

West Chester University

## Digital Commons @ West Chester University

---

West Chester University Doctoral Projects

Masters Theses and Doctoral Projects

---

Winter 2020

### Federal Health Reform: Breast Cancer Outcomes

Nia Imani Bailey  
nia\_bailey@yahoo.com

Follow this and additional works at: [https://digitalcommons.wcupa.edu/all\\_doctoral](https://digitalcommons.wcupa.edu/all_doctoral)



Part of the [Other Public Health Commons](#), [Public Health Education and Promotion Commons](#), and the [Women's Health Commons](#)

---

#### Recommended Citation

Bailey, Nia Imani, "Federal Health Reform: Breast Cancer Outcomes" (2020). *West Chester University Doctoral Projects*. 90.

[https://digitalcommons.wcupa.edu/all\\_doctoral/90](https://digitalcommons.wcupa.edu/all_doctoral/90)

This Dissertation is brought to you for free and open access by the Masters Theses and Doctoral Projects at Digital Commons @ West Chester University. It has been accepted for inclusion in West Chester University Doctoral Projects by an authorized administrator of Digital Commons @ West Chester University. For more information, please contact [wcreator@wcupa.edu](mailto:wcreator@wcupa.edu).

A Dissertation  
Presented to the Faculty of the  
Department of Public Policy and Administration  
West Chester University  
West Chester, Pennsylvania

In Partial Fulfillment of the Requirements for  
the Degree of  
Doctor of Public Administration

By  
Nia Imani Bailey, M.A.Ed, RT(T)

December 2020

## Dedication

To God, in your word you promise if I keep my eyes on you, you would never leave me, nor forsake me— THANK YOU! “For I know the plans I have for you says the Lord; to give you a hope and a future”. Jeremiah 29:11

To Narda J. Fields, thank you for teaching and showing me what it is like to be a strong and beautiful woman in every sense! I have been watching you lady, and what a wonderful example you are!

To Curry J. Bailey III, thank you for always believing in me and teaching me that the sky is not the limit, but just the beginning! You have always been a force to reckon with, continually breaking down barriers, thank you for being the example I needed in this life!

To Jarrod K. Hill, thank you for being the best friend and brother a girl could ever have. Sometimes you would wonder if I was listening or watching you, I was and I am. Thank you for being a great example!

To Dr. Jacqueline Bailey-Davis, thank you for always pushing me! You have been the best cousin, sister, friend. I appreciate your love, and I could not have made it without you! Thank you.

To Sensei, thank you for always praying with me, ALWAYS picking up the phone to listen to me vent, and always being a shining light in my life. You pushed me to Make Up My Mind (MUMM) to get through life, and thanks to you—that is exactly what I did!

To Kywannia, on your death bed you asked me how the research was going, and I was unable to give you an answer—I will spend my last breath to make sure your passing was not in vein.

To Jaclynn, you said that you had faith in me that I would “find a cure,” and to be honest, that was a whole lot of pressure. I do not know if I can “find the cure,” but I will always fight for you my friend, until my dying day.

To Lukas W. Kusters, you were the reason I got out of bed some days—because you made a difference, I knew I had to. You will always be in my heart. I love you and miss you. Can’t wait to see you again at the heavenly gates, prom date!

I remember her. She was 25 years old, brown skin with box braids, an ankle bracelet and wore puma sneakers. She looked just like me. She had two children. She was diagnosed with breast cancer. She tried other treatment methods, but eventually had to be treated in multiple areas of her body because the cancer metastasized (spread). She died of breast cancer. Triple Negative Breast Cancer (TNBC) to be exact.

I loved her. She was my friend. 31 years old. Caucasian with a short pixie cut, beautiful brown eyes, beautiful smile, and a contagious laugh. She loved life. She had a loving boyfriend, great job, and eventually wanted children of her own. She loved her sister, nieces and family. She wanted to be a voice for breast cancer and fight for young woman's rights. She told me to not forget about her, and always tell her story. I listened to her and always will. She died of Triple Negative Breast Cancer.

I valued her. She was in her forties. Beautiful caramel complexion and had a feisty and fiery spirit. She was a mother, a friend, a sister and so much more. While in the hospital, she asked me how the breast cancer research was going. I had no answer for her then; I will before the day I part this earth. She died of Triple Negative Breast Cancer.

I admire her. She is a very close friend. She is a beautiful Jamaican, Hispanic woman who is 32 years old. She is a mother of two beautiful children. A career woman, who is the most grounded and spiritual person I have ever met. She is the best daughter, and friend, anyone can ask for. She has Triple Negative Breast Cancer, and as a Radiation Therapist who has worked in the field for over 5 years, I am determined to make sure her story does not end.

## Acknowledgements

Thank you to Dr. Crossney for laboring with me during this tedious, but life affirming journey. You are certainly a blessing and I am forever grateful for you and your expertise. You pushed me and believed in me, when I did not even believe in myself. You are such a great example of a woman and teacher! Thank you!

Dr. Farash, you have no idea much you have helped me through this time in my life. You pushed me, focused me, and directed me; and thanks to you, I am now Dr. Bailey. Thank you!

## Abstract

Young women are diagnosed with breast cancer; and young women die from breast cancer. This qualitative dissertation seeks to prove the significance of lowering the mammography age from 40 years old to 30 years old. Current policy and programs correlate to the mandated age of 40 years old, unless the woman is at high risk; such as having a family cancer history. This dissertation also seeks to implement an addendum to insurance policies to cover for younger women to have mammography screening in the event they are younger than the recommended age. The purpose of this study was to examine policy frameworks of screening mammography's and insurance coverage.

This qualitative dissertation will examine what are women's early experiences with their medical providers who have been diagnosed with breast cancer; and are there components of the women's early experiences that served as barriers to them getting treatment I recommend women who are 30 years of age having mammography screenings, women being taught how to perform self-examinations, and educate women how to decrease their risk of developing breast cancer.

## Table of Contents

Chapter 1: Introduction.....	1
Chapter 2: Literature Review.....	11
Chapter 3: Research and Design Methods.....	33
Chapter 4: Findings and Recommendations.....	41
Chapter 5: Conclusion.....	81
References.....	90
Appendices.....	94

## **Chapter One: Introduction**

The impact of mammograms on treatment options, patient survival and patient trajectory continues to be a debate in public policy. Screening recommendations according to The American Cancer Society (ACS), The National Comprehensive Cancer Network (NCCN), and The U.S. Preventive Services Task Force (USPSTF) recommend women having mammogram screening starting at the age of 40 years old, unless they are at high risk (Susan G. Komen, 2020). Other recommendations state depending on family history and the results of the initial mammogram, women can have mammograms performed every two years, instead of annually. Mammography screening offers detection for a breast cancer diagnosis. Patient care and survival outcomes are related to the use, and timing, of 3D mammography screenings. This dissertation considers the experiences of women who have been diagnosed with Triple Negative Breast Cancer (TNBC), and other types of breast cancer in the context of existing policies, and will make policy and program recommendations that may also be able to improve patient care and survival outcomes. In this chapter we will review the problem statement, purpose of study, significance of study/rationale, research questions and summary.

### **Problem Statement**

Mammogram screening policy needs to be updated to represent women who are diagnosed younger than the age of 40 years old. There are shortcomings in care due to insurance policies and treatment protocols. In clinical practice and relevant research, women who have been diagnosed under 40 years old have higher mortality rates. The problem may be that medical providers are not in routine of the discipline of women's health protocols; therefore, women are not set up to get treatment as early as possible. General women's healthcare practice guidelines

do not include breast care/breast health screening early enough to help detect aggressive forms of breast cancer in young women.

Women's early experiences with their medical providers predicts the trajectory of their breast cancer treatment. The potential barriers that are present before and after diagnosis are access to screening age, healthcare/health insurance, financial responsibility, familial responsibility, distrust and education. All these factors play a role in the access to treatment once a woman is diagnosed with breast cancer.

After the breast cancer diagnosis, the woman and her provider, need to determine and agree, whether she will have the tumor removed (lumpectomy), a portion of her breast removed (segmental mastectomy), her affected breast removed (mastectomy), or both breasts removed (double mastectomy). In addition, several lymph nodes will be taken out to determine the extent of the breast cancer, which can result in lymphedema—which can be manipulated with physical therapy. The woman needs to decide who will help her through this process, and during the recovery stages. Women typically must have chemotherapy to kill the cancerous cells, which result in hair loss, neuropathy (more than likely), fatigue, weight loss or gain (steroid), possible nausea, and a host of other side effects. Radiation therapy may be needed to be utilized for local control, and to kill any cancerous cells that are microscopic. Immunotherapy may be used which helps the woman's healthy cells combat the cancerous cells. If a woman is diagnosed with estrogen receptor breast cancer then she will be placed on an estrogen receptor blocker, which she would have to take for 5 to 10 years. In all of this, the woman is still a person. She is a mom, wife, sister, friend, cousin, worker, confidant, and so much more. She must carry the diagnosis, but also other things that life offers because life does not stop because of a cancer diagnosis.

Although eradicating breast cancer may not be plausible due to genetics and environmental factors, the goal ought to be catching the disease in its infancy stage; so that when women are diagnosed with breast cancer, it is manageable and *curable*. JamRiv, who is also a metastatic cancer survivor, says she wants breast cancer to turn out the way HIV/AIDS and diabetes is. In the 1980s, HIV/AIDS was a death sentence to the millions of people that contracted it. Now, if diagnosed, the disease is manageable, and millions of people live healthy, manageable lives. Similarly, with millions of people with diabetes—it can be controlled. For JamRiv, that is the goal of breast cancer. To hopefully discover a blood test, that can detect if a woman has breast cancer. The goal is to kill the breast cancer in its infancy and to monitor the women who have/had breast cancer and give them the tools to look out for changes in their health pre and post treatments. By doing so millions of lives can be saved, and breast cancer will be manageable.

### **Purpose of Study**

The purpose of this qualitative dissertation is to examine what are women's early experiences with their medical providers; and to determine if there are barriers in the initial contact with their medical providers. The purpose is also to determine if that initial contact prevented them from seeking diagnostic screening prior to their diagnosis, and to the access and timing of treatment. Women are not getting screened early enough, and they are dying of breast cancer. Although research has shown a small (in comparison) number of young women being diagnosed with breast cancer, there is still little research that has been done to understand the barriers to screening; or the factors that lead to delayed diagnosis.

The goal is to educate women regarding breast health and breast cancer. Developing policies and programs should include breast health education, in addition to giving women the nec-

essary information regarding breast lumps, breast density, 3D mammograms, family cancer history and genetic counseling. In the next section, this qualitative dissertation will aim to fill the gap of knowledge by providing an in-depth examination of a sample of women's early experiences that navigates their breast cancer diagnosis. This qualitative dissertation will provide information on how to redesign policy and programs to have better outcomes such as early mammography screening, insurance approval/coverage and women's early experiences with their medical providers.

### **Significance of Study/Rationale**

The significance of this qualitative dissertation is to determine ways to refine and improve federal policies and healthcare programs in order to: short term goal, uncover more details about women's early experience with breast cancer; long term goal, save the lives of women who are diagnosed with breast cancer. In terms of public policy, The American Cancer Society (ACS), The National Comprehensive Cancer Network (NCCN), and The U.S. Preventive Services Task Force (USPSTF) have recommended that starting at the age of 40 years old women should have annual mammography's. States therefore are mandated to cover women's mammography's starting at the age of 40 years old whether they have insurance or not; therefore increasing mammogram utilization. The issue is there needs to be an addendum to the guidelines for women less than 40 years of age due to certain risk factors, such as genetics and family history. This qualitative dissertation aims to research if there are gaps, in regard to women's awareness, patient-provider relationship, if recommendations need to be amended, insurance protocols should change, and screening guidelines should alter.

The suspected problem is women are experiencing barriers in their early experiences with their medical providers, therefore creating a barrier to their access to early treatment. Finding potential gaps and preventing the barriers will make the trajectory of breast cancer manageable. Screening 3D mammography improves breast cancer survival through early detection (Chen, et. al.,2020, p. E1). Younger women are more likely to have higher-stage and higher-grade disease, and their tumors were more likely to be triple negative (Partridge, et. al.,2016, p. 3). Women less than 40 years old were 90% more likely to die of breast cancer than were women ages 51 to 60 years at diagnosis (Partridge, et. al.,2016, p. 3). Young women, on average, have an increased risk of disease recurrence and decreased survival; also, young age at diagnosis has long been considered a poor prognostic factor (Partridge, et. al.,2016, p. 3). A potential barrier begins with breast health.

Breast health is simply women knowing their bodies and knowing what her breasts feel like and look like. What is included in breast health is knowing the difference between what the breasts look and feel like before, after, and during menses. The term also includes what women put into their bodies; such as, eating healthy, eating balanced meals, not smoking, exercising, achieving a health body weight, and reducing the consumption of alcoholic and sugary drinks. It is also equally important that women breastfeed after birth (Helen F. Graham Community Advisory Board, 2019). Additionally, breast health encompasses knowing the family history of breast cancer and other cancers in the family—on both the maternal and paternal side. High-risk women include those with a strong family history of the disease (Guo, Kuo, Shih, Giordano & Berenson, 2018, p. 3500). This is important because depending upon the family history, may increase the likelihood of the woman being diagnosed with breast cancer. It is also important to

know who had the cancer, what type of cancer, and at what age the family member was diagnosed (Helen F. Graham Community Advisory Board, 2019). All this information is crucial in the screening process, and in the early experiences. Without this information women risk the chance of developing breast cancer.

It is important that women talk with her healthcare provider, such as her primary care doctor, or gynecologist, and discuss screening recommendations regarding when they should have a clinical breast exam, an ultrasound, mammogram, and/or MRI performed to detect or rule out cancer. Depending upon the woman's history, clinical breast exams, and the other diagnostic tools that were described above, could be utilized every six months, as well as, annually. One of the other potential barriers is education.

Education is the steppingstone to eliminate barriers. Women with Medicaid and no insurance are less likely to have a primary medical doctor. There is lack of knowledge of general breast cancer prevention strategies (Sims-Mourtada, et. al., 2019, p.e2). They are also less likely to have screening 3D mammograms and have a based line of breast health. Research has found women without insurance are 60% more likely to die from breast cancer compared to women who have insurance. Kimberly Johnson, an epidemiology professor at Washington University stated that improving medical care and diagnostic screening can change the trajectory of cancer outcomes. Educated women will able to advocate for their breast health, but not all women do just that. A myriad of women, especially young women have fibrocystic breasts, which makes the breasts feel "*bumpy*," and therefore, may ignore the feel of a lump because of previous clinical presentation.

In addition, there are some potential barriers to access of healthcare. Many women who are part of a low socioeconomic class may not have access to a primary care doctor or gynecologist; therefore, their health is hindered. This particular group of women may not have insurance which prevents them from seeing a healthcare provider because of out-of-pocket costs. Additionally, having Medicaid, could limit certain resources of having a medical provider, and the types of services that are included in the insurance package. Belonging to that class could also mean not fully understanding breast health and the ramifications of delaying treatment. This is not to say that women part of a higher class does not ignore signs and symptoms of breast health, or completely understand breast health; it does mean that statistically those who are in the lower socioeconomic class experiences are different, and arguably harder. The results confirm that mandating insurance coverage for low-cost preventative health services can meaningfully increase utilization rates (Bitler and Carpenter, 2016, p. 2). If insurance will cover the cost of diagnostic tools, then research shows women would get the diagnostic testing done.

There is also the notion that women, as a group, regardless of race or ethnicity, are seen as strong beings and simply ignore their body signs because they are taking care of their families and others; and unfortunately, by the time their bodies make them listen, it is often too late. Historically, women place themselves on the back burner to ensure everyone else's health and safety, but unfortunately to the detriment of themselves. Women typically always "push through" and make themselves the last priority. This is another barrier that needs to cease. This barrier is created by society and women themselves. There is nothing wrong with taking care of others, and self, but when the body gives a sign, it is up to the woman to listen. If not, she cannot take care of others, or help others, if her body is not cooperating or healthy. Given the demonstrated effi-

cacy of endocrine therapy in reducing the risk of recurrence and death among women with luminal disease, adherence in this population is a critical issue that needs to be addressed (Partridge, A. H., et. al., 2016, p. 6). It is researched that even when women are diagnosed with breast cancer, they still have the task of taking care of others; therefore, delaying (in some way) their treatments. Other women may not know their family history to the extent, and accuracy as they should.

Some women are also only concerned with their maternal side of medical information, and do not understand the paternal medical information is just as important to know for breast health. Depending on the family history and the density of cancer diagnoses, genetic testing might be offered to the young woman; therefore, determining the likelihood of her developing certain cancers such as: breast, cervical and ovarian. With that specific information, a woman is given the autonomy to determine what she wants to do with her body and reproductive system. Once a woman has children, or decides she does not want children, or physically bare the children; she may opt to have not only a mastectomy/breast removal (single or double), but also a total hysterectomy—to lower the incidence of developing cancer.

Genetic testing can be performed before a cancer diagnosis or after the initial diagnosis. The importance of genetic testing is for health and abundant knowledge. Also, genetic testing is not just for the woman who is being tested, but for her family as well. Based on their tumor type and the molecular characteristics, genetic testing in young patients with cancer also enables them to receive tailored treatments (Guo, et. al., 2018, p. 3506). If she knows she is a BRCA1 or BRCA2 carrier, for example, then that information is needed for what she needs to do for her health, but also what her children, mother, sisters, cousins, etc., need to do for their health as well.

Younger women are more likely to harbor a BRCA1, BRCA2, or other cancer-related genetic-associated tumor (Partridge, A. H., et. al., 2016, p. 6). This type of information will also allow insurance companies (private, Medicare, Medicaid, no insurance) to pay for certain screenings and procedures. If a woman does not have insurance, grants can be provided. There are always financial resources for women in need. The questions are: What are women's early experiences with their medical providers who have been diagnosed with breast cancer? Are there components of women's early experiences that served as barriers to getting treatment? The potential barriers that are being investigated are lack of knowledge and education, insurance, and fear. Women's early experiences with their medical providers, doctors, vary, and their experiences can either help or hinder their access to screening and treatment.

There are some types of breast cancers that are more advanced than others, such as in situ breast cancer versus inflammatory breast cancer. In situ breast cancer has a better prognosis than inflammatory breast cancer. The point is, to an extent, once any breast cancer is caught early, it is more manageable. Women then can live healthier and better lives because their quality of life has shifted.

### **Research Questions**

- What are women's early experiences with their medical providers who have been diagnosed with breast cancer?
- Are there components of women's early experiences functioning as barriers to getting treatment?

### **Summary**

My qualitative dissertation questions are: *What are women's early experiences with their medical providers who have been diagnosed with breast cancer? Are there components of their early experiences that served as barriers to getting treatment?* The questions will be answered in the depth and explain why this is not just a woman's issue, but a problem for humanity.

This qualitative dissertation is organized by five chapters. Chapter One is the introduction which introduces the issues faced by women who have breast cancer who are less than the age of 40. Chapter Two is the Literature Review and backs up the information that woman under 40 years old are being diagnosed with breast cancer and outlines the barriers to their access to treatment and preventative care. Chapter Three outlines the Research Design and Methods which describe the qualitative interview methods which were obtain by breast cancer survivors and discussed their stories. Chapter Four concludes the Research and Findings which are the main themes which were found through the collection of interviews. Chapter Five are given Recommendations for policies and public recommendations.

