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‘I Fell between the Cracks:’
A Qualitative Analysis of the Factors that Influence Mammography Use among
Low-Income and Uninsured/Underinsured Women

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ABSTRACT

Background: Breast cancer is a leading cause of cancer death among women in the United States. Prevention strategies for breast cancer typically focus on early detection and initiation of treatment through routine mammography screening. Despite the availability of free breast cancer screening services, mammography rates among low-income and uninsured/underinsured women remain substantially lower than that of the general population.

Objectives: The purpose of this study was to explore the factors that influence the mammography use of low-income and uninsured/underinsured women. In particular, the reasons that women do or do not receive routine screening mammography are of interest.

Methods: The data consisted of 21 interviews with African American and Caucasian women who had a breast cancer diagnosis and were currently enrolled in the Georgia Women's Health Medicaid Program. The transcripts were coded using MAXqda 10 software, and the data were analyzed qualitatively using a deductive approach. Descriptive analyses were compiled for 1) the factors that influenced mammography use among women who received routine mammography, and 2) the factors that influenced mammography use among women who did not receive routine mammography.

Results: Two main behavioral patterns of mammography use were identified: 1) women who were receiving routine mammography screening, and 2) women who were not receiving routine mammography screening. For both these groups, the influence of a healthcare provider was a main influential factor of their mammography use. Healthcare insurance status appeared to only affect receiving mammograms for the women who were not routinely screened. Additionally, knowledge about breast cancer either motivated women to seek mammograms or caused delays in receiving mammograms for these women.

Discussion: The recommendation for mammography by a healthcare provider was one of the most influential factors observed in women's mammography use behavior. There is an apparent need for all healthcare providers to be aware of the available free breast cancer screening services. All women at risk for breast cancer should also be educated about the importance of self breast exams and having abnormal breast changes examined by a healthcare provider.

**‘I FELL BETWEEN THE CRACKS:’
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MAMMOGRAPHY USE AMONG LOW-INCOME AND
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I. INTRODUCTION

A. Background/Problem Statement

In the United States, breast cancer causes extensive health burden on women each year. It is second only to lung cancer as the leading cause of cancer death among women.¹ According to the American Cancer Society, 207,090 women were diagnosed with breast cancer in 2010 in the United States and 39,840 died.² Given the etiology of breast cancer, primary prevention strategies to reduce breast cancer mortality in the general population are not realistic. For this reason, prevention strategies traditionally focus on early detection.³ Routine screening mammography has been shown to reduce breast cancer mortality by as much as 40% in some trials.⁴ When identified and addressed at an early stage, the prognosis for breast cancer is much better and additionally far less costly to treat.

Screening mammography is recommended as the means to detect breast cancer by all advocacy groups within the United States; however, there is currently disagreement as to when routine screening should begin. In November 2009, the United States Preventive Services Task Force (USPSTF) updated its recommendation statement by advising against routine mammograms in women aged 40 to 49 years and proposing biennial screening from ages 50 to 74 years.⁵ However, the methods used in the evaluation studies by the USPSTF are controversial, and several groups, including the American Cancer Society and the American College of Radiology, maintain their recommendations to initiate annual mammograms at age 40.⁴

Despite recommendations, the number of women receiving routine mammograms in the United States is inadequate. As part of the Healthy People 2010 campaign, the US

Department of Health and Human Services set a goal of increasing to 70% the percentage of women over age 40 who have received a mammogram in the past two years. While this objective has been met in the general population (the national, age-adjusted prevalence of up-to-date mammography is 81.1%), women of a lower socioeconomic status, uninsured women, women without a regular source of care, and women who live in rural areas still have unacceptable rates of screening mammography.^{1, 6} Data from the 2008 Behavioral Risk Factor Surveillance System (BRFSS) revealed that only 56.3% of uninsured women aged 50-74 years had a mammogram in the past two years in comparison to 83.8% of insured women.¹ There were also relatively low rates of up-to-date mammography screening among women in the annual household income bracket of less than \$15,000 and women with less than a high school education (69.4% and 72.6%, respectively). Up-to-date mammography is defined as having had a mammogram at least once in the past two years.

In 1991, in order to address disparities in breast and cervical cancer screening rates, the United States Congress established the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Through this program, states receive federal funding to provide screening services for low-income and uninsured women. Although cutoffs vary with individual state policy, most states allow women who are within 250% of the federal poverty level to receive free testing.⁷ From its inception through 2004, the NBCCEDP provided 6.5 million screening services to 2.7 million women, which resulted in 26,000 breast cancer diagnoses.⁸ In 2004 alone, the program paid for 565,197 mammograms, screening about 1.2% of women aged 40-64 years.⁹ While overall

mammography rates have increased in the past two decades, there remains a 27.5% difference in up-to-date mammography screening between insured and uninsured women.

B. Purpose Statement

The purpose of this study is to identify the factors that influence low-income and uninsured or underinsured women's mammography use. The factors that differentiate women who receive routine mammograms and those who do not receive the recommended routine screening are of particular interest. To the best of our knowledge, there has been no qualitative research investigation of the reasons why mammography rates among low-income and uninsured or underinsured women remain low despite the availability of free screening services through the NBCCEDP. With a greater understanding of these barriers and facilitators, prevention programs can perform targeted outreach to this remaining underserved population.

C. Specific Aims

1. To identify factors that women cite as the reasons why they do or do not receive routine mammography screening,
2. To understand how insurance status influences mammography use.

D. Study Significance

In the past two decades, the United States government has invested enormous resources to increase mammography screening rates, with a focus on targeting low-income, uninsured/underinsured women. While the program is considered successful,

statistics show that this subgroup of the general population remains underserved. Through a qualitative investigation, the reasons why low-income or uninsured/underinsured women do not receive routine mammograms despite the availability of free services can be identified. With this knowledge, the NBCCEDP can conduct better-informed outreach to this marginalized population. As research shows, routine mammography screening leads to earlier detection of breast cancer and subsequently better treatment outcomes. Improving mammography use among low-income uninsured/underinsured women will thus avert avoidable breast cancer deaths.

In this study, women who have breast cancer diagnoses and are enrolled in the Georgia Women's Health Medicaid Program are interviewed about their prior mammography use. This will provide a particularly useful perspective on breast cancer screening behavioral patterns as these were both low-income and uninsured or underinsured at the time of their diagnosis, but also were obviously at high-risk of developing breast cancer.

II. LITERATURE REVIEW

II.A. Breast Cancer: Facts and Statistics

Approximately one out of every eight women in the United States will develop breast cancer in her lifetime.⁶ Breast cancer has a much better prognosis, or outcome, when it is detected at an earlier stage. In fact, stage at diagnosis is the strongest predictor of breast cancer survival.¹⁰ The stages of breast cancer are ranked from 0 to 4. As the number of the stage increases, so does the severity of the cancer. Stage 0 indicates a non-invasive condition with the abnormal cells confined to a small area of the breast while the stage 4 designation is given to cancer that has spread to other organs of the body.¹¹ The lower the stage at the time of diagnosis and initiation of treatment, the more likely the patient will have a favorable treatment outcome.

Breast cancer can be detected before it starts to cause symptoms through screening. Mammograms are the gold standard for screening the general population for breast cancer. The purpose of screening is to achieve earlier detection of the cancer. Given the fact that the risk factors for breast cancer are essentially beyond the control of the individual, early detection of breast cancer has traditionally been the preferred means of breast cancer prevention. It is estimated that early detection of breast cancer with mammograms can reduce mortality by 15-30%.

There are several risk factors for developing breast cancer, most of which beyond the control of the individual. Not surprisingly, the main risk factor is gender. Although it is extremely rare, men can develop breast cancer. The disease is 100 times more common among women than men.¹² Additionally, as women age they become at higher risk, with the most cases of breast cancer occurring in women 55 years or older.

Having a family history of breast cancer is a well-known risk factor. If a first-degree relative, such as a mother, sister or daughter, has breast cancer, a woman is two times more likely to develop the disease. When a woman has two first-degree relatives with breast cancer her risk is tripled.¹² Despite this substantial increase in risk, however, 85% of women who have breast cancer do not have a family history.¹²

In the past few decades, researchers have identified several gene mutations that are associated with hereditary breast cancer. The most common genetic defects that cause hereditary breast cancer are mutations in the BRCA1 and BRCA2 genes. Individuals who have such mutations can have a risk of as much as 80%.¹² While genetic testing can identify these defects, it is very expensive and not a part of routine screening for breast cancer.^{13, 14}

While some people never experience any warning signs that they have breast cancer, some women can develop symptoms that may indicate the disease. According to the Centers for Disease Control and Prevention (CDC), warning signs for breast cancer include a new lump in the breast or underarm, thickening or swelling of the breast, irritation or dimpling of the skin of the breast, a pulling in of the nipple, nipple discharge, or pain anywhere in the breast.

