hockenbury & Hockenbury, 2007; Myers, 1999; Smith & Mackie, 2007).

Biopsy: The removal of sample tissue to make a diagnosis; the three types of biopsy procedures are (a) incisional, where a small sample is removed; (b) excisional, where an entire lump or a suspicious area is removed; and (c) needle, where the sample tissue or fluid is removed by needle (NCI, 2012).

Breast-conserving surgery: The removal of breast cancer and a small part of normal breast tissue surrounding the cancer. This process also might involve removal of the lymph nodes (ACS, 2009).

Breast self-examination (BSE): According to Nelson et al. (2009), BSE is a screening method to detect early breast cancer: The woman looks at and feels each breast for lumps, swellings, or any other distortions.

Cancer health disparities: The differences in new cases of cancer, all existing cases of cancers, mortality, survivorship, and the burden of other health conditions among a specific population in the United States (NCI, 2013b).

Cancer stages: Stages of cancer based on the size and location of primary tumors and whether they have spread to other parts of the body (ACS, 2013).

Clinical breast examination (CBE): An exam performed by a health care provider knowledgeable in inspection and palpitation of the breast for lumps and other signs and symptoms of cancer (CDC, 2013).

Cultural competency, or *cultural awareness and sensitivity:* "The knowledge and interpersonal skills that allow providers to understand, appreciate, and work with individuals from cultures other than their own. This involves an awareness and acceptance of cultural differences, self-awareness, knowledge of a patient's culture, and adaptation of skills" (Fleming & Towey, 2001, p. 1).

Culture: The dynamic and multidimensional context of many aspects of life, including gender, faith, sexual orientation, profession, tastes, age, SES, disability, ethnicity, and race (Wells, 2000).

Ductal carcinoma: A breast cancer that begins in the cells lining the breast ducts (NCI, 2013b). The NCI (2013b) stated that this is the most common type of breast cancer, with 70% of women having this type.

Malignant tumors: Tumors that threaten life by invading nearby organs and tissues and other parts of the body such as lymph nodes, axilla (under the arm), above the collarbone and in the chest behind the breastbone, and the lungs (NCI, 2013b). These cancers can be removed, but they sometimes grow back.

Screening: Searching for a disease such as cancer in individuals who are not yet experiencing symptoms or showing signs of the disease (ACS, 2009).

Assumptions

Leedy and Ormrod (2005) noted that although assumptions are the foundation of any study, what researchers assume might not be viewed or thought of by others in the same ways, making it important to document the assumptions. Documenting the assumptions showed that I had considered the content of the study thoroughly before conducting it (Leedy & Ormrod, 2005). Qualitative researchers are mainly interested in understanding the meanings inherent in the phenomena being investigated, which in this study were the behaviors, beliefs, and perceptions among women of color about breast cancer health in relation to breast cancer awareness, screening, treatment, and follow-up care after abnormal screenings. I assumed that the phenomenological method was appropriate to shed light on the experiences of the participants and explain how they arrived at their meanings and how these meanings influence their daily lives (Merriam, 2002; Polit & Beck, 2004).

This study was based on the assumption that the participants would cooperate fully and answer the interview questions honestly and openly. I also assumed that the participants were aware of breast cancer preventive programs offered by their local department of health and that they were familiar with mammography and BSE. Most often, perceptions, SES, and lifestyle choices are associated with individuals' health and well-being (Wagner, Good, Whitaker, & Wardle, 2011).

Scope and Delimitations

The term *delimitation* refers to what researchers will not do in their studies (Leedy & Ormrod, 2005). I used delimitations to set boundaries for the research, constrain the scope of the study, and make the study more manageable (Leedy & Ormrod, 2005). I specifically studied the perceptions, behaviors, knowledge, attitudes, and beliefs toward breast cancer awareness, screening, treatment, and follow-up care after abnormal screenings of women of color from South America and the Caribbean who were residing in Atlanta, Georgia, at the time of the study. I selected this target population because of their high mortality rates and lack of research data about their perceptions of and behavior toward breast cancer. This study was limited to first-generation women of color from South America and the Caribbean between the ages of 35 and 69 years. Men and individuals identifying themselves as European American were excluded from this study. However, South American and Caribbean women who had survived breast cancer were eligible to participate.

Generalizing the results to other populations was limited because of the unique nature of this target population's lifestyles and cultural and ethnic backgrounds (Consedine et al., 2009). However, the results can be generalized to individuals with similar cultural and ethnic backgrounds. The findings are limited to interpretation rather than quantitative analysis.

Limitations

According to Creswell (2005) and Leedy and Ormrod (2005), studies have limitations or potential weaknesses identified by the researchers. Therefore, even when researchers discuss the limitations of their studies, others might have to use their own judgment to determine the extent to which the findings can or cannot be generalized (Creswell, 2005). Limitations of the study included the final sample size and composition, the sample comprising only first-generation women of color from South America and the Caribbean living in Atlanta, Georgia, who were insured or uninsured and who had or did not have regular medical care.

Use of the HBM could have limited and influenced the participants' responses to the interview questions because as noted by Kominiarek, Vonderheid, and Endres (2010), SES, previous experience, culture, race, and ethnicity can play a role in the responses of individuals. The U.S. Census Bureau (2010) stated that individuals from mixed-race families are identified by cross-referencing the race of the mothers and the fathers for the major groups: Black/African American; White; American Indian; Pacific Islander; Asian an Eskimo. Participation in the study was limited to women of color from the Caribbean and South America who were living in Atlanta, Georgia, at the time of the study. Furthermore, interpretation of the data was limited because of the phenomenological nature of the study.

Significance of the Study

Waller et al. (2009) stated that it is important to address the influence of culture when addressing the behaviors of different ethnic groups toward cancer. In Brazil, incidence rates of breast cancer are on the rise, and mortality rates are increasing among women ages 55 to 64 years (Lima, Rangel, Macedo-Lima, & Da Silva, 2012). According to Donenberg et al. (2011), Bahamian women experience a high incidence rate of early-onset breast cancer in the Caribbean; however, research has shown that the mortality rate from this disease is the highest in Trinidad and Tobago (Joseph et al., 2013). World Cancer Research Fund International (2014) listed women in the Bahamas as having the highest incidence rate at 98.9/100,000, followed by Barbados at 94.7/100,000 and the United States at 92.9/100,000. Many women of color who receive breast cancer screenings and have abnormal findings on mammograms do not return in a timely manner for follow-up diagnostics and treatment (Wujcik et al., 2009).

The high mortality rates of breast cancer among women of color can be the result of the lack of follow-up care, an action that can mean delayed treatment and poorer outcomes (Hirschman, Whitman, & Ansell, 2007). Hirschman et al. (2007) further stated that late entry into the health care system with advanced-stage cancer could lead to poorer health outcomes or early death. Factors relevant to culture, diet, and SES also can contribute to the high mortality rate of breast cancer within this population (Spector et al., 2009). However, no researchers have studied the perceptions of this disease by South American and Caribbean women of color living in Atlanta, Georgia.

The results of my study identified health care gaps among racial ethnic groups; add to the sparse literature; and ultimately increase current knowledge and understanding of specific cultural influences, such as coping strategies, dietary and physical habits, and socioecological factors. The results, which provided insight into the participants' perceptions and attitudes, might lead to a better understanding of the issues unique to their perceptions of and behaviors toward breast health. The results also identified factors that can positively influence breast health outcomes, thereby aiding in the education of the participants about breast cancer.

The findings might be instrumental in the implementation or revision of policies and procedures regarding the education and treatment of breast cancer among the target population. The findings also might be integral to the development and implementation of specific modes of delivery of information appropriate to the linguistic, cultural, and literacy needs of the target population, and clinical practice guidelines. The findings can be important to the design of effective interventions to reduce breast cancer disparities in care and treatment, thereby improving the quality of life and effecting positive social change.

Summary

Breast cancer is one of the most common killers of women of color in the United States. Although the incidence rate of breast cancer is lower among women of color than their European American counterparts, the mortality rate is higher. In Chapter 1, I described the significant problem of breast cancer among women of color living in Atlanta, Georgia, a population that continues to be at increased risk for breast cancer mortality. The reason for this disparity remains unknown; however, it appears to be multifactorial (CDC, 2012). Over the past 20 years, federal and state government health agencies and private health care organizations such as the ACS have encouraged women to use preventative measures such as screening to detect breast cancer early (CDC, 2012). Although research has identified differences in the way women of color and European American women are screened and treated for breast cancer, data on the perceptions and behaviors of first-generation women of color from South America and the Caribbean living in the United States regarding breast cancer awareness, screening, treatment, and follow-up care after abnormal screening have been limited. I also described the conceptual framework; the nature of the study; the delimitations, limitations, and assumptions; and so on.

In Chapter 2, I discuss the history of the conceptual framework and present an overview of current literature on the barriers to early screening and detection among the study sample. This chapter presents a history of breast cancer among women of color in the United States, and it addresses trends, disparities, survival, and mortality and morbidity rates among the target population. In Chapter 3, I describe the methodology, design, and rationale of the study; characteristics of the sample; ethical considerations; measures; data collection and analysis; and verification of findings. In Chapter 4, I present the results of the study, and in Chapter 5, I interpret the results, draw conclusions, and offer suggestions for future research.

Chapter 2: Literature Review

In this chapter, I present a review of the literature on breast cancer related to Caribbean and South American women of color living in the United States. Although gains have been made in the prevention, detection, and treatment of breast cancer, disparities between underserved and better served groups, as well as different ethnic groups, remain (Allicock, Graves, Gray, & Troester, 2013). Despite the lower incidence rates among women of color, they continue to have higher mortality rates than their European American counterparts (Hennis et al., 2009) that might be the result of delays in screening (Conway-Phillips & Millon-Underwood, 2009); limited access to care and resources; and a lack of social support.

There has been a gap in the literature regarding the perceptions, knowledge, behaviors, and beliefs of women of color from the Caribbean and South American toward breast cancer awareness, screening, treatment, and follow-up care after abnormal screenings. To educate the study sample and enhance, develop, and design preventive programs, it was important for me to understand how the participants perceived breast health and why they behaved the way that they did in terms of breast cancer screening, treatment, and follow-up care after abnormal screenings.

Search Strategies

Strategies useful to this review included using my knowledge of the target population (i.e., what motivated them, what they wanted for their health, and what their knowledge was about breast cancer and barriers to obtaining health and well-being at the time of the study); reading peer-reviewed journals, and accessing online sources to obtain relevant literature. Relevant terms used in the search included *breast cancer*, *women of color*, *Caribbean women*, *South American women*, *African American women*, *West Indies women*, *perceptions*, *beliefs*, *behaviors*, *mammography*, *breast cancer screening*, *barriers*, *knowledge*, *treatment*, *benefits*, and *conceptual framework*. Sources of literature included field studies; surveys and interviews; Google Scholar; and a variety of online databases accessed through the Walden University Library: Academic Search Premier, Medline, ProQuest, EBSCO, WHO, American Cancer Society, and Pub Med.

Health Belief Model

To increase awareness and disseminate knowledge, researchers have developed and implemented a variety of strategies regarding health issues such as breast cancer, HIV/AIDS, diabetes, and cardiovascular disease. According to Glanz and Bishop (2010), public health and health promotion interventions using social and behavioral science theories are more effective than programs not using these strategies. The NCI (2005) noted that health behavior theories can help researchers to identify why people either do or do not participate in specific health behaviors. Using theories and conceptual frameworks is important and valuable during the planning, implementation, and evaluation stages of interventions. Theories and conceptual frameworks also can be useful to researchers who strive to explain community and population behaviors and suggest behavior changes (Davis, Buchanan, & Green, 2013).

The HBM is a framework used to examine the overall perceived risks of health concerns and illnesses. It is considered a leading theory in the field of health care. This theory was developed in the 1950s by social psychologists Hochbaum, Rosenstock, and

Kegels to examine health behaviors (as cited in Glanz, Burke, & Rimer, 2010). The premise of the HBM is that individuals who are ready to change and take control of their health will meet the following criteria:

1. They believe that they are susceptible to the disease (perceived susceptibility).
2. They believe that the disease has serious consequences (perceived severity).
3. They believe that taking action would reduce their susceptibility to the disease or the severity of the disease (perceived benefits).
4. They believe that the costs of taking action (perceived barriers) are outweighed by the benefits.
5. They are exposed to factors that prompt action (e.g., a television commercial or a reminder from a physician to get a mammogram).
6. They are confident in their ability to perform the action successfully (self-efficacy; Glanz et al., 2010).

An instrument linked to the HBM and breast cancer screening behaviors was developed by Champion (1984) and tested on a sample of 301 female participants ages 16 years and over who could read and write English. The instrument was first disseminated by mail or by hand, with a 47% return rate. It was then either mailed or disseminated by hand again, with a 95% return rate being achieved. The responses were highly consistent, enabling Champion (1984) to conclude that the scales for susceptibility, barriers, and seriousness were internally reliable and consistent. In 1999, Champion modified the scales for perceived susceptibility to, benefits of, and barriers to breast cancer screening and applied them to mammography.