## **Chapter Two: Literature Review**

What are women's early experiences with their medical providers who have been diagnosed with breast cancer? Are there components of their early experiences that served as barriers to getting treatment? This chapter will seek to explain the significance and purpose of these proposed questions. In this chapter, public policy, types of breast cancer, incidence and prevalence of breast cancer, risks that are associated with breast cancer, potential barriers that prevent women from accessing treatment, and screening/policy recommendations are discussed.

### **Public Policy**

The public policy implications of this study in general and specifically with respect to the federal health reform is simple, if a greater scientific consensus were to be reached regarding the more appropriate screening frequencies for women of difference ages, policies could be amended accordingly (Bitler & Carpenter, 2016, p. 21). Mandating diagnostic mammogram screening at little to no out-of-pocket cost would prevent potential barriers or gaps to women receiving care and treatment. In order for this to happen the rational goal model can be used, which incorporates goal setting and attainment, and productivity and efficiency (Tompkins, 2005, p. 28). By setting a goal that women should be covered regardless of their age if they need diagnostic mammogram, attainment can be monitored, and aspects of productivity can be utilized. Efficiency will be determined by how many young women had a breast health concern, and were able to receive a diagnostic mammogram, that was covered, by insurance.

Ethically, it is the duty of the medical professionals to see that women are being screened of breast cancer regardless of their age or insurance coverage. Denhardt, Denhardt, and Blanc (2014) define ethics as "the process by which we clarify what is right and wrong and by which

we act on what we take to be right; it involves the use of reason in determining a proper course of action” (p. 150). What is right is to use the tool of mammography as intended, to detect cancer. The proper course of action should require a woman, regardless of status, to have the screening if truly needed. This is the concept of equity. That regardless of the woman’s status, she is still able to receive a diagnostic mammogram. “Social equity further recognizes the importance of public servants and public sector organizations in fulfilling the democratic principle of fairness” (Guy and Rubin, 2015, p. 212). Younger women receiving diagnostic mammograms is fair, is equitable. The patient-provider relationship is also important for the woman to receive the mammogram screening.

Every patient-provider relationship is different. There are also different types of patient-provider relationship, the first is paternalistic. The paternalistic model, the provider is very active and directive; this person is often seen as the expert, and thus, patients often follow the recommendations (Kelly, et. al., 2019, p. 104). The approach is very direct, and maybe useful in the relationship where the patient is very unattached and needs direction and guidance. The second approach is the informative model. The informative model, the provider is more passive; the physician provides the patient with all the information and options, often serving as an educator, while waiting for the patient to decide (Kelly, et. al., 2019, p. 104). The provider allows the patient to determine what the patient wants. The third model, interpretive model, enables the providers to take an advising position to help patients understand their values and give patients the information they need to facilitate decision-making for the patient (Kelly, et. al., 2019, p. 104). The last model is the deliberative model. It is characterized by the patient and provider openly engaging in a mutual discussion of treatment options and exploration of the patients

moral and value systems associated with treatment (Kelly, et. al., 2019, p. 104). This allows the patient to have more autonomy regarding how they want to proceed with treatment. In other words, the paternalistic model is low in information giving, high in provider involvement; informative is high information giving, low provider involvement; interpretive is high information giving, high provider involvement; and deliberative is low information giving, low provider involvement (Kelly, et. al., 2019, p. 104).

Some patients come to the provider with a slew of information and the bulk of the responsibility is not on the provider. On the other hand, there are situations where the provider takes on a role for both the patient and provider due to the lack of knowledge that the patient has coming in regarding their breast care. Patients often view their medical provider as an “expert” in medical knowledge with the skills to extend the quality and quantity of their life (Kelly, et. al., 2019, p. 101). Yet, providers may often assume the patients want the autonomy of their care. It is important to adapt the clinical relationship in a way that is most comfortable and engaging for the individual patient rather than generalizing the patient role or “standardizing” every patient-provider relationship (Kelly, et. al., 2019, p. 101). Overall patients with secure attachment had a better working alliance with their physician and perceived more support from their provider than patients with an insecure attachment (Kelly, et. al., 2019, p. 104).

The attachment theory is important to note because it shows the importance of the patient-provider theory. This theory is also vital because as explained in Chapter 3, the patients’ experiences were based on, in many ways, this theory.

### **Types of Breast Cancer**

The most common types of Breast Cancer are Ductal Carcinoma In-situ (DCIS), Triple Negative Breast Cancer (TNBC), Inflammatory Carcinoma, Infiltrating Carcinoma, Metastatic Breast Cancer (MBC), and Invasive Ductal Carcinoma (National Breast Cancer Foundation, Inc. ,2019). The least common types of Breast Cancer are Medullary Carcinoma, Tubular Carcinoma, Mucinous Carcinoma (Colloid), and Paget Disease of the Breast or Nipple or also known as Mammary Paget Disease. (N.,2019). Breast cancer is not the same in every woman, and reacts, and is different in each woman. How many women are diagnosed with breast cancer, and at what rate are they being diagnosed is to be explained.

### ***Incidence and Prevalence***

Breast cancer is the second leading cause of death for women in the United States. “The incidence rate for female breast cancer in the United States from 2010 to 2014 was 123.6 per 100000 population” (Sisti A, Huayllani MT, Boczar D, et al., 2020, p. 1). “A total of 2,423,875 women were diagnosed with breast cancer between 2004 and 2015. 136,525 breast cancer patients (5.6%) were less than 40 years old (Sisti A, Huayllani MT, Boczar D, et al., 2020, p. 3). The predominant race was white (2022918 patients, 84.3%), followed by black (271401 patients, 11.3%), Asian (6138 patients, 0.2%), Native American (78535 patients, 3.2%) and other (18256 patients, 0.7%) (Sisti A, Huayllani MT, Boczar D, et al., 2020, p. 3). The average number of days between the date of diagnosis and the date on which the most definitive surgical procedure was performed on the primary site was 51 (Sisti A, Huayllani MT, Boczar D, et al., 2020, p. 3). With respect to stage, 486,856 (20.88%) patients corresponded to Stage 0, 961981 (41.27%) patients to Stage I, 587352 (25.20%) patients to Stage II, 203159 (8.71%) patients to Stage III, 91864 (3.94%) patients to Stage IV (Sisti A, Huayllani MT, Boczar D, et al., 2020, p. 4). Women are

being diagnosed with breast cancer at alarming rates. Early detection, and screening mammography is needed to detect that cancers in the women's breasts.

Broadly, invasive characteristics were noted more frequently in younger patients ; the presence of tumor cells in lymphatic channels (not lymph nodes) or blood vessels within the primary tumor was noted more frequently in younger patients, as well as a higher grade at diagnosis (Sisti A, Huayllani MT, Boczar D, et al., 2020, p. 6). As described, young women are being diagnosed with advanced breast cancer, and there is certain risk that increase their chances of developing the disease.

### **Risks**

The following are risks that increases women's chances of developing breast cancer— race, age, family cancer history, genes, menstrual status, oral contraceptive use, birth history, lack of education, age of first and last birth, and maternal smoking. All these risks increase the incidence, and in some cases, the mortality of women being diagnosed with breast cancer. There has not been enough research on investigating how women's awareness of their risk relates to the timing of their screening. This qualitative study will aim to fill that gap.

### **Race**

Race is a risk factor when it comes to breast cancer. African American women have a higher prevalence of being diagnosed and dying from Triple Negative Breast Cancer (TNBC). Just being African American can put a woman at a higher risk than other races. There is a concept that is being researched by Dr. Lisa Neumann determining which country in Africa predisposes women to Triple Negative Breast Cancer. The issue arises that African American women typically do not know their country of origin, hints the blanket and broad name of *African Amer-*

ican. The term African American just means that, in this case, the women do not know which country they derive from in that continent. Dr. Neumann's research shows that women that derive from Ethiopia typically have a lower chance of being diagnosed with TNBC, compared to women whose origin stems from Nigeria. Black women are also most likely to be diagnosed with tumors that are  $\geq 5.0$  cm (12%) or high grade (42%) (DeSantis, et. al., 2019, p. 441).

Moreover, black women are the only group for which high-grade tumors are more common than low-grade or intermediate-grade tumors (DeSantis, et. al., 2019, p. 441). Likewise, 8% of black patients with breast cancer are diagnosed with distant-stage (metastatic) breast cancer compared with 5% to 6% of patients of other races/ethnicities. (DeSantis, et. al., 2019, p. 441).

Black-white disparities in breast cancer incidence and mortality are largest in young women and decline with age. Black women have the highest breast cancer incidence rate before age 40 years and are most likely to die from breast cancer at every age. (DeSantis, et. al., 2019, p. 442). According to DeSantis, et. al. (2019) "Approximately 19% of breast cancers diagnosed in black women are HR-negative/HER2-negative (triple negative) compared with 11% in Hispanics, 9% in whites, 6% in APIs, and 5% in AIANs" (p. 441). One of the most evident information was not just age, but race. "Breast cancer incidence rates are highest in whites (130.8 per 100,000), followed closely by blacks (126.7 per 100,000), and are lowest in APIs (93.2 per 100,000); however, black women have the highest breast cancer death rate (28.4 per 100,000), which is 40% higher than the rate in white women (20.3 per 100,000) and more than double the rate in API women (11.5 per 100,000)" (DeSantis, et. al., 2019, p. 442). Also, Black women are more likely to be screened at lower resourced and non-accredited facilities and to experience

longer intervals between screening mammograms and between abnormal findings and follow-up. (DeSantis, et. al., 2019, p. 445).

According to Chen, Y., et. al., (2020), “Population-based breast cancer mortality is 40% higher among African American women compared with Caucasian American women, a disparity partly explained by 2-fold higher incidence of biologically aggressive triple negative breast cancer (TNBC) in African American women” (p. E1). What is especially true for young black women is that incidence rates of invasive breast cancers in African Americans (AA) are rising (0.9%/year 2005-2014). (Sims-Mourtada, et. al., 2019, p. e1). This may be attributed to the fact that Black women younger than 40 years experienced the largest increase in mean body mass index (BMI) compared to white women over the same period (Sims-Mourtada, et. al., 2019, p. e1). Another potential risk factor is the age of the woman. There has not been enough research on investigating how women’s awareness of their risk relates to the timing of their screening. This qualitative study will aim to fill that gap.

## Age

Age can be a risk factor for women being diagnosed with breast cancer. Typically, women who are diagnosed under 40 years old have a higher stage of breast cancer; therefore, in some cases lessening their chance of survival.

Breast cancer is typically overlooked in young women [women less than 35 years old]. In a study performed in Norway, it was looked at as to why young women are being diagnosed with breast cancer—*Breast Cancer Incidence before Age 55 in Relation to Parity and Age at First and Last Births: A Prospective Study of One Million Norwegian Women*. The idea is simply, young women can be diagnosed with breast cancer, too. Therefore, when young women are di-

agnosed with breast cancer, their children and relatives are often screened at an even younger age. For example, if a woman is diagnosed with breast cancer at the age of 35, then her daughter needs to start having diagnostic screenings performed at the age of 25. There has not been enough research on investigating how women's awareness of their risk relates to the timing of their screening. This qualitative study will aim to fill that gap.

### **Family Cancer History**

Family cancer history is very important. For women, it is important to know who in their family had or has cancer, at what age they were diagnosed, and what type of cancer he or she had or has. This information determines the risk or likelihood of the woman being diagnosed with cancer. For example, if a woman's mother was diagnosed with breast cancer at 40 years old, the daughter and some clinicians would even recommend the son, to have a yearly baseline clinical breast exam at the age of 30; including a mammogram depending upon the type of cancer and other family history that the mother has. All this information is very much important because it can save the woman's life, and additionally if this medical issue is documented, it can be possible for a person's insurance to cover the screening. There has not been enough research on investigating how women's awareness of their risk relates to the timing of their screening. This qualitative study will aim to fill that gap.

### **Genes**

There are genes that women must be aware of that can increase their incidence rate of being diagnosed with breast cancer. The young women who are being diagnosed with breast cancer in their younger years, it is being attributed to their mutated genes that they have received from their mother or father, as their donors. Therefore, women who are diagnosed with breast

cancer, especially at a young age should have genetic testing done to determine their risk of developing breast cancer. If a woman turns out to have the genes, such as BRCA 1 and 2, then her children, boy or girl, need to be screened for breast cancer, and other cancers, at an early age.

According to DeSantis, et. al. (2019) “A recent study reported that the prevalence of the triple-negative subtype in black women in the United States varied substantially by country of birth; compared with US-born blacks, the prevalence was 47% lower in women born in countries in Eastern Africa but only 8% lower in Western Africa-born blacks. In another study of women in California, those of Korean, Filipina, Chinese, and Southeast Asian descent had a higher risk of HER2-positive breast cancers compared with white women, whereas those of Japanese and Asian Indian descent had a lower risk. Differences in breast cancer subtype within and between racial/ethnic groups likely reflect variations in the prevalence of breast cancer risk factors and mammography use, but may also be related to genetic variations” p. 443.

Genetics play a potential role in the risk of breast cancer. Menstrual status also may play a role in the potential risk of developing the disease. There has not been enough research on investigating how women’s awareness of their risk relates to the timing of their screening. This qualitative study will aim to fill that gap.

### **Menstrual Status**

It is noted and has been researched that woman who had their menstrual early on have a higher incidence of being diagnosed with breast cancer. Women who developed breast cancer were more likely to have short, regular cycles, and had more cycles before the first full-term pregnancy than healthy women and those with benign breast disease (Olsson & Olsson, 2020, p. 1). Though it is not yet understood why. One of the theories is that cell division is generally considered a prerequisite for carcinogenesis and women with short and numerous cycles may therefore have a higher risk of developing cancer as a result of increased cell proliferation (Olsson, et al., 2020, p. 1). Researchers are determining that a high number to menstrual cycles, and menstrual activity increases breast cancer risk for women (Olsson, et al., 2020, p. 1). Though the

concept of menstruation status is being keenly researched as a risk of breast cancer, it is known that it can be a potential risk and should be noted and reviewed; as well as the use of birth control or oral contraception. There has not been enough research on investigating how women's awareness of their risk relates to the timing of their screening. This qualitative study will aim to fill that gap.

### **Oral Contraceptive Use**

The theory is that oral conception use can increase the risk of breast cancer diagnosis in women. Researchers noted that women were diagnosed 5 years prior with oral contraceptive use, who were less than 35 years old. There has not been enough research on investigating how women's awareness of their risk relates to the timing of their screening. This qualitative study will aim to fill that gap.

### **Health**

An unhealthy lifestyle can increase the risk of breast cancer. Eating unhealthy foods, smoking, drinking alcohol, and not exercising, unfortunately increases the risk. "Maintaining a healthy body weight, increasing physical activity, eating a nutritious diet, avoid smoking and reducing alcohol consumption may be helpful to mitigate increasing breast cancer incidence in African Americans" (Sims-Mourtada, et. al., 2019, p. e1). Keeping the body at a healthy state, decreases the risk of the disease. Eating a healthy diet decreases the risk of breast cancer. Drinking more water and drinking less of alcohol and drinks with a lot of sugar decreases cancer. Avoiding smoking also decreases the risk. All these factors reduce the risk of developing breast cancer. There has not been enough research on investigating how women's awareness of their risk relates to the timing of their breast screening. This qualitative study will aim to fill that gap.

### **Age of First and Last Birth**

Research states when women give birth at a young age, or have children later in life, that increases their incidence of breast cancer (Chakravarthi & Varambally, 2013, p.1). Also, women who gave birth between the ages of 20 to 24 had an increase risk. To clarify, if a woman gives birth in her early 20s, or gives birth in her late 40s, both scenarios increases her risk of developing breast cancer. These researchers are correlating at what age women were when they had their first full term birth, and last term birth; and how many children did they have total. All this information plays a role in the breast cancer diagnosis. From their research, women from the age of 20 years old, and from the time a woman delivered her first child, was at risk for developing breast cancer. This mean if a woman starts birthing her child or children starting at the age to 20, she increases her risk of developing breast cancer. With that information young women have a greater incidence of tumors, primary tumors, being in the ovaries. There has not been enough research on investigating how women's awareness of their risk relates to the timing of their screening. This qualitative study will aim to fill that gap.

### **Maternal Smoking**

There was also an increased risk in maternal smoking among women 30 years and younger. There is an interesting realization if the hypothesis is proven to be sound. When women smoke during puberty, they are essentially negatively affecting their genetic make-up; therefore, increasing their incidence of breast cancer. Also, when women smoke during puberty they are also affecting the fetal tissue, which is being exposed to cancer cells; hypothesizing that if mothers spoke during pregnancy their female children have a higher incidence of being diagnosed with breast cancer. Also, when women smoke before the age of 17 years old or before menarche,

they are more likely to be diagnosed with ER positive breast cancer (Jones, Schoemaker, Wright, Ashworth, & Swerdlow, 2017, p. 4). This is how critical the effects of health and especially smoking is during adolescence.

Breast cancer risk increased significantly with number of cigarettes smoked per day for all breast cancer (Jones, et. al., 2017, p. 4). Breast cancer risks were raised significantly after 10+ years' duration of smoking (Jones, et. al., 2017, p. 4). Though it is noted that breast cancer risk did not increase after the 10-year mark. Breast cancer risks were significantly raised within the first 20 years after cessation of smoking and decreased with greater time since cessation (Jones, et. al., 2017, p. 4). Breast cancer risk was significantly increased if smoking started at age < 17 years or between the ages of 17 to 19 years old (Jones, et. al., 2017, p. 4). The risk was significantly increased for ER-positive subjects, only for smokers starting at ages < 17 years (Jones, et. al., 2017, p. 4), ER-negative subjects were not significant.

Relative to age at menarche, breast cancer risks were highest if smoking started at or before menarche (Jones, et. al., 2017, p. 4). For nulliparous ever smoking women, there was a statistically significantly increased risk of breast cancer (Jones, et. al., 2017, p. 8). Unfortunately it was found a significant but modestly raised risk of invasive breast cancer in ever and former smokers, in women who smoked more than five cigarettes per day, had 10+ pack-years of use, or had stopped for < 20 years (Jones, et. al., 2017, p. 8). There is also an association between smoking and breast cancer was significantly larger among women with a family history of the disease (Jones, et. al., 2017, p. 12). The relative risk of breast cancer associated with smoking was significantly greater for women with a family history of the disease (Jones, et. al., 2017, p. 12). It is concluded that smoking was associated with increased risk of breast cancer, among those who

started at adolescent or peri-menarcheal ages (Jones, et. al., 2017, p. 12). It is important to know the effects that smoking has on breast tissue because it can affect the outcome later in life. There has not been enough research on investigating how women's awareness of their risk relates to the timing of their screening. This qualitative study will aim to fill that gap.

## **Barriers**

The following are barriers that prohibit the trajectory of treatment of effective treatment for breast cancer patients: screening age, health insurance, education/women's awareness, and distrust.

### **Screening Age**

As aforementioned, the recommended screening age is 40 years old, unless the subject has a family history or other factors, but that can create a barrier because women younger than 40 are being diagnosed with breast cancer.