Like the staging of breast cancer, tumors are also given a “grade” based on how aggressive its cancerous cells are. The tumor grade is on a scale of 1 to 4, with 4 being the most aggressive type of tumor. The higher the tumor grade, the faster its cells divide and the more quickly the cancer will spread.

An estimated 4,475 breast cancer deaths could be prevented each year if all women in the US received the recommended cancer screening services.¹⁵ Additionally,

early detection of breast cancer through mammography screening and decrease the cost of medical treatment substantially. A study by Subramanian et al. analyzed treatment cost data from a Medicaid registry and found that as the stage of cancer at the time of diagnosis became more advanced, the total cost of treatment steadily increased. At 24 months after diagnosis, the average cost of treatment for breast cancer that was diagnosed at stage 0 was \$33,218 dollars. In comparison, the average cost of treatment for breast cancer that was stage 4 at the time of diagnosis was \$127,114 dollars at 24 months.¹⁶ Thus, maintaining adequate mammography screening rates not only saves lives but is highly cost-effective.

II.B. The Issue of Race

In the United States, the incidence of breast cancer is significantly lower among African American women than Caucasian women. However, according to the Surveillance, Epidemiology, and End Results (SEER) program, mortality among African American women is much higher, with 32.4 deaths per 100,000 in comparison to 23.4 deaths among Caucasians in 2007. Traditionally it was thought that this disparity in breast cancer outcome was the result of lower screening mammography utilization among African American women.^{17, 18} As discussed, lower rates of mammography are associated with later stages of breast cancer at the time of diagnosis. However, the gap in mammography rates between African American and Caucasian women has generally closed in the past few decades.¹⁹ While most studies find that there are no remaining differences in mammography use between these two races, there are still research findings suggesting that discrepancies persist.

A study in 2006 by Smith-Bindman et al. asserted that there are still differences among African American and Caucasian women in mammography use when examined based on surveillance data of medical records and not self-report surveys. Researchers pooled data from seven mammography registries dispersed throughout the United States of the Breast Cancer Surveillance Consortium. The data included information on mammographic evaluations, radiology reports, and breast health surveys performed at the healthcare facilities. The breast health surveys contained demographic information about each patient, symptoms of breast cancer at the time of the mammogram, and previous mammography use. Through data matching with state tumor registries, the SEER program, and hospital pathology reports, treatment outcomes for the breast cancer patients was obtained. Of the 1,010,515 women age 40 years or older who had mammograms between 1996 and 2002 with the Breast Cancer Surveillance Consortium data on the 17,558 women who received a first-time breast cancer diagnosis were analyzed.¹⁰

Overall, researchers found that African American women had higher rates of larger, high-grade, and advanced-stage tumors with lymph node involvement. Additionally, it was found that the rates of large tumors increased with the time interval between women's mammograms. With a one-year screening interval between mammograms, 1.8 large tumors were diagnosed per 1,000 mammograms. In comparison, 2.8 and 4.8 large tumors per 1,000 mammograms were diagnosed at three- and four-year intervals, respectively. Interestingly, rates of advanced-stage breast cancer did not differ between African American and Caucasian women when time-intervals between mammography screening were taken into account. African American women, however,

had higher rate of high-grade tumors at all time-intervals. Additionally, of the women who were received a mammogram for the very first time and were subsequently diagnosed with breast cancer, African American women had higher rates of advanced-stage cancer and lymph node involvement.

To assess whether differences in mammography use could account for these differences, frequency of breast cancer screening among African American women versus Caucasian women was analyzed. In comparison to 18% of Caucasian women, 34% of African American received inadequate mammography screening with a screening frequency of less than one mammogram every two years.¹⁰ The Smith-Bindman et al. posited that the lack of differences in mammography use found in other studies is due to the fact that they use self-report data. It has been shown that such data is subject to overstatement, especially among minority women.

As found in the study by Smith-Bindman et al., there are biological differences in the average breast cancer of African American women versus Caucasian women. Breast cancer in African American women is known to be generally more aggressive, and they also are more likely to have estrogen receptor-negative tumors.¹⁸ These tumors are more difficult to treat and have poorer outcomes.²⁰ The reasons for these differences are not clear.²¹

In another study on disparities in mammography use by Schueler et al., it was found that differences among African American and Caucasian women in mammography rates persist when income and socioeconomic status are taken in to account.²² Uninsured Caucasian women are less likely to receive mammograms in comparison to uninsured African American women. This is consistent with the finding that not having health

insurance was more commonly a barrier to mammography use for Caucasian women than African American women. However, in a meta-analysis of the factors associated with mammography utilization, it was found that a higher proportion of African American women versus Caucasian women reported financial concerns as the reason they did not have mammograms (25.9% vs. 16.1%, $p < 0.001$).²² The Schueler et al. hypothesized that populations that have lower rates of health insurance coverage, like African American women, are less affected by lack of insurance,

Interestingly, Caucasian woman who have less than a high school education less commonly receive routine mammograms than similarly educated African American women²³ This is consistent with the finding that breast cancer mortality rates vary by education level, with women of lower education levels experiencing greater mortality.²⁴

The results from this recent study present a new factor that affects mammography screening rates: socioeconomic status.

II.C. Income Level and Insurance Status

Although the gap between African American and Caucasian women's mammography rates has more or less closed, there still remains a significantly higher mortality rate among African American women due to breast cancer.²⁵ It has been suggested that the higher mortality rates among uninsured women and women of lower socioeconomic status account for this difference.¹⁹

A 2008 study by Sabatino et al. from the Centers of Disease Control and Prevention analyzed mammography use among women stratified by insurance status, income level, and race. Two cross-sectional surveys from 1993 and 2005 of women aged

40-64 years were compared to examine changes in disparities over time. The data were obtained from the National Health Interview Survey (NHIS). In 1993, 4,167 women aged 40-64 years were interviewed, and 7,434 women were interviewed in 2005. In the data from both 1993 and 2005, there was no significant difference seen in the percentage of African American women versus Caucasian women that reported a mammogram within the previous two years. There were still no observed screening differences between Black and White women when stratified by income level and insurance status. This is in contrast to the data from the 2005 National Healthcare Disparities Report (NHDR) which found that mammography use was greater among low-income African American women than low-income Caucasian women. The researchers stated that this difference in results may be attributable to variations in the definition of “low-income.”

Mammography use within the previous two years for low-income women within 250% of the federal poverty threshold significantly increased from 48.4% to 55.0% between 1993 to 2005.¹⁹ Interestingly, there was no observed change in mammography use among uninsured women, who reported the lowest screening use with only 38.3% receiving a mammogram within the previous two years. However, when both factors were considered together, the percentage of low-income, uninsured women reporting a mammogram within the previous two years increased from 28.9% in 1993 to 36.1% in 2005. Still, this was not a significant difference. When stratified by both insurance status and income level, the data showed disparities between uninsured and privately insured women at all income levels with the lowest screening rates among uninsured, low-income women. The researchers posited that the increases in screening among low-income

women could be attributed to programs like the NBCCEDP that promote breast cancer screening in underserved populations.¹⁹

Research is currently divided as to whether not having health insurance is an independent predictor of mammography use or if it is affected by whether women also have a regular healthcare provider. Access to a primary care physician in itself can also be a major factor of mammography use. Some studies have found that having a primary healthcare provider and health insurance are two independent factors, while others assert that only when both are taken in to account do they affect mammography use.²⁶

In some studies, access to a physician was more influential on mammography utilization than income level. The meta-analysis study by Schueler et al. which examined the factors associated with mammography use found that the traditional socioeconomic barriers of low-income and education level were less important than expected.²² The two most influential determinants of mammography use that Schueler et al. identified for all women were past screening use in the form of pap tests and clinical breast examinations and access to physicians. Women not having a healthcare provider recommend mammography was the most important reason women did not receive a mammogram.

Lack of physician access includes not having a primary care provider, not having visited a physician within the past year, and not having a physician recommend a mammogram. Primary care is extremely important in disease prevention, early detection of disease, and health promotion. Access to a primary care physician is associated with utilization of preventive services and, in particular, cancer screening practices.²⁶

II.D. Available Free Screening Services

With the establishment of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) in 1991, low-income and uninsured/underinsured women could receive free breast cancer screening services. While the program is administered by the Centers for Disease Control and Prevention (CDC), each state contributes supplemental funding to the program and can dictate the cutoffs that make women eligible for the program. In most states, women within 250% of the federal poverty limit can receive free testing services. The breast cancer screening services offered through the program include mammograms, clinical breast exams, diagnostic testing for abnormal results, and referrals for treatment.⁹ By 1998, all 50 states and the District of Columbia were participating in the program.⁷

Georgia adopted the NBCCEDP in 1994.²⁷ Within the state it is known as the Breast and Cervical Cancer Program or the Cancer Screening Program. It was formerly called the BreasTest and More. In order to be eligible for its free screening services in Georgia, women must be 40-64 years old, have an income less than 200% of the federal poverty limit, have no health insurance or be underinsured and otherwise not eligible for Medicaid or Medicare, and they must not have had a mammogram within the past year. An exception to the last criterion is if a woman is displaying a symptom of breast cancer, she may receive free screening.