Katapodi, Dodd, Facione, Humphreys, and Lee (2010) conducted a community-based study of breast cancer risks, using the HBM to examine the participants' knowledge of risk factors, experiences, and heuristics. Katapodi et al. looked at family histories, the participants' stress levels about getting breast cancer, their perceived susceptibility of contracting the disease, and their overall knowledge of the risks of breast cancer. They found that the women in the study tended to overestimate their risk of getting breast cancer, subsequently becoming unnecessarily stressed, and that worries about family history and breast cancer were significant predictors of this tendency.

Literature on Breast Cancer

History of Breast Cancer in the United States

Although breast cancer can affect men and women, it rarely affects males (NCI, 2013b). Cancer is a disease in which normal cells become abnormal and begin to divide uncontrollably throughout the blood and lymph systems (National Institutes of Health [NIH], 2009). According to the NCI (2013b), there were approximately 232,340 new cases of breast cancer among U.S. women and 2,240 U.S. men in 2013. The NCI also reported that there were 39,620 female and 410 male breast cancer deaths during the same year. The most common type of breast cancer is ductal carcinoma, which begins in the cells lining the breast ducts and accounts for 70% of women who are infected with this disease (NCI, 2013b).

To understand breast cancer, it is worthwhile to consider its origin. The female breast has 15-20 lobes, and each lobe is made up of smaller lobules with glands that can produce milk. Fat and fibrous tissues fill the spaces between the lobules and ducts. It should be noted that cancer begins in cells, where normal cells in the body grow and divide to form new cells. When these cells grow old or are damaged and die, they are usually replaced with new cells. However, this process does not always happen as it should; sometimes, new cells are formed when they are not needed, and old and damaged cells do not die. This action results in a buildup of extra cells that can form a mass of tissue. This mass of tissue can be a lump, a growth, or a tumor that can be noncancerous (benign) or cancerous (malignant; NCI, 2013b).

According to the NCI (2013b), breast cancer cells can break away and travel to other parts of the body. These cancer cells can then attach themselves to other tissues and organs, including the lymph nodes, collarbone, and lungs, or in the chest behind the breastbone. Once attached, these cells form new tumors that can damage those tissues and organs. This spread of cancerous tissues is known as metastasis breast cancer (NCI, 2013b).

To determine whether breast cancer cells have spread to other parts of the body and to choose the best form of treatment, health care professionals will perform staging tests. Some common forms of staging tests are lymph node biopsies, computer tomography scans, magnetic resonance imaging scans, bone scans, and position emission tomography scans. Breast cancer is staged based on the size of the tumor and whether it has spread to the lymph nodes and other parts of the body. Stage 0 is the least invasive, and Stage IV is the most invasive (NCI, 2013b), meaning that the cancer cells have spread to different parts of the body, such as the liver, bones, brain, or lungs (NCI, 2013b). The NCI (2013b) further stated that inflammatory breast cancer is a rare type of breast cancer that affects 10% of women in the United States. When diagnosed, mostly in younger women, this cancer is already staged between III and IV (NIH, 2009).

U.S. Incidence Rates for Different Ethnic Groups

According to the CDC (2013) and the NCI (2013b), approximately one in every eight women will develop breast cancer in her lifetime. The WHO (2013) reported that cancer accounted for approximately 7.6 million deaths globally in 2008. Siegel, Naishadham, and Jemal (2012) asserted that cancer is a major global public health issue and the cause of 25% of all deaths in the United States.

Breast cancer rates overall have been declining in the United States, but there also have been significant differences by ethnic group; the CDC (2013) reported that in 2010, the incidence rates were 140/100,000 for European American women, 117/100,000 for African American women, 99/100,000 for Hispanic women, 86/100,000 for Asian Pacific/Islander women, and 72/100,000 for American Indian/Alaska Native women, respectively. By 2012, the overall rate for European American women had dropped to 120/100,000, 60/100,000 for American Indian/Alaska Native women, and 88/100,000 for Hispanic women, respectively. However, for African American women, the incidence rate remained approximately the same (116/100,000) and increased to 88/100,000 for Asian/Pacific Islander women (CDC, 2013).

According to Jemal, Siegel, Xu, and Ward (2010), the discontinuation of hormone replacement therapy (HRT) among postmenopausal women and a decrease in mammography screening might have impacted the decrease in the incidence rate of breast cancer. Jemal et al. further stated that from 2003 to 2006, there was no change in the incidence rates of breast cancer in the United States, which led them to believe that postmenopausal HRT might have promoted, but not initiated, the incidence of breast cancer. The ACS (2015) estimated that there would be approximately 232,000 new cancer cases of invasive breast cancer and an additional 60,000 cases of in-situ breast cancer cases in 2015. The ACS also estimated that approximately 40,000 individuals would die from this disease in 2015. Over the past 5 years, there has been a 0.6% per year decline in delayed-adjusted cancer incidence rates among all men, but no change among women (Siegel et al., 2013). Siegel et al. (2013) noted that there has been a 1.8% decrease in cancer death rates per year for men and 1.5% for women and that the overall death rates have declined by 20% since 1991.

Lopez-Carrillo (2009) asserted that breast cancer is the primary cause of cancer among women in Latin America and the Caribbean, with approximately 120,000 new cases each year, or approximately 12% of breast cancer cases globally. Of the 120,000 cases, 90,000 have been diagnosed in South America. Barbados has led the Caribbean with an overall 62/100,000 incidence rate for breast cancer, followed by the Bahamas with 56/100,000, Trinidad & Tobago with 50/100,000; and Jamaica with 41/100,000 (Pan American Health Organization [PAHO], 2014). In South America, the breast cancer incidence rate in Brazil has been reported at 44/100,000, Venezuela at 37/100,000, and Surinam and Guyana at 30/100,000 (PAHO, 2015). Shirley et al. (2010) reported that in Jamaica, women over the age of 70 years were the most affected by breast cancer. Hennis et al. (2009) reported an incidence rate of 107.3/100,000 among Barbadian women ages

40 to 44 years, compared to an incidence rate of 140.6/100,000 among women of color in the United States within the same age group.

Different results emerged in Guyana, South America. This nation’s national disease surveillance system was established in 2000, giving the county’s policymakers the opportunity to receive reliable data based on pathologically supported diagnoses (Plummer et al., 2009). The data showed that Guyanese women of Indian descent had the highest incidence rates of breast cancer.

Breast Cancer Mortality in the United States

Breast cancer is the second most common form of cancer among women in the United States and the second leading cause of all cancer-related deaths (NCI, 2009). The ACS (2011) stated that one in eight women will be diagnosed with breast cancer within her lifetime, with African American women having the highest death rate of 32.8/100,000 among minority women (DHHS, 2009). In 2009, the DHHS found that African American women ages 35 to 44 years had a breast cancer death rate more than twice the rate of European American women in the same age group (20.02/100,000 vs. 10.2/100,000).

In its 2009 report, the NIH reported that approximately 190,000 women were being diagnosed with breast cancer yearly in the United States and that mortality rates overall were gradually declining (from 27/100,000 in 1999 to 23/100,000 in 2010), even though women of color continued to experience the highest death rates (35/100,000 in 1999 and 31/100,000 in 2010; CDC, 2013). During this same period, the mortality rate for European American, non-Hispanic women dropped from 26/100,000 to 23.5/100,000; 16.5/100,000 to 15.5/100,000 for Hispanic women; 16/100,000 to 12/100,000 for

American Indian/Alaska Native women; and 13/100,000 to 12/100,000 for Asian/Pacific Islander women (CDC, 2013). The ACS (2009) attributed this decline in mortality rates to the collaborative efforts of governmental and private agencies in early detection and preventive programs. The conclusion is that more patients are being diagnosed at an early stage and are being treated in a timely manner, thus increasing their chances of survival.

The CDC stated in 2012 that although breast cancer deaths were decreasing the fastest among European American women, African American women were still 40% more likely to die from the disease because they presented with a more aggressive form of cancer and also lacked sufficient social and economic resources. However, despite this recently reported decrease, African American women have remained at a disadvantage, and breast cancer has continued to be a significant public health concern not only in the United States but also globally (CDC, 2013; NCI, 2013b). PAHO (2014) further noted that in 2008, there were 226 female cancer-related deaths in Barbados, with 21% of those deaths attributed to breast cancer.

Breast Cancer Survival Rates

Adams et al. (2009) argued that because minorities often do not receive timely treatment or are treated at a late stage of cancer, their survival rates are lower than those of European Americans. Social environments lacking basic resources continue to present the highest public health risk for serious illness and premature death (CDC, 2009). A feature of breast cancer that often is not discussed is the age at which the disease appears in different racial ethnic groups. African American women frequently develop breast cancer at a younger age than European American women; the same phenomenon applies to Hispanic American women (Vona-Davis & Rose, 2009).

The ACS (2015) noted that when all stages of breast cancer are combined, the 5-year survival rate for European American women is 90% versus 79% for American women of color. The DHHS (2009) stated that American women of color had the highest age-adjusted breast cancer incidence rates among minority groups (111.9/100,000 new cases). Among women of other racial and ethnic populations, American Indians and Alaska Native women had the third highest age-adjusted breast cancer incidence rate among minority groups (97.2/100,000) but a lower breast cancer mortality rate (15.2/100,000 population) than European American and African American women. In fact, American Indian women had the poorest survival rate from breast cancer among the racial and ethnic groups (DHHS, 2009; see Table 1).

Table 1

Breast Cancer Death Rates by Age and Race/Ethnic Origin

Age (years)	AI/AN*	A/PI**	Hispanic American	European American	African American
35-44	—	6.7	8.0	10.2	20.2
45-54	12.9	18.5	20.0	26.2	50.0
55-64	21.0	35.0	34.7	52.4	81.1
65-74	65.8	32.1	46.9	79.3	96.2
75-84	117.4	52.2	73.3	120.7	126.6
85+	—	62.0	95.1	179.1	201.8

Note. — denotes insufficient data

* American Indian or Alaska Native

** Asian American or Pacific Islander.

Source: Death rates for malignant neoplasm of breast among females, by race, Hispanic origin, and age: United States, selected years 1950–2005, Health, United States 2008.

According to data from the ACS (2011), survival rates for breast cancer in developing countries have generally been lower than those rates in developed countries. For example, the ACS reported survival rates of 36.6/100,000 in Brazil and 12/100,000 in

Gambia versus 90/100,000 in the United States. Coleman et al. (2008) and Sankaranarayanan et al. (2010) noted that the stage at which a diagnosis is made is important in increasing the survival rates. Taioli et al. (2010) stated that women born in the Caribbean and living in the United States had a worse survival rate from breast cancer than women born in the United States. Research has shown that 89% of women born in the United States have a 5-year survival rate following a diagnosis of breast cancer versus 40% of women living in Campinas, Brazil (Jemal et al., 2010; Sant et al., 2009).

Factors Influencing Risk for Breast Cancer

The strongest risk factor for breast cancer is age (NCI, 2013b), and the disease has been found to be the most aggressive in younger women of color. However, multiple other factors also play a role, including genetic alterations, breast density, family or personal history of breast cancer, other reproductive health problems, changes in the breast, excessive alcohol consumption or body weight, low physical activity level, previous radiation therapy, and the long-term use of HRT (NCI, 2013b). The ACS (2013) and the CDC (2013) noted that diet, income, education, culture, exercise, gender roles, attitudes, and beliefs are interrelated and could be contributory factors to the prevalence of breast cancer. In addition, evidence has indicated that carcinogens in the environment that can cause errors in normal cell division can contribute to breast cancer. Underwood, Richards, Bradley, and Robertson (2008) stated that carcinogens are responsible for approximately 70% of all diagnosed breast cancers.

Several lifestyle-related risk factors have been linked to the increased risk of developing breast cancer, namely, consuming two to five alcoholic drinks daily, being involved in the long-term use of HRT, being obese, consuming foods high in saturated fats, and smoking tobacco (NCI, 2013b). Physical inactivity, living conditions, and environmental toxins also have been shown to increase the risk of breast cancer (NCI, 2013b).

Age is the most significant and strongest risk factor for breast cancer, but as mentioned earlier, the disease is more aggressive in younger women of color (NCI, 2013b). Hamilton, Williams, Bowers, and Calzone (2009) stated that women between the ages of 18 and 39 years with a family history of breast and ovarian cancer and who have the BRCA1 and/or BRCA2 mutation are at higher risk of developing breast cancer before the age of 50 years. Hamilton et al. also stated that these individuals' offspring have a 50% chance of contracting the disease.

Knowledge and Beliefs About Breast Cancer

Although early detection of breast cancer is associated with higher rates of survival, many women continue to not adhere to the recommended guidelines (Glenn, Chawla, & Bastani, 2012). Anderson-Lewis et al. (2012) reported that women of color believe that pain is always present with breast cancer; that bumping or bruising the breast contributes to the development of cancer; and that surgery can precipitate the spread of breast cancer. In an effort to disseminate accurate information about breast cancer awareness, screening, treatment, and follow-up care after abnormal screenings among Caribbean and South American women living in the United States, I found it necessary to first understand their levels of knowledge, perceptions, and beliefs about the disease.

Ackerson and Preston (2009) stated that fear of the unknown is the greatest emotion guiding the decision to receive or decline cancer screening.

