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A Mixed Methods Approach to Examine Racial Disparities in Adherence to Surveillance Mammography Among Breast Cancer Survivors

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A Mixed Methods Approach to Examine Racial Disparities in Adherence to Surveillance Mammography Among Breast Cancer Survivors.

A dissertation submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

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Dedication

This dissertation is inspired and touched by my mother “Denise” lived experiences. You are forever with me and engraved in my heart.

Acknowledgements

"Trust in the Lord with all your heart; do not depend on your own understanding. Seek his will in all you do, and he will show you which path to take"
Proverbs 3-5

My journey to get this PhD started in August of 2016. When I think back to who I was at the start of this journey and who I am today, I cannot help but get emotional. I want to first start my acknowledgments by thanking God, my heavenly father! My world stopped when I lost my best friend, my biggest supporter, my cheerleader, my mother on August 23, 2018 from a 3rd battle of breast cancer. During this time, I was in my 3rd year of the doctoral program and had my mind made up that I was not coming back to complete this doctoral degree the idea of school and breast cancer research was too painful for me to even think about, and at times this feeling is still so VERY true; However, I am here at the finish line because I surrendered all of my faith in God, which surpassed my understanding and has been the ONLY source of my strength to persevere, through my toughest days! I am a living and breathing testimony that all things are possible with the help of God. Even through the countless days and nights of struggling with the emotions of grief, depression and imposter syndrome- deep down I still wanted to fight for what I believed in, to honor my mother's legacy. My research interest is fueled by my lived experiences of being a caregiver to my mother. My devotion to completing this dissertation was certainly not by my own strength- Yes I completed all of the requirements for this PhD; but I wouldn't have without my faith for, *"When I'm weak I am strong in the Lord"1 Corinthians*. Thank you, God, for restoring and replenishing me and guiding me over every stumbling block in this journey!

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Abstract

A Mixed Methods Approach to Examine Racial Disparities in Adherence to Surveillance Mammography Among Breast Cancer Survivors.

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PURPOSE: Annual surveillance mammography is a critical part of routine cancer care for breast cancer (BC) survivors; reducing mortality by 39%. However, disparities exist with regard to adherence to surveillance mammograms among BC survivors; Black women are 44% less likely to adhere than their White counterparts. Despite the existence of this racial disparity for over a decade, little is known about factors that explain reasons for Black BC survivors' non-adherence. This is because most studies have not evaluated the role of healthcare delivery or psychosocial factors. Guided by the Behavioral Model for Vulnerable Populations, the purpose of this mixed methods dissertation is to examine the influence of *predisposing (race, residential area), enabling (health care access) and need factors (years from diagnosis)* on adherence to surveillance mammography in Black and White BC survivors. Specific study aims are to: (a) Determine racial differences and influential factors in survivors breast cancer beliefs (b) Evaluate the contribution of health care access, socioeconomic status and perceived health on adherence to surveillance

mammography (c) Explore surveillance mammography experiences of survivors engaged in social media.

METHODS: Three cross-sectional studies were conducted of which two analyzed data from datasets and one collected primary qualitative and quantitative data. All studies evaluated theory driven determinants to better understand adherence to nationally recommended surveillance mammography guidelines. Adjusted multivariable logistic regression models were used to assess the independent and joint associations between independent study variables (e.g., race) on study outcome (e.g., adherence). Eight virtual focus groups were conducted with BC survivors through social media platforms (e.g., Facebook, reedit) to further explore barriers and facilitators of survivor's surveillance experiences. A thematic analysis approach using grounded theory techniques analyzed online focus group to identify thematic findings.

RESULTS: Overall, survivors reported high rates of adherence to surveillance mammography (72-70%). Influential factors on adherence involved an interaction with race, rather than just race alone: Black women living in non-metropolitan areas were more likely to be non-adherent compared to White women living in non-metropolitan residential areas. Similarly, Black women with lower levels of patient provider communication had lower adherence versus White women with lower communication levels. The presence of health care access, and health insurance were salient enabling factors on survivor's adherence, across qualitative and secondary findings. Longer time from diagnosis and having underwent mastectomy surgery were the top need factors associated with non-adherence. Regarding breast cancer beliefs, satisfaction with financial aspects regarding health care and clinical factors such as BC stage were influential factors in survivors perceived severity and cancer recurrence beliefs.

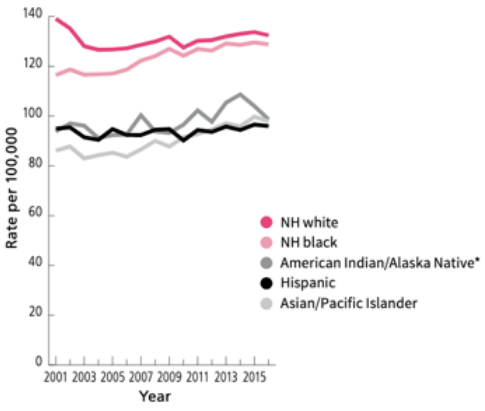
CONCLUSION: This was the first mixed method study to describe psychosocial and healthcare delivery factors in adherence to surveillance mammography guidelines among Black and White BC survivors. Study findings extends scientific knowledge in BC survivors health beliefs and predictors (e.g., provider-communication) of surveillance mammography, with special attention on Black women's surveillance experiences. This study provides new insight in cancer care delivery by: (1) advancing breast cancer survivorship research, (2) informing future research direction and (3) clinical implications to refine current surveillance guidelines and to improve barriers to surveillance, with special attention to racial/ethnic populations.

Chapter 1: Introduction

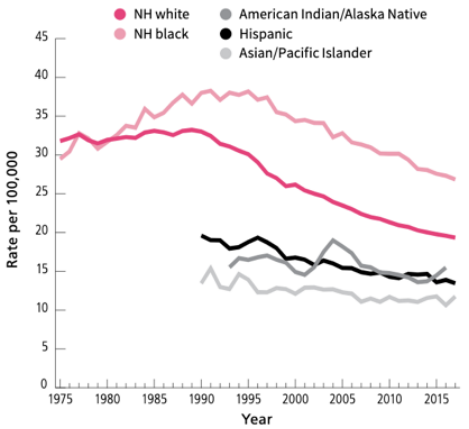
Breast Cancer Health Disparities

Breast cancer (BC) is the most common diagnosed cancer and second leading cause of death among women in the U.S.[1,2] An estimate of 276,480 BC cases and 42,170 BC deaths was expected to occur in 2020, among women.[2] Despite advances in BC treatment modalities (e.g., endocrine therapy) and survival rates, **African American (Black) women bear the greatest burden of BC morbidity/mortality across all racial/ethnic groups of women in the U.S (Figure 1).** [3-6] For example, death rates are 42% higher in Black women, despite their lower incidence rate (126.7) when compared to European American (White) women (130.8).[1]Trends of this unfortunate racial mortality disparity has persisted over the last 4 decades and is continuing to widen. [7,8] Reasons for BC survival disparities are multifaceted involving factors of underlying tumor biology, healthcare access and organizational approaches (e.g., tracking patients for follow-up), adherence to adjuvant treatment, lower socioeconomic status (SES), and late-stage diagnosis of relapse BC.[9-13] **However, BC survivors who adhere to surveillance mammography have better outcomes** (e.g., cancer specific mortality).[14-16]

Figure. 1 Breast Cancer-Incidence and Mortality Rates per 100,000 by Race/Ethnicity, US, 1975-2016[17]



NH indicates non-Hispanic. *Statistics based on data from PRCDA counties.
Note: Rates are per 100,000 and age adjusted to the 2000 US standard population. Rates were adjusted for reporting delays.
Source: NAACCR, 2019.



Note: Rates are per 100,000 and age adjusted to the 2000 US standard population.
Source: NCHS 2019. Rates for American Indian/Alaska Native are based on the PRCDA counties and are 3-year moving averages.

Receipt of annual surveillance mammograms decreases BC mortality by 39%,[16] but unfortunately Black survivors have poorer rates of adherence compared to their White counterparts.[18-21] When Black BC survivors adhere to surveillance mammography, their BC specific mortality is lower compared to Black survivors who are non-adherent.[14,22] **Some factors associated with** adherence to surveillance mammography include socio-demographics and health care utilization (e.g., visits with medical oncologist); [18,19,22] however, these data are limited for Black women and generally have not extended beyond clinical factors to examine healthcare related experiences (e.g., patient-provider communication). Given the important role of the patient-provider relationships for Black women during treatment,[23,24] an examination of how healthcare experiences impact surveillance mammography may be crucial for behavioral interventions.

Observational research studies have provided insight regarding BC adherence related behaviors that may aide in understanding surveillance adherence.[25-28] For example, studies that examine non-adherence to adjuvant endocrine therapy (AET), among hormone receptor-positive BC patients suggest that potential reasons Black women have lower adherence compared to White women[29,30] involve out-of-pocket cost, physician recommendation and pharmacy type.[31-34] These studies have identified modifiable health care factors for intervention targets to improve AET treatment disparities; however modifiable factors to address surveillance mammography disparities are poorly understood among BC survivor's.[35] Further investigation is needed to understand reasons of non-adherence to surveillance mammography to help uncover key opportunities to improve the delivery of surveillance among Black BC survivors.

National data reveal disparities throughout the continuum of cancer care for Black women.[3-6] From diagnosis, to treatment Black women are diagnosed at later stages[13], have lower

adherence rates to clinically significant systemic therapies (e.g., adjuvant endocrine therapy)[36,37], have lower quality of life following treatment,[38] and are less likely to comply to breast surveillance guidelines when compared to White women.[18] Following treatment, reports also suggest that Black women are more likely to experience deficits in follow-up information from providers and experience unique challenges such as, financial barriers at survivorship compared to White women, [36,39,40] which may in part, contribute to their surveillance behaviors.

Breast Cancer Surveillance and Follow-up Care Recommendations

Advances in early detection and life-saving treatments has contributed to the estimated 3.5 million BC survivors in the U.S.[41] However, BC survivors face a heightened risk for health complications, including recurrence within the first five years after their treatment. [42]To improve early detection of BC recurrence adherence to breast surveillance guidelines, such as a yearly mammogram are beneficial for survivorship. [14,43,44] Following a BC diagnosis and completion of definitive treatment, survivors may face: a series of follow-up appointments with their cancer care team for breast reconstruction and late treatment effects (e.g., lymphedema, joint pain). While each of these health aspects and delivery of care are tailored to a women's treatment plan, a continuum of postoperative care guidelines, such as a surveillance mammograms are recommended for surveillance for BC recurrence among survivors.[45] The American Cancer Society (ACS) and American Society of Clinical Oncology (ASCO) recommends that every 6-12 months following completion of breast surgery and/or systemic treatment (e.g., radiation) survivors should adhere to a individualize clinical follow-up visit during the first five years and an annual mammogram (Table.1). [46,47]

Other breast imaging surveillance guidelines include: monthly breast self-examination, follow-up with physician/oncology appointments [18,48] and MRI exams for women who meets high risk criteria. [49-51] After completion of treatment, it is unclear whether BC patients know about these guidelines and who discusses these follow-up care guidelines with them (primary care provider vs. oncologist).[40]

Table. 1 ASCO Surveillance Guidelines

Recommendation: History and physical	
(a) individualize clinical follow-up care based detailed cancer-related history on age, specific diagnosis, and treatment protocol as recommended by the treating oncology team	✓ Physical examination ✓ Every 3-6 post-treatment for first 3 years ✓ Every 6-12 ✓ Annually thereafter
Recommendation: Screening breast for local recurrence or a new primary breast cancer	
(a) Should refer women who have received a unilateral mastectomy for annual mammography on the intact breast and for those with lumpectomies an annual mammography of both breasts	✓ Mammography
(b) Should not refer for routine screening with MRI of the breast unless the patient meets high risk criteria for increased breast cancer surveillance as per ACS guidelines	✓ MRI

Research supports that higher levels of BC related knowledge is associated with clinical benefits such as, uptake of screening guidelines and adjuvant treatments.[52-55]Unfortunately women from underserved racial/ethnic groups are more likely to report lower BC knowledge. In a cohort of BC survivors, Black women that reported lower levels of BC knowledge resulted in latter delays in BC diagnoses, and adjuvant treatment initiation and accessibility compared to White peers.[56] While studies among women from the general population have examined mammography knowledge,[52] data are lacking about BC survivors surveillance mammography knowledge. A better understanding is needed about BC survivor's knowledge and experiences with BC surveillance and their perceptions about moving ahead and getting back to a since of normalcy. Understanding their perceptions about their follow-up care after completion of their BC treatment, will help reveal key mechanisms that contribute to survivors suboptimal adherence to surveillance mammograms, which will have the potential to close gaps and help mitigate survival outcomes. [57]

Surveillance Mammography

Annual adherence to American Society of Clinical Oncology (ASCO) and National Comprehensive Cancer Network (NCCN) surveillance mammography guidelines (Table 1) is

strongly recommended,[45,46] for early detection of disease relapse, increase in overall survival by 39% and ultimately optimal survivorship care.[15,44,57,58] National adherence rates to surveillance mammography range from 85-75%[19,20,59]among 65 and older BC survivors; however, rates are as low as 44% among young (<45) Black and Hispanic BC survivors. [60-63] While studies consistently highlight low adherence rates to surveillance mammography among Black women compared to their White counterparts, there are very few explanations for these disparities. [18,19,64,65] Moreover, examination of non-adherence to surveillance mammography is critical to identify modifiable factors that can inform behavioral interventions that can be integrated for minority women during their survivorship care.