### **Health Insurance**

Women without health insurance are less likely to have diagnostic screening mammograms (Shakib, Inungu, & Jahanfar, 2019, p. 1). The importance of health insurance is for ensuring positive healthy behaviors such as screening such as mammograms, and other diagnostic tools (Shakib, et. al., 2019, p. 1). Women who reported of having no health insurance coverage were less likely to have reported a recent mammogram test compared to women who had private health insurance (Shakib, S. H., et. al., 2019, p. 4). Research shows that screening education needs to be focused on the population of women who do not have insurance because they are less likely to have a diagnostic screening mammogram; due to their insurance status. "Although stan-

standard practice guidelines for breast cancer are clear, the interplay between insurance and practice patterns for the US is poorly defined” (Churilla, Egleston, Bleicher, Dong, Meyer, & Anderson, 2016). This population is typically unaware of the resources available to cover their mammogram screening regardless of the state of their insurance. “Compared with adequately insured adults, underinsured and never insured women were 6% and 41% less likely to receive breast cancer screening, respectively” (Zhao, Okoro, Li, & Town, 2018). The group that is particularly affected are those who typically do not have their high school diploma. “Effects are larger for women with less than a high school degree in states that ban deductibles, a policy like a provision of federal health reform that eliminates cost-sharing for preventive care. Finally, we find a substantial proportion of the increased screenings were attributable to mandates that are not consistent with 2014 recommendations of the American Cancer Society” (Bitler & Carpenter, 2016). Increased screenings are occurring despite the recommendations because women are being diagnosed with breast cancer younger than the recommended age. The recommended bodies and insurance companies need to be educated regarding what is happening with young women. Education and awareness are pivotal in the detection and survival of women diagnosed with breast cancer.

### **Education/Women’s Awareness**

There must be some accountability. The medical providers can only do so much. That is where the patient-provider relationship, or attachment is vital. While it is the medical providers responsibility to educate the patient regarding the disease and the process of the treatments, the patient also needs to investigate the given literature to educate herself about her type of breast cancer, stage, treatments, prognosis, etc. Younger women require more information on what

breast cancer is and options of treatment regardless of their preference for participation in the decision-making process (Rocio-Saucedo, Gilbert, Gerty, Cutress, Eccles, & Foster, 2018, p. 166). This way the young woman is educated regarding her options, and she can make the best decision for herself and her family. This is similar to that of the attachment theory. The level of detail in some categories of information was influenced by individual life circumstances, including if women were single or in a relationship, had or planned to have children, or had started a professional career (Recio-Saucedo, et. al., 2018, p. 168). Overall, women strongly felt the need to be informed before making decisions when choices were available (Recio-Saucedo, et. al., 2018, p. 170). In order for breast cancer patients to be more aware, at diagnosis, clinicians should be required to provide patients with a supportive atmosphere in which women feel more prepared to voice their concerns, values, and preferences regarding the treatment path chosen (Recio-Saucedo, et. al., 2018, p. 173). This highlights the patient-provider relationship. In addition, the results urge researchers and public health officials to promote health education at secondary educational institutions such as high school because it can increase women's understanding of health messages which may result in positive health behavior (Shakib, et. al., 2019, p. 1).

### **Distrust**

In the African American culture, privacy and a form of secrecy is not uncommon. It is not rare for family members to not know who is battling cancer, and if they do know, they do not know the type. Also, in the African American culture, which I can only speak to because I am African American, there is a sense of mistrust and disloyalty to the medical community because of past medical atrocities such as the Tuskegee Experiment.

Briefly, the Tuskegee Experiment was conducted in the 1940s (and lasted for 40 years) on African American men who had the disease of syphilis. The men were from a very poor town in Macon County, Georgia, and were told that they were going to be helped for their “bad blood”. The medical providers, which was also funded by the United States government, were watching the latent effects that syphilis had on their bodies. Unfortunately, it was already known that penicillin helped with the disease, though it was incurable. Though the experiment happened over 70 years ago, it has been taught to the African American community to not trust the medical community because of the fear that has been instilled. This fear now in some ways affects women, and specifically African American women because they saw and were told about what happened to their men and are fearful what could happen to them. A similar act happened to a poor African American woman by the name of Henrietta Lacks.

Henrietta Lacks is another example of why women from low socioeconomic groups are not being seen in the hospital or clinic setting. Mrs. Lacks was a poor, African American woman from Baltimore, Maryland. She was diagnosed with cervical cancer, and had her cells removed from her, which was taken for science and discovery; unbeknownst to her. Later her cells were used for the vaccine of polio, and other medicines and therapies, such as some chemotherapy agents. The disease killed Mrs. Lacks, but her cells enabled the livelihood of millions of people around the world. The distrust stems from her not knowing her cells were used, and dying poor; especially while scientists, and pharmaceutical companies benefited financially from her DNA. Now, in 2020, something like that would be unethical. Back then, and without informed consent, that behavior was justified.

The lack of trust therefore happens because some African American women feel like if they help the medical community concerning their health (breast health) they will not be helped. Many African Americans, male or female, do not trust the medical community because they are fearful of the mismanagement of their DNA. Racism has a lot to do with medical mistrust. “Our research also elucidated that decision-making needs to happen in the context of a trusting clinical relationship for patients to label the process as “shared””(Hagiwara, Lafata, Mezuk, Vrana, Fetters, 2019, p.1740). The patient-provider interaction can be positive if from its’ infancy it is trusting and cooperative. The issue regarding the Tuskegee Experiment and the story regarding Henrietta Lacks is that African Americans did not have a positive interaction with their medical providers. To combat that, necessary factors such as informed consent and joint decision-making, were implemented during consultations so patients felt autonomous over their care and lives.

### **Screening/Policy Recommendations**

Early detection starts with the patient. It is important the patient know her body, breast health, family history, and understand the patient-practitioner relationship. There are many rules and standards regarding when women should get their mammography. I will give a multitude of opinions, attitudes, and recommendations regarding the mammography screening recommendations according to The American Cancer Society (ACS), The National Comprehensive Cancer Network (NCCN), and The U.S. Preventive Services Task Force (USPSTF).

### **Table 1**

U.S. Preventive Services Task Force (USPSTF)  
Recommendation Women at Average Risk

Age	Frequency	Clinical Breast Exam	Screening Tool
40-49	Annual	N/A	Mammogram
50-74	Every 2 years	N/A	Mammogram

*(Source: Susan G. Komen, 2020)*

The U.S. Preventive Services Task Force (USPSTF) recommends women at average risk to have mammograms performed, with informed consent from their medical provider between the ages of 40-49 (Susan G. Komen). Every two years, they state women should have mammograms from the ages of 50-74. USPSTF does not recommend for or against clinical breast exams, as they find there is not enough evidence for either argument. USPSTF found there was no difference in risk of women dying from breast cancer from the ages of 39-49 who had mammograms regularly, and if there was a difference, they found the difference to be very small (Susan G. Komen, 2020).

Women should have 3D mammograms annually regardless of their average risk status. If women had 3D mammograms every two years, then there is a potential to miss a potential carcinogen (cancer) growing; especially if the women are classified to have dense breasts. Additionally, mammograms are the tool to save the lives of women, so the claim that women between the

ages of 39-49 are not distinct in dying, is false. 3D mammograms are the tool to detect the problem, so no matter the age, there is a difference in risk compared to women who do not have mammograms performed. Another saving tool is self-breast exam. When women are in tune with their bodies, and understand the difference in how their breast feels, and looks makes a difference in survival. If a woman sees any differences, then she will seek help (depending of circumstances) and have a mammogram or ultrasound to either confirm or deny the suspicion. The National Comprehensive Cancer Network (NCCN) has different guidelines compared to USPSTF.

The National Comprehensive Cancer Network (NCCN) recommends that women with an average risk of breast cancer, start mammography's at the age of 40 (Susan G. Komen, 2020). NCCN recommends every 1-3 years women having clinical breast exams starting from age 25 to 39; and every year starting at age 40 (Susan G. Komen, 2020). There is a noted discrepancy between the recommendation of clinical breast exams between USPSTF and NCCN. While the USPSTF ultimately sees no benefit in clinical breast exams, NCCN recommends it.

Clinical breast exams should be performed, but perhaps it would be best if they are performed annually with a family doctor or a gynecologist. When clinical breast exams are performed annually, the patient and the practitioner are able to have a baseline of what the woman's breast looked and felt like and compare it to proceeding years. Additionally, as aforementioned, women should perform breast self-exams monthly, after their cycle, to understand how their breasts look and feel, too. The NCCN has more detailed recommendations for women who have a higher risk of developing breast cancer based on their genetic predispositions. Screening guidelines relates to early detection of lack thereof. There are specific guidelines; however, women are still dying and there has not been any research discussing knowledge prior to the screening, how

do women and what factors lead them to getting screened earlier? Younger women are dying earlier before these recommendations, no one has examined, qualitatively, women’s early experiences from when they first noticed the problem to when they get screened and diagnosed.

**Table 2**

The National Comprehensive Cancer Network (NCCN)  
 Recommendation Women at Average Risk

Age	Frequency	Clinical Breast Exam	Screening Tool
40	Annual	Annual	Mammogram
25 to 39	N/A	1-3 Years	N/A

*(Source: Susan G. Komen, 2020)*

**The National Comprehensive Cancer Network (NCCN) (SEE APPENDIX E)**

**Recommendation Women at Higher than Average Risk**

The American Cancer Society (ACS) recommendations for women at higher risk of breast cancer is different from the NCCN recommendations. ACS recommends women at average risk to start the informed decision-making with their health care provider at the ages of 40-44 (Susan G. Komen). Every year starting at age 45-54, ACS recommends having a screening mammogram performed. Every two years (or every year if a woman chooses to do so) starting at

age 55, ACS recommends a mammography, if the woman is in good health. ACS does not recommend clinical breast exams.

**Table 3**

The American Cancer Society (ACS)  
 Recommendation Women at Average Risk

Age	Frequency	Clinical Breast Exam	Screening Tool
45-54	Annual	N/A	Mammogram
55	Every 2 years, or if a woman chooses annually	N/A	Mammogram

*(Source: Susan G. Komen, 2020)*

**The American Cancer Society (ACS) (SEE APPENDIX F)**  
 Recommendation Women at Higher than Average Risk

The consensus regarding the recommendations from ACS, NCCN and USPSTF are that women are recommended to have screening performed if they have a family history of cancer, have certain genetic makeup and may have had previous radiation exposure. The issue is that many women may not know their family history or understand their genetic makeup. In order to understand their genes, genetic testing and counseling could be set up, which insurance could possibly pay for if the woman had family history and it was justified by the practitioner. Where

an injustice may lie is many women may not know they have a family history of cancer or may not have a family history but that does not exempt from being diagnosed from breast cancer. These three organizations have different recommendations for when screening should occur and what type of screening should be conducted. Regardless few studies have looked at the time between awareness of the problem and actual screening. There is no research regarding women's early experiences and what potential barriers were in place in getting them screened early enough.

According to DeSantis, Gaudet, Newman, Miller, Sauer (2019) "Breast cancer is the most common cancer diagnosed among US women and is the second leading cause of cancer death among women after lung cancer" (p.438). In 2019, DeSantis, et. al. (2019) states that approximately "268,600 new cases of invasive breast cancer and 48,100 cases of DCIS will be diagnosed among US women, and 41,760 women will die from this disease. Eighty-two percent of breast cancers are diagnosed among women aged  $\geq 50$  years, and 90% of breast cancer deaths occur in this age group" (p. 440). There is not just one type of breast cancer, in fact, there are multiple types and are varied in stage.

## **Chapter Three: Research and Design Methods**

The purpose of this study was to investigate potential barriers and gaps in the experiences of young breast cancer patients. This was done by using a semi-structured, qualitative interview design to explore their medical provider experience and to determine if there were any delays in their treatment trajectory by using the methods of phenomenology and social constructionism.

### **Research Questions**

For this qualitative study, I have sought to answer the following questions:

- What are women's early experiences with their medical providers who have been diagnosed with breast cancer?
- Are there components of women's early experiences functioning as barriers to getting treatment?

### **Study Methods**

I conducted a series of twenty-one qualitative interviews and used ethnographic coding to analyze the data. Ethnographic coding is used to discover knowledge by organizing their behaviors and interpreting their experiences. Since the research questions are designed to discover new information arising from the interactions between the subjects' subjective experiences and their dynamic environments, the research methods used for this study were guided by theories of phenomenology. Phenomenology is a theory of experience. "Answers to such questions constitute the underpinnings of our field. To answer such questions, we can use phenomenology to learn from the experiences of others. Some of the questions might be: What is the experience of shame and the impact of that experience for medical learners? What does it mean to be an empathetic

clinician? What is the medical learner's experience of failure on high stakes exams? How do experienced clinicians learn to communicate their clinical reasoning in professional practice? These questions that phenomenology can answer, and the insights this kind of research can provide, are of foundational importance to Health Professions Education (HPE) (Neubauer, Witkop, & Varpio, 2019, p.91). The impact of shame is that medical providers are still stuck in the thought that women can be "too young for cancer", and that women are not insured for certain screening or diagnostic testing. To be an empathetic medical provider, the patient-provider relationship needs to develop and be strengthened; from that a bond is formed, and empathy ensues. At times because medical providers may not listen to their patient, or may mistake a malignant tumor for a benign mass, there is fear when going into the Doctor's office. This is how clinical reasoning transitions into professional practice because not every patient is the same; therefore, not every breast cancer necessarily looks the same.

Phenomenological research can broaden our understanding of the complex phenomena involved in learning, behavior, and communication that are germane to our field. Incorporating phenomenological research methodologies into health professions education (HPE) scholarship creates opportunities to learn from the experiences of others." (Neubauer, Witkop, & Varpio, 2019, p.95). From a healthcare perspective, I was able to learn the experiences of the breast cancer survivors and gather information regarding shared behaviors and experiences that were shared. I specifically used hermeneutic phenomenology for this qualitative dissertation. Hermeneutic phenomenology "seeks to understand the deeper layers of human experience that lay obscured beneath surface awareness and how the individual's lifeworld, or the world as she pre-reflectively experiences it, influences this experience" (Neubauer, Witkop & Varpio, 2019, p.

94). Listening to the breast cancer survivor of the interviews allowed me to gain insight into their lived experiences. It gave me a moment of clarity through the eyes of the breast cancer survivors. I made assumptions about the breast cancer survivors' experiences and how they perceived boundaries and interplays.

Consequently, breaking into their reality was the goal. I was able to view the breast cancer survivor's social world and make sense of it. From that point, I was then able to make an objective and valuable point of the problem and raise potential solutions. Qualitative interviews were the option of choice because as the interviewer, I was able to gain their trust easily, and they were able to share their personal experiences with me one-on-one; which could have not happened during a focus group. "In many structured interviews the questions are restricted or the process is more free-flowing and indeterminate. As with focus groups, an interviews may possess a set of questions, but would not see to impose them" (Litosseliti, 2018, p.198). Through the qualitative interviews, I was about to gather dynamic, fluid and objective truths from the breast cancer survivors.

I have chosen to interview these patients to truly understand their experiences in their breast cancer journey. Asking the same set of questions enabled me to get a frame of reference of how breast cancer patients feel and what they typically go through during their initial presentation, treatment, and follow-up. The main topics in the interview guide asked the women about their early experiences about their breast cancer journey, how old they were at diagnosis, if they had children or were on birth control, if they lived a healthy lifestyle, and if they had a family history of breast cancer. See Appendix C for the interview guide. Qualitative interviewing supported the kind of information and probing that was done because I was able to understand their

feelings, how they felt toward their doctors, what they understood, and so much more. To some degree, I was able to step into their shoes and live in their journey through the interview process. In order to understand their early experiences, I had to ask certain questions about their early experiences such as how did their breast cancer present, and what was their journey from clinical presentation to their breast cancer treatment? In learning their stories and following their journeys, I was able to conclude potential barriers that may have hindered or impeded their process to early treatment.

### **Study Procedures**

Each breast cancer survivor was interviewed [See Appendix C for interview guide] between 45 minutes to an hour via Zoom application with the video component. The breast cancer survivor had the option to not use the video, if she did not feel comfortable. After the interview, the file was saved under the survivor's initials and date of the meeting and transcribed by Otter. Otter is a safe artificial intelligence (AI) service that transcribes dialogue.<sup>1</sup>

*Ethnographic coding.* Ethnographic coding was chosen due to reflexivity. Reflexivity is me viewing my own beliefs, and how it may or may not have influenced the research. The women's breast cancer experiences was observed through a reenactment by interview. Ethnographic coding allowed for a single source to be identified, collected, and triangulated the ideas—to ultimately develop a grounded theory.

---

<sup>1</sup> Otter is a safe and secure platform in which no other person has access to the interview but me, the researcher.

*Informed Consent Process.* Zoom was the platform that was used, as aforementioned. I used Qualtrics to collect and store consent forms. [See the Informed Consent template located in Appendix B]. As described above, I contacted the breast cancer survivors via text message and then sent them a flyer, via email, with more detailed information. The consent was signed virtually before the interview.

## **Participant Characteristics**

I enrolled 21 breast cancer women into the research study. All participants were asked screening questions to ensure that they met the following criteria. All of the women were over the age of 18 years old. The women were younger than 50 years old at the time of diagnosis. The breast cancer patients also all were able to speak English and had been diagnosed with breast cancer in the United States of America. The women were not hospitalized or on hospice at the time of the study or interview. I interviewed 21 breast cancer survivors. One hundred percent of them were women. Forty-three percent of the participants were Black, 29% were White, 24% Hispanic, and 4% Asian. Thirteen of the breast cancer survivors were diagnosed before the age of 40 years old. Thirty-three percent of the participants were married before their diagnosis, while the remainder were single (not widowed or divorced). Ninety percent of the participants tested negative for the BRCA1 and BRCA2 genes. A breast cancer survivor tested positive for the BRCA1 gene. Another breast cancer survivor could not remember her result. Sixty-seven percent of the participants have dense breasts and that was either known before, or after diagnosis. Ninety percent of the participants were employed before their diagnosis with 2 of the participants not working (or having insurance). Ninety percent of the breast cancer survivors also had insurance prior to their diagnosis. Eighty-six percent of the breast cancer survivors exercised to some extent, before their diagnosis. Seventy-six percent of the breast cancer survivors drank alcohol socially before their breast cancer diagnosis. Eighty-one percent of the women did not smoke. Thirty-eight percent of the women had a history of breast cancer (or cancer) in their family and 52% of the women knew about their family history of lack thereof before their diagnosis.

Two breast cancer survivors had stage one breast cancer. Thirty-three percent of the breast cancer survivors were stage II. Nineteen percent were stage III. Nineteen percent were stage IV. Other breast cancer survivors could not recall what stage they were diagnosed with. Thirty-eight percent of the women were diagnosed with Triple Negative Breast Cancer (TNBC). Seventy-six percent of the breast cancer survivors had 1 or more biological children. Ninety percent of the breast cancer survivors were on birth control for either five years or more or a couple of days. Fifty-seven percent of the women saw their OB/GYN when they noticed their issue. Thirty-three percent of the women saw their primary care provider (PCP). The other 10% were referred to a breast surgeon. Ninety percent of the breast cancer survivors had chemotherapy. Ninety-five percent of the breast cancer survivors had radiation therapy. One hundred percent of the breast cancer survivors had some sort of surgical intervention (biopsy, lumpectomy, mastectomy).