Faith and religion are influential in the lives of individuals from certain racial and ethnic groups, particularly older Latina American, Hispanic American, and African American women (Umezawa, Kagawa-Singer, & Maly, 2012). These women believe that God or a higher power has control over all things in their lives; African American women exhibit a stronger belief in God than non-Hispanic Whites and turn to God as a health communicator (Umezawa et al., 2012). Asian American women do not believe in preventive medicine, and they view their traditional medicine and genetic testing as incompatible (Glenn et al., 2012). They also believe that receiving information about breast cancer and genetic testing might affect their ability to find husbands (Glenn et al., 2012). Lee-Lin, Menon, Pett, Nail, and Mooney (2007) stated that Asian American women distrust health care professionals, are afraid of pain and poor diagnoses, and do not believe in the efficacy of breast cancer screening. However, literature on the beliefs of Caribbean and South American women and the ways in which these beliefs affect their seeking breast cancer health care has been scant, thus supporting the need for this study.

Culture and Breast Cancer

Little is known about the relationship between culture and breast cancer, thus preventing health care professionals from providing quality care (Kagawa-Singer, Dadia, Yu, & Surbone, 2010). Culture has a major influence on individuals’ perceptions of cancer risk, treatment, and trust in health care professionals and institutions (Kagawa-Singer et al., 2010). Physicians, especially oncology specialists, must be culturally competent and proficient in communication skills in order to achieve outcomes that reflect lower mortality rates (Kagawa-Singer et al., 2010). Women of color tend not to discuss breast cancer, so the barriers to screening and treatment must be identified, and sensitive approaches to their care must be taken (Welch, 2003).

Costas and Gany (2013) reported that Latina American women experience shame and fear about breast cancer, and tend to keep such diagnoses private rather than share them with friends or family members. Very few researchers have examined the influence of culture in engagement in health-seeking activities, but many women of Latina or Hispanic ethnicities believe that their breast cancer is the result of sugar substitutes, spicy foods, antibiotics, breast feeding, sexual activity during menstruation, bruises from physical abuse, and fondling (Jean-Pierre et al., 2010). Surbone and Baider (2009) stated that health care practitioners should acknowledge patients' spiritual and religious beliefs because these beliefs have become a major component of psychosocial research. In addressing culture and breast cancer, Baider (2012) noted that different groups and their families have cultural beliefs that become the basis for their attitudes.

Women of color from the Caribbean believe that although family members and friends support them during their diagnosis and treatment, these individuals have no understanding of what the women are experiencing (Blows, 2009). Caribbean women of color also do not talk to others or share their experiences and concerns (Blows, 2009). Part of the rationale for this study was to understand the culture of families and groups because culture influences their perceptions and health-seeking behaviors. To cope with breast cancer or other illnesses, women of color from the Caribbean and South America use their religious beliefs and practices to decrease their stress and improve their confidence (Bache, Bhui, Dein, & Korszun, 2012). Health care practitioners in the United States tend to underestimate the results of traditional indigenous healing systems that are used either alone or in conjunction with the Western biomedical system (Haiso et al., 2006).

Breast Cancer Screening Diagnosis and Treatment

Screening

The NCI (2013b) stated that minority populations in the United States have less access to health care services because of poor education, low income, unemployment, and lack of or inadequate health insurance. Kiviniemi et al. (2009) noted that the poor availability of or access to resources such as transportation and money (cost), previous negative experiences with health care providers, and the inconvenient hours of service are barriers to mammography screening. Distrust of the health care system, along with fear and fatalism about treatment, are other barriers to obtaining preventive and screening services (T. C. Yang, Matthews, & Hillemeier, 2011). In general, the trust of people living in the United States toward the health care system has decreased, although more than 80% have reported in previous research that they trusted their personal health care providers (D. S. Yang et al., 2011; T. C. Yang et al., 2011).

Women of color have less access to and underuse health care services (Akinyemiju et al., 2013). Other identified barriers include difficulty prioritizing preventive and screening activities in the context of more immediate survival needs such as food, clothing, and shelter. Women of color also might lack information about current guidelines for cancer screening and prevention, and they might find preventive approaches inappropriate or culturally insensitive, making this population unresponsive (Mauad, Nicolau, Haikel, Longatto-Filho, & Baracat, 2009). Medical mistrust among women of color in the United States has been negatively correlated with adherence to screening recommendations, and although mammography is an effective way to detect breast cancer early, minority ethnic groups living in the United States seem to have less belief in and trust of the health care system than European American women do (Cronan et al., 2008).

In 2010, women of color equaled their European American counterparts in the percentage who were receiving mammography screening, but approximately 45% of women of color, compared to 35% of European American women, had breast cancer that spread (CDC, 2012). About 20% of the women of color with abnormal screening results received follow-up treatment in 60 days; only 12% of European American women fell into the same lengthy time line (CDC, 2012). This time lag could have increased the likelihood that the cancer would spread, resulting in difficulty treating it successfully (CDC, 2012). The CDC (2012) also reported that after the cancer had been detected, 69% of the women of color received treatment within 30 days, compared to 83% of European American women and that fewer women of color received radiation, surgery, or other life-saving treatments.

The reasons for breast cancer disparities among races and ethnicities have not been well understood, but Meade et al. (2009) identified them as interrelated complex factors (e.g., culture, level of education, literacy levels, poverty levels, and social injustice) preventing individuals from receiving screening or follow-up care, and having limited access to care. The CDC (2012) stated that racial disparities exist in breast cancer among women of color, beginning with the stage of presentation, which more often is late-stage cancer. Even though women of color have an overall lower incidence of breast cancer than European American women, they have a higher mortality rate. Women from other countries living in the United States have lower incidence rates of breast cancer but higher mortality rates than European American women that are the result of a combination of lack of access to care, language problems, citizenship, health care navigation miscommunication, economic marginalization, and poor social conditions (Meade et al., 2009).

When addressing adherence rates to mammography screening guidelines, there have been inconsistencies in how the rate of mammography screening has been reported. According to Conway-Phillips and Millon-Underwood (2009), even though some data have reported high rates of mammography use among American women of color, results have shown that they are more often diagnosed with late-stage tumors. Song, Hamilton, and Moore (2012) noted that outcome disparities are mainly related to health care providers' relationships with their patients that can sometimes result in insufficient screening, poor follow-up of abnormal screening results, and nonadherence to treatment guidelines.

Age and Diagnosis

According to Watanabe-Galloway, Hill, Shostrom, and Nsiah-Kumi's (2012) study of breast cancer disparities among women of color in Nebraska, 41/100,000 of the women were diagnosed at age 59 years or younger, with the average age being 54 years. Women of color ages 45 years and younger have been found to have a higher risk of breast cancer than their European American counterparts, with women of color under the age of 30 years having a 52% risk factor (Lewis, Sheng, Rhodes, Jackson, & Schover, 2012). Brinton, Sherman, Carreon, and Anderson (2008) stated that although European American women are most often diagnosed with breast cancer, this trend is different among younger women of color (under the age of 40 years) because they most often present with a more aggressive form of cancer and poor prognosis factors. Brinton et al. associated the increase in the number of breast cancer diagnoses with the increase in the number of screening measures as well as the use of HRT among postmenopausal women.

Breast Cancer Treatment and Care

The cancer care continuum disparities model begins with prevention and early detection and continues through the survival period (Press, Carrasquillo, Sciacca, & Giardina, 2008; see Figure 1). Factors contributing to cancer disparities can occur at each end of the continuum or at each stage in between, such as diagnosis and treatment, where economic, social, and cultural factors can play a role (Press et al., 2008). Berlin (2009) found that approximately 74% of women believe that if cancer is detected early, lives can be saved because the individuals will receive treatment and that 62% believe that mammography screening can decrease the mortality rate of breast cancer.

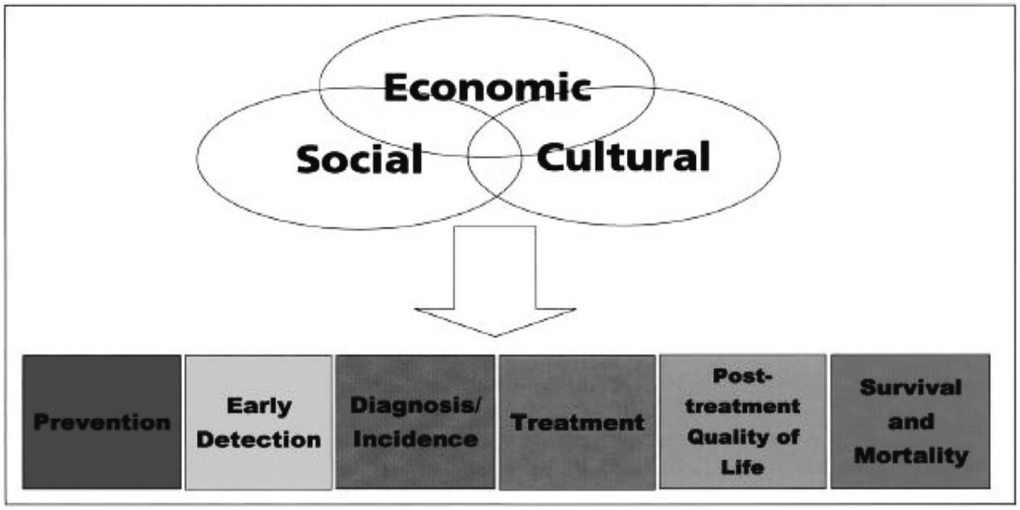

Figure 1. Factors contributing to disparities in the cancer care continuum. From Ward et al., 2004.

Health Care Provider Role

Poor communication between health care providers and patients can adversely affect the delivery of health care services. Women of color are less likely than European American women to receive standards of care according to medical guidelines, and fewer women of color with Stage II node-positive cancer receive conserving-breast surgery such as a lumpectomy, rather than a mastectomy, or removal of the entire breast (Worthington et al., 2008). Song et al. (2012) contended that health care providers communicate more effectively with European American patients than with patients from racial or ethnic minorities. Recommendations from physicians are important determinants in patients' decisions to have or decline cancer screening, but many physicians do not adhere to national guidelines for cancer screening with their patients (Song et al., 2012), which means that many cases remain undetected and untreated.

Meade et al. (2009) stated that health disparities can affect immigrants living in the United States negatively and can impact their access to health care. Young, Schwartz, and Booza (2011) noted that the participants in their study had limited access to preventive care and fewer board-certified providers practicing within the participants' community, and also faced personal barriers such as a perceived lower risk for breast cancer.

Past and Present Breast Cancer Prevention Strategies

When addressing health promotion and disease prevention strategies, it is important that health care professionals use effective communication to ensure that patients adhere to preventive health guidelines. Arguably, the U.S. federal government has the most critical role in this measure and has allocated funding for the early detection, diagnosis, and prognosis of breast cancer. According to the NCI (2013b), it is one of 27 agencies making up the NIH, which is part of the DHHS. The NCI's budget for Fiscal Year (FY) 2013 was $4.8 billion, which was approximately $293 million less than FY 2012 mainly because of sequestration. The NCI further noted that it spent $602.7 million on breast cancer research in FY 2012.

The number of resources, projects, programs, and services dedicated solely to the early detection, diagnosis, treatment, and prognosis of breast cancer in the United States, continues to expand and improve, as well as become more accessible to low-income or unemployed women (ACS, 2010). A number of initiatives, including the International Breast Cancer Screening Networks, the Minority-Based Community Oncology Program, and the Specialized Program of Research Excellence in Breast Cancer, have addressed breast cancer (NCI, 2009). These initiatives continue to assist women with screening, treatment, and self-empowerment strategies to cope with breast cancer. The ACS's (2010) Making Strides Against Breast Cancer project also has raised awareness of breast cancer and funds to fight the disease. However, despite the efforts of these initiatives and programs, breast cancer still threatens the health and quality of life women of color across the United States.

Summary

Breast cancer is a global public health issue, and disparities in screening, diagnosis, treatment, and follow-up care among different ethnic groups in the United States have been acknowledged. However, a lack of education, insufficient or no health care insurance, fear, and the mistrust of health care providers and systems are contributing to the increasing disparities facing women of color living in the United States. Women of color are predisposed to a more aggressive form of cancer than their European American counterparts, so they require earlier screening and more treatment options (Anders, Johnson, Litton, Phillips, & Bleyer, 2009).

Programs are in place to educate women about the need for breast cancer screening; however, these programs do not focus on women under the age of 40 years who might be at high risk for breast cancer. The programs also do not address the perceptions and behaviors of Caribbean and South American women or provide strategies to increase their participation in breast screening programs.

In Chapter 2, I discussed current literature related to the history of breast cancer in the United States focusing specifically on the increasing incidence, prevalence, mortality, and morbidity rates and survival rates of women of color from the Caribbean and South America in particular. I also presented information about the risk factors associated with breast cancer, including age and the increased use HRT. SES barriers, cultural traditions, current trends, the burden of breast cancer, knowledge and beliefs, and past and present preventive breast cancer strategies in place also were examined.

In Chapter 3, I explain the study design, participant selection, sample size, instruments, and data collection and analysis protocols. In Chapter 4, I present the results of the study, and in Chapter 5, I interpret the results, draw conclusions, and offer recommendations and suggestions for further research.

Chapter 3: Methodology

The purpose of this phenomenological study was to examine the perceptions and behaviors of first-generation women of color from South America and the Caribbean living in Atlanta, Georgia, regarding breast cancer awareness, screening, treatment, and follow-up care after abnormal screenings. The results will add to the sparse literature regarding the psychosocial factors of breast cancer among this population. In this study, I described the individual characteristics of a sample of women who had received abnormal mammograms, their relationships with their primary health care providers, and their use of health services following abnormal breast screening results. Included in the chapter is information about the study design and rationale, my role as the researcher, the methodology, the target population, sampling and sampling procedures, data collection and data analysis, issues of trustworthiness, and ethical procedures regarding confidentiality and access to the data.