Potential Factors Related to Poor Adherence to Surveillance Mammography

Reasons for non-adherence to surveillance mammography are complex and relate to patient, provider and healthcare factors. The Behavioral Model for Vulnerable Populations [66] posits that healthcare utilization is directly influenced *by three characteristics: predisposing factors (e.g., sociodemographic), enabling factors (e.g., environmental constraints), need factors (e.g., perceived need for the use healthcare delivery system)* (Figure 3). Influential factors on non-adherence to surveillance mammography are operationalized by these key constructs from this framework. *Predisposing factors* consistently related to non-adherence to surveillance mammography include Black race, age, and single marital status. Married women were more likely to adhere to surveillance mammography when compared to unmarried women.[19] There have been mixed results with regard to the role of age—some studies have concluded younger age ($\leq$50) [21,67] predicts better adherence whereas more studies have shown this relationship among older age ($\geq$65) women. [18,21,68] [19,69,70] *Enabling factors* linked with non-adherence include higher out of pocket cost, lack of health insurance [19,20,71]lower SES,[63,72] lack of routine care[73], living in low-

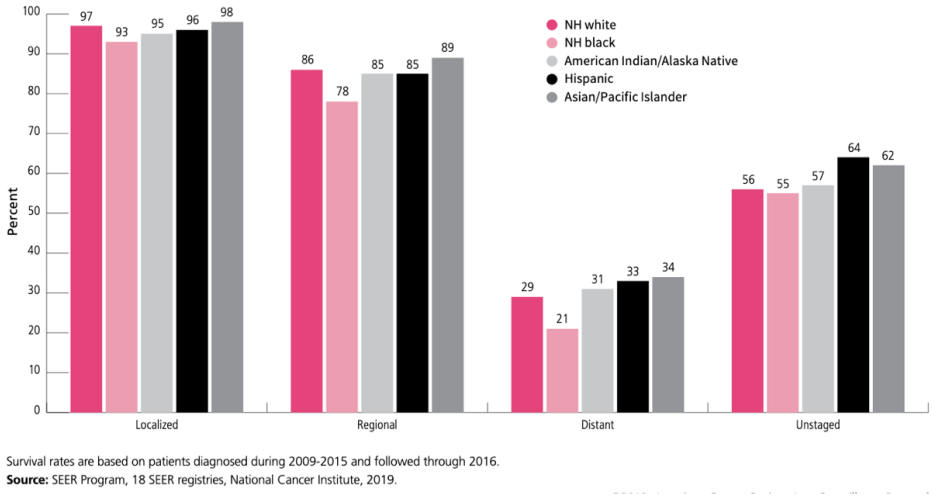
income residential neighborhoods and lower health-related quality of life.[64,74] *Need factors* associated with non-adherence involve lack of provider recommendation,[75,76]lack of physician follow-up visits and clinical factors such as later BC stage[19,73], larger tumor size[19] and surgery without radiation and the presence of more comorbidities. [64,73] Women who received breast conserving surgery and radiation therapy had higher surveillance mammography rates (63%) compared to women who only received surgery (mammography rates = 49%).[18] Data are limited in the association between healthcare experiences (e.g., provider communication) and non-adherence. For example, gaps in follow-up care may also be attributed to inadequate patient-provider communication (*Enabling Factors),* [50,77-80] lack of access to health care (*Enabling Factors*) [19,20], lack of coordination between patients and providers, (*Enabling Factors)* and not being contacted for follow-up routine visits *(Need Factors*) [81] One study found that frequent contact with primary care physicians better predicted the use of mammography and improved BC outcomes. [82] Inadequate communication and coordination between patients and providers, [50,77-80] negatively impacts the quality of information and healthcare BC survivors experience. [19,20] No work to date, has described predictors of sociocultural, psychological factors and healthcare experiences in Black BC survivors, including the patient-provider relationship contributing role in surveillance mammography. When compared to White women, Black patients have lower participation in care, less effective patient-provider communication about prognosis and treatment. [77] These findings further support the hypothesis of the race/ethnicity influence in communication with providers and psychosocial factors (e.g., quality of life) within the delivery of cancer care. [83,84] Addressing these influential healthcare experiences are modifiable and can be used to address non-adherence surveillance behaviors in BC survivors within health care settings. Furthermore, accounting for social determinants such as where women live further explicate the proportionate

of disparities in surveillance mammography adherence. This study will advance scientific knowledge on modifiable predictors of surveillance mammography among BC survivors, and will be the first to retrospectively characterize the relationship between adherence and patient-provider communication.

Surveillance Mammography Behaviors in Black Women

Poor adherence to surveillance mammography guidelines may contribute to suboptimal BC outcomes in Black survivors; however much of what is known about factors that influence mammography behaviors is drawn from unaffected women. It would seem that having been diagnosed with BC would heighten fear appraisals about the risk of BC recurrence and thus result in optimal adherence to surveillance mammography. Nevertheless, data from several large retrospective cohort studies consistently found lower mammography screening [or adherence] for Black BC survivors relative to White BC surviors.[18-21,67] **In part, this disparity may explain** Black women's lower BC specific survival rates when they do not adhere to surveillance mammograms (Figure 2). [7,8]Poor adherence to guidelines for surveillance mammography, after completion of BC treatment, are linked with adverse BC outcomes. [57]Results from a meta-analysis concluded that mortality for Black women elevated after controlling for patient and tumor characteristics, treatment-type, socioeconomic status and comorbidity; however, controlling for surveillance mammography reduced the difference in all-cause mortality between Black and White women.[44]**These data highlight the need for research focused on improving surveillance mammography among Black BC survivors, an area where there is a dearth of research.[64,85,85]**

Figure. 2 Five-year Breast Cancer-specific Survival Rates (%) by Stage at Diagnosis and Race/Ethnicity, US, 2009-2016[86]



Survival rates are based on patients diagnosed during 2009-2015 and followed through 2016.
Source: SEER Program, 18 SEER registries, National Cancer Institute, 2019.

Psychosocial Determinants and Breast Cancer Outcomes

Psychosocial factors such as health beliefs, mental health and social support are widely known interpersonal levels of influence in BC survivor's health and behavioral outcomes (e.g., adjuvant treatment adherence, mammography). [54,55,83,87] There is a strong theoretically based rationale from prior research to examine the contribution of psychosocial factors in adherence related behaviors (e.g., treatment) among BC survivors.[88,89] Prior work has found that lower adjuvant treatment knowledge, beliefs and greater attitudes about medical mistrust were associated with BC survivor's underutilization of adjuvant BC therapies. [55]In the context of cancer surveillance guidelines, research has indicated that BC survivors with fewer life stressful events are more likely to meet recommended guidelines compared to survivors with more stressful life events.[60] While, studies investigating psychosocial factors have furthered our understanding of BC disparities broadly, there is still more work needed to help mitigate surveillance disparities at survivorship among Black women.

Black women experience unique BC challenges throughout their continuum of care. Commonly reported barriers that negatively influence Black women's BC morbidity/mortality

include: lack of health care access (e.g., cost) and lower health-related quality of life outcomes (e.g., psychosocial). [76,90,91] [92] Specific barriers Black women face for early presentation of disease include: poor knowledge of BC symptoms and risk, fears, embarrassment and disclosing symptoms.[13] For treatment adherence (e.g., delays, discontinuation) Black women often experience barriers such as: medical cost, physician recommendation, pharmacy type.[36,93-95] Despite these exasperated health care barriers among Black women, research is still underdeveloped around this groups psychosocial needs during their breast surveillance period.

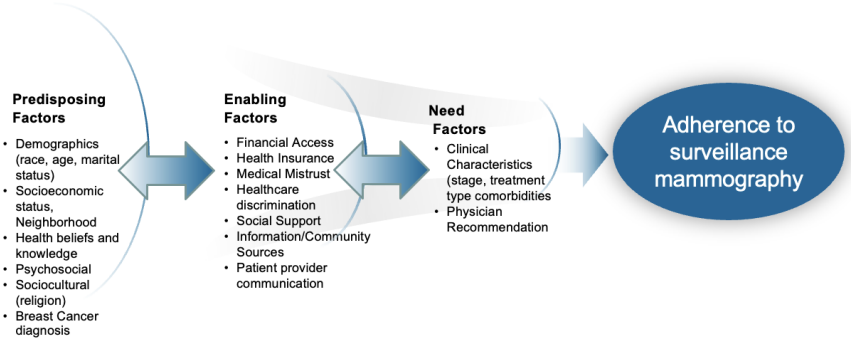
To help mitigate racial disparities in survival outcomes, a better understanding of Black survivor's health beliefs, surveillance mammography barriers and experiences during their acute period of survivorship (3 years) is warranted. In my first-author publication, I examined Black women's beliefs toward adjuvant BC therapies to better understand treatment making decisions among Black patients. In this work we found that Black women's positive adjuvant treatment attitudes for chemotherapy was associated with having greater perceived susceptibility to a cancer recurrence.[87] To provided more insight on Black women's surveillance behaviors, further examination of BC survivors' beliefs about their disease is needed. To advance survivorship research, this study will further investigate the role of psychosocial factors such as their perceived health beliefs and psychological distress as potential predictors in adherence, to explicate surveillance behaviors in Black survivors'. This dissertation will also further evaluate survivors health beliefs about the severity of their disease, susceptibility to a cancer recurrence, and cultural and contextual factors (e.g., religiosity and perceived discrimination with care).[96-99]Through the use of robust data, this study will add to survivorship research literature by examining new relationships (e.g., provider-communication) with surveillance mammography that are important to Black survivors adherence to treatment.

Social Determinants and Breast Cancer Outcomes

Breast cancer (BC) outcomes are widely driven by social determinants of health,[100,101] which involve the interplay of the individual (age, income), social (social support) environmental (neighborhood) and structural allocation of resources (education, health care). Common social determinants of health that significantly influence BC health disparities are access to, health care, medical mistrust, racism, discrimination, level of education, social support, socioeconomic status (SES) and neighborhood context.[102-105] Trends of data among BC populations empirically support that lower socioeconomic status in terms of income and education level indicators are associated with increased BC risk, poorer survival and treatment disparities. [102,106] One study found the level of education and residential area (urban, rural) were related to three-year BC survival rates.[107] Other works have examined different indicators of socioeconomic status (residential segregation, income/education, neighborhood disadvantage) related to disparities in BC morbidity/mortality.[108-111] When observing latent class levels of socioeconomic status (SES) in terms of income, education, marital status and comorbidities adjuvant treatment delays was higher among Black women across all SES levels compared to White counterparts. [112] However, no racial disparities were reported for treatment duration when observing low SES and the presence of more health care barriers with regard to health insurance, employment, financial and transportation treatment duration among Black and White women.[112] Unfortunately, very few studies have observed the varying role of SES in surveillance behaviors following treatment. Three studies have found disadvantages from socioeconomic position, in terms of public insurance (vs. Medicare, Private insurance)[61] and living in low-income neighborhoods (vs. high-income neighborhood)[19,72] were linked with non-adherence to surveillance mammography.

Lower socioeconomic status neighborhoods are four times more likely to be represented with Black Americans compared to Whites.[113] Thus, Black BC survivors disease burden is further infuriated given their disproportionately experience of poverty, lower educational attainment, and higher unemployment rates.[113] Data also suggest that Non-Hispanic White women have similar mortality rates, among those living in low-income neighborhoods.[114] Given socioeconomic disadvantages among survivors this research study will use different indicators of SES: income, residential area, insurance type, access to health care, and education to extend current work. While the role of SES has been investigated in the context of surveillance mammography among survivors, there is still a lack of understanding of how much of the socioeconomic experience explain racial disparities in non-adherence rates compared to psychosocial, and contextual factors. Thus, describing the role of SES in adherence may help target important subgroups to help identify targeted groups. **This research project will advance scientific knowledge, as it will be the first to characterize the relationship between adherence with SES and contextual determinants (patient provider interactions).**

Figure. 3 Behavioral Model for Vulnerable Populations



The Behavioral Model for Vulnerable Populations[66] is an adaptation from Anderson Behavioral Model[115] that posits that health care utilization is directly influenced by three domains: (1) *predisposing factors* including demographic characteristics, health beliefs and social structure*; (2) enabling*

factors involving social and community resources; and (3) *need factors*, which includes perceived need for the use of healthcare services and actual need based on health condition/illness. The Behavioral Model of Vulnerable Populations expands Andersen's model to include vulnerable factors within the three constructs that should be considered for underserved populations, in terms of differential social structure and enabling resources (Figure 3.).[66] **The rationale of selecting this model include: (1) the selection of study variables to characterize underserved women's adherence to surveillance mammography (primary outcome); and (2) to reveal the influential role of multilevel factors on BC survivors adherence. Furthermore, the original model is notably used to study the utilization of mammography screening, while the revised model has not been considered. [116]** Utilizing the Behavioral Model to guide this study will provide a further understanding of behavioral determinants that influence adherence to routine mammograms post-treatment in a sample of BC survivors- a highly vulnerable group to treatment side effects and disease relapse.[40,117,118] The ascertainment of study measures will include *predisposing (e.g., sociodemographic) enabling (e.g., health insurance communication) and need factors (e.g., surviving years).*

Research Study Specific Aims and Hypotheses

The underlying premise of this research study is that non-adherence to surveillance mammography contributes to suboptimal BC outcomes among Black BC survivors, and that a better understanding of the complex interplay of *predisposing (e.g., sociodemographic), enabling (e.g., communication, access*) *need (e.g., stage, treatment type*), will provide a multilevel examination of adherence to surveillance mammography. Guided by the Behavioral Model for Vulnerable Populations the goal of this research study is to identify adherence predictors relevant to Black survivors' surveillance behaviors and delineate modifiable factors amenable, to inform

future intervention developments to improve rates of surveillance mammography. These goals are accomplished by a rigorous mixed methods approach utilizing data from a BC survivor cohort *(paper 1),* Behavioral Risk Factors Surveillance System (BRFSS) population-based survey *(paper 2),* and primary data collection through Qualtrics survey and online focus groups via social media platforms (e.g., Facebook) supported by engagement of community stakeholders to leverage survivor knowledge and experiences *(paper 3).* The specific aims and study hypotheses that are tested in each paper are outlined:

Paper 1 Aim. Determine racial differences and influential factors (e.g., medical mistrust) in survivors BC beliefs.

H_1: Black women will have higher ratings of perceived susceptibility and higher ratings of perceived severity compared to White counterparts

H_2: Having underwent a mastectomy compared to lumpectomy will positively predict higher BC severity and lower ratings of susceptibility beliefs

H_3: Having underwent chemotherapy or radiation compared to not receiving adjuvant treatments will be positively associated with higher BC severity and lower susceptibility to cancer recurrence

Paper 2 Aim. Evaluate the contribution of socioeconomic status, perceived health and health care access on adherence to surveillance mammography using BRFSS data.

H_1: White race, increased health care access, and lower levels of psychological distress and perceived health, will predict adherence to surveillance mammography

H_2: Residing in a non-metropolitan county will predict non-adherence to surveillance mammography and differ by race

Paper 3 Aim. Describe surveillance mammography experiences of survivors engaged in social media and determine predictors of annual adherence to surveillance mammography among a diverse community-based cohort.