In 2000, the United States Government passed the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA). This act enabled states to provide Medicaid to uninsured women less than 65 years old who are screened through the NBCCEDP and

diagnosed with breast or cervical cancer. All 50 states adopted BCCPTA, thus establishing a new publicly funded health insurance program.⁷

With the intention of increasing access to this health insurance, 12 states modified the BCCPTA policy to allow uninsured women diagnosed with breast or cervical cancer but not screened through the NBCCEDP to enroll in the program. Georgia was one of those states, and it began enrolling women in its new Women's Health Medicaid Program (WHMP) in 2001.²⁷ In order to be eligible for the WHMP, women must be Georgia residents, have an income level within 200% of the federal poverty limit, be under 65 years of age, and cannot have health insurance coverage or be otherwise eligible for Medicaid or Medicare.

As a result of the program, by 2003 Georgia had increased its coverage of women with breast or cervical by 33%.²⁷ In 2006, about 20,000 women in Georgia received a mammogram or a clinical breast examination and 200 breast cancer cases were detected.²⁷ The time between diagnosis of cancer and enrollment in Medicaid for treatment also significantly decreased.⁷

In 2004, NBCCEDP provided 565,197 mammograms, screening about 1.2% of women aged 40-64 years.⁹ This resulted in 2,111 cancer diagnoses, or four cases per 100,000 women.⁹ According to a recent study by Howard et al., there are 0.6 fewer deaths annually from breast cancer among women aged 40-64 years for every 1,000 women screened under the NBCCEDP.⁹ However, given the federal funding as of 2000, NBCCEDP was able to provide services for just 12-15% of eligible women.³ In Georgia, it is estimated that only 15% of the 131,000 eligible uninsured women were able to receive the free screening services.²⁷

Thus, while the introduction of free breast cancer screening services has resulted in improved mammography screening rates, the NBCCEDP is reaching only a small portion of its intended population. Additionally, mammography rates among low-income and uninsured/underinsured women remain low in comparison to the general population. Further knowledge is needed on why how these women access mammograms and what the influential factors are of whether they receiving mammography screening. Although numerous studies have been conducted on such factors among the general population, there is relatively little research on low-income and uninsured/underinsured women.

III. METHODS

This study involved in-depth interview data being analyzed using qualitative methods. The data utilized for this study was generated as part of a mixed methods research study investigating the differences in treatment patterns among women enrolled in the Georgia Women's Health Medicaid Program (WHMP). This research work was supported by the American Cancer Society through a grant [grant number RSGT-05-004-01-CPHPS] awarded to E. Kathleen Adams (PI), Karen L. Andes (Co-PI), and Sarah C. Blake (Co-PI). The opinions reflected herein are those of the author and do not necessarily reflect those of the funding agency.

There were two aims of the qualitative component of the research study: 1) to interview women about their experiences with breast or cervical cancer, and 2) to interview physicians who are actively serving women with breast and cervical cancer. Only the interviews with women with breast cancer diagnoses were used in the qualitative analysis of this particular study.

Before initiation of the study, Institutional Review Board (IRB) approval was obtained from the Emory University (IRB).

III.A. Study Design

A "life history" approach was used in interviewing 64-72 women about their experiences with breast or cervical cancer and enrollment in the WHMP. These interviews focused on five key "moments" in the cancer experience: suspicion of a problem, cancer screening, diagnosis, treatment, and follow-up care. The Co-Investigators of the study, Dr. Karen Andes and Sarah Blake, designed informed consent

documents (Appendix B) and drafted the interview guide based on the cancer experience moments of interest. The interview guide was then finalized through collaboration with the study interviewers (Appendix A). Interviews ranged in length from 30 minutes to two hours, and took place either in the participant's residence, the facility where they received their cancer care, or a public facility such as a public library. All interviews were recorded using digital audio recorders.

III.B. Study Population and Recruitment

Participants were Caucasian or African American women currently or previously enrolled in the Georgia WHMP. At the time of enrollment in WHMP, women must have a diagnosis of breast or cervical cancer, be a Georgia resident less than 65 years old, have an income level within 200% of the federal poverty limit, and be uninsured and not otherwise eligible for Medicaid or Medicare. Women who enroll in the WHMP were not necessarily screened for breast cancer through the NBCCEDP.

Georgia Medicaid beneficiaries including women in the WHMP must be enrolled in one of three care management organizations (CMOs): Amerigroup Community Care, WellCare, and Peach State Health Plan Through collaboration with the staff of each CMO, beneficiaries were invited to participate in the interviews in letters sent out to their home addresses. They were offered an incentive (\$50) for participation in an interview.

In order to gain a representative sample of Georgia women in the WHMP, the goal was to recruit evenly distributed numbers of women with breast and cervical cancer stratified by race (African American versus Caucasian) and type of area of residence

(urban versus rural). Women were classified as living in an urban or rural area based on their county of residence.

III.C. Data Analysis

For the purposes of this study, 21 interview transcripts with women with breast cancer diagnoses were selected. Data that had to be present in a transcript for it to be selected for analysis included timeline information on previous mammogram use, information on pre-diagnosis insurance status, and discussions of pre-diagnosis access to healthcare providers. Of the transcripts that were selected, eleven were interviews with African American women and ten were interviews with Caucasian women. The age range of the women was 42-65 years.

The transcripts were coded using the qualitative data analysis software, MAXqda 10. A set of deductive codes was applied to the data that represented the study objective to understand key moments in the women's cancer experiences. Of these codes, five were used to complete the analysis for this particular study: Suspicion, Screening, Diagnosis, Socioeconomic Status, and Cancer Perceptions/Beliefs. The definition for each of these codes is outlined in the table below.

Through systematic retrieval and review of data by codes, an in-depth qualitative analysis was conducted. Upon preliminary analysis of the data, two separate behavioral patterns of mammography were identified: 1) women who had been receiving routine mammograms at the time of their breast cancer diagnosis, and 2) women who had not been receiving routine mammograms at the time of their diagnosis.

First, descriptive analyses of the factors that influenced the mammography use for women who had been receiving routine mammogram was performed. A second set of descriptive analyses was conducted on the factors that influenced the mammography use of the women who were not receiving routine mammograms.

For the purposes of the analysis, routine mammograms were defined as having a mammogram at least once every two years, which is the current recommendation by the USPSTF. A regular healthcare provider was identified as a physician whom a woman saw more than once on a regular basis for routine healthcare.

Code	Definition
Suspicion	Discussions of feeling like “something was wrong.” Includes any discussion of pre-diagnosis health problems that the participant links to her cancer experience.
Screening	Discussions of screening such as pap smears, mammography, breast self-exam, including post-treatment re-screening. Includes discussions of not seeking screening and the reasons for this.
Diagnosis	Discussions of screenings, biopsies, lab tests, etc. that lead to diagnosis and staging of cancer. Includes the “quest for a diagnosis” of knowing that something is wrong and seeing a provider, even if they do not immediately produce a diagnosis.
Socioeconomic Status	Discussions about living and economic conditions, employment status, insurance status, access to primary care providers, educational background, and community conditions (e.g. violence, poverty).
Cancer Perceptions/Beliefs	Discussions of beliefs about health and cancer, experiences with friends or family members’ cancer, and how these perceptions and beliefs influence behaviors related to seeking care, making decisions, etc.

IV. RESULTS

Two main patterns of mammography use preceding a breast cancer diagnosis were evident in the data. In the first, women were receiving regular mammograms. For these women, the mammogram that led to their diagnosis was either a routine mammogram or a follow-up mammogram that the women solicited from their provider because they developed breast symptoms. In the second observed behavioral pattern of mammography use, women were not getting routine mammograms and they developed breast cancer symptoms. They either went immediately to a healthcare provider or they delayed in seeking care and a mammogram. In the sections that follow, I outline the experiences of women in each of these behavioral patterns.

IV.A. Women Who Received Routine Mammograms

About half of the women in this analysis had been receiving routine mammography screening before their breast cancer diagnosis. There were ultimately six factors that women provided as reasons they sought routine mammography screening. This includes every explanation that was given during the interviews regardless of how many women discussed it; some of these explanations were given by several women while others were cited by only one woman. The individual explanations for why women sought routine mammography are outlined below.

Almost all of the women had primary care physicians or gynecologists who they saw on a regular basis and who initiated their routine mammograms. One woman explicitly stated that because she had health insurance, it was easy for her to get her regular check-ups, which included regular mammograms. A few women had benign

lumps in their breasts or under their arm removed at an earlier age and learned the importance of routine mammograms. One woman said that getting regular mammograms is one of those things that you have to do, even if you don't want to. A couple women had one or more family members with breast cancer or a similar diagnosis, and this affected their mammography use. Several women also stated that they asked their doctors for mammograms or sought them at free screening locations because they had heard a lot about breast cancer and the importance of screening through television, posters and word of mouth. Of the reasons provided, there were essentially three overarching factors that influenced mammography use behavior of these women: the recommendation of a healthcare provider, having a previous medical condition, and knowledge about cancer.