Women of color in the United States have a higher mortality rate from breast cancer than any other ethnic group, which might be the result of their underuse of preventive measures that could lead to early detection (CDC, 2012). Differences in access to and use of screening and treatment, SES, and aggressiveness of tumors contribute to the survival rate disparity between women of color and their European American counterparts (O'Keefe, Meltzer, & Bethea, 2015).

Research Design and Rationale

The design of any study is important in providing the structural foundation of the research. With any studies, researchers need to control as many confounding variables as possible in order to draw meaningful conclusions (Creswell, 2009). After examining different research designs, I decided that the best approach for this study was phenomenological. Although an ethnographic approach would have been useful in looking at the beliefs, values, and cultural norms associated with the participants' perceptions of breast cancer screening and awareness, a phenomenological approach allowed me to obtain deeper and richer descriptions of the lived experiences of the participants. I was then able to generalize the results to the target as well as similar populations. Using a phenomenological approach allowed me to answer the six RQs:

1. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the severity of breast cancer in this population?
2. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the barriers to receiving breast cancer screening or treatment?
3. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the benefits or hazards of breast cancer screening?
4. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about their susceptibility to breast cancer?
5. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about what would

motivate them to seek breast cancer screening or treatment?

6. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about their confidence in taking care of their own breast health?

In using the HBM concept to focus on perceived susceptibility to breast cancer and benefits of mammography screening, I anticipated that my sample of 20 women from the Caribbean and South America would be representative of the target population.

Role of the Researcher

It was important for the participants to know about my biases, assumptions, expectations, experiences, and abilities so that they could understand why I felt qualified to conduct this research (Greenbank, 2003). I informed the participants that I was born in British Guyana, South America, and that I had personal experience with breast cancer in my family. I also let the participants know that I would remain sensitive to my own biological and social identities. In addition, I did not have any personal or professional relationship with any of the study participants that would have given me any power over them.

I made notes on my personal reflections and reactions to different situations in order to identify and recognize whether these factors biased my later analysis of the data. I remained adaptable and flexible so that I could respond to different situations with skill, tact, and understanding. This study was not conducted at my place of employment, and I did not offer the participants any incentives to join the study. I was responsible for collecting and analyzing the data collected from the interviews.

Methodology

I collected the data for this study by conducting interviews with the 20 participants or by allowing them to submit written responses to the interview questions if their schedules did not give them enough time to be interviewed. According to Creswell (2007), there are five ways in which qualitative methods can be approached: narrative, phenomenology, grounded theory, ethnography, and case study. Creswell further stated that qualitative inquiry is a legitimate method of social and human science exploration. Qualitative research methods are probing, require small samples, require interviewers with special skills, have a mode of analysis that is subjective or interpretive, have low or no opportunity to be replicated; and are mainly exploratory in design (Creswell, 2009). This type of research is more likely to take place in a natural setting (Marshall & Rossman, 1989). The phenomena under study deal mainly with everyday life, and the research is not driven by hypotheses and categorical frameworks (Symon & Cassell, 1998).

Participants

The target population comprised women of color ages 35 to 69 years old who were residing in the Fulton, DeKalb, and Clayton Counties in Georgia at the time of the study. The term *women of color* denoted women of primarily African American descent; women from the Caribbean (African, East Indian, and Mixed descent); and women from South America. When researching areas with high proportions of women of color from South America and the Caribbean, I found that the three counties in Georgia had large minority populations from which I could draw my sample (U.S. Census Bureau, 2010). Excluded from this study were men and European American women.

Sampling Strategy

The sampling strategy followed a purposive design to ensure the collection of useful information while maximizing the participation of women from the Caribbean and South America of different ages who were living in Atlanta, Georgia, at the time of the study. To recruit the participants, I posted and inserted flyers on the bulletin boards as well as in the weekly newsletters of local churches and health and community centers. To be eligible to join the study, the participants had to be first-generation immigrant women of color of South American or Caribbean heritage between the ages of 35 and 69 years who were living in the Fulton, DeKalb, and Clayton Counties of Georgia at the time of the study.

Sample Size

Frankfort-Nachmias and Nachmias (2008) noted that an adequate sample size depends on several factors, including, but not limited to, cost, variability within the target population, sampling method, design of the research, and size of the target population. All of these factors have to interact with each other in a complex way. In qualitative research, the sample size depends on the goal of the study and the time and resources available to the researcher (Patton, 2002). Patton (2002) further stated that qualitative studies have no set rules regarding the number or size of the samples. For my study, I chose a sample of 20 women of color who were representative of the target population of women from the Caribbean and South America who were living in Atlanta, Georgia, at the time of the study.

Procedure/Measures

Individuals interested in participating in the study were asked to complete a 12-question demographics questionnaire to determine eligibility to join the study. The questionnaire contained questions about age, ethnic background, country of birth, level of education, and household income; breast cancer screening behaviors; whether or not they had health insurance; availability of mammography screening; frequency of mammography screening; family history of breast cancer; and whether their primary care physicians recommended breast screening. Once I confirmed the women's eligibility, I asked them to complete the informed consent.

Data Collection

This study involved use of an interview guide that I designed to measure the participants' perceptions, knowledge, attitudes, and behaviors about breast cancer. I conducted telephone interviews with the participants to gain a better understanding of their breast health practices (e.g., smoking habits, whether they smoked, ever smoked, age at cessation, and age at initiation); physical activity levels; menopausal status; and other lifestyle factors (e.g., alcohol consumption, oral contraception use, and HRT use). Questions about height, marital status, education, age, place of residence, and age of menarche also were included in the interview guide.

I conducted the interviews over 3 months. Because of the number of interview questions, I conducted each interview in segments of two to three each week, with each segment lasting 15 to 20 minutes. I worked with each participant over 2 to 3 weeks. The interviews were audiotape recorded and transcribed verbatim. I collected data until the point of saturation.

Data Management

Data management is the process of managing data that requires specific steps and guidelines. According to the DHHS (2011), data management includes the following factors:

1. Data ownership: "who has the legal rights to the data, and who retains the data after completion of the project."
2. Data collection: done in a "consistent, systematic manner, with an established system of evaluating and recording changes to the protocol."
3. Data storage: addresses "the amount of data to be stored in order for reconstruction of the project."
4. Data protection: the "protection of written and electronic data from physical damage, tampering or theft, and data integrity."
5. Data retention: "the length of time the data is [*sic*] kept according to the sponsor's or funder's guidelines, and the secure destruction of data."
6. Data analysis: "how the raw data are chosen, evaluated, and interpreted where it can be understood by others."
7. Data sharing: "how the data and research results are disseminated to others and when it should not be shared."

8. Data reporting: “the publication of findings, both positive and negative upon completion of the project.” (p. 3)

To adhere to these guidelines, I documented and managed the data using NVivo v.10, described the methods that I used to collect the data, explained how I documented the data, showed how data quality was ensured, provided backup procedures, described how I intended to make the data available for public use, and detailed how I protected the participants’ privacy and the confidentiality of their responses.

Data Analysis

Data analysis is an ongoing and iterative process in qualitative research. It involves the collection and analysis of data that continues until the research topic is understood or time runs out (Creswell, 2007). According to Thorne (2000), even though data analysis is the most complex of all phases of a qualitative project, it receives the least thoughtful discussion in literature. Thorne noted that in order to obtain findings that can transform raw data into new knowledge, qualitative researchers have to engage in analytic processes during their investigations. As such, it is important that researchers understand the process and be able to read and interpret it.

I read each transcription of each telephone interview or completed interview questionnaire thoroughly to understand the participants’ perceptions, behaviors, beliefs, knowledge, awareness, and experience with breast cancer. I used NVivo v.10 to identify codes, significant information, and phrases gleaned from either the transcriptions of the written responses to the interview questions. I conducted member checking to verify the accuracy of all information received from the participants.

Data Confidentiality

I kept all of the interview data private and confidential, as mandated by the Health Insurance Portability and Accountability Act guidelines. I exercised due care in handling the records to avoid the possible loss or leakage of data. I did not disclose any individual data; only aggregate or population data were used in the results. I kept the collected data secure and confidential. I gave all participants numeric identifiers and pseudonyms, along with unique IDs and passwords to access their files. I backed up the files regularly on and off site in hard and electronic copies.

Issues of Trustworthiness

Patton (2002) discussed three elements relevant to the credibility of qualitative research: (a) the credibility of the researcher, (b) the rigor of the methods, and (c) the philosophical belief in the value of naturalistic inquiry. Patton stated that a rigorous methodology will yield high-quality data and that a researcher’s history, status, presentation of self, and training will help to establish the credibility of a study. To ensure the quality, trustworthiness, and credibility of this study, I became familiar with the culture of the participants to gain a better understanding of the problem and establish a relationship of trust with them.

I ensured the credibility of the results by using random sampling to select the participants, adopting an established research method, becoming familiar with the cultures of the participants, and giving each participant the opportunity to refuse to participate in the research. I also used member checking so that the participants could check and verify the contents of their interview transcriptions.

Strategies of transferability included collecting sufficient detailed descriptive data in context and reporting them accurately (Lincoln & Guba, 1985). I had an adequate trail of raw data, including copies of questionnaires completed by participants who chose to answer the interview questions as written responses, field notes, audio recordings, and results. I made these data available in order to determine whether the conclusions, interpretations, and recommendations supported the inquiry (Lincoln & Guba, 1985). I also maintained a daily journal and a running account of the study, both of which can be examined by peer auditors to validate credibility (Lincoln & Guba, 1985).

Quality Control Measures

I took quality control measures to ensure the credibility and reliability of the data, including examining and measuring my experience in conducting interviews. Techniques overseeing this provision included receiving proper training (i.e., interview techniques, map reading, ethics, and cultural sensitivity relevant of the questionnaire); having committee members monitor the interviewing process; checking the completeness of the questionnaires and validating the collected data by reading the individual participants' transcriptions back to them verbatim over the telephone.

Ethical Considerations

According to Frankfort-Nachmias and Nachmias (2008), research requires the informed consent of the participants. Before conducting the interviews, I ensured that all participants signed the informed consent and returned it to me. There are several reasons why it is necessary to adhere to ethical norms: promote the aims of the research, promote values that are essential to collaborative work, be held accountable to the public, build public support for research, and promote moral and social values (Resnik, 2011). I ensured that the risks and benefits of being in the study, monitoring of data collection, and protection of privacy and confidentiality were clearly stated and understood by the participants. I also advised them that they had the right to withdraw from the study at any time (Resnik, 2011).

I will continue to store the data on a password-protected computer in a locked office for 5 years, as required by the university, before I destroy them. All data are stored in NVivo v.10, and backup files of all data, including interview transcriptions, are saved in a single folder on a personal computer and an external hard drive (Van den Eynden & Chatsiou, 2011). Only I have access to the data, and I control who can view them.

Summary

I chose a phenomenological method of inquiry for this study because it gave the participants the opportunity to share with me their perceptions, beliefs, knowledge, awareness, behaviors, and lived experiences toward breast cancer. The sample comprised 20 women of color between the ages of 35 and 69 years who were residing in Clayton, DeKalb, and Fulton Counties in Atlanta, Georgia, at the time of the study. I collected the data via interviews. I analyzed the data to identify themes emerging from their responses to the interview questions. In Chapter 4, I describe the participants, discuss the themes, and present the results. In Chapter 5, I interpret the results, draw conclusions, and offer suggestions for further research.

Chapter 4: Results

This chapter presents the findings based upon the responses to 34 in-depth interview questions from 20 first-generation South American and Caribbean women of color living in the United States regarding their perceptions and behaviors toward breast cancer. The purpose of this study was to examine the perceptions and behaviors related to the women's breast cancer awareness, screening, treatment, and follow-up care. I also examined the participants' individual characteristics and their relationships with health care providers and health services, and the factors motivating them to seek breast health care and follow-up treatment. Included in the chapter are descriptions of the research instrument, setting, and recruitment protocols; participant profiles; explanations of the data collection, storage, and analysis; and discussions of the data verification, themes, and discrepant findings. Interpretation of the data follows in Chapter 5.

I used a phenomenological research design because it allowed me to look at the sample as representative of the target population as a whole to determine how they experienced the phenomenon of breast cancer and what they had in common (Creswell, 2007). Included in the chapter are profiles of the 20 participants. I collected the qualitative data by conducting in-depth telephone interviews with the participants in June, July, August, and September 2015. As mentioned previously, participants who were not available for the telephone interviews were allowed to write their responses to the interview questions and submit them to me.

Research Tools

I used a demographics questionnaire comprising 12 questions to determine the women's eligibility to join the study. The demographic questionnaire included basic information such as age, self-identification, country of birth, height, marital status, and level of education. I asked the 20 participants 34 open-ended interview questions once I had received their signed informed consents. The interview questions addressed lifestyle factors, including smoking habits and contraceptive and HRT use, and breast cancer background. The study was guided by six RQs:

1. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the severity of breast cancer in this population?
2. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the barriers to receiving breast cancer screening or treatment?
3. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the benefits or hazards of breast cancer screening?
4. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about their susceptibility to breast cancer?
5. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about what would

motivate them to seek breast cancer screening or treatment?

6. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about their confidence in taking care of their own breast health?

Setting

Upon receiving approval from Walden University's Institutional Review Board (IRB approval #05-19-15-0065589), I conducted the study in the Clayton, DeKalb, and Fulton Counties of Atlanta, Georgia. After the participants completed the demographics questionnaire to establish that they met the criteria to be in the study and signed the informed consent, I gave them the option to respond to the interview questions via e-mail or by telephone. Five participants chose e-mail; the other 15 participants agreed to be interviewed by telephone. I did not offer any participants monetary compensation to be in the study, and I reminded them all that their participation was voluntary and that they could stop the interview if they felt uncomfortable or simply did not want to answer a question or withdraw from the study at any time.

Recruitment

Participants were invited through flyers posted on the bulletin boards and in the weekly bulletins of three churches: St. Philip Benizi Catholic Church in Clayton County, St. John the Evangelist Church in Fulton County, and St. Thomas More Church in DeKalb County.

Participant Profiles

All names were coded to protect the participants' privacy. A short description of each participant is provided next.

Janie

Janie is between the ages of 40 and 69 years. She comes from Guyana, South America. She is divorced and has three children who are 12, 19, and 27 years of age, respectively. She was the first in her family to move to the United States through marriage. Janie holds a professional degree and lives in Clayton County with her children. She does not smoke or use oral contraception or HRT. She has a family history of breast cancer, she has health insurance, and she received her first mammography at the age of 42 years. Janie receives a mammogram yearly. She stated that she was not referred for screening by her health care provider, despite speaking with her provider about breast cancer and her mother's diagnosis of subsequent death from breast cancer. She further stated that breast cancer screening is available in her community.

Alaine

Alaine is between the ages of 40 and 69 years. She comes from Brazil, South America. She is married and has a 42-year-old child. Alaine resides in Clayton County, Georgia, with her husband. She was the first member of her family to move to the United States in 2002. She has an associate's degree and is employed at a full-time job. She no longer smokes. She stopped smoking when she was 35 years old, and she exercises regularly. She does not use oral contraception or HRT. Alaine does not have a family history of breast cancer, but she has spoken to her health care provider about breast cancer. He has never referred her for screening. Breast cancer screening is available in her community, and she had her first mammography at age 25. She continues to receive screening every 2 years.

Laney

Laney is between the ages of 40 and 69 years. She comes from Jamaica, West Indies. She is divorced and has two children ages 15 and 18 years. She arrived in the United States in 1993. She has an associate's degree. She resides in Fulton County, Georgia, with her children and works at a full-time job with a yearly income of $60,000+. Laney has never smoked, practices physical exercise, and does not use oral contraception or HRT. She does not have a family history of breast cancer, but she does have friends who have experienced breast cancer. She has health insurance and has received screening for breast cancer. She had her first mammogram when she was 40 years old. Laney has spoken to her health care provider about breast cancer, and she was referred by her provider for screening. She receives a mammography every 2 years. Breast cancer screening is available in her community.

Zoe

Zoe is between the ages of 30 and 39 years. She comes from Guyana, South America. She is single and has a 10-year-old child. She came to the United States to attend school. She holds a master's degree, is employed at a full-time job, and earns a yearly income of $60,000+. Zoe resides in Clayton County, Georgia. She has never smoked or used oral contraception or HRT. Zoe does not exercise regularly. She has a family history of breast cancer, and despite having health insurance, she has never had breast cancer screening or mammography. She has spoken to her health care provider about breast cancer, and he has referred her for screening, but she has not had it done. Screening is available in her community.

Shelly

Shelly is between the ages of 30 and 39 years. She comes from Guyana, South America. She came to the United States in 2006 through marriage and has an 8-year-old child. She resides in DeKalb County with her family. Shelly has a master's degree, is employed on a part-time basis, and has a yearly household income of $60,000+. She has never smoked or used oral contraceptives or HRT. She does not exercise. She does not have a family history of breast cancer. She has health insurance and has received breast cancer screening. She has spoken to her health care provider about breast cancer, and he has referred her for screening. She has never had a mammography, but will be getting one in the near future. There is no breast cancer screening in her community.

Karolyn

Karolyn is between the ages of 40 and 69 years. She comes from Barbados, West Indies. She is married and has two children, ages 35 and 31, respectively. She resides in Clayton County with her husband and holds a master's degree. Karolyn is currently unemployed, but she did have a yearly household income of $60,000+. She began smoking when she was 19 years old and stopped at the age of 42 years. She exercises regularly, has a family history of breast cancer, and has received breast cancer screening. Karolyn has never used oral contraception, but she has used HRT. She had her first mammogram when she was 33 years old and receives one every 2 years. She has spoken to her health care provider about breast cancer and has been referred by the provider for screening. Screening is available in her community.

Elisha

Elisha is between the ages of 40 and 69 years. She comes from Jamaica, West Indies. She arrived in the United States in 1976 and is divorced. Her two children are 23 and 26 years of age. She resides in Clayton County, Georgia. She has a bachelor's degree, is employed at a full-time job, and has a yearly household income of $30,000 to $45,000. Elisha has never smoked or used oral contraceptives or HRT. She does not have a family history of breast cancer, but she has been diagnosed with breast cancer. A very close friend also was recently diagnosed. She has health insurance and has received breast cancer screening. She received her first mammography when she was 35 years old and receives one every year. She often speaks to her health care provider about breast cancer, and she has referred her for screening. Breast cancer screening is available in her community.

Joanne

Joanne is between the ages of 40 and 69 years. She comes from Guyana, South America. She is married and has five children ranging in age from 26 to 40 years. She came to the United States in 1996 and resides in Clayton County, Georgia, with her oldest daughter, grandchildren, and husband. She completed high school and is unemployed. Joanne has never smoked or used oral contraceptives or HRT. She has no family history of breast cancer but has a friend who has breast cancer. She has health insurance, had her first mammography when she was 50 years old, and receives one every 2 years. Joanne’s health care provider has neither spoken to her about breast cancer nor referred her for screening. She is unsure about the availability of breast cancer screening in her community.

Dottie

Dottie is between the ages of 40 and 69 years. She comes from Jamaica, West Indies. She is single; has no children; and lives in DeKalb County, Georgia. She arrived in the United States in 1985 to attend school but did not complete it because of financial difficulties. She is employed on a part-time basis and has an annual income that ranges from $0 to $15,000. Dottie has never smoked or used oral contraceptives or HRT. She does not exercise regularly. She does not have a family history of breast cancer, but she has friends who have been affected by breast cancer. Dottie has health insurance and has received breast cancer screening. She received her first mammography when she was 20 years old and continues to receive a yearly examination. She has spoken to her health care provider about breast cancer, and he has referred her for screening. Breast cancer screening is available in her community.

Julie

Julie is between the ages of 40 and 69 years. She comes from Jamaica, West Indies. She is single and resides in DeKalb County, Georgia, with her parents. Julie arrived in the United States in 1985 to attend school. She has a bachelor’s degree, is currently unemployed, and has a family annual household income of about $45,000. She has never smoked or used oral contraceptives or HRT. She does not exercise regularly. She had her first mammography when she was 35 years old. She does not have a family history of breast cancer, but she has a couple of friends who have experienced breast cancer. Julie has never talked to her health care provider about breast cancer screening. She is aware of available screening services in her community.

Heidi

Heidi is between the ages of 40 and 69 years. She came to the United States from Jamaica, West Indies, in 1988. She is married and has two children who are 23 and 27 years old. She resides with her husband and a daughter in DeKalb County, Georgia. She has a doctoral degree, is employed at a full-time job, and has a yearly household income of $60,000+. Heidi has never smoked or used oral contraceptives. She has used HRT and exercises regularly. Heidi has a family history of breast cancer. She had her first mammography when she was 45 years old and continues to receive one every year. She has health insurance, has received screening, and has discussed breast cancer with her health care provider. Her provider has referred her for screening, and breast cancer screening is available in her community.

Zelda

Zelda is between the ages of 40 and 69 years. She comes from Barbados, West Indies. She is married and has a 22-year-old child. She currently resides in Clayton County, Georgia, with her husband and son, who is attending college. She has a master's degree, is employed at a full-time job, and has a yearly household income of $60,000+. Zelda has never smoked or used HRT, but she has used oral contraceptives. She exercises regularly. She does not have a family history of breast cancer, but she knows individuals who have been impacted by breast cancer. She has health insurance and has received breast cancer screening. She had her first mammography when she was 40 years old. She receives a mammogram every year and has discussed breast cancer with her health care provider. She was referred for screening by her provider. Breast cancer screening is available in her community.

Kim

Kim is between the ages of 40 and 69 years. She comes from Jamaica, West Indies. She arrived in the United States in 1978 to find work. She is married and has four children in their 40s. She resides with her daughter and family in Clayton County, Georgia. She has a high school education and is currently unemployed. Her yearly household income is $60,000+. She has never smoked or used oral contraceptives or HRT. She does not exercise regularly. Kim has a family history of breast cancer and has received screening. She had her first mammography when she was 30 years old. She continues to have a mammography every 6 months, as advised by her health care provider. She has spoken about breast cancer on numerous occasions with her provider, who has referred her for screening. Breast cancer screening is available in her community.

Sharon

Sharon is between the ages of 30 and 39 years. She comes from Trinidad and Tobago, West Indies, and resides in Fulton County, Georgia. She is single and is the only member of her family in the United States. Sharon has a bachelor's degree and is currently working to obtain her master's degree. She is employed at a full-time job and has a yearly household income of $30,000 to $45,000. She began smoking in adolescence, but she stopped about 4 years ago. She exercise daily and has used oral contraceptives for several years. She has never used HRT. She has a family history of breast cancer. Sharon has health insurance through her employer, but she has never received breast cancer screening or mammography. She has never discussed breast cancer with her doctor, and he has never mentioned screening. She is aware of breast cancer screening being available in her community.

Mel

Mel is between the ages of 40 and 69 years. She comes from Jamaica, West Indies. She came to the United States in 1984 to further her education. She has a nursing degree. Mel is married and has a 30-year-old child and an 11-year-old grandchild. She resides in Fulton County, Georgia, with her husband, daughter, and granddaughter. Her yearly household income is $45,000 to $60,000. Mel has never smoked or used oral contraceptives or HRT. She exercises regularly and has a family history of breast cancer. Mel’s mother and grandmother were diagnosed with breast cancer, and she was diagnosed about 2 years ago. Although she has a family history of breast cancer, her health care provider has never referred her for screening. She has health insurance and has received breast cancer screening. She had her first mammography when she was 40 years old. She receives mammography screening every 6 months. She talks to her provider about breast cancer and knows that breast cancer screening is available in her community.

Kara

Kara is between the ages of 40 and 69 years. She comes from Brazil, South America. She moved to the United States in 1998 for work. She is married and has four children between the ages of 18 and 26 years. Kara resides in Fulton County, Georgia, with her husband and children. She has a bachelor’s degree and is employed at a full-time job with a yearly household income of $60,000+. She has never smoked or used oral contraceptives or HRT. She has a family history of breast cancer and has lost several friends to breast cancer. Although she has health insurance, she has never received screening or mammography. She has a health care provider, but they have never discussed breast cancer or screening. She believes that breast cancer screening is available in her community, but she is not sure because she never checked.

Anna

Anna is between the ages of 30 and 39 years. She comes from Antigua, West Indies. She moved to the United States in 2010 to complete her medical degree. She is married and has a 3-year-old child. Anna resides in DeKalb County, Georgia, with her family; works at a full-time job; and has a yearly household income of $60,000+. She has never smoked or used oral contraceptives or HRT. She does not have a family history of breast cancer, but she does have friends who were impacted by this disease at an early age. She exercises daily and had breast cancer screening and mammography for the first time this year. She will continue to have one at least yearly or every 2 years. Her health care provider has never referred her for screening, but they have discussed breast cancer. There are many opportunities for breast cancer screening in her community.

Betty

Betty is between the ages of 40 and 69 years. She comes from Grenada, West Indies. She moved to the United States to provide a better life for her and her children. She is divorced and has five children between the ages of 17 and 34 years. She lives in Clayton County, Georgia, with three of her children. Betty has a bachelor's degree, is employed at a full-time job, and has a yearly household income of $45,000 to $60,000. She has never smoked or drunk alcohol, and she has never used oral contraceptives or HRT. She has a family history of breast cancer, losing her mother and a sister to breast cancer. She has never been diagnosed, but she receives screening and mammography yearly. She had her first mammography when she was 35 years old because she had found a lump in one breast. She has discussed breast cancer with her health care provider because of her family history, and she has asked for a referral for screening and mammography. Breast cancer screening is available in her community.

Janice

Janice is between the ages of 40 and 69 years. She comes from Trinidad and Tobago, West Indies. She arrived in the United States in 1972 and has since brought her parents and siblings to the United States. She is married and has three children between the ages of 34 and 42. She resides in DeKalb County, Georgia, with her husband and her mother. Her dad died from pancreatic cancer several years ago. She has a bachelor's degree, is employed at a full-time job, and has a yearly household when she was 31 years old because of her child's health. She has never used oral contraceptives or HRT. She exercises regularly. She has insurance coverage and has received breast cancer screening.