### **Data Analysis and Coding**

After the interviews were conducted, they were converted into a PDF file and uploaded into the safe and secure Dedoose database<sup>2</sup>. Dedoose is a qualitative program software. This database allowed me to perform first level and second level ethnography coding. The first level coding allowed me to gather the information that would primarily answer the two research questions, by identifying relationships. The second level coding is more refined, allowing for more themes to emerge, confirming ideas. Reaching the second level coding allowed me to find the themes. The themes that arose allowed coding to ensue based upon the same questions that were asked to the 21 breast cancer survivors. Similar answers were derived from the women, and

---

<sup>2</sup> <https://www.dedoose.com>

themes emerged. The themes will be discussed later in chapter four, but some of the themes that emerged were the concept that women are “too young to get breast cancer,” familial responsibility, prioritizing self, cultural implications, support, self-examinations, patient-provider relationship, religion/spirituality, accurate/adequate screening tools (diagnosis tools), how cancer is viewed, education, guidelines and recommendations, earlier diagnosis, privacy, insurance/money making, and genetics.

*Recruitment strategy.* As a Radiation Therapist at a local cancer treatment center, I had contact with these women being their caregiver; and I developed relationships with the patients over the 6 to 7-week treatment period. During informal conversation occurring over treatment period patients often initiated request to exchange phone numbers, to remain in contact after treatment ended for the purpose of friendship and to simply check in. After 6 to 7 weeks of treatment, at times, the term patient changed to friend. This was not an attempt of early recruitment. As a result, I now have a list of breast cancer patients who met the inclusion criteria and did not meet any of the exclusion criteria, and who had given me their information with permission to contact.

I contacted the patients of whom I have become friendly with, to ask for their email, and sent them a flyer for the interview [See Appendix G for the flyer]. There was compensation for participation in this study. If the patients wanted or needed more information, we arranged a time to talk over the phone to go over the screening script.

### **Threats to Validity**

Some of the women were unable to recall the stage they were diagnosed with, their hormonal status, genetic status, if they have cancer in their family, and if they have dense breasts. Some of the information they were unable to recall or remember was due to the trauma occurred in their lives due to a cancer diagnosis. Every breast cancer survivor is within a year to six years of their initial diagnosis, for the exception of one participant who is 23 years from her initial diagnosis but had three other cancer diagnosis since then. That could present a potential problem based on remembrance or recall bias, but one thing a cancer patient can remember is their diagnosis.

### **Summary**

The purpose of this qualitative interview was to explore breast cancer patients and their medical provider experiences, to determine if there were any delays in their treatment trajectory by using the methods of phenomenology. In addition, the purpose of this study was to investigate potential barriers in their experiences as patients.

## **Chapter Four: Findings and Recommendations**

### **Introduction**

The purpose of this qualitative dissertation is to determine, the gaps and barriers, if any, to breast cancer patient's treatment; and if their medical providers played a role in that process. In this chapter, I will cover the breast cancer survivors background and qualifications for the basis of the interview, and themes. The research questions are: What are women's early experiences with their medical providers who have been diagnosed with breast cancer; and are there components of women's early experiences functioning as barriers to getting treatment?

### **Patient Background Information**

Each of the 21 breast cancer patients shared three commonalities: they are women, have breast cancer, and were diagnosed at an age less than 50 years old, all within the United States. The participants have various backgrounds ranging from genes, menstrual status, marital status, children, careers, education, race, religion, family cancer history, being premenopausal, maternal smoking and age. Each of these women were brave enough to share their story in the hopes that they can inspire patients, medical providers and in my hopes, policy change.

I have interviewed women who are Black, Hispanic, White and Asian. The age of which they were diagnosed with breast cancer ranges from 28 to 40 years old. Many of the women interviewed are within 5 years post their diagnosed age. Many of the women have been on birth control from 5 years to longer, with someone being on birth control for days, and others not being on birth control at all. All the women have and birth children, except for four women who have not had children at all (birthed, surrogacy or adopted). Many women knew of their breast cancer stages, while few of them did not remember. There stages ranged from Stage I to Stage

IV. Including knowing their stages, many women could remember their hormonal status, while some could not. Some women were ER- PR- HER2- (Triple Negative) and others were estrogen, progesterone and HER2+ (ER+ PR+ HER2+), with a range of other variables. Many of the women were negative in carrying the BRCA1 or BRCA2 genes, while one woman was positive in being a BRCA1 carrier. All the women were either married or single at the time before their diagnosis —none of them were divorced, or widowed.

The women either knew their family history, did not know, or found out after their diagnosis. For the most part, the women did not smoke, they did drink socially, and ate relatively healthy, as well as, exercised. It is interesting to note that the mothers gave birth at young ages, ranging from 19 to 35 years of age. All the women had insurance prior to their diagnosis, except for two. Additionally, all the women worked during treatments, except for two women. The type of medical provider that they women reached out to or was referred to, OB/GYN, PCP or a Breast Surgeon. Many of the women either knew, and later realized they had dense breasts, except for one, and four other women who were not certain. All the women have had some sort of surgery, the majority had chemotherapy as well as radiation therapy.

## **Themes**

General themes that arose were the concept that women are “too young to get breast cancer,” familial responsibility, prioritizing self, cultural implications, support, self-examinations, patient-provider relationship, religion/spirituality, accurate/adequate screening tools (diagnosis tools), how cancer is viewed, education, guidelines and recommendations, earlier diagnosis, privacy, insurance/money making, and genetics. The first section below describes the themes relating the women’s early experiences with their medical providers, and the second section describes

the themes that relate to components of women's early experiences functioning as barriers to getting treatment.

I have incorporated the voices of the twenty-one women who wanted to share their stories. You will meet JR, MC, CP, LM, TM, SFR, MW, CW, CR, AD, JamRiv, TD, LynMit, KS, JK, SMC, DD, DSM, BMD, YMD, and MV. Their stories embody all of the themes that emerged. Their stories are the reason why literature, policy, recommendation, and guidelines, cannot always be followed; and the rules must be broken to save the lives of the women who were also diagnosed with breast cancer.

### **Women's Early Experiences**

#### **Too Young for Cancer**

A lot of the women expressed that their providers kept telling them they are too young for cancer. Many of the women advocated for themselves to get screened despite their age. Now some of those women, young women, have stage IV breast cancer. The breast cancer spread from their breast to their bones, lung, and brain. They were originally told they were "too young" for cancer, and they could wait a couple to see what happens. Now, they only have a couple months for the rest of their lives.

Meet MC. MC is a young married woman, with one beautiful daughter, who felt her mass, and decided to seek help. MC<sup>3</sup> stated, "I was young, it was so tiny, and I have no family history. They [the medical providers] said they weren't concerned". She was diagnosed with stage II breast cancer at the age of 34. Similarly, another young woman, single woman was diagnosed with breast cancer at a young age.

---

<sup>3</sup> Using Initials to protect breast cancer survivor confidentiality.

Meet CP. CP is a young, African American woman. CP stated, “He was like you’re young. So, it’s probably not cancer”. She was diagnosed with Triple Negative Breast Cancer (TNBC) at the age of 28 years old. “I think it is common, especially in a lot of young survivors hearing, you're too young for cancer, you know. I think depending on the person, they might take that further than I would and say, Well, I'm too young. So, I'm not going to prioritize this.” CP emphasized that she was one of the young women that pushed for more diagnostic testing, regardless of her age. She is happy that she did because it saved her life. CR is another young woman who fought for further diagnostic testing despite her young age.

CR is a young Caucasian woman. She has been engaged for years to her long time boyfriend. She discovered her lump herself, and sought help. CR wants to let everyone know that, “You're never too young for cancer. I'm 29 years old, and I was diagnosed with cancer, you need to check yourself. Don't wait until you go for GYN appointment; You’re never too young for cancer. You see children get cancer all the time.” CR mentioned that she does not understand how medial providers can mention that women are too young for breast cancer when children are diagnosed with cancer all the time. She states the notion of “too young” for breast cancer needs to be null and void, regardless of age.

Meet LynMit. LynMit has two amazing sons, and was diagnosed with Triple Negative Breast Cancer (TNBC) at the age of 41. She stated, “I actually begged and pleaded to get mammograms at like, I don't know, like, 35 or something I had started because I knew about my mom [who was diagnosed with breast cancer]. You know, they said that I was too young. And don't worry about it unless I feel something.” Although since her diagnosis she has had a wonderful experience, this unfortunately highlights the notion of once again, women being “too young” for

cancer. Literature and research will stand on that if her genetic testing was negative, there would be no need for her to have further screenings performed because of her mom's breast cancer diagnosis. I would have to insert my opinion from what I have seen, and from the interviews conducted, it is possible, that had she had been screened years prior; her diagnosis might have been less severe. Another young woman, DSM, had a similar story to tell.

DSM had a similar experience, stating, "I tried to call the doctor. And I was like, Hey, listen, there's a lump. And the doctor was like, No, you're only 28." She was also diagnosed with TNBC at the age of 28 years old. Meet DSM. DSM at the time was a young African American woman, who later married, and had two beautiful children (a girl and a boy). DSM story is quite different, she had fought through three cancer diagnosis all stemming from her original breast cancer diagnosis from her early twenties. She wants every woman to know, listen to her body, push, and be her own advocate. Similarly, JanRiv is another young woman who had to be her own advocate.

Meet JR. JR is a young Caribbean woman who birthed two beautiful children, a girl and a boy. JR was told, "When I got there, they kind of gave me a little bit of pushback, saying Oh, you're so young. Why do you need this? And I'm like, Well, I have a referral. Yeah, my breast hurts. And I will pull it out if you need me to. But they eventually saw me. And once they saw me, they were like, nope, you can't leave we have to do some other tests." She was later told she had TNBC at the age of 29 years old. Not even two years later, she was told she had a tumor in her lung, which was able to be removed. Months later, she was told she had a tumor in her brain, which was also able to be removed. I guess she is not too young for breast cancer.

Women are not “too young for cancer.” As themes emerged, women can be as young as 28 years old who are diagnosed with breast cancer. Literature states that mammograms should be performed at a baseline, annually, starting at the age of 40 years old—I believe these women in their twenties beg to differ. These findings are not consistent with the literature that I presented in Chapter Two, especially related to the age of patients. As discussed in Chapter Two, we learned that age can be a risk factor for women being diagnosed with breast cancer (Sisti, Huayllani, Boczar, et al., 2020). Meaning women who are diagnosed under than age of 40 years old have a higher stage of breast cancer, therefore, in many cases, decreasing their prognosis. We also learned a study in Norway took place endorsing that young women are indeed being diagnosed with breast cancer, therefore, the mammogram age should be lowered (Albrektsen, Heuch Tretli & Kvåle,1994). The women that I have interviewed not only are some younger than 40 years old, and are diagnosed with breast cancer, they are being diagnosed with aggressive types breast cancer.

Their cancer is metastasizing (spreading) to their bones, lungs and brains; and many of them did not have a family history. This notion of women are “too young” for breast cancer needs to cease. It is most certainly unfortunate because women those ages should not have to deal with a breast cancer diagnosis, but the reality is, they are. The baseline of annual mammograms, starting at the age of 40 years old should be modified to a younger age to incorporate the younger women who are being diagnosed. It is interesting because many of the women felt their lumps during their breast self-examinations, although most literature, as presented in Chapter Two, does not necessarily endorse self-examinations. As previously stated, USPSTF does not

recommend for or against clinical breast exams, as they find there is not enough evidence for either argument (Susan G. Komen, 2020).

### **Self-Examinations**

Self-Examinations are extremely important. This gives the woman a baseline of what her breast looks and feels like. From that initial presentation, she is able to see any potential changes that occur. Many of the women self-examined themselves, and self-palpated their own masses. This is important because as stated in Chapter Two, this goes against literature. Current guidelines, according to the ACS, and USPSTF, do not recommend or endorse palpation as there is not seen an increase of mortality from palpation to screening. Although, the women who felt their masses, would beg to differ.

Meet SFR. SFR is a woman who was diagnosed with breast cancer at a young age. She is a wife and a mother of two wonderful children. SFR said, “So I had actually had my mammogram, like in February. And I just decided in April, can we do a self-examination and I found this lump like right above my breast on the on my on my left side.” SFR was diagnosed with stage IIB, ER+ PR- HER2+ breast cancer. CR also mentions self-examination as part of her journey.

CR expresses, “So you definitely need to do self-breast exams, no matter if it's, you know, how they want you to. I found mine in the shower. I lifted up my arm and was just feeling around because you know, you're soaping up yourself.” DSM also endorse self-breast examinations.

DSM states, “It is so important for women to know and learn to be comfortable with their body so that they can know what is good and what isn't good.” This is how a lot of the woman found their masses, from feeling their breasts, and knowing their bodies.

There is a controversy regarding if and when women should perform self-breast examinations. The multitude of women that felt their lumps when feeling their breasts, in the shower or while laying on the bed, or because their medical provider felt their lump, would agree with the concept that breast examinations are lifesaving. These findings are not consistent with the literature that I presented in Chapter Two. The U.S. Preventive Services Task Force (USPSTF) does not endorse or recommend for or against clinical breast exams, as they find there is not enough evidence for either argument, as aforementioned. Similarly, The American Cancer Society (ACS) does not recommend clinical breast exams. Additionally, The National Comprehensive Cancer Network (NCCN) would recommend women between the ages of 25 to 39 to have a breast exam 1 to 3 years, and starting at 40 years old, annually. The women I interviewed would agree the breast exam saved their lives, and the breast exams should occur regularly and often.

The literature suggests that self-examinations has no survival rate, compared to women who have annual mammograms (Susan G. Komen, 2020). There is not seen to have a significant mortality rate between the two. The issue is there is an obvious mortality rate increase because the women who are “too young” to have a screening mammogram due to their ages would have to wait until they reached the age of 40 to have the screening, unless self-palpation occurred—therefore, decreasing mortality, presumably. This is why it is very important to have a relationship with the medical provider and the patient. The patient-provider relationship is paramount. This relationship allows the patient to trust the doctor with the needs that she has, and allows the provider to follow through.

### **Patient-Provider Relationship**

A myriad of women stated the importance and effectiveness of the patient-provider relationship and expressed their feelings on the matter.

MC expressed, “At that time, I thought, well, she's not concerned. She's right. I am young. I'm looking back. I'm like, thank goodness that the type of breast cancer that I had wasn't worse, you know, thank God, it wasn't, triple negative or, you know, worse or more aggressive”. MC had to advocate for herself despite her provider not believing she could have breast cancer. She was diagnosed with stage II breast cancer at the age of 34 years old, as previously mentioned.

Meet LM. LM is a beautiful successful, Caucasian woman. LM states, “I wish that the doctor maybe did things a little bit differently. Fortunate for me, I, did advocate for myself to make sure I got the mammogram and everything, but I feel like there's probably a lot of women that would have just taken her word for it and moved on.” LM was 35 years old when she learned she had ER+ PR+ HER2+ breast cancer. LM had hoped that the relationship had been a little bit stronger. Sometimes you wish you do not have to advocate for yourself that much or that hard, or that often. On the other hand, MW had a positive experience with her provider.

Meet MW. MW was diagnosed with the BRCA1 gene prior to her breast cancer diagnosis. As she would explain, although the provider explain that one day she could possibly be diagnosed with breast cancer, the provider also made it seem like because she was young, she was far off from that fact. MW is a young woman with a son, and has a loving husband. MW expressed, “In the beginning (after her diagnosis), everybody was amazing. And I will say that every doctor here was caring because they challenged me. I've never felt just like a number. I felt like we were actually involved in my case.” This relationship is important. Especially Never feeling like a

number. Although physicians are extremely busy, patients should feel just as important, and cared about as the next. Also, in feeling comfortable in the care of the medical provider, that includes, talking in a common language.

CW expressed, “Like, what is his language?” In addressing medical providers using medical terminology, instead of Laymen’s term. And additionally, she wanted to know, “What questions should I ask?” She wanted to be educated about the cancer process. Also, she states, “But there's no consideration for the person who has never entered that space. I'm a layman. I don't know your terminology. I don't know your inferences.” Meet CW. CW is a single mother who has a two children. She followed the mammogram guidelines perfectly. She was told because her previous mammogram was clear, she could wait two years for another one. She wished that was not a sound guidelines. She was diagnosed with breast cancer.

CW also expressed, “But my point is no explanations in there. You know that communication will allow for a patient to understand what they're walking into. Emotionally, the level of anxiety was very much heightened. I was very vulnerable. I had to give all my trust to this person that I quite frankly did not know.” This is another reason why the patient-provider relationship is so important. During the times in their lives where some of these women are meeting these medical provider for the first time, care needs to be established, as well as, trust, commitment and adequate care.

CR talks about how her male provider did not seem to be concerned about the lump that she found. He had a female provider palpate the area of concern. “You know, he's a man. So of course, he had to go get a female to come in. So, I feel like he would have brushed it off if I didn't push for it.” She felt like because of his gender, he would not have pushed for more test-

ing, nor maybe not knew what to look for. She is very thankful that the female provider came in and palpated her mass, and sent her for further testing. She also explained the frustration of when getting treatments and the lack of communication in regard to screening in between treatments.

CR also expressed, “And that's one thing that I can say, that really bugged me and was always in the back of my mind the entire time was, Why do they not check you like midway through?” “It's just the unknown of, is it working? Or am I just sick for nothing? And some people may not even want to know, but they should at least ask.” Patient-provider relationship also includes communication. It is important that throughout the woman's journey she is being communicated to, if that is what she wants. CR also remembers a time when there was poor communication and seemingly insight.

CR also states, “I was telling her about symptoms and my tumor and she's looking at the ultrasound she's like, Oh, it's a cyst. She's like, you wouldn't have this shadow you wouldn't have any pain either. Well, guess what? You have pain with a tumor!” CR wants to reiterate that she is not sure how other women's diagnosis presented, but this is how hers presented. She had pain, and on her image, there was obviously a shadow, and it was not a cyst. She is not taking anything away from the work that medical providers do. CR is simply emphasizing that every woman is not textbook. Every woman is different. Some women experience pain prior to their breast cancer diagnosis, just like she did.

Meet JamRiv. JamRiv is a young married woman. She has two boys and was diagnosed with stage IV breast cancer. The cancer was all over her body at the time of diagnosis. She initially thought she had a cold, then a pinched nerve. An ultrasound was performed, and many masses was seen on her liver. JamRiv was diagnosed at the age of 39, shortly after her husband

was diagnosed with colon cancer. JamRiv stated, “I had a history of fibrocystic breasts and from 16 years old and then in 2015 I had a miscarriage where my breast engorged, and the right breast didn't necessarily go back to its original state. And I did share that with my OB/GYN at the time. And she wasn't too concerned just because that breast was always the one that produced the most milk and all of that, so I thought that it was maybe a blocked milk duct or something like that.” She had a conversation with her medical provider about her breast history and her gynecological history. Also, there are many instances where medical providers advocate for their patients.

Meet TD. TD is a beautiful woman, and great mother to two women. TD was diagnosed with TNBC. TD expresses how her medical provider advocated for her. She stated, “He kept saying, you know, something is there, we see something, it's hidden. So, he didn't give up and according to him, he said they had a whole bunch of other doctors from a different state looking at my imaging.” This is a beautiful example of a wonderful patient-provider paternal relationship. Her medical provider fought for her because he saw something, and she trusted him because of his expertise. It is always important that the medical providers always look at the patient, and not just the disease.

Meet JK. JK was diagnosed with Stage IV, HER2+ breast cancer at the age of 30 years old. She was one daughter that she keeps fighting for. JK mentions, “I wish that the doctors took a step back and looked at the person and not just at the cancer.” This is very important. To treat everyone as if they were part of your family, friends, or special group of people.