H_1: Lower levels of provider communication will predict non-adherence to surveillance mammography and differ by race

H_2: White race, and higher ratings of surveillance mammography benefits, and knowledge will predict adherence

Overview of Dissertation format:

In this dissertation I employ novel mixed method approaches to describe Black and White BC survivors' adherence of mammography use, to enhance our knowledge in survivors' beliefs and socioeconomic experiences to help explain racial disparities in surveillance mammography. This dissertation includes 5 sections: an introduction; three papers written as manuscripts that are prepared for peer-review publication in a cancer survivorship journal; and a discussion section that integrates and synthesizes the key findings from the overall study and implications on future research, clinical practice and intervention development. All three papers coherently tell a story that uniquely examines *predisposing (beliefs), enabling (health care access)* and *need (stage)* experiences among Black and White BC survivors' adherence to surveillance mammography guidelines, with special attention on Black women in three different samples. The first paper provides a foundation in the study outcome by highlighting survivors' beliefs about their disease measured as perceived susceptibility of a recurrence and disease severity, to reveal novel correlates of beliefs among BC survivors following primary treatment. The second paper utilized a robust dataset to further examine the contribution of socioeconomic factors on adherence to surveillance mammography. Adherence in this paper is operationalized as adherent to ASCO/ACS

recommended guidelines ("received mammogram in the last 12 months"), or non-adherent with ASCO/ACS recommended guidelines ("received a mammogram in the last 2-5 years, 5 or more years or unsure).[60]Building from the first two papers, the third paper integrates primary collected data: the qualitative data explores survivors' facilitators and barriers toward surveillance behaviors, which informed the quantitative examination of predictors (e.g., knowledge, financial barriers) on annual surveillance mammography. In this paper adherence is defined as adherent to ASCO/ACS recommended guidelines (received a surveillance mammogram within the last 12-months).

This study advances priorities identified by national organizations (e.g., ASCO, NCCN) and the NCI's goal to mitigate cancer disparities, in the following ways: (1) special attention in surveillance behaviors in underserved women; (2) and elucidate novel modifiable individual factors (beliefs, attitudes) and structural factors (health care access) contribution to non-adherence to surveillance mammography. Understanding determinants of surveillance mammography among underserved women has significant clinical implications to improve early stage detection of new and recurrent cancers and to improve adherence to follow-up care by understanding key barriers and facilitators in Black survivor's adherence to surveillance.

Findings from this body of work serves as a guide to develop targeted health promotion interventions to improve the utilization of surveillance mammograms in underserved women. There are limited evidence-based interventions available to improve rates of surveillance mammography or follow-up care among Black survivors. This research also provides a better understanding of predictors that influence underserved women's non-adherence behaviors and could be used to inform development of innovative adherence communication messages designed with scalability and future dissemination in mind, utilizing new health technology approaches.

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Chapter 2: Paper One

Influential Factors in Black and White Breast Cancer Survivors' Beliefs about Breast Cancer

Abstract

Purpose Breast cancer beliefs are widely studied to improve preventative screening behaviors in women without cancer; however, limited research has examined breast cancer beliefs among breast cancer survivors. We investigated racial differences and the predicting role of influential factors (e.g., stage) in survivors' beliefs about their breast cancer.

Methods This study is a secondary analysis of data from the Narrowing Gap in Adjuvant Therapy Study (2006-2011), where Black (N=210) and White women (N= 149) were interviewed within 20 weeks following their breast cancer diagnosis and primary surgery in Washington D.C and Detroit, MI. Outcomes of this analysis were perceived susceptibility to a breast cancer recurrence and perceived severity of breast cancer. Bivariate analyses were conducted to assess racial differences in sample characteristics, and on the study outcomes. Adjusted multiple regression models examined correlates between independent variables (e.g., sociodemographic/clinical) and women's breast cancer beliefs about susceptibility of a recurrence and disease severity.

Results Most of the sample were Black women (58%), had breast-conserving surgery (64%), and were privately insured (67%). Black women reported higher perceived disease severity beliefs than White women (p= 0.004). Other associated factors with greater perceived severity beliefs included lower education (p=0.008), public health insurance (p=0.021) and greater levels of medical mistrust (p=0.016). In our adjusted multiple regression models' women with lower satisfaction regarding financial aspects of their healthcare were more likely to have higher perceived severity beliefs (p=0.007); women with stage II cancer compared to stage I had greater susceptibility beliefs to a cancer recurrence (p=0.001).

Conclusion We identified important sociodemographic and clinical factors associated with BC specific beliefs and found racial differences in BC survivor's disease beliefs. Specifically, survivors with significantly greater perceived susceptibility to a recurrence were diagnosed at earlier stages (II) compared to stage I. Survivors diagnosed at earlier (I and II) and later stage cancers (III) may serve as important target groups to monitor their surveillance and follow-up behaviors. This study furthers our understanding of survivors' health beliefs and informs navigation strategies to improve cancer survivorship recommendations in the context of psycho-oncology and follow-up cancer care.

Introduction

While breast cancer (BC) incidence rates are higher among White women (130.8) when compared to Black women (126.7),[1]the distribution of BC mortality is not equally shared across women in the U.S[1,2 3] Black women bear the greatest burden of BC morbidity/mortality compared to all racial/ethnic groups of women. [4,5] Reasons for survival disparities are multifaceted involving the underuse of adjuvant treatment, screening, late stage diagnosis, as well as structural factors (e.g., medical mistrust), and inequality of social factors such as, health care access and neighborhood inequity. [6-11] To better understand and improve racial disparities in cancer outcomes e.g.,(cancer screening behaviors) health beliefs are widely studied ;[12-15] however limited research has observed BC survivors health beliefs.[16-18 19]Given BC survivors' 40% increased risk of disease relapse in the breast or distant sites, a robust description of survivors BC perceived beliefs about their cancer is needed. For example, understanding influential factors in survivors' BC beliefs is salient to inform effective planning of navigation strategies during survivorship care, such as breast surveillance guidelines. [20,21]

There is extensive BC-related research on perceived severity and susceptibility in the general population of women, [22-27] however very few studies have observed susceptibility to a BC recurrence and disease severity among BC survivors.[15,19,28 29]More recently we investigated Black BC survivor's adjuvant treatment attitudes, and found women reporting higher susceptibility to a BC recurrence had more positive adjuvant endocrine therapy attitudes, and women with higher disease severity and susceptibility to a BC recurrence had more positive chemotherapy attitudes.[15] Another study found a positive association with readiness for genetic counseling among high-risk BC survivors with greater perceived severity of their cancer. [19] While these studies demonstrated a positive relationship in survivors BC beliefs with acceptance to the use of adjuvant treatment and

screening modalities; it is less understood how adjuvant treatment utilization is influenced by survivor's BC beliefs.

Much of what is known regarding racial differences in BC beliefs is drawn from women without cancer.[30-34] One study reported that low-income Black women did not perceive themselves to be more susceptible or to suffer more severely from BC, nor did they believe this for other racial groups across economic levels.[33]Conversely, another study found Black women compared to White women had greater susceptibility of being diagnosed.[34] Given, these studies have contributed to cancer screening advancements among minority women without a BC history, more work is needed to capture racial differences in survivors' beliefs about BC to address BC survival dispairties.[35-37] Examining racial differences in survivors BC beliefs will extend current survivorship research and provide clinical professionals a well-rounded understanding of survivor's health beliefs to inform behavioral interventions.

The goal of this study was to determine racial differences in survivors' BC beliefs and to identify associated factors guided by The Behavioral Model for Vulnerable Populations which conceptualizes that health outcomes and health care utilization is directly linked with an individual's, *predisposing factors (perceived beliefs), enabling factors (health care access) and need factors (comorbidities).(Figure 4).*[38] This study sought to highlight influential factors in a novel *need factor* of survivors' beliefs of their BC, through examination of two-subscales (perceived susceptibility to a BC recurrence and perceived disease severity). Findings from this study may inform future targets to enhance survivorship care interventions in the delivery system.

Study hypotheses tested in this study included:

Hypothesis $_1$: Black women will have higher ratings of perceived susceptibility and higher ratings of perceived severity compared to White women

Hypothesis $_2$: Having underwent a mastectomy compared to lumpectomy will positively predict higher BC severity and lower ratings of susceptibility beliefs

Hypothesis $_3$: Having underwent chemotherapy or radiation compared to not receiving adjuvant treatments will be positively associated with higher BC severity and lower susceptibility to cancer recurrence

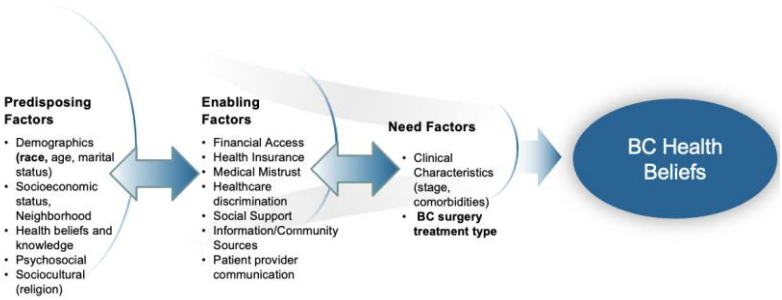

Figure 4. Paper 1 Conceptual Model

Methods

Setting and Population

This study is a secondary analysis of data obtained from the Narrowing Gap in Breast Cancer Adjuvant Therapy Study (2006-2011), an observational trial that investigated factors associated with receipt of adjuvant therapy in Black and White female breast cancer patients. Detailed methods and recruitment strategies has been previously described.[39] Women were recruited from 3 organizational health facilities including two NCI-designated Cancer Centers in Washington, DC and Detroit MI. Women included in the study: self-identified as Black/African American or White/European American, 21 years old or older, diagnosed with non-metastatic breast cancer, and <20 weeks past their definitive surgery. Institutional Review Boards from each participating site approved all study procedures.

Data collection

Trained clinical research assistants (CRA) screened 678 women for study eligibility from electronic pathology reports and appointment logs. CRA's interviewed the women 3-months post-surgery utilizing a computerized telephone interview system (CATI). Clinical data were abstracted from medical records. Of the 477 women identified and meeting study eligibility requirements, 82% (N=395) were consented into the study. Due to missing clinical data and the exclusion of women who did not identify as Black/African American or White, 36 women were excluded from the analyses leaving a final analytic sample of 359.

Measures

The Behavioral Model for Vulnerable populations guided selection of study measures. [38] The primary outcomes of this study were perceived severity and perceived susceptibility of cancer recurrence, which characterizes the needs domain of our guiding model. These outcomes utilized two subscales from the Adherence Determinants Questionnaire.[40] Four items captured women's agreement or disagreement about their perceived severity (e.g., "There are many diseases more severe than my breast cancer"), and four items assessed agreement or disagreement on perceived susceptibility to a recurrence ("The chances I might develop cancer again are pretty high") on a 5-point Likert scale. Items were reverse coded for each subscale when needed. Responses ranged from 4-20 for each subscale. (Perceived Severity: Cronbach's = 0.41). (Perceived Susceptibility: Cronbach's = 0.42).

Predisposing Factors

Predisposing factors included demographic information including age at the time of diagnosis and race (Black and White). Marital status was categorized (married/living as married or currently single. Employment was dichotomized as full time employed or other. Education was categorized

(no college, some college, bachelors and above). Religiosity was assessed using Lukwago et al. 9-item scale. Higher scores from the scale were indicative of high religiosity (e.g., "I am often aware of the presence of God in my life") (Cronbach's alpha overall = 0.95) Collectivism assessed women's connection with their family using Lukwago et al. 6-point Likert scale, where higher scores reflected greater collectivism.

Enabling Factors

Perceived racial discrimination in healthcare settings was ascertained using 7-items from the Race-Based and SES-Based experience scale. [41] Women were asked questions to reflect on their experiences within the medical system (e.g., "felt like a doctor or nurse was not listening to what you were saying"). Responses were dichotomized to any versus none. A subscale from the Group-Based Medical Mistrust scale measured perceived level of group-based distrust in healthcare settings (Cronbach alpha= 0.84). [42] Questions asked women to think about relationships between various racial/ethnic groups and the American medical system and to rate how strongly they agreed or disagreed. Higher scores reflected higher levels of medical mistrust. We used two subscales from The Patient Satisfaction Questionnaire Short Form (PSQ-18) to measure women's satisfaction about financial aspects of their care (e.g., "I feel confident that I can get the medical care I need without being set back financially") and their satisfaction with provider communication (e.g., Doctors sometimes ignore what I tell them). Higher scores were indicative of greater satisfaction with financial aspects and provider communication. [43]

Need Factors

Estrogen receptor status was dichotomized as ER-positive and ER-negative, breast cancer surgery was ascertained as mastectomy or lumpectomy, tumor size was described as <2cm or $\geq$ 2cm. Comorbidities were evaluated using the Charlson comorbidity index score.[44] Adjuvant treatment

initiation to chemotherapy and radiation were medically abstracted from women's medical records and categorized (yes vs. no).

Statistical Analysis

Descriptive statistics (means and frequencies) were computed to describe the characteristics of the sample. In bivariate analyses, p-values from F-test were used to assess differences on both outcomes and covariates (e.g. marital status, age) by race. Multiple regression models were employed to determine the association of covariates (e.g. perceived racial discrimination) with perceived severity and susceptibility scores. Multivariate analysis adjusted for predisposing (e.g., race, age, marital status) enabling (e.g., health insurance type) and need (e.g., comorbidities, BC stage) factors, consistent with prior research among BC survivors.[45-47] Power analysis was conducted prospectively to determine if the study sample size would have an effect size (Cohen's w=0.2) to test study hypotheses. An F-test power analysis concluded that the sample N=359 had a 96% power at significant alpha level 0.05. Normality assumptions were validated with Q-Q plots. All statistical analyses were conducted using SAS Version 9.4, using two-tailed alpha level of 0.05.