She had her first mammography when she was 40 years old. She receives mammography yearly and has discussed breast cancer with her health care provider. He did not initiate a referral for screening; rather, she had to ask for a referral. Breast cancer screening is available in her community.

Sara

Sara is between the ages of 40 and 69 years. She comes from Grenada, West Indies. She moved to the United States in 1970. She is married and has two children, ages 38 and 31, respectively. Sara resides in Fulton County, Georgia, with her husband. She is employed at a full-time job. She has never smoked or used oral contraceptives or HRT. She does not exercise as much as she should or wants to because she is too tired most days after work. Sara does not have a family history of breast cancer, but she has several friends who have been diagnosed or who have family members who have been diagnosed with breast cancer. She has health insurance and receives screenings when advised by her health care provider. She had her first mammography when she was 38 years old and continues to receive a yearly screening. She has spoken to her provider on numerous occasions about breast cancer and is aware of breast cancer screening being available in her community.

Data Collection and Storage

I interviewed each of the 15 telephone participants twice, with each interview lasting approximately 15 to 20 minutes. I conducted these interviews from my home office to ensure additional confidentiality. I followed an interview guide with probes and follow-up questions to ensure that I asked all 15 participants the same questions. I transcribed the interview responses and stored them in a locked cabinet in my home office. Following the interviews, I directed the participants to websites with information about breast cancer as well as other health-related resources within their respective counties. I also kept a journal to record my thoughts and reactions, self-reflect, and identify themes. All answers and notes were uploaded to NVivo v.10 for data management.

Data Analysis

I used NVivo v.10 to identify the most common themes that emerged from the participants' responses to the interview questions. To gain a general understanding of each transcript, I read them multiple times while looking for underlying key words and phrases. Specific themes significant to each participant included, but were not limited to, the role of genes in breast cancer, environmental factors and their influence on breast cancer, and radiation exposure.

Data Verification

I verified the data by providing information about research bias; the member-checking protocol; and the use of rich, thick descriptions (Creswell, 2009). I used direct quotes taken from the participants' transcriptions to support the lived experiences that they described in the interviews. The emerging themes also gave me more understanding of their perceptions and behaviors toward breast cancer awareness, screening, treatment, and follow-up care. There was some disagreement among the participants regarding whether their health care providers referred them for screening and whether breast cancer screening was available in their communities. I discuss the discrepant findings after I explain the identified themes.

Themes Identified

I examined the perceptions and behaviors of first-generation South American and Caribbean women of color regarding breast cancer awareness, screening, treatment, and follow-up care. I also examined their relationships with their health care providers. Common themes were identified from the participants, regardless of their various locations in Georgia, countries of birth, and educational backgrounds. Recurring themes included, but were not limited to, the role of genes in breast cancer, lifestyle influences and risk of breast cancer risk, environmental factors, positive notions of foods and their consequences on breast health, the role of culture on health care decisions, fear of harm from radiation exposure, family relationships, understanding why they sought screening and/or treatment, and family and increased risk of breast cancer.

Knowledge

Meaning of the term breast cancer. I asked the participants several questions to assess their understanding of breast cancer and what the term breast cancer meant to them. Four themes emerged under this category and one of the strongest themes was death. Karolyn said that it meant “terminal illness”; Elisha said that it meant “death”; Mel said, “Death”; Julie said, “Death”; Joanne said that “it means that I am dying”; Dottie said, “I am going to die”; Zelda said, “Death”; Sharon said, “I guess that I need to begin saying goodbye to my family and friends, because I am going to die”; Kim said, “Death, no cure”; Kara said, “Everyone in my family who had this disease died; therefore, it means a death sentence to me"; Janie said, "Both of my parents died from cancer. My mother had breast cancer, and my father had pancreatic cancer. Therefore, I often associate the term cancer with death"; Anna said that "it means terminal illness with no cure"; Sara said, "Death, because I cannot afford to pay for treatment."

Another theme was loss of hair, chemotherapy and surgery. Zoe said that "the term breast cancer meant "surgery, chemotherapy, and hair loss." The next theme was expensive treatment. Shelly stated, "When I hear that term, I immediately see dollar signs, because the treatment is very expensive." The last theme was don't think about it. Alaine said, "I don't think about cancer at all"; Heidi said, "Who wants to think about cancer, not me"; Betty said, "I do not think about it at all, because I will be depressed"; Janice said, "I just think about that"; and Laney said, "Who wants to think about breast cancer? I don't." It was evident that the majority of the participants associated death with breast cancer, and therefore, found the topic very dismal.

Lifestyle influences and breast cancer. I asked the participants whether they believed that staying healthy could influence their risk of getting breast cancer. Themes emerging under lifestyle included watching what they ate, alcohol usage, smoking, radiation exposure, use of oral contraceptives, use of HRT, and exercise. Zoe sated, "I ensure that I eat vegetables and fruits daily, I refrain from fatty foods, I no longer eat red meat (over 10 years now) and recently stopped eating chicken"; Janie added, "I try to live stress free, watch what I eat, try to exercise regularly and make an effort to get at least 7-8 hours rest every night"; Karolyn stated, "I eat nutritious meals, partake in regular exercise program and get 7-8 hours sleep daily." Betty, Anna, Joanne, and Sharon commented that they tried to eat nutritious meals and exercise regularly. Elisha, Heidi, and Mel stressed the need to eat a healthy diet but stated that it was difficult to find the time to get to the gym or get involved in an exercise program. Zelda, Kara, Shelly, Dottie, and Alaine stated that they tried not to take on any added stress, tried to exercise at least 2 or 3 days a week, tried to watch what they ate, and tried to take vitamins. Kim stated that she tried to walk at least 1 or 2 miles daily because she did not go to the gym, tried to eat lots of fruits and vegetables, and tried to drink plenty of water. Laney added that she just tried to live stress free, and Julie stated that she ate, slept, and lived a healthy lifestyle. Both Janice and Sara noted that they tried to eat healthy diets but found it difficult at times. Neither of them exercised as much as they would have liked.

The participants were asked whether smoking, alcohol, oral contraceptives, HRT, and radiation could be risk factors for breast cancer. Following are examples of some responses to those questions:

> "I don't know whether contraceptives or [HRT] play a role in the disease." (Alaine)
>
> "I believe that because contraceptive pills interferes with the hormones that there is a likelihood that it can contribute to increasing or decreasing the risk for breast cancer cells, although I have not read any research to this effect." (Karolyn)
>
> "Tobacco contains a lot of cancer causing compounds that can affect one's health, whether it directly or by second-hand inhalation." (Janie)
>
> "I do not know if smoking is a risk factor." (Heidi)
>
> "I believe that alcohol may increase the risk for breast cancer." (Shelly)

> "Don't know whether alcohol, contraceptive pills or [HRT] affect breast cancer risk." (Joanne)
>
> "Being exposed to radiation and things in the environment can increase your risk for breast cancer." (Laney)
>
> "Maybe being exposed to radiation can cause you to get breast cancer." (Janice)
>
> "Yes, smoking increases one's risk." (Betty)
>
> "No, alcohol is not a risk factor." (Dottie)
>
> "Large consumption of alcohol can be a risk factor." (Mel)
>
> "No, contraceptives are not a risk factor." (Elisha)
>
> "There is a likelihood that contraceptives can be a risk factor for breast cancer along with [HRT]." (Zoe)
>
> "No, [HRT] is not a risk factor." (Anna)
>
> "Radiation, maybe, depending on the amount of exposure." (Sara)

Food choices and the consequences. The next emerging theme was positive notions of foods and their consequences. All of the participants viewed processed foods as a health risk. Janie mentioned that "they contain preservatives and pesticides making them very unhealthy. Mel stated that "they are stripped of all it nutrients." Shelly added, "Fatty foods are a health risk." The participants recognized that lack of exercise, smoking, alcohol consumption, and unhealthy diets could have an impact on their health. However, some of them could not make the connection between these variables and the onset of breast cancer.

Genes and breast cancer. Another theme was on perceived risk factors and the role of genes in breast cancer. Laney, Janie, Zoe, Shelly, Karolyn, Julie, Zelda, Sharon, Mel, and Sara all believed that genes played an important role in whether they were at risk of breast cancer. Betty, Kara, Kim, Heidi, and Elisha were not sure whether genes played a role. Dottie added that her mother had had breast cancer, so she believed that breast density can be inherited and that people with dense breast tissue are 6 times more likely to develop cancer. Alaine, Joanne, and Sara had never really thought of it that way, so they did not really know much about it; Alaine added that she probably needed more information. Anna stated that genes did not play a role in whether or not someone gets breast cancer.

It was surprising to me that none of the participants identified genes as being one of the highest risk factors associated with breast cancer. The ACS (2011) stated that genes are highly associated with breast cancer, along with other factors such as inactivity, gender, obesity, environment, and age.

Family and increased risk. The next theme emerging from the study was family and increased breast cancer risk. When asked whether they believed that if their mothers, aunts, fathers, or grandparents had experienced breast cancer, they would be more at risk of breast cancer, all participants but Alaine believed that their chances of getting breast cancer were high. Alaine said, “I don’t know whether if my mother had breast cancer, I would be at more risk. Maybe, [but] I have not had enough information to make this statement.” Participants were asked whether genes played a role in getting breast cancer, and many were not sure or did not believe that they played a role; regardless, the majority believed that family played a role.

Awareness

Fear of harm from radiation exposure. The participants were all aware of breast cancer screening and mammography centers, as well as the benefits of mammography. However, fear of harm from radiation exposure emerged as a theme. Although many of the participants had access to breast cancer centers, information, and health insurance, some participants (Joanne, Heidi and Sara) refused to know or read about or discuss breast cancer with their health care providers because they were frightened and associated breast cancer with fatalism. Following are examples of some of their responses:

> "I don't want to know about it, because it might happen to me." (Kara)
>
> "We can benefit from mammogram as early detection saves lives." (Karolyn)
>
> "One can benefit from receiving a mammogram, early detection." (Zoe)
>
> "Early detection is the best cure… my own personal mammogram showed early abnormal signs, so action was taken." (Sharon)
>
> "Too much radiation exposure may be harmful but the benefits far outweigh the damage of not having a mammogram." (Laney)
>
> "The amount of radiation from a single mammogram is quite low, but receiving it too often is not good." (Janie)
>
> "I believe that I can benefit from receiving a mammogram or treatment because early detection can save or extend my life." (Betty)

“I don’t know, I don’t like to be exposed to radiation of any kind unless extremely necessary.” (Shelly)

“I believe one can benefit from receiving a mammogram … early detection … if there are any cancerous cells in the early stage in your breast, the mammogram will detect it.” (Janie)

“There are several places in the community where anyone can get information or screening if they want.” (Kim)

Behavior

Understanding why they seek screening and/or treatment and breast cancer and family relationships. The themes of understanding why they seek screening and/or treatment and breast cancer and relationship with family emerged in response to the question about what a diagnosis of breast cancer would mean to them and whether it would change their relationships with their family members and friends. Although family was the major motivation for most of the participants, I received a variety of other responses:

“Yes, my children and grandchildren are my motivation.” (Janie)

“Yes and no, I am a self-motivated to live.” (Kim)

“Yes, family is my motivation.” (Zoe)

“If you are sick, just being alive is enough motivation.” (Shelly)

“Knowing my family history motivates me.” (Zoe)

“If there is any indication that I needed it.” (Shelly)

“Age or health concerns and the need to have it done, are my motivation.” (Kara)

“Just knowing what the consequences of not being properly screened or treated …a desire to live… I desire to live a good quality of health.” (Betty)

“Based on my recent experience, it is important to keep abreast and maintain awareness.” (Janie)

I also asked them how confident they were in taking steps to take care of their breast health. Their responses varied:

“Extremely confident …self-advocate for my health and well-being …take regular screenings and keep current on procedures etc.” (Janie)

“I always take care of my health.” (Heidi)

“I have had three screenings in this year and one surgery, so I am very confident in taking the necessary steps.” (Janice)

“Very, I have always followed health screening guidelines.” (Anna)

“100%, very confident in doing my screening and self-checks.” (Mel)

“I perform self-check every month ….I was taught by my doctor how to check my breast.” (Sharon)

“I receive a mammogram every year …yes, I check my breast at least once a week.” (Julie)

“I have never had a mammogram …the doctor said that I was too young.” (Zoe)

“I just could not find the time to get one.” (Dottie).