DSM states, “Doctors need to listen to their patients, not everybody's a flipping hypochondriac. Listen to your patient.” She also gives advice stating, “I know that doctors see a lot of patients all the time, but this is some serious crap that we're going through. Don't treat us

like we're sitting there trying to butt in line at the grocery store with 10 packages in a five-package lane. Have some compassion. I think that they could learn emotional intelligence.”

In Chapter Two we learned that in order for breast cancer patients to be more aware at diagnosis, medical providers should be required to provide breast cancer patients with a supportive atmosphere in which women feel more prepared to voice their concerns, values, and preferences regarding the treatment plans and trajectory's (Recio-Saucedo, et. al., 2018, p. 173). This highlights the patient-provider relationship. In addition, the results urge researchers and public health officials to promote health education at secondary educational institutions such as high school and colleges because it can increase women's understanding of health messages which may result in positive health behavior and possibly prevention (Shakib, et. al., 2019, p. 1).

Many of the breast cancer patients had a variety of experiences with their medical providers in their early experiences. What can be extrapolated, is that the early experiences with their medical providers creates the trajectory of treatment success, when they are compliant. The patient-provider relationship is extremely important in the initial days of the findings, diagnostic scans, and diagnosis; leading up to treatment. These steps are imperative because it creates a bond of trust, and reliability in a vulnerable stage in their lives. What also helps these women during these vulnerable stages in their lives in connecting to God or a higher power, in their religion or spirituality.

### **Religion/Spirituality in Cancer Diagnosis**

Amid a cancer diagnosis the women still have a positive outlook on their experiences, some credited that to religion or spirituality.

MC stated, "I just feel like I'm not in control. That is partly my religion. I'm not in control; and I think God had a plan for everyone".

SFR expresses, "He [God] was my only option. But it was an option that I desired to want to do. And by me doing that, it caused them [her children] to have that same desire."

MW said, "I'm a Christian. Prayer definitely helped."

JamRiv expresses, "I try not to question his path for me. And so, with my diagnosis, it was just also unfathomable to me because my husband had already went through a colon cancer battle, so it was like, my kids have two parents with cancer and it was just, like, inconceivable to me. I am appreciative of the extra time that I have. Because if I hadn't got that ultrasound, I could have been much, much worse."

JK has a positive outlook on her journey. She states, "I try to keep my smile. Because that's one thing that people have always said, I've never lost my smile. So, I just want to tell people, you know, always think of the positives, you know, because there's a lot more people that's going through worse situations than what you are."

SMC talks about a spirituality of embracing her diagnosis, "So I embraced the cancer." She was 38 years old when she was diagnosed with breast cancer.

Meet BMD. BMD is a Mexican woman who has two children, is married, and was diagnosed with breast cancer at the age of 36 years old. She expressed that as a Mexican woman her duty is to take care of her family, and her household. She is the last on the priority list, until her body made her sit down, and listen to herself. BMD expressed, "I don't believe in God. You know, I am. I'm not going to any church right now. Or I wasn't going any church even before. Um, but I have my sister, she's a Christian And, and she's been like, you know, sending me some

messages and sending me like, some Bible scriptures. And videos about like, the pastor is talking about God and all that stuff. And I'm, and I like it, and I think that makes me feel better.” Similarly, MV has an interesting story.

MV is a mother and a wife. She is of Hispanic origin and had to wait for diagnostic testing to be performed due to lack of insurance. MV states, “I’m very positive all the time.” MV was 43 years old when she found out she had stage IV breast cancer.

The interviews revealed that a positive mindset, a healthy attitude, and/or a spiritual connection really help cancer patients get through the trials in their journey. The women who were interviewed really pointed to the positive mindset and the manifestation that they garnered in order to get them through the process of their breast cancer treatments. The themes of this magnitude were not found in previous literature.

### **Diagnostic Tools**

The women also expressed the need for more accurately applied diagnostic tools.

Meet TM. TM is a beautiful mother to a wonderful son. She was diagnosed with breast cancer at the age of 32 years old. Prior to her diagnosis she was originally told that there was nothing there until she advocated for herself and followed up. Not only does she advocate for herself, she advocates for better screening techniques and protocols. TM stated, “But they said I had dense breast tissue, so it was hard to see on the mammogram. You couldn't see it at all but could detect it on the MRI.”

TM expresses, “At this point with young women, if we have dense breast tissue, and that's a known fact. And we come in with some type of symptom. Why do we stop at a mammogram if nothing is seen on the mammogram? Like if we know that young women, this is a risk to

them, then just go straight to the MRI. And I had mentioned that to the radiologist that I met with a couple weeks afterwards and she was like, you know, insurance doesn't pay for that immediately. That's not the first line of defense. And I'm like, well, it needs to be for young women with dense breast tissue because you can't see anything on a mammogram. So, what's the purpose of the mammogram?" She was 32 years old when she was diagnosed with IIIB breast cancer, as previously mentioned. Similarly, CR endorses the breast MRI for the first line of defense for women, young women, with dense breast tissue.

CR states, "You know, when you're younger, you have denser breast tissue, and then it [mammogram] doesn't pick up that [cancer], and then maybe they need to find something that does that. Give us an MRI." ADG feels the same way.

Meet ADG. ADG has four children and was diagnosed with Stage II breast cancer, ER, PR +. ADG expresses, "I think the one thing I learned here is not just trust the mammogram. And if there's like, questionable, then you have to be your own advocate. Because I felt it." ADG is expressing that she felt her lump, but the mammogram did not pick it up because she has dense breasts. She also states, "And the thing also is the mammogram, because my breast tissue is dense. They should give us an MRI." She states it is important to always advocate for yourself. She was 45 years old when she was diagnosed with stage II HER2+ breast cancer. JamRiv asked for further screening prior to being diagnosed with Stage IV breast cancer because of her cancer history on her father's side.

JamRiv expresses, "I can say that, I would ask about any type of screenings or things like that, and they didn't think that I had a strong history in order to justify that because the breast cancer that is in my family was on my father's side." Diagnostic tools are still being debated re-

garding when they should be had, at what age, etc. The women that I interviewed, would all agree, more advanced and specified diagnostic tools should be taken for the betterment of the patients.

As we learned in Chapter Two, the screening tool of choice is the mammogram for women of average risk and high risk between the ages of 40 to 74 years old (Susan G. Komen, 2020). According to Susan G. Komen (2020) the breast MRI is an option for women who previously had cancer, or have a gene mutation, and that screening process can begin at the age of 25 years old. Women who have had radiation to their chest between the ages of 10 to 30 years old, can have a breast MRI, annually, starting 10 years after their radiation exposure; have dense breast tissue, women who have a greater than 20% risk of invasive breast cancer based on their family history (See Appendix E and F). The problem is this is the only way, seemingly, a breast MRI can be the first line of defense, and there are many women who have dense breast tissue, who are not always afforded an MRI.

The current screening recommendations state that insurance should cover mammograms annually, starting at the age of 40 years old. The issue that presents is that women who are less than 40, and some who are 40 and older have dense breasts. Dense breasts, simply put, makes breast tissue difficult to see diagnostically on a 2D/3D mammogram, at times. Other diagnostic tools such as an ultrasound or a breast MRI can be used to further evaluate breast tissue. This is what some of the women were expressing, other diagnostic tools, such as the breast MRI, would be useful. These findings are not consistent with the literature that I presented in Chapter Two, cited from Susan G. Komen. Breast MRI is not the first line of defense, diagnostically, because it is more expensive than a 3D mammogram, for example. At times, the cost benefit analysis out-

weighs performing a mammogram versus a breast MRI. The women interviewed would agree their lives, and the lives of other women far exceed the cost benefit of a breast MRI. This type of diagnostic tool, and others, help aid in early diagnosis.

### **Earlier Diagnosis**

Also, a lot of women wish they the cancer was diagnosed sooner.

LM states, “I wish that I had taken the initiative a little bit sooner.”

The breast cancer survivors also talk about finances and insurance.

TM expressed, “I couldn't financially live off the short-term disability or long-term disability. I needed my entire income. So thankfully, I had a boss that was supportive”.

CR stated, “I wish would have found it sooner. But then again, I'm like, did it [cancer] come from the miscarriage, you know, and would I have found it sooner or if it came from the miscarriage, then maybe it wasn't there to find sooner. I don't know.” It has been proven that younger women can get breast cancer; therefore, early diagnosis would be advantageous in saving lives, not just for them, but for all women. These findings are not consistent with the literature that I presented in Chapter Two. As Sisti, Huayllani and Boczar , et al. (2020) stated, 136,525 patients are diagnosed with breast cancer, and they were less than 40 years old.

Other points in the interview that were mentioned was the importance of privacy.

### **Privacy**

Some women prided privacy over their diagnosis.

SFR stated, “I don't know, for lack of a better word, grief and pain that I was experiencing some of that tried to keep private. But some things I couldn't.” Similarly, MW, expressed the need for privacy.

MW expressed, “I just need you all to respect my privacy. I’m not an attention person”. Some of the women expressed their need for privacy. In the time of their lives where so much is out of their control, they wanted to control what they could—and one of those aspects was the need for privacy. Some of these themes were not found in literature, but arose in the interviews.

## **Genetics**

MW expressed the importance of genetics and how she felt like her provider did not explain the severity of the genes. As previously mentioned, MW was diagnosed with the BRCA1 gene prior to her breast cancer diagnosis. As she would explain, although her medical provider explained that one day she could possibly be diagnosed with breast cancer because she carried the gene, the provider also made it seem like because she was young, she was far off from that fact.

MW states, “It wasn't explained to me the way they I understand it now, and the severity of being a BRCA1 carrier,” “If I would have known like I said the severity of being a BRCA1 carrier, I would have done something, no question.”

MW also stated, “They don't tell you, all you need to know about is BRCA1 and BRCA2. But now that I know the difference. BRCA1, your chances are higher, you could get breast cancer and ovarian cancer.”

MW expresses, “People don't understand. I really wish that more is put out there. There's some people that don't even know about genetic factors.”

What we learned in Chapter Two is that genes are very important because mutated genes can be inherited from the mothers or fathers side. It is important to know this type of information

because knowledge is power. For example, MW, was able to have genetic testing done because her father and the members of his family had breast cancer. It turned out she had the BRCA 1 gene. She also was later diagnosed with TNBC, which we also learned from Chapter Two that black women have a 47% prevalence rate compared to their counterparts.

The importance of genetics was a theme that really stood out in the interviews. According to DeSantis et. al. (2019) genetics is seen as important because it can determine the woman's potential increase risk of developing such cancers, such as breast, ovarian, and endometrial cancer. Additionally, such knowledge, women can have the power to give to her family members, as well as, determine what she wants to do medically to herself, such as have a double mastectomy, hysterectomy, and continued scans. The women discussed the importance of such knowledge and having the information from their medical providers and possibly a genetic counselor to make informed decisions regarding their health.

The women's early experiences related to being told they were "too young" for cancer, although most of them self-palpated their mass. The women went to their medical providers, being their OB/GYN, primary care physician or surgeon and sought help. From the initial presentation, their primary care doctor set them up for a diagnostic screening tool, primarily the 3D mammogram. Some of the women were diagnosed early, some were later in their breast cancer stage. The survivors mentioned that in their cancer diagnosis they prided and wanted privacy and wish they understood the greater concept of genetics, and the role that it plays. Their early experiences shaped their trajectory into treatment. Some of the women were able to see their medical provider, was sent for a scan, and was diagnosed, and proceeded with treatment. Other women

had to wait because they were either told due to their age, they could wait for a variety of reasons, or other women needed to take care of their families first, or wait until they had insurance.

## **Potential Barriers**

### ***Financial Responsibility***

Women have the financial responsibility of taking care of themselves and of their families; unfortunately, a potential barrier stems from having to financially take care of their families before a diagnosis therefore delaying their trajectory of treatment. Working provides financial stability needed, and sometimes women cannot afford to not work.

### ***Familial Responsibility***

Culturally, women are responsible for taking care of their families first, and then taking care of themselves second. This is a potential barrier because in place themselves last, they are not taking care of themselves therefore hindering their success of treatment and prognosis. Many women placed the responsibility of having a family and raising their family in front of their personal needs and health. The breast cancer survivors also had to consider making family decisions when being diagnosed.

CW said, “Now I’m dealing with my family because I have to make family decisions. Do I tell them? Do I not tell them? I have children!” Not only dealing with the cancer diagnosis, CW must make decisions whether to tell her family. JamRiv recalls being held accountable for her family as well.

JamRiv recalls her situation, “I saw how long when my husband had his cancer battle, how long it took him to qualify, well actually had a liver transplant and it took him like a year to be approved for disability. And I felt like with everyone being on my health benefits, and. I’m the

primary breadwinner then I couldn't afford to just roll the dice and see if I would be able to have health insurance coverage and money for bills and stuff like that. So, I figured I had to keep working.” The role of a provider is prioritizing the family regardless of the situation, and that is exactly what JamRiv had to figure out. She was 39 years old when she was diagnosed with stage IV metastatic breast cancer, as previously mentioned. The role of a mother, and caregiver is what BMD also knows all too well.

BMD states, “I didn't pay too much attention. Because I have my two kids and my son, he's now autistic. I was just too busy with my son and taking care of his behavior. You know, I didn't realize that I need that time for myself too.” She also stated, “Both of my grandma's die before my grandpa's. Oh, you know, and I believe that's because they take care of the husband and the kids, but they don't take care of themselves. And I ended up doing the same thing, because I was taking care of my son, and trying to make, make him feel better. And do better in the school. And I wasn't taking care of me, and, and now I'm glad that I can still take care of my son because I'm alive.” The role of a mother is very strong and pronounced, and oftentimes, she is not the primary concern. BMD had to learn the hard way what it means to not prioritize self.

### **Prioritizing Self**

What many of the women realized is that they did not prioritize themselves before their breast cancer diagnosis. They were prioritizing their families, work, and dealing with the stressors of everyday life. After their diagnosis, the women noted to put themselves first, and take care of themselves. Literature has shown that although women typically chose their families over themselves, which has turned out to be true; during diagnosis the women learn putting themselves first was also priority.

MW expressed, “I can't worry about anyone else.” She was diagnosed with TNBC at the age of 37, after testing positive for carrying the BRCA1 gene.

CW who was diagnosed with breast cancer at the age of 48, after being told 2 years prior she did not need a mammogram because her previous mammograms had been clear said, “Still trying to take care of myself.” The theme of self-prioritization is paramount.

KS stated, “The most thing that I reflected on during all of this was that I need to prioritize my health. My physical health or mental health as well. Understanding that it is important to put yourself first.” KS was diagnosed with breast cancer at the age of 47. KS is a mother of two beautiful children, a daughter and a son. She is Hispanic, a very proud Peruvian. While she would do anything and everything for her children, she also understand the importance of taking care of herself. She understands the saying, “You can't pure from an empty cup”. This is part of cultural implications.

### **Cultural Implications**

There are many cultural implications regarding why certain cultures do not get mammogram screening or enroll in clinical trials, or even deal with medical professional because of status, stigma, and pride. Some cultural implications suggest the Tuskegee Experiment, but never touched on other cultural implications such as the Hispanic or Latino experience.

TD states, “And it's something that I noticed the background or the history with African Americans or not, but, it kind of seems like to me that, um, it is kind of taboo, when you start expressing how you really feel. Or for people to really just be there for you.” In addition, TD states, “And that's why I throw the race card out there like that, because that's how I felt like as African Americans, especially women, you know, you should be there helping me through this,

but instead, because you know, I'm a strong individual. You're letting me go through this alone, basically, because you know, I got it.” Being African American TD noticed in her experience that there is a stigma for Black women to ask for help in their time of need. TD was diagnosed at 46 years old with TNBC, as previously mentioned.

KS talks about cultural implications in the Hispanic community. “When I was there, like obviously, there was like support groups and like psychologists that you can talk to and stuff, but I guess my main concern was specifically towards my race, and my kind of people, there just really wasn't like, maybe I'm assuming, like bilingual individuals to help out and just be able to help those class of women, like me. I guess what I'm just saying is I found myself being in like, a dark hole, not being able to have those resources for myself.” She expressed that at times because she is Hispanic she did not feel seen or heard, and it would help if someone looked like her, could represent her. As far as representation, JK, had a similar story.

JK states she was told, “That within African American women that we naturally have denser breasts, so they have to do more of a 3D type mammogram to really get everything.” Her medical provider gave her that information. She was diagnosed with breast cancer at the age of 30 years old, as previously mentioned.

DSM expresses the implications of clinical trials in the African American community, stating “But we think you should go through it just in case and I was like, no, not gone through it. Just get well in we'll put we'll study you. I said, Listen, I am not going to be a part of your study. I said, we have a history of this in our in our race of being people's guinea pigs directly. I'm like, I didn't want to say that the whole Tuskegee experiment, but that's another issue. I said, I'm not going I don't need to go through I'm not going through it. And so, then I wasn't comfort-

able with her.” DSM stating the provider wanting her to try a chemotherapy, but her not feeling comfortable due to historical implications. She also states, “Stop using black women as lab experiments. We are not here for your study purpose. Like, don't tell me to go through chemo because you want to see what my reaction is. Like, that's wretched.” BMD also talks about her Mexican culture.

BMD talks about her Mexican culture. “We will always think that is not going to happen to us. It's like, we know people get sick, or whatever, but we always like, I think, as a Mexican person, we always think it is not going to happen to us because we're Mexican. And we can do everything. But that's wrong. Because this concept thing, breast cancer is real. And it can happen to anybody, like, no matter, like, how old are you? Or where are you from? Or if you're Mexican, or American or Asian, it doesn't matter. I mean, it can happen to any person.” BMD was 36 years old when she was diagnosed with breast cancer, as aforementioned.

As we learned in Chapter Two, distrust can occur in minority groups stemming from the past of the Tuskegee Experiment and Henrietta Lacks. There is documentation that at times minority groups may feel unheard or unsupported, or have to feel stronger than they need to be. This was also represented by the voices of the interviewees. These particular minority groups have cultural implications that could have an impact on the trajectory of early education, early diagnosis and treatment in breast cancer.

## **Support**

The women also emphasize the importance of support in their cancer journey. There was not much information regarding support, from family, or within the body of the facilities, but that

plays a huge role in the survivorship of the breast cancer patients who are trying to make it through.

CR expresses the importance of having a cancer buddy. “I met a friend in chemo. So, she was triple negative as well. And we went through the same treatment. We became good friends and we were there for each other. That's what if I could tell somebody, find somebody, you know, that's going through the same thing as you so you guys can talk about it and be there for one another because that really helps because nobody else knows what you're going through.” TD also had a similar experience.

TD states, “I did end up befriending someone [going through similar treatments]. There was something about her that, um, just stood out to me, and we've been friends ever since.”

YMD had similar support in her close network.

YMD states, “I think a combination of faith a combination of family, love, my husband, my kids, especially the kids, you fight hard for them cause you're like, my kids, no one can take care of my kids the way I take care of my kids.” She was 35 years old when she was diagnosed with TNBC. YMD is Puerto Rican, a wife, a mother of three great children. Dealing with handling the family, and working is a lot to handle.

### **Returning to Work / How Cancer is Viewed**

MC expressed her frustrations with returning to work and the whole concept of how others view cancer.

MC expressed, “And so I feel like treating all cancer like it the same way is such an unrealistic way to go about it; I feel like as a whole, the outlook towards cancer is old”. It seems like we all need to be educated or re-educated regarding the outlook on cancer, and how breast cancer

patients feel because not everyone feels the same, therefore, not every woman should be treated the same. While there was not literature stating this thought, it was significant to note. Additionally, the women expressed the need for basic and extensive education.