Results

Study Sample

Of the 359 BC survivors, most respondents were Black women (58.7%), diagnosed at stage I (46%), and privately insured (67%). Ages ranged from 25-89 (m=54 sd= 12) years (Table 1). For predisposing study variables Black women, compared to White women were less likely to have a college degree (18% vs 28%) and more likely to be single (37% vs 11%). In comparison to White women Black women had higher ratings for religiosity (m=31.08 vs m =23.7) and reported higher collectivism (m=1.5 vs m= 1.3). With regard to enabling factors, Black women were more likely

to have public health insurance vs. White women (24% vs 8%). Black women reported higher levels of medical mistrust m=29.1 vs m=22.0), and were more likely to report health care discrimination (m=92%vs.24%) vs. White women. Black women also had less satisfaction toward financial aspects regarding the medical care they received vs. White women (m=3.8 vs m=4.0). For need variables Black women had more comorbidities (m=1.8 vs m= 1.4) and a tumor size ≥2cm (31%vs 14%; p= 0.0007); higher initiation of chemotherapy (27% vs 12%) and radiation (39% vs. 20%) when compared to White women. Survivors perceived severity scores ranged from 4-18 (m=9.8; sd=2.19). Black women had higher scores (m=10.1; Sd=2.1) compared to White women (m=9.5; Sd=2.2). Scores for perceived susceptibility of a recurrence were similar across races with an overall range from 4-18 (m = 9.7; sd=2.15).

Bivariate

In bivariate analyses, we found significant predisposing factors associated with perceived severity and susceptibility beliefs: differences by race, religiosity and educational level (Table 1). Women with higher education vs. women with lower education levels had lower perceived severity (p=0.008). Women who reported higher levels of religiosity were more likely to have greater perceived susceptibility of a cancer recurrence (p=0.029). Insurance type and medical mistrust were top significant enabling predictors for perceived severity beliefs. Women with private insurance vs. public had lower levels of perceived severity (p=0.021). For need factors, lower breast cancer stage (II) (p=0.023), and radiation (p<.0001) were linked with having higher perceived susceptibility to a recurrence; chemotherapy predicted greater perceived severity beliefs (p= 0.003). ***Hypothesis:1*** Black women were found to have higher perceived severity beliefs about their breast cancer vs. White women (p = 0.004). Perceived susceptibility to a cancer recurrence were similar across both racial groups. ***Hypothesis:2*** While there were no significant racial

differences in severity or susceptibility beliefs among survivors who had a mastectomy; yet a decline trend in levels of perceived severity beliefs among women who received a lumpectomy (m=9.75; sd=2.2) vs. mastectomy (m=10.12 sd=2.1) was observed. Similar trend of findings was found for susceptibility to a recurrence (lumpectomy m=9.61, sd=2.1; mastectomy m=9.91 sd=2.0). *Hypothesis:3* Both chemotherapy and radiation use were associated with BC beliefs. Radiation use was associated with higher ratings of susceptibility of a recurrence ($p<.0001$), while higher levels of severity beliefs was associated with chemotherapy use ($p= 0.003$).

Multivariate Analyses

In multivariate analyses race did not remain a significant factor for greater perceived severity beliefs among Black women ($p= 0.4113$), after controlling for potential confounder variables (education, stage tumor size, and health insurance). (Table 3). In our adjusted regression model for perceived severity, financial satisfaction was the only significant factor. Women with lower levels of financial satisfaction had higher perceived severity beliefs toward their breast cancer ($p=0.006$). When modeling perceived susceptibility breast cancer stage remained significant. Women with stage II cancer ($p=0.001$) had greater perceived susceptibility to a cancer recurrence compared to women with Stage I or III cancers (Table 3).

Discussion

Breast cancer (BC) survivors health beliefs are important drivers of their health behaviors[48,49] including adjuvant treatment decisions and uptake of preventative health care services.[15,19] Unfortunately, BC beliefs are understudied in BC survivors. To fill this gap, in BC survivorship research, we examined predictors of Black and White BC survivors' perceived susceptibility to a cancer recurrence and perceived severity of their breast cancer. Black race, breast cancer surgery, education, health insurance type and medical mistrust were top predictors

with perceived severity attitudes. In adjusted analysis, women with lower financial satisfaction in their health care had higher perceived severity; lower cancer stage was associated with greater perceived susceptibility to a recurrence.

Black women were found to have greater perceived severity compared to White women. This finding builds upon our earlier study where we investigated correlates of positive versus negative adjuvant treatment attitudes in Black BC patients, which considers the connection between positive treatment attitudes and higher odds of chemotherapy initiation. [39] In our study Black women with higher perceived severity levels was positively associated with positive chemotherapy attitudes.[15] These findings suggest higher levels of perceived severity beliefs may heighten survivors fear appraisals toward BC and, result in optimal adherence to adjuvant treatment; however Black BC survivors have the highest non-adherence rates for adjuvant endocrine therapy and surveillance mammography, thus Black women's adherence behaviors are complex.[47,50-52] One explanation behind Black women's adherence behaviors may be supported by Black women's higher ratings of medical mistrust and health care discrimination, which was observed in our sample. Higher medical mistrust contributes to the underuse of clinically recommended guidelines, in the context of cancer survivorship care. [42,53,54] One study found greater mistrust in Black women was associated with their underuse of adjuvant therapies.[8] Other studies commonly report the relationship between medical mistrust and impaired BC cancer screening rates, genetic counseling uptake and poorer satisfaction ratings in medical care.[42,53,55,56] Medical mistrust is a historical issue in the medical delivery system.[56,57] Further, the negative role medical mistrust plays in the uptake of cancer screening behaviors among Black women,[56,58] brings an imperative argument to further investigate pathways of mistrust from a survivorship

delivery perspective. Future research should develop educational strategies to mitigate the negative effects from medical mistrust attitudes among Black women in support of their continuum of care.

Women's educational level (predisposing factor), insurance type and satisfaction about financial aspects of their healthcare (enabling factor) were top predictors in survivors' beliefs about their BC. Women with private insurance (vs. public insurance) reported greater susceptibility to a cancer recurrence. Black women with higher education (vs. lower education) had greater levels of perceived severity, which may illuminate why better cancer screening behaviors are associated among women with higher education (vs. lower educational levels).[59] In our adjusted multiple regression model women's greater satisfaction regarding financial aspects of their healthcare predicted lower severity beliefs. Similar findings reported that having financial concerns was a commonly unmet healthcare barrier among BC survivors following diagnosis.[60]These findings inform important subgroups for further analysis, and extend delivery of cancer care such as surveillance behaviors. Survivors with more financial concerns regarding aspects of their healthcare may be a targeted group to intervene to support their survivorship care.

Survivors clinical characteristics (e.g., stage) were influential factors in their BC beliefs. Regarding survivors' beliefs about their susceptibility to a cancer recurrence, receipt of adjuvant treatment and breast cancer stage were top need predictors. When comparing women who had chemotherapy and radiation versus women who did not, greater perceived susceptibility to a recurrence was found among women with receipt of treatment. These findings suggest higher susceptibility beliefs toward a cancer recurrence are important in treatment utilization behaviors among women diagnosed with BC. In our final model, women with stage II cancer (vs. II and I) was the only predictor for having greater perceived susceptibility of a recurrence. One study obtained similar results, but measures were different, survivors with lower health literacy

perceived a lower risk to a recurrence toward BC survivors diagnosed at earlier stages.[61] Although chemotherapy and radiation use was no longer significant in the multivariable model, it is important to note the contribution of BC beliefs with adjuvant treatment utilization. While we did not observe racial differences in survivors perceived susceptibility, a prior study found that lower ratings of perceived susceptibility to cancer recurrence were more likely among non-white BC survivors.[62] Future work should observe racial ethnic groups of survivors to determine whether survivors' BC beliefs influence completion of BC treatment options. Our findings are unique and add novel predictors of survivors perceived susceptibility of disease relapse and provide context to better understand survivors' health beliefs. Secondly, findings suggest a connection between surgery choice and beliefs, while insignificant there was a higher trend of greater perceived severity beliefs among survivors with a mastectomy versus a lumpectomy. Future studies should include survivor's health beliefs as intervention targets and investigate whether there are behavioral differences in survivorship care among BC survivors diagnosed at earlier stages vs. later stage cancers.

Strengths & Limitations

While our findings contribute salient predictors in survivor's beliefs about their BC in an over sample of Black women, there are some limitations to consider. Limitations in this study include our cross-sectional study design and potential sampling biases. The majority of our sample were highly educated, had private health insurance, diagnosed at early stages (vs. later stage) and received breast surgeries with radiation for their BC; women diagnosed at later stages without a history of treatment may provide different results. Further, we must acknowledge that women in this sample had non-metastatic BC, thus our sample may not be generalizable to every women perspective with a history of BC.

Conclusion

This study provided new evidence regarding BC survivors' beliefs about their cancer that should be considered in treatment adherence intervention development. We found Black-White differences in women's perceived severity beliefs, and identified theory-based clinical and psychosocial correlates in survivor's breast cancer beliefs by race. Findings from this study build upon prior research, and identified key subgroups of survivors to target in future studies, and provide clinicians with relevant factors that may inform delivery of survivorship care quality of life and interventions. Moreover, this study improves our understanding of survivor's psychological responses about their cancer and provide context on potential determinants that may influence adherence to surveillance regimens, such as genetic counseling and surveillance mammograms among survivors.

Table: 2 Descriptive statistics for breast cancer survivors by race N=359

	All Women	Black Women	White Women	P-value
	N (%)	N (%)	N (%)	
	359	210 (58.0)	149 (41.5)	
Predisposing Factors				
Education				
≤HS diploma/GED	78 (21.7)	65 (18.1)	13 (3.6)	
Some college	106 (29.5)	74 (20.6)	32 (8.9)	<0.001**
Bachelor's or more	175 (48.7)	71 (19.7)	104 (28.9)	
Marital status				
married	182 (50.7)	74 (20.6)	108 (30.0)	<0.001**
single	177 (49.3)	136 (37.8)	41(11.4)	
HR Status				
Negative	274(76.3)	154 (42.9)	120 (33.4)	0.113
Positive	85(23.6)	56 (15.6)	29 (8.0)	
Tumor Size				
≥ 2cm	152 (46.0)	104 (31.5)	48(14.5)	<0.001**
<2cm	178 (53.9)	89 (26.9)	89 (26.9)	
Age (M+SD)	54.8 (11.7)	54.1 (12)	55.7 (11.2)	0.197

Religiosity (M+SD)	16.8 +6.7	31.08+4.7	23.7 +7.0	<0.001**
Collectivism (M+SD)	1.4 +0.5	1.54+0.59	1.3+0.5	0.007*
Perceived Severity(M+SD)	9.8 +2.1	10.1+2.1	9.5+2.2	0.004*
Perceived Susceptibility(M+SD)	9.7 +2.1	9.7+2.0	9.7+2.2	0.997
Enabling Factors				
Insurance				
Private	218 (67.7)	108 (33.5)	110 (34.1)	<0.001**
Public	104 (32.2)	78 (24.2)	26 (8.0)	
Employment				
full time	210 (62.3)	64 (18.9)	63 (18.6)	0.084
not full time	127 (37.6)	126 (37.3)	84 (24.9)	
Healthcare Discrimination				
Any	116 (32.3)	92(25.6)	24 (6.6)	<.0001***
None	243 (67.6)	118 (32.8)	125 (34.8)	
Medical Mistrust (M+SD)	26.1 +6.8	29.1+6.0	22.0+5.5	<.0001***
Communication(M+SD)	4.1+0.6	4.06+0.7	4.1+0.6	0.144
Financial Aspects(M+SD)	3.8 +0.7	3.8+0.7	4.0+0.8	0.021*
Need Factors				
Surgery type				
Lumpectomy	230 (64.4)	141 (39.5)	89 (24.9)	0.154
Mastectomy	127 (35.5)	68 (19.0)	59 (16.5)	
Stage				
I	156 (46.4)	82 (24.4)	74 (22.0)	
II	135 (40.1)	84 (25)	51(15.18)	0.161
III	45 (3.3)	29 (8.6)	16 (4.7)	
Chemotherapy				
Yes	141 (39.2)	97 (27.0)	44 (12.2)	0.001**
No	218 (60.7)	113 (31.4)	105(29.2)	
Radiation				
Yes	214 (59.6)	141 (39.2)	73(20.3)	<0.001***
No	145 (40.3)	69 (19.2)	76 (21.1)	
Comorbidities(M±SD)	(1.6+1.7)	(1.8±1.8)	(1.4+1.5)	0.012*

M=mean SD= standard deviation

* $p<0.05$; ** $p<0.01$, *** $p<0.001$

Table 3: Bivariate Analysis of women's perceived severity and susceptibility beliefs

	Perceived Severity Attitudes N= 359		Perceived Susceptibility Attitudes N=359	
	Estimate	***p* value**	Estimate	***p* value**
Predisposing Factors				
Race				
Black	10.17+2.1	0.004*	9.72+2.0	0.997
White	9.50+2.2		9.71+2.2	
Education				
<HS diploma/GED	10.44 ± 2.2		9.69 ± 2.2	
Any college	10.04 ± 2.0	0.008*	9.39 ± 2.1	0.143
Bachelors and above	9.55 ± 2.2		9.92 ± 2.1	
Marital status				
Married	9.84 ± 2.0	0.657	9.73 ± 2.2	0.924
Single	9.94 ± 2.3		9.70± 2.0	
HR Status				
HR positive	10.24 ± 2.0	0.098	9.80 ± 2.2	0.670
HR negative	9.78 ± 2.2		9.69 ± 2.1	
Tumor Size				
≥ 2cm	9.99+2.0	0.583	9.66+2.2	0.889
<2cm	9.74+2.2		9.74+2.1	
Age		0.701		0.368
Religiosity		0.365		0.053
Collectivism		0.089		0.902
Enabling Factors				
Employment				
full time	9.78+2.3	0.405	9.61+2.3	0.831
not full time	9.99+2.0		9.66+1.9	
Insurance type				
private	9.78+2.1	0.021*	9.73+2.1	0.853
public	10.54+2.1		9.67+2.2	
Health care discrimination				
Any	10.13+2.0	0.157	9.61+2.1	0.196
None	9.77+2.2		9.93+2.0	
Medical Mistrust		0.016*		0.524
Communication		0.905		0.694

Financial Aspects		0.003*		0.447
Need Factors				
Breast Cancer Stage				
Stage I	9.84 ± 2.7		9.42 ± 1.8	
Stage II	9.88 ± 2.2	0.733	10.10 ± 2.3	0.023*
Stage III	10.14 ± 1.8		9.47 ± 2.4	
Breast Cancer Surgery				
Mastectomy	10.12+2.1	0.132	9.91+2.0	0.211
Lumpectomy	9.75+2.2		9.61+2.1	
Chemotherapy				
Yes	10.19+2.1	0.037	9.55+2.2	0.242
No	9.69+2.1		9.82+2.0	
Radiation				
Yes	9.78+2.2	0.273	9.50+2.1	0.021*
No	10.04+2.1		10.0+2.1	
Comorbidities		0.446		0.790