“I am aware of when I need to have it done, and just go.” (Alaine)

“It saddens me at times when I know that I should have the screening, but due to finances, I am unable to have it done.” (Elisha)

"I am a self-motivator, but if I cannot afford it, I would not go; however, my family is important to me." (Joanne)

"I do not like it, but I go anyway for my family sake." (Zelda)

"It all depends on the options available … no it will not change our relationship … yes, I would involve my family and close friends in my decision making." (Janie)

"It would mean treatment and not just from traditional medicines but also alternative medicines …no, they would be supportive …no." (Zoe)

"It would mean fear, then I would look at ways to fix it …I would not receive treatment because I want to be sure that it is cancerous … no; yes, I will let my prayer partners and good friends know." (Mel)

"I would get a second opinion and then deal with the extent … not essentially … depends, my closest friends." (Laney)

"My God (faith), my family and friends have always played a key role in every aspect of my life whether good or bad; likewise if I receive a diagnosis of breast cancer I would want to have them share that burden with me … I would tell my friends and co-workers … I believe that support helps." (Karolyn)

"I can't think of it, have no idea … maybe … I don't know." (Alaine)

"I would be disappointed but would do all that is necessary to cure it … I don't think so, we are a loving supportive and cohesive family …. Perhaps, I don't feel that breast cancer is something to be ashamed of, but I do not feel that my life/health has to be an open book for the world." (Shelly)

Culture and health decisions. The next theme that emerged focused on culture and health decisions. I asked the participants whether culture or ethnicity played a role in their health care decisions and whether being South American or Caribbean influenced their decisions in asking or not asking for support from family and friends. Examples of their responses follow:

> “No, my culture is family oriented, we hurt when a family member is hurting … knowing that family is always ready to help, it would make it easy to reach out to them.” (Zoe)
>
> “No, this does not affect my decision.” (Anna)
>
> “Yes, to a certain extent, because I have knowledge about my body and how it functions.” (Zelda)
>
> “No … no.” (Laney)
>
> “Yes … no.” (Sharon)
>
> “Culture sometimes, beliefs no; I may try homemade remedies depending on the perceived illness like fever or colds, simple burns or cuts, headaches, and belly pains etc. … It hasn’t, and my family has been bashful about asking for help if it is needed, it does not matter the size of the problem.” (Janie)
>
> “No, definitely, it is not important.” (Anna)
>
> “Yes, my culture is very health conscious and based on my experience, act on prevention than cure … the influence has made it very easy and comfortable for me to ask for help. In fact, help was readily given without my asking.” (Dottie)

> “Not mine, but I do think that for some culture/ethnicity play a large role. Also, education and religious beliefs play a role.” (Joanne)

Coping factors. The last theme that emerged was about coping factors. I asked the participants about their coping strategies during stressful situations, such as receiving unfavorable health news. I also asked them whether living in the United States rather than in the Caribbean or South America influenced their receipt of screening, diagnosis, and treatment of cancer emotionally, spiritually, and socially in terms of care and support. They provided responses that included the following comments:

> “I research the matter, discuss with someone who is knowledgeable on the subject and always let God lead and guide me in my decision … It works for me.” (Sharon)
>
> “Sharing with family and friends of the situation … no man is an island …. A blessing, the USA has been a vehicle for me to be provided with the most up-to-date health care …. Employment helped in more ways than one to keep me through my struggle.” (Zoe)
>
> “I share it with my mother and spouse then the rest of the family and come up with the best solution, if there is one … living in the US has improved my health options for testing, early detection, and treatment. Socially, there is less support because of distance and schedule, but emotionally, I feel there is a greater level of competency and accountability in the experience of receiving screening, diagnosis and treatment of cancer.” (Shelly)
>
> “Exercise and talking to family and friends.” (Zara)

> “I am a great believer in that we are given no more than we can bear.” (Betty)
>
> “Prayer and music takes me away from the present situation, I feel connected to God …. There are more resources here in the US than in the Caribbean, more technology, better outcomes.” (Mel)
>
> “Learn the facts and get different opinions and views. Remain calm until gaining a full understanding of the situation …. Just having more access to care and specialists; pray … there are some countries in the Caribbean who are not equipped to perform proper screening for breast cancer. Hence, they misdiagnosis, and as a result, there is a higher mortality/death rate.” (Laney)

Discrepant Findings

Some discrepant responses emerged during this study. As an example, Mel stated that culture influenced her health care decisions, but the other 19 participants stated that it did not. In another instance, Alaine believed that HRT was not a risk factor in whether someone got breast cancer, but the other participants believed that it did play a role in increasing their risk. She also did not know or believe that genes played a role in breast cancer.

Process of Confirmability

To ensure the confirmability of the results, I used rich descriptions provided by the participants, and I included quotations from the participants’ interview transcriptions. I also took notes during the interviews and highlighted the emerging themes during the data analysis. I also documented the procedures for checking and rechecking the data.

Results

RQ1: What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the severity of breast cancer in this population? Based upon the analysis of the interview responses, the women were aware of the severity of breast cancer and the importance of taking care of themselves by maintaining healthy lifestyles, such as participating in regular physical exercise and not smoking. The participants also stated that getting an adequate amount of rest, trying to remain as stress free as possible, and eating a balanced and healthy diet were essential to good health and well-being. They believed that genes and a family history of breast cancer increased their risk of breast cancer.

When addressing environmental risk factors, some of the participants felt that these factors could contribute to their developing breast cancer. According to Gray (2011), there are approximately 85,000 registered synthetic chemicals in the United States, with toxicological screening data available for only 7% of them. Gray (2010) as well as Rudel, Fenton, Ackerman, Euling, and Makris (2011) also noted that the effects of more than 90% of these chemicals on human health have never been tested and that about 216 chemicals and radiation sources are registered by international and national regulatory agencies as breast cancer causation agents. Kelly (1991) asserted that diet can play a role in the risk of developing breast cancer. Many of the participants believed that processed and canned foods could play a role in increasing the risk of breast cancer. In addition, many of them either did not know or were not sure whether alcohol consumption, oral contraceptives, or HRT could be other risk factors for breast cancer.

RQ2: What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the barriers to receiving breast cancer screening or treatment? Some of the participants did not want to think about breast cancer, much less talk about it. The lack of access to services and poor communication with health care providers were seen as other barriers to screening. The majority of participants stated that their health care providers did not refer them for screening, despite family histories of breast cancer. Some participants had no access to breast cancer screening or mammography in their communities and that the tests were expensive. Factors such as the high cost of testing and multiple responsibilities (e.g., working, going to school, and taking care of family) were mentioned as barriers to receiving screening.

Telling friends and coworkers were two other factors that the participants perceived as barriers to receiving screening and treatment. They felt that being diagnosed with breast cancer would result in their being treated differently by friends and coworkers. Although some participants saw culture and ethnicity as playing a role in their health care decisions, the majority of participants did not see them playing a role.

RQ3: What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the benefits or hazards of breast cancer screening? Perceived benefits appeared to be a predictor of having breast cancer screening or mammography. The majority of participants considered mammography and breast cancer screening important in saving lives, especially if the tests could help to detect the cancer early. Although some participants had concerns about the benefits or harms of breast cancer screening, most of them chose to have the procedure.

RQ4: What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about their susceptibility to breast cancer? When age and family history of breast cancer were taken into account, most participants believed that a family history of breast cancer increased their own chances of getting it. Most of the women believed that they were susceptible to breast cancer, regardless of family history, so they stressed the need to take care of their own health.

RQ5: What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about what would motivate them to seek breast cancer screening or treatment? Most of the participants saw family as a motivational factor in seeking breast cancer screening, and all of them said that the desire to live was the only motivation that they needed. Even though it was clear that family played a major role in the lives of the participants, many of the women indicated that they were self-motivators and were willing to seek health care when they needed it.

RQ6: What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about their confidence in taking care of their own breast health? The majority of participants were very confident in taking care of their own breast health. When I asked the participants how they would cope with a diagnosis of breast cancer, they stated that they would learn the facts, discuss breast cancer with someone who was knowledgeable on the subject, get different opinions and views, and remain calm until they had a full understanding of the situation.

Some participants also mentioned that sharing their experience with family and friends, exercising, listening to music, and praying would help them to cope with a diagnosis of breast cancer.

Summary

The purpose of this study was to examine the perceptions and behaviors of first-generation women of color from South America and the Caribbean living in the United States related to breast cancer awareness, screening, treatment, and follow-up care. I also examined the individual characteristics of the participants, their relationships with their health care providers and health services, and the factors and barriers relevant to their seeking breast health care and follow-up treatment. Chapter 4 provided an overview of the recruitment of the participants, the data collection process, and the data analysis procedure. I selected the participants using purposeful sampling techniques, and I informed them of their rights before conducting the interviews.

I asked 34 interview questions. Eleven examined the participants’ behavior toward breast cancer, 11 examined their knowledge, 11 examined their awareness, and the last question asked how they felt about discussing breast cancer and their experiences. The majority of the participants had more than a basic knowledge of breast cancer and some risk factors for the disease.

In ensuring the credibility and reliability of the results, I read all of the transcripts back to the participants over the telephone for clarification and confirmation. Strategies of transferability included collecting sufficient detailed descriptive data in context and reporting them as precisely as possible in order to allow the reader to judge whether the data were transferable (Lincoln & Guba, 1985). In Chapter 5, I interpret the results, address the study’s limitations, offer recommendations, and explain the social change implications.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this study was to examine the perceptions and behaviors of first-generation women of color from South America and the Caribbean living in the United States related to breast cancer awareness, screening, treatment, and follow-up care. Understanding this population's perceptions and behaviors toward breast cancer is critical to developing educational programs that might help to reduce their mortality rates. Lima et al. (2012) noted that incidence and mortality rates for breast cancer are on the rise among women in Brazil, and Joseph et al. (2013) stated that women in Trinidad and Tobago have the highest mortality rates of breast cancer in the Caribbean.

This study was guided by six RQs:

1. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the severity of breast cancer in this population?
2. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the barriers to receiving breast cancer screening or treatment?
3. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about the benefits or hazards of breast cancer screening?
4. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about their susceptibility to breast cancer?

5. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about what would motivate them to seek breast cancer screening or treatment?
6. What are the perceptions of first-generation women of color from South America and the Caribbean living in the United States about their confidence in taking care of their own breast health?

To answer the RQs, I followed a phenomenological approach and conducted in-depth interviews with 20 first-generation South American and Caribbean women of color who were living in the Atlanta, Georgia, area at the time of the study. Taking a phenomenological approach allows researchers to understand the participants' common meaning of their lived experiences of breast cancer (Finlay, 2009). Finlay (2009) stated that a phenomenological approach evokes a deeper understanding of the lived experiences, when the focus is on the individual's perceptions or beliefs, which often are taken for granted. As Husserl noted, "Phenomenologist has to be a perpetual beginner, returning always to the things themselves" (as cited in Giorgi & Giorgi, 2003, p. 85).

I recorded the interview responses to ensure the accuracy of the transcriptions, which I read back to the participants over the telephone. I used NVivo v.10 to manage the data on a password-protected computer and employed an inductive coding method to analyze the data. Inductive coding analysis allowed me to establish a clear link between the objectives of the study and the summary findings (Bryman & Burgess, 1994), and to focus on the findings in context of the RQs.

Included in the chapter are an interpretation of the findings based upon the RQs and themes identified in Chapter 4; a discussion of the findings and their relationship to the conceptual framework; and an explanation of the limitations of the study, recommendations for future research, and implications for social change.

Interpretation of the Findings

More than half of the participants had family histories of breast cancer, and all but two participants had family members or friends who had either passed away from or had received treatment for breast cancer. Four participants did not have health insurance and expressed concerns about seeking preventive health care. However, the lack of insurance did not stop them from receiving screening or mammography scheduled by their health care providers. The average age when the participants received mammography was 33 years. Nine participants received a mammogram every year, six every 2 years, four every 6 months, and 1 never had a mammogram.

Theoretical/Conceptual Considerations

The HBM provided the framework to explain complex issues of breast cancer awareness, screening, follow-up care, and treatment relevant to the sample. It also provided the framework for the guidance and development of the RQs, the data analysis, and the discussion of the findings to understand health behaviors among individuals and populations, and provide possible reasons for compliance and noncompliance with health guidelines (Becker & Rosenstock, 1984). According to Glanz et al. (2010), age, sex, ethnicity, knowledge, and SES will likely cause individuals to take action. The premise of the HBM is that if individuals are ready to change and take control of their health, they will do so based upon several criteria: They believe that they are susceptible to a disease, the disease has serious consequences, they need to take action, the benefits outweigh the costs, they are prompted by their health care providers or television advertising, and they are confident in their ability to perform the actions.

The participants believed that they were more susceptible to breast cancer if they had family histories of breast cancer; some also believed that even though all women are susceptible to the disease, this susceptibility does not influence them to perform breast cancer screening, BSEs, or mammography. The majority of the women considered breast cancer a serious disease that caused them worry, anxiety, and depression but one that had no effect on their screening or mammography behaviors. Personal experience of family members or friends with breast cancer also did not influence their susceptibility or screening behavior; instead, they were influenced to receive breast cancer screening or mammography based upon cues to action and their confidence in taking care of their own health. More than half of the participants believed that they would benefit from screening and mammography, however nerve-racking and painful the test might be.

Based upon the findings, the participants' cues to take action were influenced by knowledge, health insurance coverage, confidence, educational attainment, age, income, family support, and self-motivation. In addition, being knowledgeable about breast cancer and the consequences of not seeking health care had more influence on how the women took care of their health and well-being. Culture, race, or ethnicity had little to no effect on whether the women received or did not receive breast cancer screening or mammography.

Limitations of the Study

There were some limitations to this study. One limitation was the potential influence of the Hawthorne effect, meaning that some participants might not have been truthful in their responses and might have provided answers that they believed that I wanted to hear. Criteria for participation in this study required that the participants be first-generation South American or Caribbean women of color between the ages of 35 and 69 years and that they could read, write, and speak English. These criteria limited the generalization of the results only to individuals similar to the target population who shared the same characteristics represented in this sample.