Influence of a Healthcare Provider

The majority of the women who had been receiving routine mammography had a regular healthcare provider. Of these women, many stated that they first began regular mammograms at the suggestion of their regular healthcare provider. For the purposes of the analysis, a regular healthcare provider was identified as a physician that the woman saw more than once for routine care. Regular healthcare providers who women discussed included primary care physicians or gynecologists. The primary care physicians were either private doctors or physicians who worked at local health departments or free clinics.

One woman who was getting regular mammograms explained that she was getting her routine check-ups with a primary care physician because she had health insurance and it was "easy to do." This woman had been living in Florida and had health insurance through her husband's work. When they moved to Georgia, however, she

explained that the new doctor she tried to go to wouldn't accept her insurance. As a result, she decided to switch her insurer, which took her about one year to do, and she did not have a mammogram that year. When she resumed her routine mammograms, her healthcare provider was able to detect her breast cancer.

“I had to drop [my insurance] because when I moved up here, they didn't accept it. So that's what made me a little longer getting my mammogram because I didn't get it, like for I think a year or so after I moved here. Because I had to get insurance. And I didn't know nothing about the insurance up here. So, I got Blue Cross and Blue Shield...”
(131_BUA, 78)

A sense of responsibility or obligation was expressed by several women who received routine mammography screening through their regular healthcare providers. When asked why she had mammograms every year, one woman said:

“...It's just one of those things you have to do as bad as you hate to.”
(137_BUW, 80)

Even though this woman participated in regular screening, she never thought that she could develop breast cancer because no one in her family had ever had it. She explained that she denied the possibility that she had breast cancer when her doctor said that he wanted to perform additional testing after an abnormal mammogram.

Interestingly, only half of the women who had a regular healthcare provider had health insurance during the time they were receiving routine mammograms. Of the women who had health insurance, they typically were receiving mammograms as part of their regular, preventative healthcare with primary care physicians or gynecologists. Women who did not have insurance were generally accessing healthcare for treatment of a chronic condition like diabetes or they were receiving annual pap tests. One such

woman had been going to the local health department for several years for free pap tests so that she could get birth control. She was 40 years old when the health department recommended that she start getting regular mammograms. She provided this as the reason when asked why she started getting routine mammograms.

“[The health department] said because at that age, a woman needs that. That’s a test that they would be told to give patients, I mean, people who come in. Because I had always accept them to help me with pap smears, birth control. I never let myself unprotected as far as that because I didn’t want to have a baby on an unexpected or to have unplanned pregnancy.” (146_BUW, 83)

In this instance, the woman’s desire to avoid an unplanned pregnancy essentially led her to be a regular patient at the health department. She went to the health department for care because she didn’t have health insurance and knew that they offered free healthcare services. This provided the health department with an opportunity to initiate routine mammograms for her, which she clearly presents as the reason she started having regular mammograms. In a similar case, a woman without health insurance began routine mammography screening at the age of 40 because of the recommendation of her local health department, where she was being seen regularly for treatment of her high blood pressure. In addition to receiving medication to regulate her blood pressure, the woman was also receiving regular physical examinations and pap tests. When she turned 40 years old, her providers signed her up for free breast cancer screening services through the Breast Test and More program. As in the previous story, even though this woman didn’t have health insurance she was able to see a provider on a routine basis by taking advantage of free healthcare opportunities. With her first mammogram in the Breast Test and More program, her breast cancer was detected.

Influence of a Previous Medical Condition

In three cases in the data, women had a history of benign lumps in their breast area and consequently had been getting routine mammography screening from a young age. Two of these women had lumps in their breasts while the other had a growth under her arm. Although these were found to be benign, their doctors recommended that they begin regular breast cancer screening after removal of the lump.

One of these women began having regular mammograms at the young age of 21 years, when her doctor felt a lump in her breast. It was removed and found to be benign, but she was told that she had fibrocystic breasts and would have to get mammograms done on a regular basis. By the time she was in her 30s, doctors had detected and removed four benign lumps. All of her medical services were covered by health insurance at the time. When she was in her mid 30s, she learned that her younger sister was diagnosed with hyperplasia and consequently had a double mastectomy. This event motivated her to start having mammograms every year instead of every two years.

“From the time I was like 34, 35, I would go religiously in to get my mammograms because my sister, my younger sister (...) she had fibrocystic breasts as well, but her doctor said that she, she ended up having a total mastectomy years ago and she’s three years younger than I am because hers was, that he, he said she had something called hyperplasia, which I had never heard of at the time, but told her that her chances of, of, you know, it turning in, I guess it’s pretty cancerous, so her chances of it being full blown cancer were really great so that’s what they did.” (144_BUW, 309)

Although this woman had already been getting regular mammograms, it appears from her discussion that hearing of her sister’s diagnosis and the possibility that she could develop cancer greatly influenced her mammography use behavior. She explains that as a result of

her sister's situation, she began to get mammograms "religiously." Nevertheless, when she was about 39 years old, two events affected her ability to continue to receive regular mammograms: she separated from her husband and subsequently lost her health insurance, and her mother passed away. Fortunately, this woman had a friend who knew of the free screening services available at the local health department.

"I met a nurse when my mom was sick at hospice and she worked part-time at the health department and part-time at hospice and she and I became really close, and I kept in contact with her after my mom passed and she, I talked to her when my husband and I separated and then I lost my insurance and everything, and um, she said, you know, now that you're 40, there's this program at the health department, it's free, you know, just go down there and get your mammogram, because I wouldn't have, you know... I had just lost my mom, you know, I was, I had just recently separated from my husband, you know. My son was my whole concentration, you know, and I wasn't even caring about my annual exams or anything like that... But, I was like, well, okay, it's free, you know, I don't have any insurance, I guess I'd better take advantage of it." (144_BUW)

In the first mammogram that she received at the health department, her provider recognized the early sign of breast cancer and she was able to be diagnosed and treated in a timely manner.

In a similar case, a woman who had a benign lump removed from her breast when she was 26 years old began having annual mammograms until she lost her insurance a few years later.

"...When I was laid off I lost my insurance so I wasn't able to have [a mammogram] for like 3 years I would say..." (135_BRW, 266)

In this woman's story, it is clear that she was concerned about getting breast cancer. She explained that when she was 15 years old she first realized that it was a possibility for her

when two of her aunts and her grandmother passed away from breast cancer. When she lost her health insurance, she stopped getting regular mammograms through her provider and began performing self breast exams. She performed them every month for three years while she didn't have insurance. However, in the six months preceding her diagnosis, she explained that she had not done any self exams because she was extremely busy. It was her husband who found the lump that had started to form in her breast.

“I was always very good at doing self breast exams but I had so much stuff going on at the point in my life, I just didn't have time and I just forgot about it. So I was planning a wedding, my daughter was starting pre-K, we had just moved, and I was just juggling all this stuff and it wasn't until 2 weeks after I was married that my husband found a lump. And my husband thought at first that I had known about it, because there was no way that I wouldn't have known about it. And I was able to get in to see my doctor, her order the mammogram and stuff...”
(135_BRW)

Although this woman didn't have access to a regular healthcare or routine mammograms after she lost her insurance, she remained proactive in her breast health by performing regular self exams. When she noticed the lump, she did not delay in going to have it checked by a healthcare provider and subsequently receiving a breast cancer diagnosis.

In the third story of having a previous medical condition that influenced routine mammography screening, the woman was in her 40s and had been going to a free clinic to receive treatment for her diabetes. She explained that she did not have health insurance and that was why she was accessing medical care at the free clinic. She had never had a mammogram. In 2008 when she was 47 years old, she had a growth under her arm that kept growing and eventually started to hurt her. When the providers at the clinic noticed it, they sent her for her first mammogram.

“...A free clinic down at [local hospital] (...) that’s where I was going because I had no insurance, I was going to them and they was treating me for my diabetes (...) And the [clinic] sent me to get a mammogram back on ’08 because you know they seen the growth under my arm too, that’s how I get that done.” (145_BUA, 128)

Eventually the growth under her arm was removed and found to be benign. However, even though it was not cancer, this woman’s providers began routinely screening her for cancer. After the initial mammogram in 2008, she had another mammogram as a check-up at the same clinic the following year in 2009. Although regular mammograms had previously not been recommended for her by the physicians at the clinic, once she had a medical condition that necessitated a mammogram they started including one in her regular check-up. Shortly after her second routine mammogram, this woman felt a lump in her breast.