* $p<0.05$; ** $p<0.01$

Table 4. Multivariable Analysis of women's perceived severity and susceptibility beliefs

	Perceived Susceptibility		Perceived Severity	
	Estimate	***p* value**	**Estimate**	***p* value**
Predisposing Factors				
Race				
Black	0.18	0.638	0.38	0.344
White	Ref.		Ref.	
Education				
<HS diploma/GED	Ref		Ref.	
Any college	-0.08	0.824	-0.2	0.615
Bachelors and above	0.27	0.506	-0.62	0.145
Marital status				
Married	-0.01	0.949	0.43	0.171
Single	Ref.		Ref.	
HR Status				

HR positive	0.24	0.444	0.44	0.180
HR negative	Ref.		Ref.	
Tumor Size				
≥ 2cm	-0.59	0.088	-0.04	0.903
<2cm	Ref.		Ref.	
Age	0	0.969	0	0.743
Religiosity			0.04	0.111
Collectivism	0.16	0.500	0	0.974
Enabling Factors				
Employment				
full time	-0.01	0.950	0.18	0.568
not full time	Ref.		Ref.	
Insurance type				
private	0.15	0.740	-0.38	0.422
public	Ref.		Ref.	
Health care discrimination				
Any	0.4	0.229	-0.03	0.911
None	Ref.		Ref.	
Medical Mistrust	0.02	0.406	0.04	0.133
Communication	0.24	0.267	0.31	0.236
Financial Aspects	0.02	0.899	-0.52	0.007*
Need Factors				
Breast Cancer Stage				
Stage I	Ref.		Ref.	
Stage II	1.18	0.001*	-0.28	0.443
Stage III	0.44	0.354	-0.01	0.976
Breast Cancer Surgery				
Mastectomy	0.24	0.445	0.45	0.159
Lumpectomy	Ref.		Ref.	
Chemotherapy				
Yes	-0.28	0.382	0.57	0.091
No	Ref.		Ref.	
Radiation				
Yes	-0.44	0.169	-0.12	0.704
No	Ref.		Ref.	
Comorbidities	0.08	0.398	-0.02	0.837

* $p<0.05$; ** $p<0.01$

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Chapter 3: Paper Two

Adherence to Surveillance Mammography Screening Guidelines in Black and White Breast Cancer Survivors: Utilizing the 2016 Behavioral Risk Factors and Surveillance System Data

ABSTRACT

Purpose Breast cancer survivors are recommended to adhere to annual surveillance mammograms, for early detection of disease relapse; yet Black women have poorer national adherence rates compared to White women. Factors that influence racial disparities in surveillance mammography rates are poorly understood among survivors. The purpose of this study is to evaluate the contribution of health care access, socioeconomic status and perceived health status on breast cancer survivor's adherence to surveillance mammography.

Methods This is a secondary analysis of a cross-sectional survey among women ≥18 years, who reported a breast cancer diagnosis and completed breast surgery and adjuvant treatment from the 2016 Behavioral Risk Factor Surveillance System National Survey Dataset (N= 963). Bivariate associations (chi-squared) for independent variables (e.g., health insurance, marital status) were analyzed with adherence to nationally recommended surveillance guidelines defined as two levels: adherent (received mammogram in the last 12 months), vs. non- adherent ("received a mammogram in the last 2-5 years, 5 or more years or unsure). Multivariable logistic regression models were used to evaluate the relationship between study variables with adherence, while adjusting for potential confounders.

Results Overall, 70% of breast cancer survivors reported a surveillance mammogram within the last 12 months. Women were more likely to be adherent if diagnosed ≤5 years ($p<0.001$); had a routine check- up visit within 12 months ($p=0.045$); and could not see a doctor when needed due to cost ($p=0.026$). A significant interaction was found between race and residential area ($p<0.001$). Black women living in a non-metropolitan residential area were least likely to be adherent compared to White counterparts (OR: 0.03 95% CI 0.00-0.50).

Conclusion Findings from this study further explicates racial disparities in surveillance mammography adherence among survivors. Black women living in non-metropolitan counties are an important subgroup for future screening and navigation interventions. While routine physician visits among survivors may help to facilitate adherence to surveillance mammography guidelines, there is a pressing need to better understand the influential factors of short term vs. long term survivor's surveillance behaviors.

Introduction

Three and a half million breast cancer (BC) survivors living in the U.S are a high-risk group for cancer recurrence (10-41%) compared to women without a BC history.[1,2] While biological factors (status and tumor grade) influence BC survivors risk of disease relapse,[3] adherence to surveillance mammography in women with residual breast tissue is the most salient guideline recommended by the American Cancer Society.[4] Mammographic detection has shown clinical benefit for earlier stage detection of recurrent disease and a 39% decrease in overall survival.[5] Unfortunately, reports suggest Black BC survivors are less likely to receive surveillance mammography within the first five years compared to their White counterparts, with few explanations for these disparities.[6-9] Factors that influence adherence to surveillance mammography are complex and include socioeconomic status, employment, marital status, age and health care utilization (e.g., visits with medical oncologist).[7,9,10] Most research however lack the use of a multifaced framework to fill gaps beyond sociodemographic and clinical factors that influence survivors adherence to surveillance mammography guidelines.

Theoretical Framework

The Behavioral Model for Vulnerable Populations (Figure 5)[11] represents an adaptation of the widely used Andersen's Behavioral Model[12], which posit that health care utilization is predicted and directly influenced by three domains: *predisposing (e.g., population characteristics), enabling (e.g., social resources) and need (e.g., perceived illness).* The Behavioral Model for Vulnerable Populations extends the original model by assessing multi-level factors (e.g., residential history) that may influence vulnerable groups health service utilization, such as mammography screening.[13-15] For example, low-income uninsured minority women within the U.S has been a priority group to improve mammography screening rates;[16-18] In this study, we

apply the conceptual framework to study surveillance mammography adherence among BC survivors-a group highly vulnerable to late effects from cancer treatment (e.g., joint pain), and risk of cancer recurrence compared to women without a history of cancer.

Studies observing screening mammography have found that lower socioeconomic status, residential area (*predisposing factor*) and lack of insurance (*enabling factor*) are associated with not screening; [19,20] [21,22] yet very few studies have observed these factors among BC survivor's surveillance mammography behaviors. [7,23] A study using NCI's Surveillance, Epidemiology, and End Results (SEER)-Medicare data reported that socioeconomic disadvantages in terms of SEER geographic regions, and having lower income were key determinants of non-adherence to surveillance mammography.[7,23] Another study found higher adherence was linked with having private or Medicare insurance when compared to public insurance.[24] Further examination is needed to determine whether racial differences exist in the associated role of health care access and residence composition with surveillance mammography, using robust national population-based datasets. Doing so will help to widen our understanding of socioeconomic disparities among survivors.

A breast cancer diagnosis followed with adjuvant treatment can remarkably impact one's quality of life. [25] Reports suggest, after completion of treatment survivors overall well-being is negatively affected with increased levels of psychological distress *(predisposing factor),* changes of pain tolerance *(need factor),* body image *(predisposing factor)* and adverse side effects *(need factor).*[26-28,29,30] Further, changes in survivors physical and mental health functions may in part, influence their choice to adhere to surveillance mammograms. Results from a large-population based study found young and uninsured Black BC survivors, with a lack of social support represented the poorest health-related quality of life profile at 25 months post diagnosis.[31]

Similarly, another study reported that Black race, lower socioeconomic status, younger age and single status were top risk factors for psychological distress. [21] In the context of surveillance mammography one study found higher levels of distress specific to breast cancer and mammography-related anxiety were associated with lower mammography adherence.[32] Research is needed to further understand the nature of survivor's well-being and whether their perceived health influence surveillance behaviors. This study will fill important knowledge gaps by assessing the relationship between perceived health outcomes with adherence to surveillance mammography.

The overall goal of this study was to examine adherence to surveillance mammography, with salient adherence related factors, such as (health care access, perceived health and geographical area) [28,33-35] Guided by the Behavioral Model for Vulnerable Population, this study will fill scientific gaps by assessing psychosocial and healthcare study variables with adherence: *predisposing (e.g., race, residential area), enabling (e.g., health care access, perceived health*), and *need (e.g., provider recommend routine follow-up*) (Figure. 5). This study is the first to retrospectively examine surveillance mammography among Black and White BC survivors, utilizing the 2016 Behavioral Risk Factor Surveillance System Study (BRFSS) nationally represented dataset. Moreover, results from this study seeks to better understand surveillance mammography disparities to better inform future research direction and clinical practice.

Hypotheses tested in this study included:

H_1: White race, increased health care access, and lower levels of psychological distress and perceived health, will predict adherence to surveillance mammography

H_2: Residing in a non-metropolitan county will predict non-adherence to surveillance mammography and differ by race.

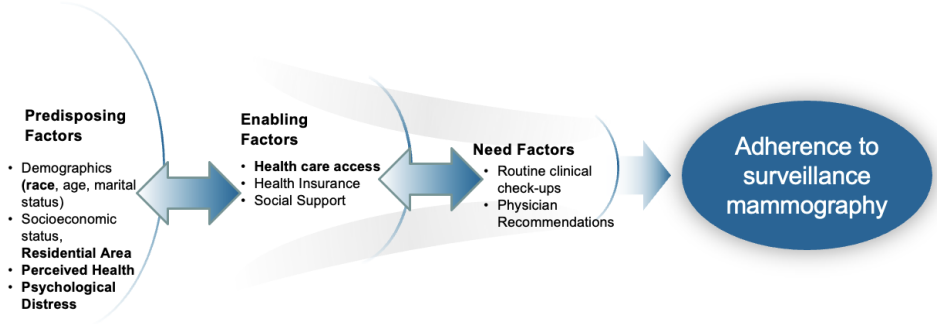


Figure 5. Paper 2 Conceptual Model

Methods

Data Source

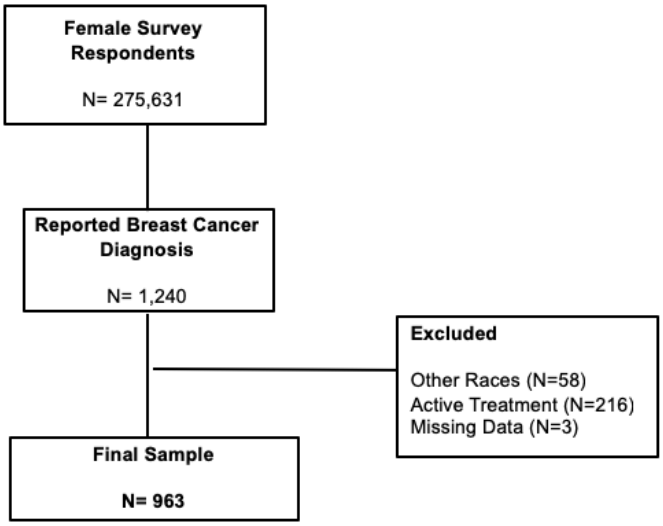
Data from the 2016 Behavioral Risk Factor Surveillance System (BRFSS) was utilized in this study to construct a cohort of breast cancer survivors. BRFSS is the largest state-based representative telephone health survey in the US, with more than 500,000 respondents operated by public health departments, across 50 states and selected US territories, that utilizes a stratified design to collect landline samples.[36,37] BRFSS is administered annually among 18 $\leq$ US adults to observe preventative health care practices (e.g., physical activity), chronic health conditions (e.g., diabetes), health risk behaviors (e.g., smoking) and demographic factors (e.g., age, race), which represents items from BRFSS core section.[38] State-added questions and optional modules on specific health topics such as cancer survivorship, are available by request for state health departments to administer, using computer aided telephone interviewing.[37] The 2016 BRFSS was selected as an ideal survey year to observe trends of surveillance mammography among BC survivors, because this survey year measured personal history of breast cancer and mammography screening utilization.[39]

Study population

This cross-sectional study design included a cohort of Black and White Non-Hispanic female BC survivors (N=963), who self-reported a diagnosis of breast cancer. Participants were

included in the analytic sample when meeting the following criteria: Black Non-Hispanic/or White Non-Hispanic female, reported a breast cancer diagnosis, had no missing values of their last mammogram or their race/ethnicity, and completed cancer treatment such as surgery and adjuvant treatment, to avoid a diagnostic mammogram at the time of the study (Figure 6). The cohort procedure followed a similar schema of recently published studies of BC survivors (Figure 3).[7,40]

Figure 6. 2016 BRFSS Breast Cancer Cohort Schema



Outcome Variable

Adherence to surveillance mammography was determined using ASCO/ACS 2016 recommended screening guidelines of surveillance for breast cancer recurrence (defined as annual mammography screening).[4]Adherence was ascertained from the question "when was your last mammogram". Survivors responses to this question were categorized into two levels: adherent to ASCO/ACS recommended guidelines ("received mammogram in the last 12 months"), or non-adherent to ASCO/ACS recommended guidelines ("received a mammogram in the last 2-5 years, 5 or more

years or unsure).[41]Our adherence definition is consistent with prior studies classification of mammography use among BC survivors.[42,43] (Note there were only 3 women who were unsure).

Independent Variables

Predisposing Factors included age at the time of survey categorized as (≥50; 50-65; >65), race was classified using race and ethnicity grouping (Non-Hispanic White, Non-Hispanic Black), and marital status (married, non-married). Socioeconomic status was measured using women's metropolitan statistical area (MSA) categorized as residing in the center city of a metropolitan county vs. not residing in a metropolitan county.[44] Perceived health status was evaluated with three survey items: (1) women's overall perceived health, "Would you say that in general your health is?" Responses were categorized as "Very good", "Good" and "Poor"; (2) women's perceived psychological distress was measured from the question, "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?"; and (3) women perceived physical or mental health "During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?" Respondents possible scores ranged from 0 (none of the past 30 days) to 30 (all of the past 30 days).