The study also was limited to three church parishes in three counties in Atlanta, Georgia. However, despite these limitations, I believe that the 20 women in the study were representative of the women in the countries being studied. I was able to obtain data on the breast cancer awareness, screening, treatment, and follow-up care of first-generation South American and Caribbean women living in the United States.

Recommendations

The findings can contribute to the education of South American and Caribbean women of color regarding their breast health. Examination of the participants' knowledge and behaviors toward breast cancer awareness, screening, treatment, and follow-up care identified a need for comprehensive breast health education for the target population. To meet the needs of this population, policymakers and health care providers should consider reviewing and revising breast health programs and information.

Continuing to conduct research with women from South America and the Caribbean living in other areas of Georgia and the United States is recommended. Researchers might want to consider studying members of a younger target population from the same target area to compare differences in knowledge and behaviors. I also recommend that health care providers communicate with and educate their clients on the need for, as well as the procedures and benefits of, BSE, CBE, and mammography because many of the participants did not know the differences among the three procedures. Providers should be more personable, communicate the results of testing in reasonable times, and practice cultural sensitivity in addressing breast cancer screening and care with their clients.

Implications for Social Change

The findings have the potential to generate positive social change for the target population and to fill gaps in the literature. The social change implications might address the educational needs and behaviors of the target population and lead to the development of policies and guidelines to reduce the incidence and mortality rates of breast cancer among South American and Caribbean women of color living in the Clayton, DeKalb, and Fulton Counties of Atlanta, Georgia. The results also might help to identify health care gaps among racial ethnic groups; add to the literature; and increase current knowledge and understanding of specific cultural influences such as coping strategies, dietary and physical habits, and socioecological factors.

The results might be instrumental in the implementation or revision of policies and procedures regarding the education and treatment of breast cancer among this population of women. The results could be integral to the development and implementation of population-specific information, including clinical practice guidelines appropriate to the linguistic, cultural, and literacy needs of the target population. The results also might facilitate the design of effective interventions that could help to reduce breast cancer treatment and care disparities, thereby increasing the quality of life for all and effecting positive social change within this population.

Researcher Reflections

When I began this study, I did not believe that a sample of older women would be involved in breast cancer screening and treatment, but my assumption was wrong: The women in my study were very much in tune with their health and, in most cases, initiated discussions about breast cancer screening with their health care providers. I experienced satisfaction as well as dissatisfaction while completing my dissertation, but I will be forever grateful for the experience because it gave me a deeper understanding of the need to be patient, diligent, and stubborn to meet a goal as lofty as obtaining a doctoral degree. Researchers who conduct true and exceptional research must have a passion for their work. By reading many journal articles and books, by discussing the research with many individuals, and by rewriting and refining the study multiple times, I became more knowledgeable of my subject matter. The most rewarding part of this process was interviewing the participants and listening to their lived experiences. Their willingness to share their lived experiences was humbling. This research journey has increased my desire to continue investigating breast cancer disparities among minority populations living in the United States.

Summary

I used the HBM framework to identify the perceptions, knowledge, and behaviors of 20 first-generation South American and Caribbean women of color living in the United States toward breast cancer awareness, screening, treatment, and follow-up care. Despite numerous studies of breast cancer among African American and European American women, little to no previous research had been conducted specifically with South American and Caribbean women of color living in the United States. The results showed that although age, family, health insurance status, and employment status determined whether the women received breast health screening, cues to action had a stronger influence. More significant was the finding that culture had a minimal role in determining the women's behaviors. The results also showed that the women lacked information about ways to maintain breast health and available breast health facilities in their communities, two factors that contributed to their nonadherence to breast care guidelines.

I hope that the study will make a positive contribution to the lives and health of the women who participated. More broadly, the study might assist in the implementation of screening and treatment protocols tailored to this population and serve as a platform for further research.

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Appendix A: Demographics Questionnaire

Although women of color have a lower incidence rate, they have the highest death rate from breast cancer, so it is vital that we find out as much as possible about your knowledge base of breast cancer, your beliefs, and how you perceive breast health in regards to screening and treatment. This is necessary in order to develop and implement policies and procedures geared towards you. In this way, we will be better able to serve you, improve your quality of life and reduce mortality/death rate.

Below are two questionnaires, and we could have some answers to our most important questions regarding breast cancer screening and treatment. I would be very grateful if you could set aside some time to answer these questions. It should take no more than 10-15 minutes. Also, please know that you can decline to answer this questionnaire, but your participation would be greatly appreciated. Therefore, I am asking for you to please answer every question and do not leave blanks as all the information that you provide me is very useful. If you are not sure about exact dates or ages an approximate answer is better than none. Thank you for your time.

Please check (√) the appropriate box.

Age	18 - 19	☐
	20 - 24	☐
	25 - 29	☐
	30 - 39	☐
	40 and older	☐

How do you describe or identify yourself?

American Indian or Alaska Native	☐
Hawaiian or Other Pacific Islander	☐
Asian or Asian American	☐
Black (Caribbean Descent)	☐

Hispanic or Latino (Black) ☐
Non-Hispanic White ☐
Other ☐

Where were you born?

Jamaica ☐
Guyana ☐
Trinidad & Tobago ☐
Barbados ☐
Brazil ☐
Other (Please identify)

Were you the first one in your family to move to the USA? Yes ☐

No ☐

How tall are you? ☐

Marital Status

Married ☐
Divorced ☐
Separated ☐
Single (never been married) ☐

Educational Background: Choose all that apply

High School ☐
Associate Degree ☐
Bachelor's Degree ☐
Master's Degree ☐
Doctoral Degree ☐
Professional Degree ☐
☐

Where do you live?

City
State ☐

Employment status:

Employed full-time ☐
Employed part-time ☐
Employed as needed ☐
Voluntary worker (unpaid) ☐
Unemployed ☐

Yearly Household Income
Less than $15,000 ☐
Less than $30,000 ☐
Less than $45,000 ☐
Less than $60,000 ☐
$60,000 and above ☐

Lifestyle factors (Check box which applies)
Do you smoke? Yes No
How many packs a day? 1 2 3 or more ☐ ☐ ☐ ☐
At what age did you begin smoking? ☐

At what age did you stop smoking? ☐
Do you regularly practice physical exercise? Yes ☐ No ☐
At what age was your first menstruation? ☐

Do you use oral contraception? Yes ☐ No ☐
Have you ever used Hormone Replacement Therapy (HRT)? Yes No ☐ ☐

Breast Cancer Background

Do you have a family history of breast cancer? Yes No ☐ ☐
Has a family member or friend experienced breast cancer? Yes No ☐ ☐
Have you ever been diagnosed with breast cancer? Yes No ☐ ☐
Do you have Health Insurance? Yes No ☐ ☐
Have you ever receive breast cancer screening? Yes No ☐ ☐
At what age did you receive your first mammogram?
How often do you receive a mammogram?
Every six months ☐ once a year ☐ ever 2 years ☐ or more ☐

Did your provider or doctor refer you for screening? Yes No ☐ ☐
Have you ever talked to your provider or doctor about breast cancer? Yes No ☐ ☐
Is there availability of breast cancer screening in your community? Yes No ☐ ☐
Has your father, brother or son had breast cancer? Yes No ☐ ☐
Has your mother, father, sister, brother, daughter or son had breast cancer before the age of 40? Yes No ☐ ☐
Have any 2 of the following had breast cancer: mother, father, sister, brother, daughter or son? Yes No ☐ ☐

Appendix B: Interview Guide

These questions are being asked in order for the researcher to have a better understanding of your knowledge, beliefs, behavior, and practices toward breast health.

1. Can you please tell me a bit about yourself?

Probe:

- Job/hobbies, describe yourself

2. Can you tell me about your family?

Probes:

- Do you have any older/younger brothers/sisters?
- Are your parents living/deceased?
- What was the cause of their death?
- Do you have children if any what are their ages?

3. Do you consider yourself a health conscious person?

Probes:

- Do you exercise regularly?
- Eat healthy?
- Maintain a healthy weight?

4. What does the term “breast cancer” mean to you?

Probes:

- What comes to mind when you hear that term?
- What do you mean by that?
- Can you tell me more about that?

5. Has anyone you know has/had breast cancer?

Probes:

- Your mother, grandparents, aunts, uncle, brother, sister…?
- How was the cancer discovered?
- Can you tell me more about that?
- What kind of treatment did they receive if any?
- If they did not receive treatment, why not?
- Did they ever thought about trying or tried other complementary treatment or therapies?

6. Would you consider yourself to be a breast health aware person?

Probes:

- Do you check your breast for lumps?
- How often do you check your breast?
- When was the last time you checked them?
- Who taught or showed you how to check your breast?
- Are you confident in performing this task?

7. You mentioned that you are/aren't health conscious, do you believe that staying healthy can influence your risk of getting breast cancer?

Probes:

- You said that you are health conscious; can you please tell me in what ways, give examples?
- Can you please tell me more about that?
- What do you mean by that statement, please explain?
- If not health conscious, why?
- Can you provide more details on your reasons?

8. Have you ever had a mammogram?

Probes:

- Why or why not?
- Was this totally your choice?
- Do you believe that this choice had anything to do with being Caribbean/South American?

9. Do you believe that your genes play a role in your risk for developing breast cancer?

Probes:

- If yes, how are they a risk?
- If no, why not…?
- Please explain more?

10. Do you believe that if your mother, aunt, father or grandparent had breast cancer, you would be more at risk for breast cancer?

Probes:

- Why or why not?
- What do you mean when you say …..?
- Can you tell me more?

11. When looking at diet, do you believe that the food you eat increases or decreases your risk of getting breast cancer?

Probes:

- Which foods do you believe are health risks and why?
- Which foods do you believe are more beneficial for good breast health, why?
- Please explain more about your knowledge of canned food, meat, fats, fruits and vegetables, and their association of breast cancer risk?

12. What about smoking, does this increases your risk?

Probes:

- How do you smoking increases your breast cancer risk?
- Why is this important to you?
- Please tell me more?

13. Do you believe that drinking alcohol can increase your risk of getting breast cancer?

Probes:

- Do you know how much alcohol a woman can safely drink on a daily basis?
- Do you drink alcohol?
- How old were you when you first started to drink?
- Do your parents drink alcohol?
- Please tell me more?

14. What about contraceptive pills, do you believe that this can increase or decrease your risk for breast cancer?

Probes:

- Why do believe that contraceptives can increase or decrease breast cancer risk?
- Tell me more please?

15. Do you believe that taking Hormone Replacement Therapy (HRT) affect your risk for breast cancer?

Probes:

- If yes, in what ways?
- Please tell me more?
- If no, why do you believe so?

16. Can being exposed to radiation cause you to get breast cancer?

17. What about things in the environment such as chemicals in makeup, fertilizer, BPA in plastic, and shampoo?

18. Are you aware of things that can be done to prevent or protect yourself against breast cancer?

19. What do you believe can be done to improve people's awareness and knowledge of the risk of breast cancer?

20. Do you consider breast cancer to be a threat to you or anyone in your family?

Probes:
- Why or why not?
- I am not sure I understand, can you please explain?

21. Are there anything preventing you from receiving breast cancer screening or treatment?

Probes:
- How did this affect you?
- How did you handle it?
- How did you feel about ……?

22. Do you believe that you can benefit or receive harm from receiving a mammogram or treatment?

Probes:
- Why or why not?
- Can you give me an example of …… .

23. What would motivate you to receive breast cancer screening or treatment?

Probes:
- Why is that a motivational factor?
- Is there anything that would hinder or stop you from receiving screening or treatment?

24. Is family a motivational factor in seeking screening or treatment?

25. How confident are you regarding taking steps in taking care of your breast health?

Probes:
- Can you tell me more?
- Can you give me an example?

26. If you were to receive a diagnosis of breast cancer, can you tell me what that would mean to you?

Probes:

- Would you receive treatment if advised to?
- Why or why not?
- Would you involve your family and close friends in your decision making?
- What part would religion play in your decision making-process?
- Can you tell me more about that?

27. Would receiving a diagnosis of breast cancer change the relationship between you and your family?

Probes:

- What do you think it would be like for your family hearing of your diagnosis?
- Can you tell me more?
- How would you describe your family?
- What is your role in the family?

28. What about your friends and co-workers, would you tell them of your diagnosis?

Probes:

- Why would you tell or not tell them?
- Can you tell me more about that?
- Would you worry about finances?

29. Do you believe that your culture/ethnicity play a role in your health care decisions?
Probe:

- Can you please explain in more details about your culture, and beliefs?

30. How has being Caribbean/South American influenced your decision regarding asking or not asking for support or help from family members or friends?

Probes:

- I am not sure I understand ….., would you explain that for me?
- Why do you think so?
- How would it feel asking for help?
- What kind of help do you believe you will need?

31. What coping strategies do you use during stressful situation, such as receiving unfavorable health news?

Probes:

- Why use this method?
- What do you mean by …?
- Has it been successful for you?
- Can you tell me more please?

32. How does living in the US versus living in the Caribbean or South America affect your experience of receiving screening, diagnosis and treatment of cancer emotionally, spiritually, socially and also in receiving care and support?

Probes:

- What do you mean when you say …..?
- Can you please elaborate?
- How did that affect you?

33. Now, is there anything else you would like to talk about that we have not covered or you think is important for me to know?

34. Can you tell me what it has been like for you to talk to me about breast cancer and your experiences?