“...Then in ’09 I had went back and got another [mammogram] and they said there wasn’t nothing, and when I found this [lump] then I’m like oh that happened quick, you know, by me having a mammogram, but I guess it wasn’t showing up in the mammogram, I don’t know what else kind of test I could have took you know for it to show. Because this just got ridiculous in a short period of time, it didn’t take long, it did not take long.” (145_BUA, 96)

In this discussion, the woman clearly recognized that having a lump might indicate breast cancer. She was able to call the same provider who had been giving her mammograms and go in for a follow-up, which eventually led to her diagnosis.

Knowledge of Cancer

While most women began getting routine mammograms at the suggestion of their healthcare provider, one woman in particular explained that she made the decision herself to start regular mammography screening. She actively sought a mammogram every year

even when she didn't have a regular healthcare provider or health insurance. When asked if it was a doctor that suggested she receive regular mammograms she replied, "No. I'm the one who told her. I keep up with my own self" (108_BUA, 241). She went on to explain that she was proactive about getting regular mammograms because she had heard so much about cancer.

"...You cannot go nowhere no, these days without hearing about breast cancer. I mean, when I was living in D.C., that's all that was going on, breast cancer. And they had the great big quilt on the wall. And so, and I walked through the whole thing and I'm like my God. I mean, you can't go nowhere without hearing about it and, and about the Susan G. Komen Foundation. You can't nowhere, so yeah, you got to be on top of this thing (...) Back in my days, you did not hear about no breast cancer like you're doing now. Most people was walking around with STDs, you know. But you did not hear about that. But all of a sudden, now breast cancer seems to be just the most oppressive disease that's trying to outwiipe women. I don't know why. You know, where this thing came from, you know? But yeah, you got to be on top of this. You really do." (108_BUA, 247)

Although this woman did not always have a consistent healthcare provider, she managed to obtain regular mammography by actively seeking out screening opportunities. At one point she was living in Alabama where she didn't have a primary care physician or health insurance, yet she attended free clinics and was able to get free annual mammograms. She then moved to Washington D.C. and was able to receive free healthcare and continue her routine screening through the public program, DC Healthcare Alliance. However, she had to leave her medical care in D.C. when she moved to Georgia to support her son.

"I didn't have, I guess you could say, a steady primary care. I really didn't. It was touch and go, like get it where I can because of no health insurance. And the reason why I got it done in Alabama was because of a low-income clinic where I could go and get it done and all had to pay

was like \$20, you know, and the mammogram was free. Then I moved back home to D.C., the Alliance program was set up in D.C., and that's how I was able to get healthcare there, and I had a permanent physician there (...) I didn't want to come [to Georgia] because, you know, when you have everything set up at home, a physician (...) but my son begged please, mom, please come, you know, and I didn't want to leave him hanging. So that's why I ended up down there, and when I got here, I'm like, Lord, what am I going to do for healthcare? What am I going to do, you know, because when you started getting over in your 50s, you really need to watch out more for yourself. I'm not saying when you're younger, you don't, but when you're a little older, you need to that extra, you know. And so, uh huh, and so it was a blessing when that health fair showed up.” (108_BUA, 46-48)

Obviously the availability of free services played a major role in this woman's ability to have routine mammograms. However, it is clear that this woman was extremely motivated in seeking out these mammograms and, as she explains, it was driven by her awareness of breast cancer. The free mammogram that she received at the health fair was abnormal, and she was eventually diagnosed as a result.

In a similar case, another woman began performing self breast exams and asked her physician to start getting routine mammograms when she was about 39 years old. She explained that hearing so much about breast cancer caused her to do this.

“Just, you know, listening to different people, well, on television, reading different things, stuff, you know. Just, mainly just reading. You know, reading and looking at television and them saying that, you know, women should, you know, do their own self exam, you know, like after your period and stuff like that. So that's when I, you know, pretty much started doing them.” (130_BRA, 78)

This woman had health insurance at the time she started routine mammography, but she lost it when her husband died in 2007, when she was about 44 years old. She was determined to maintain regular screening though, and for the next two years she paid out-

of-pocket to have mammograms done at the local hospital. She said that she was charged about \$75 dollars for each mammogram. Clearly, learning about breast cancer left an impression on this woman and she remained motivated to seek regular screening even when she lost her health coverage. She had just had a normal mammogram when she developed breast cancer symptoms. She recognized that the symptoms needed to be checked, and called to get a mammogram within one week.

“...In 2009 I kind of suspected that something was wrong. That’s what made me go and have a mammogram because kept aching. They would just ache and I was at work one day and kind of pushed against myself like that and felt something sore. So what I did, I just, I called and made an appointment for a mammogram.” (130_BRA, 112)

It is fortunate that this woman did not delay in following up on her breast symptoms and getting a mammogram, as this mammogram did find an abnormality that resulted in her diagnosis of breast cancer.

Absence of Delays in Receiving Mammograms

Among women who sought routine mammography, half received their diagnosis as the result of a routine mammogram while the other half noticed a breast symptom and followed up on it by seeking a mammogram. It is notable that none of the women who experienced a symptom delayed seeking the mammogram that eventually led to their breast cancer diagnosis.

The only time lapse observed among these women was very brief, for a woman who had been getting routine mammograms for several years at the recommendation of her gynecologist. In addition to annual mammograms, she was also performing self breast exams every month. While examining her breasts, she noticed a small indentation in her skin.

“I saw an indentation. I did monthly self breast exams, and I didn’t feel any lumps, but I saw an indentation like a pucker place on my right breast. And so I didn’t think too much about it at first, and it stayed and it stayed. I’m talking two, three weeks of watching it. And I went to my gynecologist and she was pretty sure. Well, she was concerned about it and pretty sure that it was a problem. And so I had a mammogram. And it showed that it was cancer.” (141_BRW)

Although she waited a few weeks to follow-up on her breast symptom, this woman was proactive in seeking care and a mammogram after noticing the abnormality. As a result, her provider was able to detect her breast cancer in a timely manner.

In general, these women were extremely proactive in their breast health. In addition to their routine mammograms, many of them were performing regular self breast exams. If they developed a symptom, they recognized what it might indicate and made sure to get it checked by a physician with a minimal time delay. Although many of them explained that they started getting routine mammograms because their healthcare provider recommended it, they were clearly motivated themselves to maintain good breast health.

IV. B. Women Who Did Not Receive Routine Mammograms

Less than half of the women in the dataset did not receive routine mammograms. These women all developed breast cancer symptoms and either went to a physician specifically to have it checked or they were seen by a healthcare provider for an unrelated reason and this doctor decided to do a mammogram.

Of these women, only two had never had a mammogram before their breast cancer diagnosis. The majority did not have a regular healthcare provider at the time of their diagnosis. For the few that did, none of their doctors recommended routine

mammography screening. Some women explained that if they didn't have health insurance or their insurance didn't cover mammograms, they did not seek mammography screening. A couple women stated that they didn't feel mammograms were necessary if they didn't feel any lumps when performing self breast exams. Women also cited the fact that they never felt sick as a reason they didn't seek mammograms. One woman said that she did not get a mammogram even though her breasts ached because she was busy trying to start a business at the time.

In these reasons these women provided for why they didn't seek mammograms, three overarching factors were identified: the influence of a healthcare provider, health insurance status, and knowledge about breast cancer.

There was only one instance in which a woman did not adhere to the recommendation of a healthcare provider. When this woman was 39 years old, she had a regular doctor and he suggested that she start routine mammograms. However, she flatly refused to follow his recommendation. When asked why she made this decision, she simply stated:

“I didn't want to be bothered with it and I wasn't sick...” (109_BUA, 452)

This woman waited until she felt a lump in her breast before actively seeking a mammogram more than ten years later. Her rationale for not getting routine mammograms suggests that her breast health was simply not a priority for her.

Influence of a Healthcare Provider

As seen in the data, a recommendation for mammography by a healthcare provider was clearly an influential factor in mammography use behavior for these

women. Conversely, the lack of a recommendation for a mammogram also had a large impact on women's decisions to seek mammography screening.

In one case, a woman had a primary care physician but did not have health insurance. She was 44 years old and had never received a mammogram when she felt a lump in her breast. She immediately went to her regular doctor to have it checked. Upon examining the lump, however, her physician told her that she should simply cut back on caffeine and chocolate consumption and he did not screen her for breast cancer.

“...I felt it like on this side, and then you know I kept saying well what is that you know. So the doctor that was doctor that I was going to he told that he could have been cystic fibrosis, to cut back on caffeine and chocolate, because I loved it. So I cut back on the caffeine and chocolate, well all of a sudden it moved from there and it had gotten like right here, so I just kept saying well maybe it's the caffeine and chocolate. But as the months went by the knot began, well the tumor it began to like grow and I could take my hand and I could just, you know I could just you know feel it and all doing a breast self exam. But you know after the doctor said well maybe you know caffeine and chocolate.” (119_BUA, 49)

It is clear from this discussion that the doctor's assessment of this woman's symptoms influenced her mammography use behavior. Not only did he not provide her with a mammogram when she went to see him, but she rationalized her symptoms afterwards when they became worse by saying that it might be caused by her caffeine and chocolate intake. She used her doctor's explanation as an excuse to not seek another opinion even though the lump grew. It took six months of the lump becoming progressively bigger for this woman to seek care elsewhere. When she finally did get a second opinion, she went to the local health department because she had a friend who was a nurse there. She had told her friend about the lump in her breast, and her friend disputed that it could be the

result of caffeine and chocolate consumption. The woman, however, was reluctant to believe that something was wrong and argued that she never felt any pain.