Enabling Factors included having a personal doctor from the question "What type of doctor provides the majority of your health care?" emotional support which was measured with the question "How often do you get the social support and emotional support you need? Scores were assessed on a 5-point Likert scale ranging from Always to Never. Respondent's employment status at the time of interview was dichotomized as yes vs. no if they reported they were currently working vs. no. Healthcare access was measured if participants did or did not have access to health

care due to cost, with two survey items, questions included: (1) "Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?"; (2) "Were you ever denied health insurance or life insurance coverage because of your cancer?" Responses were reported as yes/no. Health care insurance was measured by asking participants if they had any form of health care coverage, with a yes/no response.

Need Factors measured surviving years since cancer diagnosis categorized as (≤5 and >5 years). Time elapsed from diagnosis was based on NCCN enhanced surveillance definition for the first 5 years.[45] Women's receipt of provider recommendation for surveillance routine check-up, "Have you EVER received instructions from a doctor, nurse, or other health professional about where you should return or who you should see for routine cancer check-ups after completing treatment for cancer? with a yes/no response. Women's routine check-up was defined by 2016 ASCO/ACS recommended clinical follow-up guidelines (defined as annual follow-up visits), using the survey question, "About how long has it been since you last visited a doctor for a routine checkup?" Responses were categorized into two categories: adherent ("visited a doctor in the last 12 months"), vs. non-adherent ("visited a doctor in the last 2-5 years or 5 or more years").[4]

Data Analysis

All data management procedures were weighted to determine national estimates of study variables and unbiased standard errors. Detailed methods about BRFSS sample weighting to account for the complex sample design are described elsewhere.[46] Descriptive statistics were employed to characterize the study cohort. Bivariate analyses χ^2 were used to test the associations between independent variables and the binary outcome: adherent to ASCO/ACS recommended guidelines (received mammogram in the last 12 months), versus non-adherent to ASCO/ACS

recommended guidelines (received a mammogram in the last 2-5 years or none at all). For adjusted analyses, we used binary logistic regression to assess the association between predisposing, enabling and need predictors with surveillance mammography adherence. An interaction was tested to assess if the association between metropolitan status and surveillance mammography differed by race. The multivariable logistic regression model was adjusted for predisposing (e.g., race, age, marital status) enabling (e.g., health insurance) and need (e.g., comorbidities, BC stage) factors, consistent with prior research assessing BC screening utilization among BC survivors. [7,47,48] A chi-squared power analysis was conducted prospectively to determine that the study sample size would have an effect size (Cohen's *h*=0.02) to test study hypotheses. Power analysis results concluded that the sample N=963 had 98% power to detect mean differences. Mean and mode imputation methods were used to handle missing data on the following study variables: metropolitan status, age, employment, routine check-up, received follow-up instructions, denied health insurance, and poor health. All statistical analyses were conducted using SAS Version 9. (Due to missing cells for reporting low to no emotional support in the study sample, emotional support was removed from all final analyses.)

Results

There were 963 BC survivors included in our analytic sample (Table 5.). The majority of women were 65 years of age or older (mean = 66), White (90%), had health insurance (99%), married (42%), and lived in a metropolitan county (75%). Most (70%) BC survivors reported that they were adherent to surveillance mammography guidelines, while 29% reported that they were non-adherent. While there were no significant differences in predisposing factors on adherence; it's important to note that the majority of survivors that were adherent had higher ratings of perceived health (54%) compared to women who were non-adherent (22%); interestingly, higher

levels of psychological distress were among adherent survivors (mean=64) compared to survivors who were non-adherent (mean=58). For enabling predictors, women who saw a doctor when needed in the last 12 months (66.8%) were more adherent to guidelines vs. women who could not see a doctor when needed due to cost (3.3%) (p=0.026); this was the only significant finding for study hypothesis 1. For need factors: women who had their last routine checkup (e.g., physical exam) within 12 months at the time of interview (64.2%) were adherent vs. women reporting their last routine checkup within 2-5 years (5.9%) p=0.045; women diagnosed >5 years (65%) were found to be less adherent compared to women diagnosed ≤5 years (34%) p<0.001.

Multivariable Analysis

The multivariable logistic regression model assessed predisposing, enabling and need factors association with adherence to surveillance mammography guidelines, while adjusting for potential confounders (survivor years, age, health insurance, employment and marital status) (Table 6.). [7,47,48] Health care access remained an enabling predictor of adherence to surveillance mammography guidelines (p= 0.037); however, when adding survivor years to the final model health care access was no longer statistically significant. When testing study hypothesis 2, a significant interaction was found between race and metropolitan status on adherence to surveillance mammography p<0.01, thus a race-residence composite variable was created in subsequent analyses. In the final adjusted model, race -residence (predisposing) and survivor years (need) were the significant predictors for adherence. A lower likelihood of adherence to surveillance mammography guidelines was observed among Black women living in non-metropolitan counties compared to White women living in a non-metropolitan county (OR: 0.03 95% CI 0.00-0.50). However, Black women living in metropolitan counties had a 3.77 higher odds of adherence 95%CI (1.32-10.81) compared to White counterparts. Women who were diagnosed

>5 vs. ≤5 years had the lowest odds of adherence to surveillance mammography guidelines (OR: 0.44;95%CI 0.28-0.71). While non-significant (p=0.071) it is important to note survivors, who had their last routine checkup within 12 months had a greater likelihood of meeting surveillance mammography guidelines.

Discussion

This study revealed potential explanations for racial disparities in adherence to surveillance mammography guidelines. Using a 2016 BRFSS Cohort of Black and White BC survivors, 70% of women reported a surveillance mammogram in the last year. In accordance with our conceptual framework, it was hypothesized that surveillance mammography adherence would be associated with predisposing, enabling and need study variables. While race was not independently associated with surveillance mammography, our results indicated that a combination of race and residence were significant factors in adherence. Black survivors living in non-metropolitan residential areas were less likely to be adherent compared to other race-residence groups. This finding remained significant even after adjusting for potentially confounding factors (e.g., survivor years, health insurance, employment marital status). Another important predictor of adherence found in our adjusted model was a shorter time from diagnosis (≤5).

These data provide insight for Black survivor's lower adherence rates to surveillance mammography in terms of area-level socioeconomic status (predisposing factor). Prior studies suggest when BC survivors live in lower-income residential areas suboptimal mammography adherence is followed.[7,23] For example, an earlier study found surveillance mammography was 30% lower for Black women versus White women who lived in areas with lower median income based on census tract of residence. [7] This study builds form this finding and demonstrate that Black women's surveillance mammography behaviors are in part, impaired by their environmental

context, in aspects of socioeconomic status disadvantages. Similar results were found, in a different sample among survivors in a deprived class quintile based on their socioeconomic status index. [23] While these studies have comparable findings, they all have different socioeconomic measures and lack racial/ethnic diverse samples, which moderately show the influential role of socioeconomic status on Black women's surveillance mammography behaviors. Given much of what we know regarding socioeconomic status influence on cancer screening disparities has been drawn from unaffected women,[49-51] there is a need to conduct more research to uncover the complexness of socioeconomic status among survivors screening behaviors to inform future interventions. Targeted public health initiatives and interventions have successfully contributed to an increase in mammography screening rates among Black women without a history of BC; [52-54] thus these initiatives are warranted among Black survivors from disadvantaged residential areas. More research from other socioeconomic positions such as health care access, which was a significant predictor in our unadjusted weighted analysis will help to fulfill data gaps in surveillance. Moreover, a better understanding of racial/ethnic BC survivors health care access barriers will identify mechanisms to improve racial disparities in surveillance mammography rates.

Longer time elapsed from breast cancer diagnosis was a significant need predictor for lower adherence. In particular, we found survivors diagnosed ≤5 years were more adherent versus women diagnosed >5 years. This finding is consistent with Breslau et al (2010) study that found higher rates of mammography adherence among short-term survivors using the same time point from diagnosis (≤5 years). Similarly, other works that measured different time points concluded that longer time from diagnosis or treatment is associated with lower rates of mammography adherence.[55-59] The consistent association between time from BC diagnosis and surveillance mammography suggest screening utilization post-diagnosis years becomes more complex as years

progress, suggesting that other explanations are contributing to survivor's adherence behaviors. One potential reason is survivor's intentions to receive a mammogram. Short-term BC survivors were found to be more likely to receive a mammogram due to breast cancer or follow-up problems, while long-term BC survivors were found to have received their mammogram for breast surveillance purposes.[47] Physician recommendation and NCCN recommendation for enhanced surveillance check-ups during the first 5-years are other potential reasons survivors adhere to screening practices.[60 7,61]While the majority of the sample (68%) reported having a personal doctor and received their follow-up instructions (59%) these factors did not predict adherence in our sample like having a routine check-up from our bivariate weighted analyses, consistent with prior studies.[62,63] Our results along with prior research suggest the importance of time from diagnosis on mammography adherence, however gaps remain in understanding short-term vs. long-term survivor's mammography decisions. Future research should investigate perceived barriers and facilitators of mammography adherence in short-term survivors.

Strengths & Limitations

This study expands current knowledge about Black-White differences in surveillance mammography adherence rates. Strengths in this examination include our approach and analysis. We utilized a conceptual framework that is widely used in healthcare utilization to guide selection of study variables to assess the relationship on adherence to surveillance mammography guidelines. We examined an interaction between race and metropolitan status, which helped us disentangle the complexity of influential predisposing and enabling factors on adherence. Despite these strengths there are limitations to highlight. The cross-sectional study design cannot confirm causality from study independent variables on adherence. The BRFSS dataset did not include clinical characteristics (e.g., surgery and or adjuvant treatment types) or medical claims data.

Survey responses were self-reported which may result in overestimated mammography use. While we restricted our sample to survivors who had completed treatment from the cancer survivorship questionnaire, their mammography reported may have been for diagnostic purposes. Lastly, there was very little representation of younger Black women, so this limits the generalizability of study results.

Conclusion

Given the clinical benefit from annual adherence to surveillance mammography guidelines, non-adherence to these guidelines among BC survivors is a public health issue. Improving minority surveillance practices may aid to help close this group high mortality and adverse morbidity outcomes from BC. Our study findings provide future research opportunities to examine adherence to surveillance mammography guidelines among survivors. Furthermore, a better explanation of racial disparities in surveillance guidelines will help to advance clinical follow-up within breast cancer survivorship care.

Table 5. Characteristics of the 2016 BRFSS Black and White BC Survivors
N=963

	Adherence		
	Yes	No	
	N (%)	N (%)	p-value
	691(70.1%)	272(29.9%)	
Predisposing Factors			
Age			
>50	25 (5.0)	15 (2.5)	
50-64	170 (23.0)	72 (10.5)	0.811
>65	496 (42.0)	185(16.9)	
Race			
Non-Hispanic Black	64 (7.3)	15 (2.4)	0.509
Non-Hispanic White	627 (62.8)	257(27.5)	
Marital Status			
Married	351(42.8)	123 (17.8)	0.749
Not married	336 (27.2)	148 (12.2)	

Residence			
Metropolitan County	553(59.9)	208 (24.9)	0.470
Non-metropolitan County	138 (10.2)	64 (5.0)	
Perceived Health			
Good	541 (54.8)	204(22.6)	
Fair	107 (11.4)	46(5.1)	0.654
Poor	42 (3.9)	22(2.3)	
Physical Health (M+SD)	58.04 ±2.0	55.13±3.5	0.479
Poor Health (M+SD)	57.73±1.6	57.09 +2.5	0.833
Psychological Distress (M+SD)	64.20 ±1.9	58.81±3.5	0.172
Enabling Factors			
Health Insurance			
Yes	684 (69.5)	268 (29.5)	0.697
No	7 (0.6)	4 (0.4)	
Employment Status			
Employed	150 (17.4)	54 (8.9)	0.311
Non-employed	541 (52.7)	218 (20.9)	
Could not see doctor because of cost			
Yes	28 (3.3)	20 (3.2)	0.026*
No	662 (66.8)	250(26.7)	
Denied health insurance due to cancer			
Yes	58 (5.3)	26(3.3)	0.178
No	633(64.8)	246(26.6)	
Have a personal doctor			
Yes	669 (68.8)	254 (29.1)	0.374
No	22 (1.4)	17 (0.8)	
Need Factors			
Survivor Years			
≤5	244 (27.6)	66(6.7)	<0.001*
>5	447(42.4)	206 (23.2)	
Received Follow-up Instructions			
Yes	565 (59.3)	206 (24.3)	0.346
Yes	126 (10.8)	66 (5.6)	
No			
Length of time since last routine checkup			
Within 12 months	622 (64.2)	237 (23.5)	0.045*
Within 2-5 years	69 (5.9)	35 (4.4)	

* $p<0.05$; ** $p<0.01$

Table 6. Adjusted logistic regression results for adherence to surveillance mammography guidelines in Black and White Breast Cancer Survivors OR (95% Confidence Intervals CI)

	Adjusted OR	(95% CI)	p-value
Predisposing			
Age			
>50	Ref.		
50-64	0.844	(0.30-2.37)	0.747
>65	0.88	(0.30-2.54)	0.812
Marital Status			
Married	1.1	(0.70-1.72)	
Not married	Ref.		0.67
Race and Residence			
Non-Hispanic Black Metropolitan	3.77	(1.32-10.81)	0.013*
Non-Hispanic Black Non-Metropolitan	0.04	(0.00-0.50)	0.013*
Non-Hispanic White Metropolitan	Ref.		
Non-Hispanic White Non-Metropolitan	1.04	(0.61-1.77)	0.878
Perceived Health			
Very good	1.31	(0.62-2.78)	0.474
Good	1.17	(0.51-2.67)	0.709
Poor	Ref.		
Physical Health (M+SD)	1.001		0.797
Psychological Distress (M+SD)	1.002		0.527
Enabling			
Health Insurance			
Yes	1.04	(0.17-6.19)	0.964
No	Ref.		
Employment Status			
Employed	0.802	(0.44-1.44)	0.4601
Non-employed	Ref.		
Could not see doctor because of cost			
Yes	0.54	(0.23-1.25)	
No	Ref.		0.152
Denied health insurance due to cancer			
Yes	0.951	(0.53-1.69)	0.865
No	Ref.		
Have a personal doctor			
Yes	0.978	(0.46-2.06)	0.952

No	Ref.		
Need			
Survivor Years			
≤5	Ref.		
>5	0.448	(0.28-0.71)	<0.001
Received Follow-up Instructions			
Yes	1.098	(0.66-1.80)	
No	Ref.		0.712
Length of time since last routine checkup			
Within 12 months	1.817	(0.94-3.51)	0.075
Within 2-5 years or 5 or more years	Ref.		