## **Education**

The women also expressed the importance of education before diagnosis, during and after.

CP stated, “Prior to the diagnosis, it would have been good to know about cancer, like I felt like I didn’t know a lot”. “I think that maybe if I or somebody educated me a little bit more about, risk factors and things like that, or if I read it, that would be good enough.” Additionally, MW also expressed the importance of education.

MW expresses the importance of education and family history, she states, “Education is important, know your family history.” JamRiv also talked about being educated about family history.

JamRiv speaks about knowing family history, “I think um, you know, it's just really important to know your family history and ask questions know, like, not just what they died from, but what they were diagnosed before. So, you know, some people now that I'm involved with advocacy, they think like that family member died of lung cancer or brain cancer, when come to find out it originated someplace outside. I think that's really, important. To understand and to, you know, if you have any of that cancer history in your family, start getting screened 10 years prior to that diagnosis, whether if it was on your mom's side or your dad's side.” This all stems from guidelines and recommendations.

We learned in Chapter Two that family cancer history is very important. It is important for the women to know who in their family had or has cancer, at what age they were diagnosed,

and what type of cancer he or she had or has. This type information determines the risk or likelihood of the woman being diagnosed with cancer. This information will also allow the woman to meet with a genetic counselor, start the process of genetic testing, and possibly, starting the screening process 10 years earlier than when the close relative was diagnosed with cancer.

### **Guidelines and Recommendations**

The women also had some insight regarding policy implementation, guidelines and recommendations.

MW expressing concern with the guidelines and recommendations, “But what made it 40 years old?” Feeling frustrated over the number the is set for insurance to cover women to starting having annual mammograms. CW also states also another guideline recommendation frustration.

CW states. “The one thing that I will say during the mammogram process, I had actually not had it the year before, because I was advised that I could wait two years.” YMD, also states her frustrations.

YMD states, “I know that they say mammograms, you're not supposed to get them till you're 40 and blah, blah, blah. I just feel like they should definitely have that, like, you get a pap smear, then I feel like you should just get a mammogram because potentially I could have found this years ago, they say that breast cancer is dormant, not dormant, it's growing. But before you find a lump, it's been in you for two to five years. Oh, imagine just getting it early, a mammogram or even an ultrasound or something, something that they can put you in through that just checks you know, even if it's every five years, five years is better than waiting till you're 40. You know, or right after you have kids, like, you know, I don't know, I just feel like they need to do a better job with that. Because 40 like, look how many people get breast cancer so early, you know,

and a lot of young people have cancer.” These findings are not consistent with the literature that I presented in Chapter Two because so many women are diagnosed with breast cancer prior to 40 years old.

We learned in Chapter Two, that The U.S. Preventive Services Task Force (USPSTF) found there was no difference in risk of women dying from breast cancer from the ages of 40 to 49 who had mammograms regularly, and if there was a difference, they found the difference to be very small (Susan G. Komen, 2020). This is where the age 40 stems from. The National Comprehensive Cancer Network (NCCN) agrees with the age, as well as The American Cancer Society (ACS). Unfortunately, the guidelines recommendations need to change so that women who are younger than 40 years old can have insured mammograms regardless of their family history, genetics, or other factors; because they too can also be diagnosed with breast cancer.

### **Insurance/Money Making**

There was also concern regarding insurance coverage, and the concept of hospitals simply making money off the patients during the time of their treatments.

SFR expressed, “I can't believe that you're treating me like I was just I don't know. It felt like it was about money at that point, and I know it is a business. But at that point, it wasn't about my treatment. It wasn't about my care.” MW also expressed her insurance coverage at the time.

MW stated, “One year went to like \$5,000 per person, with I think it was like a \$8, 000 collected deductible.” She is expressing what she went through with her insurance through her cancer treatments.

CR was unable to freeze her eggs due to the cost. “And then it came back like through like my insurance, a paper saying that they weren't paying for it. And it was like \$6,000. So, I'm

like, um, yeah, and I'm not paying.” CR was unable to freeze her eggs because she did not have the money to do so. Not realizing that there are so many costly elements that are associated before, after and during cancer treatments.

CR mentions, “I feel like people look at everybody as a number. Honestly, and I think it's all about money. But I think the main thing is everybody is just too busy.” JamRiv also had another perspective about insurance regarding how she could have paid a lot more. She is very thankful for her insurance coverage.

JamRiv talks about insurance coverage in the grand scheme of things. She states, “Sometimes, you know, scans sometimes or follow up tests and things like that and procedures, the highest I think was maybe \$500 or \$800 for a copay, but in the grand scheme of things, you know, it's much, much more expensive when you see the full bill.” Also the concept of not having insurance coverage upfront, and waiting until it happens.

TD explains how she felt her lump but waited to seek help until she had medical insurance. “I felt the lump in the summer. I just started a new job. Just so I yeah, I was waiting for medical coverage. I've been working all my life. So, I'm not thinking Medicaid at this point when I was laid off [to get screened earlier].” Or the concept of thinking medical providers just wanting to use the “good insurance” to rack up a bill.

JK expresses her providers wanting to perform further testing. “You're not poking me no more, because I started to feel like a pin cushion. And then I told him I'm like, looking at my insurance. You see, I have good insurance. So, you want to order every test under the sun.”

JK also stated, “They [her insurance] denied me of a PET scan. They were saying, you've had the MRI, the CAT scans. And a PET scan is basically just a more invasive CAT scan and

they were like, well, if you just had the CAT scan a week ago, you don't need the PET scan. And I was okay with them denying that.” There are times insurance denies claims, but in this case JK was okay with that because she already had a previous scan. There were times the women did have insurance, but there was other times, the women did not have insurance.

BMD did not have medical insurance, so she had to wait to be seen in a clinic. She states, “They always so busy, you know, because they help people that don't have insurance. And they have a wait-list. You know, it's not like, as soon as you call, you're going to have an appointment. You have to wait.” While it is apparent, insurance is not technically needed to receive screening, or care and treatment, when the woman does not have insurance, she waits longer to receive help.

JR when speaking about Medicaid insurance, she states, “I applied for Medicaid, and I was approved for the Medicaid. But once I got to Medicaid, I was limited to only my state of treatment. I couldn't really go anywhere else, because everything had to be pre-approved. And I found that the doctors didn't really want to go through all that. I mean, it is kind of upsetting because it's like, you want other choices, but because I live in Delaware, it's not many choices of where I can go. So, I found that with this state insurance, you're very limited to where you can go, especially in a smaller state. Whereas if I live, like nearby in Pennsylvania, it's better. I'm sure if I had state insurance there. It would be better because it's so many different doctors, providers there.” This is the frustration of having state insurance because you are confined to only your state to receive health care, unless you want to pay out-of-pocket costs and copays.

What we learned in Chapter Two is that the importance of health insurance is for ensuring positive healthy behaviors such as screening such as mammograms, and other diagnostic tools

(Shakib, et. al., 2019, p. 1); and women who reported of having no health insurance coverage were less likely to have reported a recent mammogram test compared to women who had private health insurance (Shakib, S. H., et. al., 2019, p. 4). Typically, when women have insurance, they are more likely to get mammograms, versus women who are not insured as described above by the interviewees, and what issues they faced.

Some of the potential barriers that the women faced was due to family responsibility and taking care of their families. Some of the women were the primary care giver and needed to help their families. Other women needed to wait to be insured by their employer or needed assistance applying for governmental help. Other potential barriers include the women not prioritizing themselves, and not being educated about breast cancer and healthy living and eating. Depending upon the woman's life other barriers included support and cultural implications. One of the biggest barriers is the recommendations and guidelines. Many of the women were told they were "too young" because there is a thought in minds that women can only get cancer at a certain age, therefore screenings may not be needed; though this information is false. The women that I interviewed were not "too young" for cancer, and therefore, the guideline recommendations would benefit from being modified so that women, regardless of their age, could receive adequate insured screening when needed.

### **Reflection**

The 21 women that I interviewed all came from various walks of life, but they all had certain variables in common, they were all younger than 50 years old when they were diagnosed, they are all women, and they all agree that early detection is what save their lives. Most of the women self-palpated their masses, and even when they might have been told they were "too

young” to have breast cancer, they advocated for themselves. These women had their husbands, children, family, friends, and medical staff support them. Though every story is different, the commonality is early detection—earlier than 40 years of age, and not having women skip a year just because of a previous clear mammogram. The other implication is what type of screening tool should be used when diagnosing young women with dense breasts; and how can providers get insurance companies on board to pay for more detailed screening, such as an MRI.

### **Public Policy Recommendations and Developing Theories**

The Affordable Care Act (ACA) requires most insurance companies to cover mammograms, every one to two years, at little to no out-of-pocket cost to women who are between the ages of 40-74 years of age. There are programs and grants that assist those who do not have insurance, and need mammograms. Additionally, public policy implications of this study in general and specifically with respect to the federal health reform is simple, if a greater scientific consensus were to be reached regarding the more appropriate screening frequencies for women of difference ages, policies could be amended accordingly (Bitler & Carpenter 2016, p. 21). Through the development and implementation of health policy, diagnostic 3D mammogram screening at little to no out-of-pocket cost could be mandated and would prevent potential barriers or gaps to women receiving care and treatment. The role of the insurance and insurance companies should be equitable and ethical to the women concerned about their breast health, regardless of the woman’s age.

The ethnographic research that took place would suggest that coverage of mammograms through the Affordable Care Act should extend to women in their twenties. Though there is limitation in interviewing 21 women, the importance is the age of their diagnosis and how and

why policy should be extended to them. Offering equality is no longer justified, equity is now the standard of care in terms of due process. Many of the women agreed that the recommended age should be lowered. The women thought that 40 years old should not be a standard number, but when a woman has a problem in her breast, it should be addressed; and it should be backed by policy, and covered by insurance, regardless of her age.

Universal healthcare could potentially aid in breast cancer prevention and catching breast cancer early or in its infancy. The World Health Organization (WHO) defines universal healthcare as “ensuring that all people have access to needed health services (including prevention, promotion, treatment, rehabilitation and palliation) of sufficient quality to be effective while also ensuring that the use of these services does not expose the user the financial hardship” (Zieff, Kerr, Moore & Stoner, 2020, p. 1). This was closely the goal of the Affordable Care Act (ACA), to ensure everyone has healthcare, and that there are preventative measures in place. Knowing the arguments against universal healthcare such as raising taxes, longer patient wait times, and big governmental interference. For the sake of this qualitative dissertation, we will focus on the benefits of such components of universal healthcare such as: reducing the vast health disparities that exist between differing socioeconomic status (SES) segments of the population and increasing opportunities for preventive health initiatives (Zieff, et. al., 2020, p. 1). This will help close the gap between younger women being diagnosed with breast cancer. Having a low SES is associated with many unfavorable health determinants, such as limited access to quality health insurance which can impact health outcomes and life expectancies (Zieff, et. al., 2020, p. 2). Therefore, it is said that those who are of that population are in most need of accessible, quality health

insurance (Zieff, et. al., 2020, p. 41). This particular group tends to be more unhealthy and uninsured, presumably.

Therefore, value-based care can be thought of as appropriate plan of action. For example, the ACA has worked with programs such as the Healthy People Initiative by targeting modifiable determinants of health including physical activity, obesity, and environmental quality (Zieff, et. al., 2020, p. 5). This aids in prevention and aids in money saving, as well as, saving lives. By getting women to exercise, and decrease their body mass index, decreasing their risk of developing such diseases such as breast cancer, as discussed in Chapter Two.

In terms of New Public Service (NPS), the medical providers should be committed to medical equity. New Public Service “urges that administrators focus on building public institutions marked by integrity, and responsiveness that serve and empower citizens by integrating citizen discourse and public interest into the decision-making process” (Denhardt, Denhardt, & Blanc, 2014, p. 400). From the interviews, the feedback is consistent with changing current public policy. This is the citizen discourse, and what starts the decision-making based on the interests of those affected. “The primary role of the public servant is to help citizens articulate and meet their interests rather than to attempt to control or steer society in new directions” (Denhardt, Denhardt, & Blanc, 2014, p. 400). This should be the goal of the government officials. The need of the people is to be able to seek an insured mammogram when medically necessary regardless of age.

That meets the interests of the people. “Public administrators must make the creation of a collective, shared notion of the public interest paramount” (Denhardt, Denhardt, & Blanc, 2014, p. 400). What is paramount is that statistically, women younger than 40 years old are being diag-

nosed with breast cancer. Therefore, it is the duty of the people to have the mammogram age lowered. More poignantly, “Policies and programs to meet public needs can be most effectively and responsibly achieved through collective efforts and collaborative processes” (Denhardt, Denhardt, & Blanc, 2014, p. 400). With the help of patients, medical providers, medical staff, insurance companies, and policymakers, the work can begin to make mammograms equitable for all women. “The public interest is the results of a dialogue about shared values rather than the aggregation of individual interests” (Denhardt, Denhardt, & Blanc, 2014, p. 400). This is what this qualitative dissertation did. It is the voice of shared opinions, thoughts, and beliefs of breast cancer survivors, who shared some commonalities.

Though they were all different and unique, a common consensus was they agreed the mammogram age should be lowered, and they all agreed they were diagnosed at a young age. “Public servants must be attentive to more than the market” (Denhardt, Denhardt, & Blanc, 2014, p. 400). There is so much more than money, and how much everything costs. Though that is absolutely important, and should be considered, lives are so much more important. “Public organizations and the networks in which they participate are more likely to be successful in the long run if they are operated through processes of collaboration and shared leadership based on a respect for all people” (Denhardt, Denhardt, & Blanc, 2014, p. 400). The ultimate goal is equity for all women, so that everyone's lives can be saved, regardless of age, or insurance coverage. Lastly, “The public interest is better advanced by public servants and citizens committed to making meaningful contributions to society” (Denhardt, Denhardt, & Blanc, 2014, p. 400). It is much better to help others in many ways (such as share their stories), so that policy makers, medical providers, and others can see the impact that such medical practices and policies are having on

real women's lives. Some components of Universal healthcare can close the health disparity gaps, and save many lives.

Equity in health policy and healthcare coverage should include aspects of participatory decision-making, advocacy from both the patient and the provider and patient-orientation. The main theories are community-owned government, customer-driven government, and anticipatory government. The goal of the community-owned government is to empower the community with the necessary tools to learn about breast cancer and advocacy to speak up for themselves when something is out of their normal. Education will be a driving factor in developing advocacy skills and building knowledge related to health conditions and treatment options. Customer-driven government is simply meeting the needs of the customer, or in this case, the patients. The purpose of this governmental insertion will garnish funding and therefore guarantee implementation. Lastly, anticipatory government may focus on trying to prevent the issue of breast cancer from arising at all; perhaps through education, scientific research, clinical trials, and policy change. From an education perspective, preventative measures will be allocated to teach the community strategies to decrease their breast cancer risk. Additionally, scientific research will propel clinical trials— and policies can be amended, changed and created to meet the needs of the people; such as lowering the mammogram age from 40 years old.

### **Possible Gaps**

The possibility of gaps from the breast cancer diagnosis to treatment can stem from screening age, health insurance, financial responsibility, familial responsibility, education/ women's awareness, and distrust. MC, CP, CR, LynMit, DD, DSM were all told they were “too young” too have breast cancer by a medical provider, and though necessary steps were eventual-

ly taken to diagnosis their breast cancers, had they have waited—they may have not been here to tell their stories. Similarly, the screening age recommendation starts at the age of 40 years old, but these women other than one were all less than 40 years old prior to their diagnosis. CW was told after a clear mammogram that she could wait two years to have a repeat screening. She was later diagnosed with breast cancer. The potential gap is age and how young women can be hindered from receiving mammography's and preventive screenings. Another potential gap is health insurance and financial responsibility.

BMD and MV did not have insurance before their diagnosis and therefore had to wait once they discovered their lumps to obtain some sort of insurance help. BMD had a difficult time because even when she sought help, the free clinic was booked to capacity, so she had to wait. TD and JamRiv both waited a period until they had medical insurance from their jobs to seek help. JamRiv also had to take on the familial responsibility of being the breadwinner of her family and the insurance carrier; therefore, not working the entire time of treatments. The potential gap in terms of insurance coverage and familial responsibility is that it can hinder when women get seen for their breast health. BMD and MV had to wait for a period because they had no medical insurance. TD and JamRiv had to wait because they started new jobs and needed to wait until the probationary period was over. In terms of family responsibly the women put their families first and focus on themselves last. BMD and JamRiv actively took care of their families before self-prioritizing themselves. All the women needed to be truly aware and educated about the topic of breast cancer.

The topic regarding breast health and breast cancer is a potential gap. The women seem to not understand the true gravity of it, and that may be due to providers downplaying because of

their age. CP, MW, CW, KB mentioned that they wish they knew more about breast cancer, breast health, and the overall process from diagnosis to treatment and everything in-between. CW mentioned it would be helpful to know what questions to ask because everything was so new to her, she did not know what she needed to know or what to ask. Questions are especially important due to mistrust.

TD and DSM both mentioned cultural differences in which medical providers should be cognizant of because it can create a gap in terms of screening, diagnosis and treatment. DSM especially mentioned the Tuskegee experiment and how that distrust in the medical community still holds true today within the culture to some degree. That potential gap should be known so a space of trust can be created between patient and provider.

### **Patient-Provider Relationship**

Patients need to be able to trust their medical providers. Medical providers need to be able to trust that the patients know and understand their body. When a patient presents to the medical provider, there needs to be trust between the two parties to solve the issue. The theory of attachment rings true within the patient-provider relationship. Attachment theory and attachment styles can be defined as working models or patterns of how individuals' function and interact within significant relationships (Kelly, E. P., Tsilimigras, D. I., Hyer, J. M., & Pawlik, T. M., 2019, p. 102). The attachment theory formally was based from mother and infant, and how the infant looks to the mother for nutrients and guidance. The same is true in the patient-provider theory. The infant or patient looks to the mother or provider for assistance because the provider is the one who can help. Attachment behaviors are often triggered when an individual attempt to seek comfort and security to cope with triggering stressful situations such as a cancer diagnosis

(Kelly, E. P., et. al., 2019, p. 103). Knowing this the provider can be aware of the role that he or she plays in the patient's life and what type of reaction the patient may have, and why they have that reaction.

Both parties need to somewhat be attached or understand/trust one another to a level of completion and comfort. Especially in the context of patient-provider relationship relating to breast cancer—the cancer diagnosis is very emotional and nuanced; it is a long journey and the patients are with their providers for a long time (Kelly, E. P., et. al., 2019, p. 101). That reason alone, the relationship must be trustworthy and attached. It is imperative that providers are sensitive to the topic of breast cancer, and the topic of narrative medicine. Secure attachments within the patient-provider relationship have been associated with better treatment outcomes (Kelly, E. P., et. al., 2019, p. 102). Insecure attachments relate to negative treatment outcomes and patient-provider relations (Kelly, E. P., et. al., 2019, p. 102).

## **Chapter Five: Conclusion**

The significance of this qualitative dissertation is to determine: What are women's early experiences in their cancer diagnosis; and are there any components serving as barriers to their treatment? Public policy refers that states are mandated to pay for women's mammograms at the age of 40 years old and older, annually (can vary), per The American Cancer Society (ACS), The National Comprehensive Cancer Network (NCCN), and The U.S. Preventive Services Task Force (USPSTF); therefore, increasing mammogram utilization. The issue is there needs to be an addendum to the guidelines for women less than 40 years of age due to certain risk factors, such as, age, family cancer history, genes, menstrual status, oral contraceptive use, birth history, lack of education, age of first and last birth, and maternal smoking.