“...[My friend] talked me into it, she told me you need to go because that ain’t no, that’s not no cystic fibrosis and that’s not caffeine and chocolate, and I kept telling them well it ain’t bothering me, it ain’t hurting me, because I promise you I didn’t hurt not one day. But see what my tumor what it had started doing it was sitting right here but it had started, that’s when I really kind of got scared, and then I said oh I better go. (...) the tumor had started growing but it was growing and it had started developing at the nipple of my breast and it had started sucking me, like pulling my nipple...” (119_BRA, 199)

When she went to the health department six months after her initial doctor appointment, she was immediately sent for a mammogram, ultrasound and biopsy. She was eventually diagnosed with stage IV breast cancer. In retrospect, the woman expressed regret in not getting a second opinion right away.

“...I should’ve got a second opinion the second when I was listening to it (...) my problem could have been preventable if I had a went you know and not waited, and then a lot of it too is I was scared, I didn’t want to go, I didn’t want to hear it, you know I was scared about hearing about it. And I think that if I had went when I was having the second thoughts about it I probably could have saved my breasts...” (119_BRA, 146)

In a similar case, a woman had a regular healthcare provider but no health insurance. She was about 57 years old when she developed a breast cancer symptom but had never received routine mammograms. During one of her visits to her doctor, she pointed out a lump in her breast that she had recently found. However, this doctor explained to her that the lump could not be cancer.

“...I noticed it was, you know, at first it was like a knot and I was like, that is so weird, what is that? But see, I had gone to my primary physician in January and it was small then at that time, very small and I said, what, I said doctor, what is this? And I said, it hurts. It didn’t hurt all the time, it hurt, you know, off and on. You never could say when it was going to hurt and it was not an unbearable pain but it was, it was painful. And he said, oh, it’s not cancer, cancer don’t hurt. Well, that was not true. But it was not his fault because I didn’t hold him responsible because I didn’t follow up on it, you know. And me being a woman, I should have. He was a male doctor.” (111_BUW, 52)

This woman did not seek a second opinion on the lump in her breast for almost a year. Her symptom really started to bother her, and she finally decided to go back to the doctor’s office. However, she saw a different physician this time who scheduled a mammogram for her right away.

The doctors’ alternative explanations for the breast cancer symptoms of these women provided them with a rationale for not continuing to seek a diagnosis. In the first case discussed, the woman explicitly stated that she should have sought a second opinion right away but she was scared about what she might hear. She did not seem to be aware that breast cancer is best treated when detected at an early stage.

Influence of Health Insurance

A barrier to routine mammography screening that several women discussed was lack of health insurance and not being able to afford healthcare services on their own. This finding is contradictory to the observation that about half of the women who were getting routine mammograms did not have health insurance.

One woman who had never received routine mammography screening did have one non-routine mammogram done when she was about 40 years old. At that time, she had health insurance through her husband’s work in the military and had been getting

regular healthcare at a Georgia military base. However, she divorced from her husband and subsequently lost this health insurance. She had been working but couldn't afford the insurance offered by her employer. She discussed the effect of not having health insurance or regular access to healthcare.

“...I was working and I really didn't have --- healthcare. So, if I wasn't hurting, I didn't bother with it. I didn't, I tried to keep up, you know, if I needed to go, something major was going on or was sick at the time, went to a doctor but other than just going to do the routine, uh uh. So that's how I fell between the cracks.” (117_BUA, 320)

At another point in the discussion, this woman explained that she would never try to get a mammogram if she didn't have health insurance because she didn't think that healthcare providers would do one without coverage. Again, this story is unlike those previously discussed in which uninsured women were able to get routine healthcare and regular mammograms.

This woman ended up developing a lump in her breast, but she did not think that it could be a sign of breast cancer. She thought that it was merely a clogged milk duct or calcium deposits, which were conditions that her mother had in the past.

“...I actually felt a, a mass myself but I thought it was due to changes being brought on by menopause, you know, like a little lump or whatever, you know, whatever. Didn't think of anything. But I knew something felt different and with her being a professional (...) you know how you just, you don't think you're, that's the last think you think about. You don't think about something being like that. You just think maybe, I thought maybe it was a clogged milk duct or maybe just calcium, you know, deposits or whatever.” (117_BUA, 89)

Evidently, this woman was not adequately aware of the symptoms of breast cancer.

Fortunately, she heard of a free screening opportunity from the West Georgia Cancer

Coalition through a friend. In her rationale for deciding to go, it is clear how strongly the fact that she didn't have health insurance played a part in her decision-making.

“...I went to the screening because not having insurance, of course you don't go and try to get a mammogram if you don't have insurance because they're not going to, so... Just fell through the cracks. Not being negligent in my own health it's just, fall through the cracks. I was working every day and still didn't have insurance because of the, you know, it being so high... just kind of fell through the cracks and it was just a door opened for me to be able to get a screening.” (117_BUA, 111)

This woman felt that the free screening was an opportunity that she didn't normally have because she didn't have insurance. The mammogram that she received at the free screening turned out to be abnormal and it resulted in her breast cancer diagnosis.

In another case, a woman did have health insurance but extremely poor coverage. Her insurance plan did not cover the cost of mammograms. She explained that this was one of the reasons she did not seek a mammogram or care after she started experience symptoms.

“...I would think about going to the doctor but, you know how my money was, you know, I called around for a doctor. The insurance that I had on the job, it kept on saying you can't do this and do that and they didn't take about mammograms and cancer. I said, huh? All the money that you all are taking out --- for me. So when I'm admitted in the hospital, they cancelled my insurance on the job.” (123_BUA, 114)

This woman felt sick for about three months, but she explained that she never let sickness interrupt her regular routine. It wasn't until she was brought in to the emergency room because of her breast cancer symptoms that she finally received a mammogram.

“...When I felt that, you know, something was going wrong, I kept getting hot and, you know, weak and stuff. But I kept myself going. I

would never stop when I'm sick. I went on to work and I kept on, kept on. I felt strange things right up on my left side over here. It was a knot but it was kind of like or sort of like a cyst or something. So I went, ignored it. And I went on, I told my boss man, I said, I don't feel good. I said my chest hurts. It felt like I was having a heart attack and I was getting sicker in the stomach. So I came on home, he sent me home early and then I came down here to my sister-in-law's house. She said, uh uh, you going to the emergency room. I said, no, no, no (...) They took me on anyway because I was getting, like, who is you all? Because my eyes and things, you know, was getting red..." (123_BUA, 74)

This woman finally stopped working when her boss saw that she was sick and told her to go home. She explained how her sister-in-law brought her to the local hospital because of her deteriorating health even though the woman didn't want to go. It is clear that this woman did not prioritize taking care of her health as she did not want to seek medical help even when her symptoms became debilitating. Luckily one of the physicians that saw her at the hospital recognized her need for a mammogram, which eventually led to her breast cancer diagnosis.

Health insurance status and money were influential factors in the mammography use behavior of these women. However, it was generally observed in the data that if women had a desire to be seen by a physician, they were generally able to find a way to access healthcare.

Knowledge about Cancer

In the same way that knowledge about cancer motivated some women to seek routine mammography screening, misconceptions and misinformation about breast cancer contributed to women's decisions to not receive mammograms. A belief that was mentioned in more than one discussion about decisions to not seek a mammogram was that if the woman did not feel a lump in her breast, mammograms were not necessary.

One woman had a non-routine mammogram when she was several years younger but never had another even though she was going to a regular healthcare provider. She had been performing self breast exams, but when asked if she had been getting annual mammograms she replied:

“No, I haven’t (...) Because me, I have been checking my breasts all the while, I didn’t feel anything. But, that morning I got up, it was there.” (134_BRA, 119)

She explained that it wasn’t until one morning that she woke up with sharp pain in her breast and discharge from her nipple that she went to see her provider and asked them to check her breast. She went to her regular doctor that same day because she was in so much pain. However, her regular doctor wouldn’t do the mammogram for her and told her to call the nearby hospital.