* $p<0.05$; ** $p<0.01$

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Chapter 4: Paper Three

A Mixed Method Approach to Examine Surveillance Mammography Experiences in Black and White Breast Cancer Survivors

ABSTRACT

Purpose Adherence to surveillance mammography following a breast cancer (BC) diagnosis is associated with early detection of disease relapse and increased overall survival; yet there are stark racial disparities in adherence to routine mammograms with limited explanation. Guided by the Behavioral Model for Vulnerable Populations, this study explores the interplay of predisposing (e.g., attitudes) enabling (e.g., provider-communication) and need (e.g., treatment, stage) factors influence on adherence to surveillance mammography among Black and White BC survivors.

Methods This is a convergent parallel mixed method study design of Black and White BC survivors (N=266) recruited from social media and community engagement, to participate in an online survey and online focus groups. The online focus groups consisted of a series of theory-informed questions via social media platforms (e.g., Breastcancer.org, Facebook, Instagram Quora, Reddit). Reponses on social media were used for an in-depth thematic analysis approach to emerge themes and subthemes. Bivariate (χ^2) and multivariable logistic regression analysis were conducted using the survey data to examine associated factors with adherence to surveillance mammography within 12 months (yes vs. no), while adjusting for potential confounders.

Results 72% of women were Black, $\leq$5 years since diagnosis (62%), had health insurance (98%), with an age range from 23-79 (mean=55) years. Women were more likely to be adherent if they reported perceived mammography benefits (<0.001), underwent lumpectomy (p<0.001) and had health insurance (p=0.04). Black women with lower communication ratings with providers had a lower likelihood of being adherent (OR:0.09,95% CI: 0.01-0.45, p=0.003). Thematic findings from online focus groups included motivators for adherence: having health insurance, regular physical exams, and knowledge of recommended guidelines; barriers for adherence included: transportation, medical cost/financial barriers, feeling ignored from providers. Additional concerns noted were medical mistrust, physician recommendation and cancer recurrence worry.

Conclusion This study explored BC survivor's surveillance experiences and identified motivators and barriers toward adhering to surveillance mammography guidelines. Survivors with health insurance and greater mammography beliefs predicted adherence. Black women who reported lower patient-provider communication was associated with non-adherence to surveillance mammography, which provides future research direction in the delivery of survivorship care. Black survivors may benefit from patient- centered communication strategies in their delivery of recommended surveillance from providers. Furthermore, breast surveillance recommendations and guidelines should consider partnering with advocacy work groups to educate and reach underserved groups in efforts to reduce survival disparities.

Keywords: Breast cancer survivors, surveillance mammography, adherence

Introduction

The American Society of Clinical Oncology (ASCO) and National Comprehensive Cancer Network (NCCN) recommend that breast cancer (BC) survivors adhere to annual breast surveillance guidelines.[1,2] Adherence to surveillance mammography, [3,4] is associated with early detection of disease relapse, and decreases mortality by 39%.[5-8] While national rates of adherence are as high as 85-75% among survivors 65 years and older,[9-11] young and minority women have lower adherence rates (44%).[12-14] Data from several large retrospective studies consistently found higher non-adherence rates to surveillance mammography among Black BC survivors relative to White women. [11,15-18] Black women's non-adherence is problematic as data shows a higher cancer specific mortality among Black women who were non-adherent during a 2-year surveillance period compared to Black women who were adherent.[19,20] Despite racial disparities in surveillance mammography following completion of primary treatment, survivors knowledge, perceptions and communication with their providers about surveillance recommended guidelines are understudied.[21]The Behavioral Model for Vulnerable populations,[22] conceptualize that health care utilization behavior among vulnerable groups (e.g., cancer survivors) is accomplished through a interplay of population characteristics (predisposing), contextual and health care system factors. Guided by this conceptual framework this study sought to observe the complex interplay of multifactorial predisposing (e.g., mammography beliefs and knowledge) enabling(e.g., provider communication) and need factors (survivor years) among Black and White surviors.[8,23,24 21]

There is a strong causal relationship between women's mammography knowledge and beliefs (e.g., benefits, barriers) and screening behaviors. [25-27] Research studies among racial/ethnic minority women have shown that having perceived barriers (lack of transportation, fear of positive result, cost) to a mammogram are significantly associated with lower mammography screening behaviors. [28,29] In fact, when interventions tailor components of their randomized controlled trials

to women's mammography beliefs such as barriers, benefits, perceived risk and susceptibility, interventions yield better outcomes such as increasing screening knowledge and the rate of mammography adherence;[30] however much of these data are drawn from women without a BC history. Survivors knowledge and beliefs about breast surveillance guidelines among women with BC are lacking in cancer survivorship literature. Limited surveillance knowledge among survivors regarding their surveillance could affect their appropriate follow- up care and BC outcomes.[31] This study seeks to delineate surveillance mammography beliefs and knowledge among a diverse sample of survivors to further explicate non-adherence behaviors among survivors, and to inform future survivorship interventions.

Associated reasons for non-adherence are complex relating to age, health insurance, BC stage, and marital status; however, data are lacking to explicate nonadherence behaviors beyond clinical and demographic factors.[11,15,23,32] Patient-provider communication is an essential process of cancer care delivery that improves women's initiation and adherence to adjuvant treatment.[33-35] One study found Black women compared to White women who reported greater communication with their oncologist (vs. less) had a 3-time higher odds of chemotherapy initiation.[34] Similarly, another study found that frequent contact with primary care physicians better predicted the use of mammography and improved breast cancer outcomes. **[36]** These findings support the importance of satisfaction in patient provider communication in promoting adherence behaviors;[37,38] however there has been limited work done on the relationship between patient-provider communication and follow-up adherence to surveillance mammography.[39]

The underline premise of this convergent mixed methodological study design is to explain how the Behavioral Model of Vulnerable Population [22] constructs predisposing *(e.g., mammography beliefs), (2) enabling (e.g., patient provider communication) and (3) need factors*

(e.g., years form diagnosis) influence BC survivor's adherence behaviors to surveillance mammograms (figure 1). Using our qualitative data, we aim to explore BC survivor surveillance experiences (e.g., barriers and promoters) using breast cancer focused online platforms (e.g., breascancer.org). This research study will further advance our knowledge about survivor's adherence to annual mammograms, by highlighting BC survivors perspectives and examining key factors (e.g., patient-provider communication) that are supported in adjuvant treatment adherence literature.

The survey data will test the following hypotheses:

H_1: Lower levels of provider communication will predict non-adherence to surveillance mammography and differ by race

H_2: White race, and higher ratings of surveillance mammography benefits, and knowledge will predict adherence.

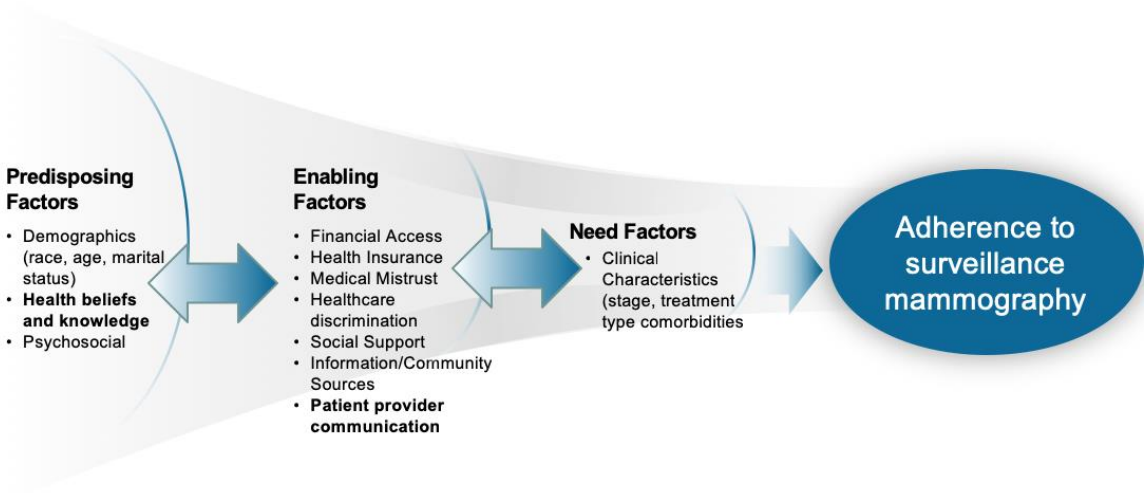


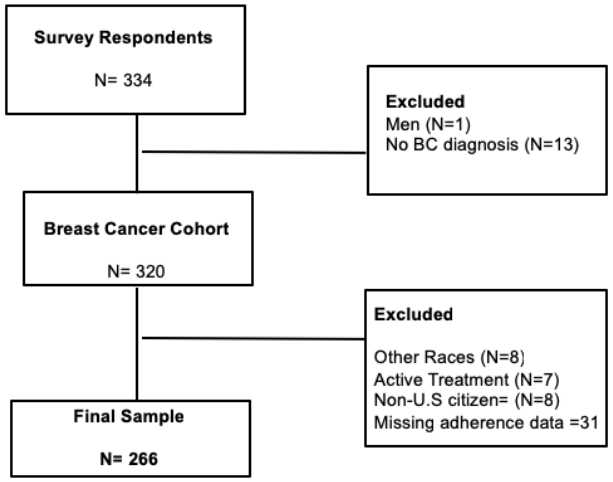
Figure 7. Paper 3 Conceptual Model

Materials and Methods

Setting and Population

The Y-WE(WOMEN) SURVIVE Breast Cancer Study utilized mixed methods to examine surveillance mammography experiences among BC survivors engaged in social media. Women were concurrently recruited through multiple recruitment strategies: virtual study ads on social media platforms (e.g. Facebook), emails listservs, and community outreach engagement events at Massey Cancer Center Office of Health Disparities and Health Equity. Study ads embedded a screening link with the study inclusion criteria. Women who met study eligibility self-identified as African American/Black or White, were diagnosed with breast cancer, ≥21 years old or older and completed definitive surgery (e.g., mastectomy, lumpectomy) before study participation (Figure 4). Study procedures were approved by Virginia Commonwealth University Institutional Review Boards.

Figure 4. Breast Cancer Cohort Schema



Data Collection

Data were collected using a two-phase strategy: an online Qualtrics survey and online focus groups using BC focused virtual platforms (Quora, Breastcacncer.org, Reddit and Twitter). Online focus group discussions were conducted publicly with women on these platforms, guided with a moderator guide of questions about perceived knowledge, provider communication preferences, barriers and promoters of adhering to breast surveillance guidelines (e.g., surveillance mammography). The PI posted questions on various breast cancer focused platforms (see Appendix 1). When needed, additional probes were posted subsequently to facilitate the discussion further. Survivor's public engagement and discussions relating to their surveillance experiences on these virtual platforms (breastcancer.org and ACS cancer survivor network) were also included. Women were given the option to privately share their experiences with surveillance through the study survey administered by Qualtrics. Both the survey and online focus group data were collected until saturation.

Survey Measures

Outcome Consistent with ASCO and NCCN recommended guidelines[3], adherence to surveillance mammography was measured with the question "In the last 12-months did you have a mammogram" with a yes vs. no response.

Predisposing factors included demographics: age (≤50, >50, race (Black and White) and marital status (single or married/living as married). We adapted a 12-item scale to measure surveillance mammography beliefs adapted from Champion's Mammography and Breast Cancer Health Belief Scale (CHAMPION). [26] Questions assessed women's perceived barriers to surveillance mammography, "How likely is it that not being able to afford a mammogram would keep me from having one?" and perceived benefits, "How likely is that having a mammogram would help me find a breast cancer recurrence early." Similar to prior studies using this scale, responses were

dichotomized as any vs. none.[40] Surveillance mammography knowledge included two-items measuring women's awareness about their individualized breast surveillance guideline to follow (yes vs.no) and women's general understanding with the question, "How would you rate your knowledge regarding breast cancer surveillance recommendations for breast cancer survivors in general?" Responses were on a four-point Likert scale, where higher scores denoted higher knowledge.

Enabling factors assessed women's household income categorized as (>15,000, $15,000-<$35,000, $35,000-<$50,000, $50,000-<$75,000 and >=$75,000), health insurance status (yes vs. no), family breast cancer history (yes vs. no) and employment status (full time employed or unemployed). Women were asked about their provider communication experiences, "Did your doctor or any healthcare provider discuss with you the need for regular follow-up care and monitoring after completing your treatment?" Responses were categorized as discussed in detailed vs. did not discuss in detailed. Survivors financial aspects specific to their cancer diagnosis was observed with the question, "Have you or your family had to make any kinds of financial scarifies because of your cancer treatment, or the lasting effects of that treatment?" where responses were yes, vs no.

Need factors included women's clinical characteristics, including cancer stage (0, I-II, III, IV), years from diagnosis (≤5 years, or <5 years), surgery type (mastectomy, or lumpectomy) and adjuvant treatment options chemotherapy, radiation and hormonal therapy (yes vs. no), and surgical treatment (lumpectomy, mastectomy).

Survey Analysis

Descriptive statistics characterized the study sample using chi-squared tests (χ^2) between study variables (e.g., financial burden) on a binary outcome and adherence to annual surveillance mammogram (yes vs. no). For adjusted analyses, a multivariable logistic regression model was used to assess the association between predisposing, enabling and need predictors on surveillance mammography adherence. The multivariable logistic regression model was adjusted for potentially confounded study variables, consistent with prior studies.[11,41,42] Champion Scale items were recoded as any vs. none for logistic analysis interpretations. [40]A chi-squared power analysis was conducted prospectively to determine that the study sample size would have an effect size (Cohen's h=0.02) to test study hypotheses. Power analysis results concluded that the sample N=266 had an 80% power. Mean and mode imputation methods were used for study variables having 5 or more missing. All statistical analyses were performed using SAS version 9.4

Virtual focus group coding procedure

Two trained coders conducted a thematic analysis approach using grounded theory techniques. [43] Data included virtual focus group text from posts that the PI initiated and from discussions posted to online breast cancer forums that fit our research question. Memo tools for reflexivity encouraged the coding team to debrief in discussions during the coding process.[44] In the initial coding scheme, dimensions from the theoretical framework were used as priori codes to guide the scheme of coding, and the research question (e.g., exploring barriers and promoters of BC survivor's experiences with surveillance mammography and follow-up visits). The analysis process began with memo summaries and transcript reading of virtual focus groups and public discussions. Using a Microsoft Word document, we developed a table that included a column of the theoretical tenants and definitions of these constructs, a column for the virtual focus group data platform, and the coding initials. In this process we: (1) systematically reviewed the text to highlight all comments

that appeared to represent the theoretical constructs, and debriefed analytical summaries of the process. In the next phase, we went through a data reduction process.[45] In this process we removed all text that was unrelated to the research question. After completing this process, coders began an open-coding procedure where they constantly compared data to narrow the text in the table to closely reflect the theoretical constructs and research question to find emergent themes and subthemes inductively.[43,44]This technique was used to eliminate bias and to gauge consistency across the team.[46] The themes were then deciphered amongst the coders for consensus across themes.