This qualitative dissertation aimed to research if there were gaps, and if so, how to lessen them by way of women's awareness, patient-provider relationship/interaction, prevent possible barriers, amend recommendations, insurance protocols, and screening guidelines.

### **Major Findings and Recommendations**

There were many themes that emerged from the interviews such as women being "too young to get breast cancer," familial responsibility, prioritizing self, cultural implications, support, self-examinations, patient-provider relationship, religion/spirituality, accurate/adequate screening tools (diagnosis tools), how cancer is viewed, education, guidelines and recommendations, earlier diagnosis, privacy, insurance/money making, and genetics. The themes that are most pressing are race and age, diagnostic tools, patient-provider relationship, the role of public policy and insurance coverage.

Black women have the highest breast cancer incidence rate before age 40 years and are most likely to die from breast cancer at every age (Desantis et al., 2019). Public policy/health care insurance policy should reflect this health disparity in cancer incidence and mortality; Black women under the age of 40 should be screened very closely. My interviews reinforced that although Black women have been found to be disparately impacted, women of all races are developing breast cancer before the age of 40. Based on these interviews, I recommend that although Black women should have additional screening and health care options, women of other races should not be excluded.

Other findings were discussed, such as the topic of diagnostic tools and MRI utilization. A policy that could be updated to address this is using MRIs as the first line of defense, if a woman is known to have dense breasts; or after a mammogram is performed, and it is seen that her breasts are dense, a MRI should be performed. MRIs are more expensive upfront, from a cost-effectiveness point-of-view; but from a lifesaving perspective, it is priceless. Therefore, tighter healthcare administration need to be performed. For example, many women fill out paperwork about family history, but nothing is usually done about it until the woman is diagnosed. In terms of healthcare administration, there should be a system in place to alert medical personnel if a women has a close family cancer history, and other key components that will aid in detection, and possible prevention. Bitler and Carpenter would agree in their concluding assessment that, “If a greater scientific consensus were to be reached regarding the most appropriate screening frequencies for women of different ages, policies could be amended accordingly.” (Bitler and Carpenter, 2016, p. 21). Additionally, healthcare reform increases mammography screening utilization, and prevents no deductibles for preventative care. This will

change and help with inequities. The inequities of women not receiving adequate healthcare due to their age, or insurance coverage. By removing those barriers, eliminates the gaps, and provides equitable healthcare for the population that is need of mammograms. In addition, the role of the patient-provider relationship is imperative.

The theme of the patient-provider relationship emerged frequently. The approach of the paternalistic model emerged at times. This approach emerges when the doctor drives the trajectory of the patients care. The majority of the time, what was found, the patient, and the provider were found to be involved in the deliberate approach, as is described in Chapter Two. While the woman primarily advocated for herself, the medical provider also agreed with their medical expertise to take certain steps toward finding common ground. Interestingly, women who advocated for themselves, and the providers who took a paternalistic approach all came to the same conclusion, around the same time. The difference is the women who were advocates, pushed through medical barriers, compared to the women who listened to their providers; who for example were told to wait because they were “too young” for breast cancer. Public policy could create a more equitable experience so that these differences are not an influential of a driver of patient screening outcomes by promoting research in language and communication tools. This would eliminate barriers between any approach and women receiving appropriate care.

The role of public policy in promoting equity in access to early screenings and often given the conceptual framework for the patient-provider relationship provided by Kelly (2019) result in understanding, researching, and concluding from the patients behaviors and needs. This is a huge component that is missed. Patients behaviors are based in many respects to what they

need, from a macro-level or mirco-level. Women need covered mammograms regardless of their age. They also need providers that are on the same page with them. All of these components determines the success and trajectory of treatment and prognosis, in some respects. Perhaps public policy should be informed by the attachment theory in order to improve equity in access to screening for all women early and often. That looks like mandating the early breast health education. Public policy could be improved to account for insecure or avoidant attachment types and the ways that patient-provider relationships are impeded by that. This way women who are in need of the paternalistic approach receives the same care as those who are more deliberate.

In Chapter Four, there were women who did not seek medical attention immediately due to lack of insurance, starting a job and waiting for the insurance to kick in, and simply needing to prioritize their families first. There needs to be an employment related policy that could help women to feel that their jobs are protected or that they are entitled to go to appointments. Many women under treatment would feel rushed because they had to get back to work, or needed to know exactly when they were finished all of their treatments because they needed to return to work. The entire mindset was on work, and not on themselves, healing their bodies. There is FMLA and disability, but that is only covered for 12 weeks, unpaid, in the calendar year. It is very difficult for patients to tolerate that. Treatments can last longer, and the remnants of the treatments can last even longer than that. Sick leave policies for different kinds of jobs/employers impact their preventative health care behaviors depending on the job services such as nannies and home-aid care. Public policy should be implemented so the patients are receiving an adequate percentage of their income, and are able to recuperate and recover during and after treatments, when needed.

In terms of public policy, it is important to bring the themes of the interview and policy in full circle. Public policy recommends all women starting at the age of 40 years old receive a screening mammogram. Due to this policy, states in the United States of America, are mandated to cover a women's annual mammogram whether the woman has insurance or not. If the woman does not have insurance, hospitals and clinics, have funding to provide free screenings. If the woman has a clear mammogram, it is her decision to wait another one to two years for a repeat screening. The issue with this policy is that women under the age of 40 are being diagnosed with breast cancer. Now, there are some caveats from younger women receiving insured mammography screening—if the woman has a family history of certain cancers, has been exposed to radiation, is a BRCA1 or BRCA2 carrier or other predetermined genetics, and alike. While this is a great loophole, the problem is it is not equitable for the women who do not fit into any of these categories, but have been diagnosed with breast cancer. The goal in public policy is to make policies that are equitable and not based on equality.

Equality gives everyone the same opportunity. For this policy, the blanket statement is if you are 40 years older, unless otherwise noted, you can receive an insured mammogram. Equity gives women who may not have the same resources, or education, alike the same opportunities, every other woman would receive. For example, the policy could change to: Women who have an issue with their breasts are able to receive an insured 3D mammography. If any of those women are high risk, they should receive either a 3D mammogram, including an ultrasound and maybe a breast MRI. There needs to be a shift in equality policy to equity policy. Some components of Universal healthcare can be implemented to help close the disparity gap and make

healthcare more equitable. Also components of the New Public Service (NPS) would help aid in such a plight.

### **Limitations and Directions for Future Research**

The limitations of this qualitative dissertation stems from the amount of breast cancer survivors that were interviewed. The number of 21 participants limits the amount pertinent and sound information. Another approach that could have been utilized is through a case study approach where each participant or one participant and their story would be carefully and succinctly analyzed for the sake of policy reform and recommendation.

For future research hospitals and clinics could be involved in research to determine how many women under the age of 40 are being diagnosed with breast cancer and what are their early experiences. Do they have a family cancer history? If yes, did they know their family cancer history before their diagnosis? Did they self-palpate their mass? Were they told they were “too young” for cancer? Also, a survey could be conducted to breast cancer survivors following the themes that arose in the interviews. What are their thoughts on genetics? If they are African American, do they know what country they come from in Africa? Do they have dense breasts? Did they receive a 3D mammogram, and did it show malignancy the first time of screening? Did they have a follow-up breast MRI for further detection?

### **Concluding Thoughts**

I recommend young women feel their breasts. I recommend that medical providers listen to their young patients when they are present with a problem. I recommend that because younger

women have dense breast tissue and when 3D mammography is not clear, breast MRI is the screening line of defense. I also recommend that women are educated regarding breast health and finding ways on how to decrease their risks of developing breast cancer. Policy reform needs to change the line of defense of breast screening and the age the women are screened.

Currently the recommendations states screening to being at the age of 40 years old unless the woman is at high risk, such as has a family history of cancer. The reform needs to incorporate women who are at average risk, and those who are less than 40 years old because they are being neglected. I recommend that women are educated about breast health and preventative measures regarding breast cancer. Women also need to have the option of receiving 3D mammography regardless of their age if they seek help to their medical provider regarding a suspicious finding. If the palpable finding is not clearly defined, then I recommend an ultrasound, but ideally a breast MRI for clarity and distinction. Too many of the women that were interviewed shared that it was not until they had their breast MRI that their cancer was clearly identified. Mammograms detect breast cancer, and if it cannot perform its job, another route must be utilized.

Additionally, insurance companies should not dictate the coverage of a woman's suspicious finding. If a woman finds that something is wrong with her breast, regardless of her age, or insurance status, she should have it checked out. The goal in policy reform is to make a difference, and in making the difference of changing the mammography age, or diagnostic tools, and determining insurance coverage will ultimately save millions of women's lives and make the difference. It is paramount that education and preventative measures are implemented, but without the support of reform, change will only go so far.

Existing policy states that women are recommended to have mammography screening annually starting at the age of 40 years old, unless at high risk; which includes having a family history of certain cancers such as breast and ovarian. I seek to revise that policy to state that women should have annual mammograms starting at the age of 30 years old as mandated. Additionally, for women who were diagnosed with breast cancer prior to the age of 30 years old, and palpated their mass, policy should be revised to allow medical insurance to cover their screening mammography, ultrasound and/or MRI. The existing programmatic changes that should be made include medical insurance coverage for the women who are not 30 years old or older, and either pay a small copay or are covered to received proper screening.

There are many programs that should implemented and funded federally and locally to help decrease the risk of women developing breast cancer. There needs to be more educational resources to educate women who to decrease their risk, such as: eating healthier, exercising, not smoking, reducing the amount of alcohol and sugary drinks, and maintaining a healthy body weight (Helen F. Graham Cancer Center Advisory Board, 2020). These types of resources are monumental in the fight and knowledge against breast cancer. In the interviews, it was noted that some women did not know much about breast cancer prior to their diagnosis, and would have liked to understand ways to decrease their risk. Some felt, if they were educated prior to their diagnosis, maybe they would have not been diagnosed.

Additionally, another program should be in place for women who do not have insurance and are uncertain if they would be able to receive diagnostic screening. Educating young women, and all women alike, the risks of breast cancer, how to feel on their breasts and look at their breasts, focus on their bodies, understand insurance (and dispel myths), give them adequate ques-

tions when meeting with their medical provider (and how to make their visit useful and successful), understand the importance of knowing their family cancer history, the differences between diagnostic tools (mammography, ultrasound, MRI), treatment options, support groups, genetics, family and cultural support, language support and host of other educational resources to help women successful to prevent cancer and in their fight of breast cancer. Education is the cornerstone of the success in breast cancer prevention, and treatment.

Women's early experiences were paramount. They experienced some barriers, but through advocacy and patient-provider relationship they were able to share their stories and help others in their journey of care. Therefore, I remember, love, value, and admire all these women who have gone before me, and who are in the present who have battled breast cancer with every bit of dignity, grace and strength they had in them. This qualitative dissertation sought out barriers and gaps to prevent deaths in women, and especially women who are younger than 40 years old. The point is to strengthen and awaken the relationship between the patient and the medical provider, so that the trajectory of treatments is lifesaving, not life ending. It is important to catch breast cancer in its' infancy through screening and detection, and when this is done, regardless of the risks, it can be maintained just like other diseases.

Therefore, I recommend for the mammography screening to be equitable and fair. Women who are 30 years old should be able to have diagnostic mammography screenings, and covered. Women who are not 30 years old, but confide in their medical providers about a breast issue, should also be able to have mammography screenings, covered, regardless of her age and insurance status. The goal of public policy is to benefit the whole, and to do that, equity must be implemented, and fairness.

## References

- Albrektsen, G., Heuch, I., Tretli, S., & Kvåle, G. (1994). Breast Cancer Incidence before Age 55 in Relation to Parity and Age at First and Last Births: A Prospective Study of One Million Norwegian Women. *Epidemiology*, 5(6), 604-611. Retrieved January 8, 2021, from <http://www.jstor.org/stable/3702297>
- Bitler, M. P., & Carpenter, C. S. (2016). Health Insurance Mandates, Mammography, and Breast Cancer Diagnoses. *American Economic Journal: Economic Policy*, 8(3), 39-68. doi:10.1257/pol.20120298
- Chakravarthi, B & Varambally, S. (2013). Targeting the link between late pregnancy and breast cancer. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3874101/pdf/elif01926.pdf>
- Chen, Y., Susick, L., Davis, M., Bensenhaver, J., Nathanson, S. D., Burns, J., & Newman, L. A. (2020). Evaluation of Triple-Negative Breast Cancer Early Detection via Mammography Screening and Outcomes in African American and White American Patients. *JAMA Surgery*, 155(5), 440. doi:10.1001/jamasurg.2019.6032
- Churilla MD, T. M., Egleston PhD, B., Bleicher MD, R., Dong MD, PhD, Y., Meyer MD, J., & Anderson MD, P. (2016). Disparities in the Local Management of Breast Cancer in the US according to Health Insurance Status. *The Breast Journal*, 23(2). doi:<https://doi.org/10.1111/tbj.12705>
- Denhardt, R. B., Denhardt, J. V., & Blanc, T. A. (2014). Public administration: An action orientation. Boston, MA: Wadsworth, CenGage Learning.

- DeSantis, C., Ma, J., Gaudet, M., Newman, L., Miller, K., Sauer, A., Jemal, A., Siegel, R. (2019, October 02). Breast cancer statistics, 2019. Retrieved June 28, 2020, from [https://acsjournals.onlinelibrary.wiley.com/doi/pdf/10.3322/caac.21583@10.1002/\(ISSN\)1097-0142.breastcancercol-lection](https://acsjournals.onlinelibrary.wiley.com/doi/pdf/10.3322/caac.21583@10.1002/(ISSN)1097-0142.breastcancercol-lection)
- Desreux, J. A. (2018). Breast cancer screening in young women. *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 230, 208-211. doi:10.1016/j.ejogrb.2018.05.018
- Guo, F., Kuo, Y., Shih, Y. C., Giordano, S. H., & Berenson, A. B. (2018). *Trends in breast cancer mortality by stage at diagnosis among young women in the United States. Cancer*, 124(17), 3500-3509. doi:10.1002/cncr.31638
- Guy, M. E., & Rubin, M. M. (2015). *Public administration evolving from foundations to the future*. New York, NY: Routledge.
- Hagiwara, N., Lafata, J. E., Mezuk, B., Vrana, S. R.,; Fetters, M. D. (2019, April 19). Detecting implicit racial bias in provider communication behaviors to reduce disparities in healthcare: Challenges, solutions, and future directions for provider communication training. Retrieved August 17, 2020, from <https://reader.elsevier.com/reader/sd/pii/S0738399119301429?token=8FA2532A3EEDBE157CA61AB93E2075DF6C23EC9E1AB028EB830F71412B1B-B13D55C9562477CB870E712093D473FEAA5D>
- Helen F. Graham Community Advisory Board (2019) PowerPoint Presentation
- Jones, M. E., Schoemaker, M. J., Wright, L. B., Ashworth, A., & Swerdlow, A. J. (2017). *Smoking and risk of breast cancer in the Generations Study cohort. Breast Cancer Research*, 19(1). doi:10.1186/s13058-017-0908-4
- Kelly, E. P., Tsilimigras, D. I., Hyer, J. M., & Pawlik, T. M. (2019). Understanding the use of attachment theory applied to the patient-provider relationship in cancer care: Recommenda-

- tions for future research and clinical practice. *Surgical Oncology*, 31, 101-110. doi:10.1016/j.suronc.2019.10.007
- Litosseliti, L. (2018). *Research methods in linguistics*. London, UK: Bloomsbury Academic, Bloomsbury Publishing Plc.
- National Breast Cancer Foundation, Inc. (2019). Types Archives. Retrieved August 30, 2020, from <https://www.nationalbreastcancer.org/types-of-breast-cancer/>
- Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). *How phenomenology can help us learn from the experiences of others. Perspectives on Medical Education*, 8(2), 90-97. doi:10.1007/s40037-019-0509-2
- Olsson, H. L., & Olsson, M. L. (2020). *The Menstrual Cycle and Risk of Breast Cancer: A Review. Frontiers in Oncology*, 10. doi:10.3389/fonc.2020.00021
- Partridge, A. H., Hughes, M. E., Warner, E. T., Ottesen, R. A., Wong, Y. N., Edge, S. B., Theriault, R. L., Blayney, D. W., Niland, J. C., Winer, E. P., Weeks, J. C., & Tamimi, R. M. (2016). Subtype-Dependent Relationship Between Young Age at Diagnosis and Breast Cancer Survival. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*, 34(27), 3308–3314. <https://doi.org/10.1200/JCO.2015.65.8013>
- Recio-Saucedo, A., Gilbert, A., Gerty, S., Cutress, R., Eccles, D., & Foster, C. (2018). “It’s Like We Don’t Exist”: Tailoring Education for Young Women Undergoing Surgery for Early-Stage Breast Cancer. *Oncology Nursing Forum*, 45(2), 165-175. doi:10.1188/18.onf.165-175
- Shakib, S. H., Inungu, J., & Jahanfar, S. (2019). Factors associated with Breast Cancer Screening among Women in the United States. *Journal of Public Health Issues and Practices*, 3(2). doi:10.33790/jphip1100144

- Sims-Mourtada, J., Catts, Z. A., Swanson, P., & Katurakes, N. (2019). Engaging African Americans in Breast Cancer Prevention Strategies: A Partnership Between a Community Cancer Center and the African American Community in Delaware. *Cancer Studies and Molecular Medicine – Open Journal*, 5(1). doi:10.17140/csmmo-5-e007
- Sisti A, Huayllani MT, Boczar D, Restrepo DJ, Spaulding AC, Emmanuel G, Bagaria SP, McLaughlin SA, Parker AS, Forte, AJ. (2020). Breast cancer in women: a descriptive analysis of the national cancer database. *Acta Bio-medica : Atenei Parmensis* 91(2):332-341. DOI: 10.23750/abm.v91i2.8399.
- Susan G. Komen (2020)
- Tompkins, J. (2005). Organization theory and public management. Australia: Thomson Wadsworth.
- Trevino, A. J. (2018). The Cambridge handbook of social problems. Volume 1. Cambridge: Cambridge University Press.
- Vygotsky, L. S. (1978). Mind in society.
- Zhao, G., Okoro, C. A., Li, J., & Town, M. (2018). Health Insurance Status and Clinical Cancer Screenings Among U.S. Adults. *American Journal of Preventive Medicine*, 54(1), e11–e19. <https://doi.org/10.1016/j.amepre.2017.08.024>
- Zieff, G., Kerr, Z. Y., Moore, J. B., & Stoner, L. (2020). Universal Healthcare in the United States of America: A Healthy Debate. *Medicina*, 56(11), 580. doi:10.3390/medicina56110580

## Appendix

[A]



Office of Research and Sponsored Programs | West Chester University | Wayne Hill  
West Chester, PA 19380 | 610-836-2557 | [www.wcupa.edu](http://www.wcupa.edu)

**Protocol ID # 20210411A**

*This Protocol ID number must be used in all communications about this project with the IRB.*

TO: Mia Bailey and Kristen Crossney  
FROM: Nicole M. Cattano, Ph.D.  
Co-Chair, WCU Institutional Review Board (IRB)  
DATE: 09/11/2020

**Project Title: Federal Health Reform: Breast Cancer Outcomes**

**Date of Approval: 9/11/2020**

**Expedited Approval**

This protocol has been approved under the new updated 45 CFR 45 common rule that went in to effect January 21, 2019. As a result, this project will not require continuing review. Any revisions to this protocol that are needed will require approval by the WCU IRB. Upon completion of the project, you are expected to submit appropriate closure documentation. Please see [www.wcupa.edu/research/irb.aspx](http://www.wcupa.edu/research/irb.aspx) for more information.