“...My breast was hurting and I was in by myself and I drove myself to the doctor... I went to the doctor and I, I told the lady. I said something, something about me ain’t right and she told me to call [a local hospital]. I called over to the hospital... and they told me to call the health department because I didn’t have no insurance. The job I was working at, I was working like up to the private school and didn’t have no insurance... I went to the health department, I went and got me a pap. They paid for me to get my mammogram and get my pap smear too.” (134_BUA)

It does not appear that this woman’s regular doctor’s office was aware of the free screening opportunity at the local health department. Fortunately, the hospital that she called was able to recommend it to her. The mammogram that she received at the health department was abnormal and she was diagnosed with breast cancer. This woman explained that she didn’t delay in seeking care for her symptoms because she was in so

much pain. Unfortunately this was not always the case for women who developed breast cancer symptoms and were not receiving routine mammograms.

Although not always explicitly stated, some women expressed not going to get mammograms because they were busy doing other things, such as work. One woman in particular cited the fact that she was trying to start a business as the reason she didn't take care of her health. She did not go for regular mammograms even when she started to feel aches in her breasts because she was busy developing her business.

“I want other women to know about my breast cancer experience is that please make sure that they don't procrastinate. I did for at least, you know, it's [the cancer] probably been there with me, realistically, since, like, 2007. But I had, I just didn't have the mindset to stop because I was just so trying to get my business off the ground. So, for those two years, even though I was sick, I was still trying to start a business, and I had my own plan of I'll get my business and then I'll take care of my health.” (107_BUA, 119)

In this case, even though she was experiencing breast symptoms the woman placed a higher priority on establishing her business. It does not seem that she was aware of the importance of having abnormal breast changes checked as soon as possible. She eventually ended up going to a hospital to get treatment for her asthma. The hospital accepted her as a patient and set her up with a primary care physician. This doctor decided to give her a mammogram because it had been awhile since her last one and this mammogram detected her breast cancer.

In other cases of breast cancer knowledge affecting mammography use behavior, having alternative explanations for breast cancer symptoms was a barrier to seeking mammograms. One woman was 43 years old and had never had a mammogram. She didn't have health insurance but had gone to free clinics before for medical treatment.

She started noticing bruises all over her body, but she thought that they could be the result of menopause. She waited six months to seek the mammogram that led to her diagnosis.

“About six months before I went to the, the health department for a check-up. I just was feeling tired all the time, noticing a lot of bruises, like every time I’d like go to take a bath, there were new bruises and nothing was going on that should have caused bruises (...) I couldn’t figure it out and I kept telling my husband, I think I need to go to the doctor and get them to check something. And I figured since I was 40 something years old maybe it was menopause, maybe it was something else.” (124_BRW, 69-71)

When she finally decided to go to a doctor and have someone look at her symptoms, she had to make several phone calls to figure out where to go. She didn’t have health insurance or a lot of money to pay for a check-up. Eventually, someone that she talked to at a doctor’s office was able to tell her about the free screening at the local health department.

“I had called around to different doctors and they were giving you prices that were, like, almost ridiculous. And one of the doctor’s offices that I called in the phone book said, why don’t you call your local health department. Some of them will do a full physical. So I called and she said, well, it depends on how much you make and I gave her what we were making at the time and she says, yeah, you’ll only have to pay, just like \$15 or something is what we were told to start with. And then when she did the paperwork, she said, you don’t have to pay that. So I wound up not having to pay anything for the physical.” (124_BRW, 196)

The mammogram that this woman received from the health department resulted in her diagnosis of breast cancer. As seen in other cases, the ability to rationalize her breast

symptoms and attribute them to something else like menopause influenced her delay in seeking care and a mammogram.

Delays in Receiving Mammograms

A defining characteristic of women that were not receiving routine mammograms is that they experienced delays in receiving mammograms. This finding contrasts the observation that there were no delays in receiving mammograms for women that were getting routine mammography screening. Of the women who were not being screened regularly, about half delayed in seeking care and a mammogram when they developed breast cancer symptoms.

In one such case, a woman did not have health insurance but had been going to the health department for annual check-ups. She had a non-routine mammogram done in her early 40s when she had health insurance, but had never receiving routine mammography screening. This woman noticed that her nipple was inverted for almost a year before she went to see a doctor. She cited fear and not thinking about it very much as the reasons why she delayed so long.

“I guess being kind of scared and just thinking oh well it’s not really nothing, got to put it in the back of your head, you know.” (142_BRW, 90)

Eventually this woman’s daughter noticed the inverted nipple and told her that she need to have it checked by a doctor. Evidently this was the prompt that the woman needed to finally seek the opinion of a healthcare provider.

“[Daughter’s name] said momma your nipple’s going in. I said I know. She said do you know what’s a sign of, she said you really need a check-up. So I called the health department and got an appointment. That was in August, and in September they found it.” (142_BRW)

After a year of not doing anything about her symptom, this woman called the health department directly after her daughter expressed concern and recommended she get a check-up.

Women who were not receiving routine mammography screening more commonly had delays in receiving mammograms. These delays occurred when they developed breast cancer symptoms but did not seek a mammogram right away. Many of them were not aware of what their symptoms could indicate and did not prioritize seeking care. Some had alternative explanations for their symptoms that also influenced delays in getting a mammogram. There were also cases in which healthcare providers did not recommend a mammogram when the women came to their offices with an indicator of breast cancer.

V. DISCUSSION

The objective of this study was to identify the factors that influenced mammography use behavior among low-income and uninsured or underinsured women. Interestingly, health insurance status did not seem to affect whether women were receiving mammograms. While some women did cite lack of insurance as a reason why they did not have routine mammograms, about half of the women who had regular screening for breast cancer did not have health insurance. In addition, out of the nine women who were not receiving routine mammograms, only two of them had never had a mammogram before their diagnosis. It is noteworthy that these two women were both under the age of 40 and would not be eligible for routine mammograms under the new screening recommendations put forth by the USPSTF.

For the women in this study, there appear to be two separate behavioral patterns of mammography use prior to their diagnosis of breast cancer. Analysis of these patterns revealed that women who had been receiving routine mammography screening seemed to be much more proactive in their breast health and there were no delays in the detection of their cancer. Conversely, women who had not been getting routine mammograms more commonly had delays in getting the mammogram that led to their diagnosis. Roughly half of these women developed breast cancer symptoms but did not seek care or a mammogram right away. This finding has implications for prevention methods for both healthcare providers and women who are at risk of breast cancer.

V.A. Prevention Messages for Healthcare Providers

None of the women who were receiving routine mammography screening experienced a delay in the detection of their breast cancer. Of the women that were getting regular mammograms, fully half were diagnosed as a result of a routine mammogram. The other half of these women noticed a breast cancer symptom and went back to their healthcare provider to have it checked. None of the women who observed an abnormal change in their breast delayed in getting it looked at by a doctor. This finding suggests that this group of women was generally proactive in taking care of their breast health. Thus, the promotion of routine mammography screening by healthcare providers can not only result in the timely detection of breast cancer, but also may impart a sense of responsibility and awareness to women that they need to be aggressive in taking care of their health and their breasts.

Due to the fact that only half of the women who had been receiving routine mammograms had their cancer detected by a routine mammogram, there is an apparent need to for these women to regularly check their breasts in between regular mammograms. Although many of the women seemed to know to monitor their breasts on their own, education about the importance of self breast exams should be ensured and promoted among this population. Having discussions about self breast exams also will provide physicians with an opportunity to teach women about breast cancer symptoms and the importance of not delaying in going to a doctor when they are observed. This education is important both for the women receiving routine mammograms and the women not getting regular mammograms.

Of the women not receiving routine breast cancer screening, many did not perform self breast exams nor did women necessarily know that abnormal changes in their breasts should be checked by a healthcare professional. Women who had alternative explanations for their breast symptoms, such as menopause, delayed seeing a doctor. Additionally, a few women cited fear as the reason they did not go to the doctor when they noticed changes in their breasts. This suggests a need to make women aware that breast cancer is treatable and the sooner that detection and treatment begins the better the prognosis.

It is also very clear from the data that women follow doctor's recommendations. In all of the women's stories, there was only one instance in which a woman did not follow a doctor's suggestion that she have a routine mammogram. Conversely, in the two cases where providers did not suggest a mammogram despite the presence of symptoms, the women did not seek a mammogram. Instead, the physicians suggested an alternative explanation for the physical changes in their breasts. For these women, although their symptoms steadily became worse, they delayed from six months to one year to finally seek care and go see another provider. In this time, their rationale for not going to see another doctor was that their healthcare provider did not think that anything was wrong.

A strong message that women who were not getting regular mammograms expressed in looking back on their mammography use behavior was that they wished they had followed up on breast symptoms sooner. Regret was a common sentiment for this group of women. While healthcare providers should increase their education of women about breast cancer symptoms, the women should also learn to be proactive in getting abnormalities in their breasts checked by doctors.