*Any adverse reaction by a research subject is to be reported immediately through the Office of Research and Sponsored Programs via email at [irb@wcupa.edu](mailto:irb@wcupa.edu).*

**Signatures:**

A handwritten signature in black ink, appearing to read "Nicole M. Cattano".

Co-Chair of WCU IRB

WCU Institutional Review Board (IRB)  
ORG#: ICR0004242  
IRB#: IR190005090  
FAR#: FWA120114155

## [B] Consent Guide

### Project Title: Federal Health Reform: Breast Cancer Outcomes

Investigator(s): Nia Bailey, M.A.Ed., RT(T); Kristen Crossney, PhD

#### Project Overview:

Participation in this research project is voluntary and is being done by Nia Bailey, M.A.Ed., RT(T) as part of her Doctoral Dissertation to determine what are women's early experiences with their medical providers who have been diagnosed with breast cancer? Also, to determine if there are components of their early experiences functioning as barriers to getting treatment? If you would like to take part, West Chester University requires that you agree and sign this consent form.

You may ask Nia Bailey, M.A.Ed., RT(T) any questions to help you understand this study. If you don't want to be a part of this study, it won't affect any services from West Chester University. If you choose to be a part of this study, you have the right to change your mind and stop being a part of the study at any time.

#### 1. **What is the purpose of this study?**

- Determine what are women's early experiences with their medical providers who have been diagnosed with breast cancer? Also, to determine if there are components of their early experiences functioning as barriers to getting treatment?

#### 2. **If you decide to be a part of this study, you will be asked to do the following:**

- Complete interview
- This study will take about 45 minutes to 1 hour of your time.

#### 3. **Are there any experimental medical treatments?**

- No

#### 4. **Is there any risk to me?**

- Possible risks or sources of discomfort include of discomfort that are associated with this interview that can stem from the conversation regarding the topic of the participants breast cancer journey. The questions have the potential to stir otherwise latent feelings that the participants had. If that were to occur, the interview may cease at any time. The participant has the right to decide not to want to proceed further in the interview process, and furthermore no longer giving consent for information. Additionally, resources to the American Cancer Society and Susan G. Komen are links that will be presented to the women, if they need assistance. Additionally, a confidentiality breach will not occur on behalf of the researcher. The researcher takes ethics, and the consent process very seriously, and in no way will break the agreement between researcher and participant
- If you become upset and wish to speak with someone, you may speak with American Cancer Society and/or Susan G. Komen

- If you experience discomfort, you have the right to withdraw at any time.
5. **Is there any benefit to me?**
- Benefits to you may include: no direct benefit to participants. The participants may feel a sense of purpose being a part of research bigger than them that will contribute knowledge that might assist in providing recommendations for breast cancer treatment and policies in the future
6. **How will you protect my privacy?**
- The session will be recorded.
  - Each participant will be given a username (their initials, approximate age, and date the interview was conducted; for example, NB2706302020) and password for the meeting space. The patient has the option to not use video, if she does not feel comfortable with doing so. After the interview, the file will be saved under the patients initials and date of the meeting and transcribed by Otter. I will only send the audio portion of the Zoom interview through Otter for transcription, without the video component. Otter is a safe artificial intelligence (AI) service that transcribes dialogue. This is a safe and secure platform in which no other person will have access to the interview but the researcher.
  - Your records will be private. Only Nia Bailey, M.A.Ed., RT(T), Kristen Crossney, PhD, and the IRB will have access to your name and responses.
  - Your name will **not** be used in any reports.
  - Records will be stored:
    - Password Protected File through Qualtrics
  - The names of the breast cancer patients will not be used. Their initials will be used instead. Also, as aforementioned, each participant will be given a username (their initials, approximate age, and date the interview was conducted; for example, NB2706302020) and password for the meeting space. The audio file of the Zoom interview will only be sent to the Otter transcription company. The information will be destructed 3 years after completion of the manuscript. The signed originals will of the informed consent forms will be stored through Qualtrics. Dr. Crossney and I, Nia Bailey, will be the only ones to have access to the consent documents and data. The data will be stored through Qualtrics and secured by measures of using a password that only we have access to. The participants initials and the date that they are being interviewed will be used. The computer will be stored at 9-3 Wilde Ave. Drexel Hill, PA 19026.
  - Records will be destroyed Three Years After Study Completion
7. **Do I get paid to take part in this study?**
- No
8. **Who do I contact in case of research related injury?**

- For any questions with this study, contact:
  - **Primary Investigator:** Nia Bailey, M.A.Ed., RT(T) at 267-886-5471 or NB744036@wcupa.edu
  - **Faculty Sponsor:** Kristen Crossney, PhD at 610-430-5838 or kcrossney@wcupa.edu

9. **What will you do with my Identifiable Information/Biospecimens?**

- Not applicable.

For any questions about your rights in this research study, contact the ORSP at 610-436-3557.

I, \_\_\_\_\_ (your name), have read this form and I understand the statements in this form. I know that if I am uncomfortable with this study, I can stop at any time. I know that it is not possible to know all possible risks in a study, and I think that reasonable safety measures have been taken to decrease any risk.

\_\_\_\_\_  
Subject/Participant Signature                      Date: \_\_\_\_\_

\_\_\_\_\_  
Witness Signature                                      Date: \_\_\_\_\_

## [C] Interview Guide

Nia: Thank you again for taking the time to participate. Just a quick overview, the purpose of this interview is to understand your early experiences with your medical provider, and to see how that translated into treatment and diagnosis. Quickly, I want to confirm with a *yes or no*, that you have signed consent— and you understand at any point during the interview you have the right to not answer any question or stop the interview.

**Participant:** [Insert Answer]

Nia: Great! Let's get started!

Nia: What type of provider/doctor did you see before your diagnosis? GYN? Family medicine? Or did the doctor find your tumor during a routine visit?

**Participant:** [Insert Answer]

Nia: Did you feel that you had a problem (lump or pain) or did your doctor find a lump?

**Participant:** [Insert Answer]

Nia: What was your thought process? Did you have support?

**Participant:** [Insert Answer]

Nia: Ok, lead me on that journey from the moment of discovery. How long did it take you to get screened?

**Participant:** [Insert Answer]

Nia: What type of imaging did you get? Mammogram? Ultrasound? MRI?

**Participant:** [Insert Answer]

Nia: Do you have dense breasts?

**Participant:** [Insert Answer]

Nia: What was your experience in those early conversations with your doctor? Did you have to wait to have a biopsy?

**Participant:** [Insert Answer]

Nia: When did you find out about your diagnosis? Do you remember that moment? Tell me about it.

**Participant:** [Insert Answer]

Nia: How old were you when you were diagnosed?

**Participant:** [Insert Answer]

Nia: Do you know what type and what stage of breast cancer you have/had?

**Participant:** [Insert Answer]

Nia: Did you choose to have a lumpectomy, or mastectomy? Why? If you had a mastectomy, did you choose to get implants? Why or why not?

**Participant:** [Insert Answer]

Nia: What was your course of treatment?

**Participant:** [Insert Answer]

Nia: Did you have genetic testing performed? If so, in what part of the process did you have this done? What were the results?

**Participant:** [Insert Answer]

Nia: Do you have a family history of cancer? At what age were they when they were diagnosed?

**Participant:** [Insert Answer]

Nia: Did you know your family history prior to being diagnosed?

**Participant:** [Insert Answer]

Nia: Do you feel you lived a healthy life? Did you smoke prior to your diagnosis? If so, at what age? For how many years?

**Participant:** [Insert Answer]

Nia: Do you think clinical trial are important? Have you enrolled in one? Are you currently enrolled in one? Would you ever enroll in one?

**Participant:** [Insert Answer]

Nia: Do you have a religion? If so, has that helped you through your journey?

**Participant:** [Insert Answer]

Nia: Are you finished your cancer treatment journey? If no, what is next?

**Participant:** [Insert Answer]

Nia: Do you have children? Want children? Want more children? After diagnosis and treatment?

**Participant:** [Insert Answer]

Nia: If you have children, how old were you when you gave birth to your children?

**Participant:** [Insert Answer]

Nia: If you want children, did you freeze your eggs? Why or why not? Also, how long do you have to wait to start the childbearing process?

**Participant:** [Insert Answer]

Nia: Have you ever been on birth control? For how long?

**Participant:** [Insert Answer]

Nia: How old was your mother when she birthed you?

**Participant:** [Insert Answer]

Nia: Did you have insurance prior to your diagnosis? Did you ever have to pay a copay or deductible? Was it affordable?

**Participant:** [Insert Answer]

Nia: Has your insurance ever denied you of a procedure—specifically screening? Or type of screening? Was it due to your age?

**Participant:** [Insert Answer]

Nia: What was your occupation prior to your diagnosis?

**Participant:** [Insert Answer]

Nia: Did you work while going through treatment? Why or why not?

**Participant:** [Insert Answer]

Nia: What was your relationship status prior to your diagnosis?

**Participant:** [Insert Answer]

Nia: What would you wish was different about the early process?

**Participant:** [Insert Answer]

Nia: Are you aware that depending on your family cancer history, and genetic testing, you could have received screening earlier in your life, according to policy guidelines?

**Participant:** [Insert Answer]

Nia: To wrap up, is there anything else you would like to share about your story?

**Participant:** [Insert Answer]

Nia: Thank you so much for allowing me to interview you about this sensitive time in your life. I look forward to highlighting in my dissertation your voice and why your life absolutely matters. Also, as aforementioned, please know that this interview is confidential, and will only be shared with *Otter* for transcription (with your initials) and for the purposes of my dissertation. Just a little secret, my hope in this interview is to change screening tools and policy; which is why my research questions are: What are women's early experiences with their medical providers who have been diagnosed with breast cancer? Are components of their early experiences functioning as barriers to getting treatment? My hope is that the answers to the questions will guide policy makers into a direction that is always patient centered. That shift will hopefully guide change in policy. Thanks again!

[D] **Support Groups**

**Susan G. Komen Philadelphia**

125 South 9th Street, Suite 202  
Philadelphia, PA 19107

Phone 215-238-8900/Fax 215-238-1419

<https://komenphiladelphia.org>

**American Cancer Society**

N/A

1-800-227-2345

<https://www.cancer.org>

[E] **The National Comprehensive Cancer Network (NCCN)**

<b>Problem</b>	<b>Age</b>	<b>Frequen- cy</b>	<b>Clinical Breast Exam</b>	<b>Screening Tool</b>
Lobular carcinoma in situ (LCIS)	Varies	Varies	Every 6-12 months they have a clinical breast exam;	Every year starting at age 30 a mammogram, and depending on the woman's provider, a breast MRI starting at age 25
Atypical hyperplasia	Varies	Varies	Every 6-12 months they have a clinical breast exam	Every year starting at age 30 a mammogram, and depending on the woman's provider, a breast MRI starting at age 25.
BRCA1 or BRCA2 gene mutation	Women 30 years old or older, it is recommended that every 6-12 months they have a clinical breast exam; and every year have a mammogram and breast MRI performed	Varies	Under the age of 25, it is only recommended to have a clinical breast exam every 6-12 months	For women between the ages of 25-29, it is recommended that every 6-12 months they have a clinical breast exam; every year have a breast MRI performed, and if an MRI is not available then a mammogram

<b>Problem</b>	<b>Age</b>	<b>Frequen- cy</b>	<b>Clinical Breast Exam</b>	<b>Screening Tool</b>
Women who have a first degree relative with a BRCA 1 or BRCA 2 gene mutation, but personally not tested for those genes themselves	Varies	Varies	Every 6-12 months they have a clinical breast exam	Mammograms to be performed starting at age 30 and encouraged to talk to their providers about genetic testing before getting an annual mammogram
Women that had radiation to their chest between the ages of 10-30	Between the ages of 25-29, it is recommended that every 6-12 months they have a clinical breast exam, starting 10 years after the radiation treatment, only	Varies	Starting 10 years after the radiation treatment	Women who are 30 years and older, it is recommended every 6-12 month starting 10 years after radiation treatment to have a clinical breast exam. A mammogram and breast MRI should be performed, every year starting 10 years after radiation treatment

<b>Problem</b>	<b>Age</b>	<b>Frequen- cy</b>	<b>Clinical Breast Exam</b>	<b>Screening Tool</b>
Li-Fraumeni syndrome or a TP53 gene mutation	Varies	Varies	Between the ages of 20-29, every 6-12 months starting at age 20 or at the age of the youngest breast cancer case in the family, should have a clinical breast exam	Every year should have a breast MRI, and if one is not available then a mammogram. Women 30 years old or older should have a clinical breast exam every 6-12 months and a mammogram and breast MRI annually.
Cowden/ PTEN syndrome or Bannayan-Riley-Ruvalcaba syndrome or a PTEN gene mutation	Varies	Varies	Every 6-12 months starting at age 25, or 5-10 years before the age of the youngest breast cancer case in the family	Mammograms and breast MRI's should happen every year starting at the age 30-35 or 5-10 years before the age of the youngest breast cancer case in the family

<b>Problem</b>	<b>Age</b>	<b>Frequen- cy</b>	<b>Clinical Breast Exam</b>	<b>Screening Tool</b>
ATM, CHEK2 or NBN gene mutation	Varies	Varies	1-3 years between the ages of 25-39, and every year start- ing at age 40	Mammograms should be had every year starting at age 40, and women should talk with their providers about breast MRI's starting at age 40
CDH1 gene mutation	Varies	Varies	Every 1-3 years be- tween the ages of 25-39, and every year start- ing at age 40	Mammograms should be had every year starting at age 30, and women should talk with their providers about breast MRI's starting at age 30.
NF1 gene mutation	Varies	Varies	Every 1-3 years be- tween the ages of 25-39, and every year start- ing at age 40	Mammograms should be had every year starting at age 30, and women should talk with their providers about breast MRI's starting at age 30-50

<b>Problem</b>	<b>Age</b>	<b>Frequen- cy</b>	<b>Clinical Breast Exam</b>	<b>Screening Tool</b>
PALB2 gene mutation	Varies	Varies	Every 1-3 years between the ages of 25-39, and every year starting at age 40	Mammograms should be had every year starting at age 30, and women should talk with their providers about breast MRI's starting at age 30
STK11 gene mutation	Varies	Varies	Every 1-3 years between the ages of 25-39, and every year starting at age 40	Mammograms should be had every year starting at age 40.
Women with a personal history of breast cancer (including DCIS) but no suggested family history of ovarian or certain other cancer	Varies	Varies	1-4 times a year for the first 5 years after treatment ends	Mammogram annually

<b>Problem</b>	<b>Age</b>	<b>Frequen- cy</b>	<b>Clinical Breast Exam</b>	<b>Screening Tool</b>
dense breast tissue	Varies	Varies	Every 1-3 years between the ages of 25-39, and every year starting at age 40	Mammograms should be performed annually starting at age 40, and a talk with their health care provider is needed to determine if a breast MRI is necessary
Women ages 35 and older with a 5-year risk of invasive breast cancer of 1.7 percent or higher	Varies	Varies	Every 6-12 months starting at the age found to be at increased risk by the Gail Model	Mammogram every year starting at the age found to be at increased risk by the Gail Model

<b>Problem</b>	<b>Age</b>	<b>Frequen- cy</b>	<b>Clinical Breast Exam</b>	<b>Screening Tool</b>
Women with a greater than 20 percent lifetime risk of invasive breast cancer based mainly on family history	Varies	Varies	Every 6-12 months starting at the age found to be at increased risk by the increased risk model	Mammograms should be performed every year starting 10 years younger than the youngest breast cancer case in the family, but not before the age of 30. A breast MRI should be performed every year starting 10 years younger than the youngest breast cancer case in the family, but not before the age of 25
If women have a first degree relative with a BRCA 1 or BRCA 2 gene mutation	Varies	Varies	N/A	Encouraged to speak with their provider about the MRI, if they do not want to get genetic testing



[F]

<b>Problem</b>	<b>Age</b>	<b>Frequency</b>	<b>Clinical Breast Exam</b>	<b>Diagnostic Tool</b>
LCIS	Varies	Annual	N/A	Mammogram every year, and talk to with a provider about having a breast MRI
Atypical hyperplasia	Varies	Annual	N/A	Mammogram every year, and talk to with a provider about having a breast MRI
BRCA1 or BRCA2 gene mutation		30 Annual	N/A	Mammogram and breast MRI every year starting at age 30 or the age recommended by the provider
has a first degree relative with a BRCA1 or 2 mutation but personally not tested for the gene mutations		30 Annual	N/A	Mammogram and breast MRI every year starting at age 30 or the age recommended by the provider

<b>Problem</b>	<b>Age</b>	<b>Frequency</b>	<b>Clinical Breast Exam</b>	<b>Diagnostic Tool</b>
Li-Fraumeni syndrome	30	Annual	N/A	Mammogram and breast MRI every year starting at age 30 or the age recommended by the provider
Cowden/PTEN syndrome or Bannayan-Riley-Ruvalcaba syndrome	30	Annual	N/A	Mammogram and breast MRI every year starting at age 30 or the age recommended by the provider
Has a first degree relative with one of these syndromes	30	Annual	N/A	Mammogram and breast MRI every year starting at age 30 or the age recommended by the provider

<b>Problem</b>	<b>Age</b>	<b>Frequency</b>	<b>Clinical Breast Exam</b>	<b>Diagnostic Tool</b>
Has a first degree relative with one of these syndromes	30	Annual	N/A	Mammogram and breast MRI every year starting at age 30 or the age recommended by the provider
Had radiation treatments to the chest between the ages of 10-30	30	Annual	N/A	Mammogram and breast MRI every year starting at age 30 or the age recommended by the provider
Personal history of Breast cancer including DCIS		Annual	N/A	Every year should have a mammogram and a breast MRI should be consulted with a provider
Dense breast tissue		Annual	N/A	Every year should have a mammogram and a breast MRI should be consulted with a provider

<b>Problem</b>	<b>Age</b>	<b>Frequency</b>	<b>Clinical Breast Exam</b>	<b>Diagnostic Tool</b>
20-25 percent or greater life-time risk of invasive breast cancer based mainly on family history		30 Annual	N/A	Mammogram and breast MRI every year starting at age 30 or the age recommended by the provider

[G]

## Share Your Breast Cancer Stories for a Research Study

with Nia Bailey, M.A.Ed., RT(T)

Young Women get Breast Cancer, too! How and Why? TELL ME YOUR STORY!



What are women's early experiences with their providers who have been diagnosed with breast cancer? Are there components of their early experiences that served as barriers to getting treatment?

I am Radiation Therapist and a doctoral student in Public Administration at West Chester University. I am looking for women 18 years or older, who have been diagnosed with Breast Cancer in the United States before the age of 50. I am interested in interviewing these women through Zoom during a 45 minute to an hour interview.

If interested, or want to learn more about this project please text or call me at the number listed.

When: September 12, 2020-October 25, 2020

Where: Zoom

Time: TBD

Other: If interested, please contact

267-886-5471

IRJ approval #: 20200911A