In the data, there were several instances in which women were influenced by their peers in mammography use behavior. In designing breast cancer prevention messages for the low-income and uninsured/underinsured women, sharing these women's stories may similarly influence this population's mammography use behavior. Taken directly from one of the women's stories, a powerful message is conveyed in the following quote:

“My problem could have been preventable (...) I was scared, I didn't want to go, I didn't want to hear it, you know I was scared about hearing about it (...) If I had went when I was having the second thoughts about it I probably could have saved my breasts.” (119_BRA, 146)

By utilizing the sentiment of regret at not having breast symptoms checked by a doctor immediately, perhaps women will become motivated to seek screening. Additionally, this message conveys the fact that had this woman's breast cancer outcome may have been more favorable had she gone to the doctor sooner, thus suggesting to women the importance of early detection and treatment.

V.B. Recommendations

Given the apparent influence of healthcare providers on mammography use behavior, all doctors, not just primary care physicians and gynecologists, should routinely ask their women patients above the age of 40 whether they have had a mammogram. Currently in the United States, there are inconsistencies among advocacy groups as to when routine mammography screening should begin and at what frequency. Every healthcare provider that provides mammograms has their own individual screening policy that they follow, and subsequently women who are not yet 50 years old may not be eligible to begin routine mammograms in their practice. However, doctors should make

women aware about the importance of getting mammograms and educate them about the variations in screening recommendations put forth by the different groups.

Healthcare providers should also be aware of the free screening opportunities available in their area or state. Evidently, the free breast cancer screening available at health departments through the NBCCEDP is not widely known by all practicing physicians in Georgia. While it is especially important for doctors who are treating uninsured or underinsured women to know about these opportunities, it was observed in the women's stories that their insurance status can change quickly as a result of losing a job or divorce. Therefore, all physicians regardless of their patient population should be aware of free screening opportunities. By suggesting such resources, physicians could increase routine mammography use in this population.

Finally, all doctors should regularly teach their female patients about self breast exams. This education should include both their importance and how to do them correctly. Even women who are getting routine mammography screening should receive this guidance. Additionally, women should be taught that when they detect abnormal changes in their breasts, they must be looked at by a physician as soon as possible. Doing so will promote the early detection of breast cancer and potentially teach women to be more proactive about their breast health.

V.D. Study Limitations and Strengths

In this study, the data on mammography use behavior was collected from women who had breast cancer diagnoses. The women were thus discussing the factors that influenced their mammography use after having a breast cancer diagnosis, which may

have affected how they discussed previous breast cancer screening. However, the data from this population provide a unique perspective on the mammography use behavior of low-income and uninsured/underinsured women who were at high-risk for breast cancer. Additionally, their stories reveal the factors that influenced how they came to be diagnosed with breast cancer, which can inform more targeted and relevant prevention methods for this population.

While there were no observed differences in the factors that influenced mammography use among African American women and Caucasian women, no conclusion can be drawn from this finding given the small size of the study population. Future research should utilize a larger sample size to investigate potential differences using a qualitative method design.

The only data on insurance status was self-reported in the interviews. There also was no data on income level beyond the fact that the women must have been within 200% of the federal poverty limit in order to be enrolled in the Georgia Women's Health Medicaid Program.

By using a qualitative methods design, women were allowed to explain how they received mammograms in an open-ended manner and the data consequently had much more context. Despite the limitations of the study, it provides valuable insight as to the reasons why women in this population do or do not seek routine mammography screening and what factors affect how these women receive mammograms.

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APPENDIX A: INTERVIEW GUIDE FOR WOMEN WITH BREAST CANCER

Life History Interview Guide - Breast Cancer

Suspicion

When did you first suspect that something was wrong? Why?

- Disclosure: Did you talk to anyone? Who? Provider?
- Thoughts/Feelings: What were you thinking/feeling at the time?
- Health Care: Did you have a regular provider then? [Where were you receiving care?]
- Delays: Did you act on your suspicions right away, or did it take some time?
- Other events: What else was happening in your life at the time?

Screening

When did you get tested/screened? What was that like?

- Process: Where did you go? What did you have done?
- Communication: How did you find out it was abnormal? When? Delays?
- Thoughts/Feelings: What were you thinking/feeling when you found out?
- Knowledge: How did you learn about your condition and the procedures?
- Support: What kind of support did you have?
- Other events: follow up on home, work, family, support, challenges/facilitators, faith

Diagnosis

What was it like hearing that you had cancer?

- Communication: What were you told about your cancer?
- Type and stage of cancer
- Diagnostic process: Did you have to have additional tests/procedures?
- What were you told about these?
- Referrals for treatment?
- Delays?
- Thoughts/Feelings: How did you react to all of this?
- Other events: follow up on home, work, family, support, challenges/facilitators, faith

Treatment

How was your treatment – or treatment options – discussed with you?

How did you decide what to do?

- Discussion: Who did you talk to about it? [provider, second opinion, support]
- Information: Did you seek out more information about your cancer/treatment options?
- Access: WHMP, Distance, referrals, enrollment in CMO [care management organization]

- What was your treatment experience like? When did it begin? What was involved? Where are you now?
- Modalities: Surgery (lymph nodes), radiation, chemotherapy, etc.

- Experience: Duration, Side-effects, Mental Health
- Other events: What else was happening in your life and how did that affect your treatment?

Closing

- Is there anything else you'd like to share with me about your story?
- Is there anything you wish that other women could know about your story?
- What about providers? What would you like them to take away from your experience?

APPENDIX B: INFORMED CONSENT FORM

Emory University Rollins School of Public Health Consent to be a Research Subject

Women's Health Medicaid Program (WHMP) Enrollee Interview

Title: Expanding Medicaid Coverage and Time to Treatment: Effects by Race

Principal Investigator: E. Kathleen Adams, Ph.D.

Funding Source(s): American Cancer Society

Introduction and Purpose

You are being invited to participate in a research study on Georgia's breast and cervical cancer treatment program, known as the Women's Health Medicaid Program, or WHMP. I am asking you to participate because either you are currently enrolled in this program, or you were once enrolled in this program. Approximately 36 WHMP providers and 72 WHMP enrollees will be interviewed for this study.

Procedures

If you agree to participate, the interview will last between one to two hours. The interview will be conducted in person, at a location that is convenient to you. The overall purpose of the study is to learn about the experiences that both providers and patients have with the WHMP. For this interview, we are interested in learning about your experience as an enrollee in this program. In particular, we are interested in understanding your 'life history' with cancer. Talking about life histories means telling about your entire experience with your breast or cervical cancer, from the time you were screened for the cancer, through the diagnosis, and through treatment as well. We will ask you to talk with us about when you were screened for the cancer, why you chose to be screened, how you learned of your diagnosis, and what courses of treatment you chose and were offered as well. In particular, we are interesting in hearing your experience with the WHMP. We will ask you to tell us how you learned about this program, how you enrolled in the program, and how you found cancer treatment providers through this program. We are also interested in learning what if any barriers you've experienced accessing your cancer treatment through this program.

A colleague and I will be taking written notes of your answers, and the interview will be digitally recorded with your permission. If you do not agree to have the interview recorded, please let me know.

Risks and Discomforts

There are no foreseeable risk or discomforts associated with this study.

Benefits

This study is not designed to benefit you directly. This study is designed to learn more about the Women's Health Medicaid Program (WHMP). The information you provide, however, will add to our knowledge about the WHMP.

Compensation

You will be given \$50 for your participation in the interview. We will give you emergency care if you are injured by this research. However, Grady Health System has not set aside funds to pay for this care or to compensate you if a mishap occurs. If you believe you have been injured by this research, you should contact Dr. Kathleen Adams at 404-727-9370.

Confidentiality

Certain offices and people other than the researchers may look at the study records. Government agencies, Emory employees overseeing proper study conduct may look at your study records. Study sponsors may also look at your study records. These offices include the Office for Human Research Protections, the sponsor(s), the Emory Institutional Review Board, the Emory Office of Research Compliance and the Office for Clinical Research. In addition, study records can be opened by court order or produced in response to a subpoena or a request for production of documents. Emory will keep any research records we produce private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

Contact Persons

If you have questions, I invite you to ask them now. If you have any questions about the study later, you may contact me at scblake@emory.edu or 404-712-9713. You may also contact the study's Principal Investigator, Dr. Kathleen Adams at 404-727-9370 or at eadam01@emory.edu.

If you have questions about your rights as a participant in this study, you may contact the Emory University Institutional Review Board at 404-712-0720 or toll free at 1-877-503-9797, which oversees the protection of human research participants.

If you are a patient receiving care from the Grady Health System, and you have a question about your rights, you may contact Dr. Curtis Lewis, Senior Vice President for Medical Affairs at (404) 616-4261.

Voluntary Participation and Withdrawal

Participation in this research is voluntary. You may refuse to participate, or refuse to answer any questions that you do not want to answer. If you decide to be in the study and change your mind, you may withdraw at any time. Your participation or nonparticipation will have no negative repercussions.

Consent

I have read this consent form (or it has been read to me). All my questions about the study and my part in it have been answered. I freely consent to be in this research study.

By signing this consent form, I have not given up any of my legal rights.

Name of Subject

Signature of Subject

Date

Signature of Person Conducting Informed Consent Discussion

Date