Results

Online Focus Group Data

Barriers to recommended surveillance mammography and follow-up visits

When responding to questions about barriers to recommended surveillance guidelines (e.g., mammogram), women commonly reported feeling ignored from physicians (enabling), limited access to transportation, financial burden and lacking knowledge (predisposing), and wanted more advocacy on surveillance (enabling)

> One participant quoted, *"deeply feel that there are metastases missed with this surveillance, including mine. Had there not been a recurrence in my incision, I would have continued with exhaustion (ignored for 3 years by all physicians) and a nagging cough (also ignored) and be an un-diagnosed Stage 4."*
>
> Another participant expressed concerns regarding providers not listening with surveillance mammography and follow-up one participant quoted "*Not much follow-up with long-term survivors, Not much concern for side effects we might have forever. Not*

much thought at all about long-term survivors. It's changing but we need advocates for that and people to listen to us. Generally, they don't or they pretend to listen and then forget it. It's good there are enough of us now to need this."

Promoters of annual surveillance mammography and follow-up visits

When asked to share what supported their adherence to surveillance mammograms: the support of family (enabler), having insurance (enabler), knowledge of guidelines (predisposing), regular physical exams (enabler), and being proactive with their care (enabler) were highlighted.

One woman shared, *"Have experienced no barriers as have insurance and doctors set up screenings and exams 6 months or year before appointment. I have been proactive in my treatment and knew guidelines (from online reading) before seeing docs...Support came from my husband, family and friends…"*

Women knowledge and surveillance behaviors also seemed to be driven by having frequent communication with their providers (need*), "I had annual mammograms…. I emailed him once a year and asked if he wanted to see me. Twenty years after my first breast cancer, I was diagnosed with triple negative breast cancer. I saw the same oncologist. I had surgery and no further treatment. … the oncologist said that it was not necessary for me to come in for any check-ups or surveillance"*

Worry about recurrence (predisposing) around follow-up visits and mammograms was continuously brought up, for some women this feeling facilitated their routine follow-up and for other it did not *"Since we are coming up on the anniversary of my diagnosis I have my mammogram scheduled for next month. I had a unilateral mastectomy so they'll only be checking*

the right breast from now on. Not going to lie, I feel a little anxiety about the whole thing but it's not enough to not get the mammogram done. I am at my treatment facility at least once a month, so I am getting physicals regularly"

Women also shared strategies for how survivors should overcome barriers women shared education (predisposing) and being proactive (predisposing) as the top drivers, *"I think being proactive about one's condition and establish a knowledge base by reading journal articles, gathering information from breastcacner.org, thus learning to know what questions to ask the medical establishment, may help to prevent or overcome barriers"*

Issues/Problems with Breast Cancer Surveillance

Women's experiences with surveillance seemed to shape their overall perceptions, the fear of cancer metastasizing (predisposing), some women expressed their concerns/issues about breast surveillance regarding the accuracy of detecting recurrences early (predisposing), *"One of my friends had an annual visit with her surgeon, and he gave her a clean bill of health. She called me and as excited to tell me that she was "good to go for another year." Several weeks later, she had a pain in her shoulder. The surgeon initially treated it as arthritis, but it was eventually diagnosed as metastatic disease to the bone. My friend died several months later*." Other women shared that surveillance mammograms alone sometimes were not enough to confirm their recurrence.

I never expected to hear that I had breast cancer when I went in for my routine exam. The thing that really disgusted me, is that my previous exam was read by a (female!) radiologist who assured me that she saw two benign cysts and made the recommendation that I return in a year.

If she had just suggested that I get a second opinion, I can't help but wonder if my cancer could've been caught at an earlier stage

When reviewing additional public comments online related to our research question similar themes emerged: continuity of care (enabler) and worry about recurrence (predisposing). New themes included medical mistrust (enabler) and physician recommendation (need), which greatly influenced their attitudes and their overall experiences with surveillance following treatment.

For some women medical mistrust was a barrier to their care, *"I asked my oncologist about follow-up testing. He said that cat scans or MRI scans are no longer considered necessary, but they will do blood tests for tumor markers every 6 months besides the physical exam...I too am concerned about this and am thinking about asking my family doc to order a cat scan anyway…I had a recurrence after 9 years. so, there is nothing they can say to me to make me think I'm safe.*

Some women commented about how their physicians did not think it was necessary to have follow-up visits, *"the oncologist said that it was not necessary for me to come in for any check-ups or surveillance."* While other women demonstrated their frustrations with their providers recommendation regarding their follow-up surveillance *"I have questioned my breast surgeon and oncologist as to what kind of follow-up I will have after the bilateral mastectomy. Both say they will just see me every 3 months and 'palpate' me, that it is not recommended to have MRIs after bilateral mastectomy or any other type of screening tests. I feel out of control when they tell me this, like there is nothing I can do"*

Survey Data

Table 1 describes surveillance mammography by predisposing, enabling and need characteristics from our study sample of 266 BC survivors. For predisposing factors majority of our sample were Black (66%) married (52%), with ages ranging from 23-79 with a mean age of 55 years (SD=10.67). Over half of the sample were employed (53%), had health insurance (98%), and a family history of breast cancer (56%) among enabling factors. With need factors, most of the sample were ≤5 years since diagnosis (62%) and received a lumpectomy or mastectomy (72%) and systemic treatments (55%). Overall, 72% of survivors had a surveillance mammography (in the last 12 months) compared to 28% of women who were non-adherent. Although insignificant, it is important to note that survivors who were adherent, were more informed about their breast surveillance guidelines from their provider (58%vs.21%; enabling factor), had more general surveillance knowledge (m=2.14 vs. m=2.08; predisposing factor), and had higher receipt of treatment adjuvant chemotherapy (55%) and radiation (55%) (need factors).

The only significant factors reported in bivariate analyses that predicted adherence to surveillance were perceived benefit of surveillance mammography ($p<0.0001$) and surgical treatment options ($p<0.0001$). Women who reported any benefit beliefs toward a surveillance mammography (78.9%) compared to women who did not report any benefits beliefs (21%) were more likely to be adherent ($p <.0001$; H_2). Survivors who received a lumpectomy versus mastectomy was associated with being adherent ($p<0.0001$).

Multivariable Analysis

Predisposing, enabling and need factors were observed in the multivariable logistic regression model, while adjusting for potential confounders (survivor years, age, race-residence, health insurance, employment and marital status). [11,41,42] When testing study hypothesis 1, a

significant interaction was found between a combination of race and provider communication (p=0.039), thus a composite variable was created in multivariate analyses. (Table 1).

Predisposing factors. Women who reported any benefits from a surveillance mammography had a greater likelihood of surveillance mammography adherence in our adjusted model (p<0.001). Table 2. While perceived barriers toward surveillance mammography were insignificant when comparing by race, we found that Black women reported slightly more (21%) barriers vs. White women (14%).

Enabling factors. Health insurance coverage was a predictor of adherence (p=0.041). Survivors who reported health insurance coverage vs. not had a higher likelihood of meeting annual surveillance mammography guidelines.

Need factors. Surgical treatment remained significant in our adjusted model, survivors who had a mastectomy had a decreased odd of being adherent to a surveillance mammogram (OR: 0.04; 95%0.01-0.17).

Race-stratified analysis revealed variations across race (predisposing factor) and provider-communication (enabling factor) combined. Black women whose providers did not discuss their surveillance guidelines with them in great detail were less likely to adhere (OR:0.09, 95% CI: 0.01-0.45, p=0.003) when compared to White counterparts.

Discussion

Adherence to surveillance mammography guidelines is linked with better survival outcomes among BC survivors. Explanations for non-adherence to surveillance guidelines are lacking outside of sociodemographic and clinical factors. In this study we sought to determine theory guided determinants of adherence and explored surveillance mammography experiences

among a racial/ethnic diverse sample of BC survivors. In adjusted analysis, having perceived benefits toward a mammogram, lumpectomy and health insurance were associated with a greater likelihood of reporting a mammogram in the past 12 months. Lower patient-provider communication was associated with a lower odds of surveillance mammography among Black women, when compared to White women with lower communication. To our knowledge, this is the first study to report within-race differences in the relationship between provider communication and surveillance mammography.

Black women's adherence to mammography screening was influenced by their ratings of provider-communication about their surveillance guidelines. Black women that reported lower communication with their provider were found to have a lower likelihood of adherence. Given the lack of data on provider-communication in the surveillance context, our finding extends possible explanations for Black women's poor adherence rates to surveillance mammography. Comparable results were found in a study that stratified race by physician-communication on chemotherapy initiation and found an interaction effect. Black women with greater communication with their physician were more likely to initiate chemotherapy, compared to their White counterparts.[34] Reports have also indicated the important role that the patient-provider relationship plays, in making treatment decisions especially for Black women during treatment. [34,35 47] One explanation why Black survivor's reported lower ratings may be that they felt that had inadequate communication with their providers, resulting in felling ignored when they had an issue, which was cited as a barrier in our online focus groups. Our results indicate that poor communication with physicians about their surveillance behaviors is problematic for Black women. Given this is the first attempt to measure aspects about surveillance communication between providers and BC survivor's posttreatment, more research is needed to better understand the communication and

preference needs from both survivors and providers perspectives. Furthermore, this finding has implications for behavioral interventions to improve the inadequate communication and coordination between patients and providers[33,48-51] which may enhance the quality of survivorship information given to racial/ethnic minority BC survivors.

Health insurance coverage was an important enabling factor for surveillance mammography in both our qualitative and quantitate findings. The lack of health insurance among BC survivors is consistently associated with non-adherence to a surveillance mammogram. [10,11,52] Our findings are aligned with prior research and suggest health insurance coverage is in part, a buffer for women's adherence to surveillance guidelines. While, having health insurance is historically linked with better health care utilization in survivors, [53,54] in the context of cancer care delivery, the type of health insurance has been noted as a salient factor. One study found that survivors with public health insurance types were less likely to adhere to surveillance mammography than those with private and Medicare insurance.[55] Similarly, other studies report lower treatment adherence for public insurance holders vs. being privately insured. [56,57]The persistent non-adherence findings for public insurance type suggest variations in the structure of payment plans and out-of-pocket costs, which may be a financial barrier for BC survivors who are publicly insured. Women form online focus groups also noted financial barriers as burdensome to having timely surveillance. Given the negative impact of financial barriers on surveillance there is a need to address this barrier during survivorship care. Additionally, further exploration of health insurance dynamics such as plan structure may help to uncover novel complexities in survivors use of cancer care delivery.

Mammography beliefs was an influential predisposing factor for survivor's adherence to a mammogram. Women who reported any mammography benefits were more likely to have a mammogram in the last 12 months. This finding is consistent with prior research in the general population of women, that support the independent association between mammography benefits and mammography screening adherence.[26,40,58] One explanation for women's beneficial beliefs about a mammogram may be linked with their breast surgery type. In adjusted analysis women with lumpectomy were more likely to be adherent than those with mastectomy. Alternatively, women's perceived benefits may have been influenced by their attitudes about recurrence. Women from online focus groups expressed that their worry about recurrences helped to facilitate their mammography adherence. These findings are consistent with an earlier study of Black BC survivor's surveillance mammography expereinces.[59] While our findings help to fulfill current gaps in survivorship research, more work is needed. For example, future work should further explore influential factors such as, surveillance knowledge that may relate to women's mammography beliefs and help identify intervention components to improve the belief system and narrow important groups of survivors to target.

Strengths & Limitations

This study has multiple strengths to highlight. Using a mixed method data collection approach, we examined BC survivor's surveillance mammography experiences from multiple perspectives. Our qualitative data informed our selection of study variables on our outcome. We discovered novel influential predictors (e.g., provider-communication) of surveillance mammography, that will lend future research to advance breast cancer survivorship. Although our study included an oversample of Black BC survivors by sampling design, there are limitations to note. Inclusion of self-reported

data may present socially desirable biases. Sociodemographic factors were not collected from online focus group participants. Clinical characteristics were not confirmed from histology reports, nor did we control for first or second recurrent cancers from survey participants. Lastly, BC survivors' surgical type may include other options beyond lumpectomy and mastectomy such as bi-lateral mastectomy or reconstruction, that may have added more context.

Conclusions

Findings from this study indicate the importance of receiving adequate patient-provider communication, mammography beliefs and having health insurance coverage regarding surveillance guidelines. We found racial variations in ratings of provider-communication, which suggest the need to better understand survivors and providers-communication in the delivery of survivorship care. Thematic results also revealed survivors' concerns with feeling ignored from their provider, medical mistrust related issues with their providers recommended surveillance and being worried about recurrences. These perspectives illuminate key points of future examination. Moreover, financial barriers, medical mistrust and provider-communication need further investigation to better address Black women's non-adherence to surveillance mammography.

Table 7. Characteristics of Black and White BC Survivors by Surveillance Mammography, Unadjusted N=266

	Surveillance Mammography		
	Yes	No	
Variables	N (%)	N (%)	P-value
	192(72.5)	73 (27.6)	
Predisposing			
Age			
≥50	53(20.2)	27(10.3)	0.158
<50	136(51.9)	46(17.6)	
Missing 4			
Race			
White	64(24.2)	24 (9.1)	0.943
Black	128 (48.3)	49 (18.5)	
Missing 1			
Marital status			
Married	97 (36.6)	30 (11.3)	0.222
Single	43 (16.2)	95 (35.9)	
Missing 1			
Do you know your breast surveillance to follow?			
Yes	154 (58.1)	58 (21.9)	0.89
No	38 (14.3)	15 (5.7)	
Surveillance Mammography Benefits			
Any	165 (62.3)	44 (16.6)	<.0001**
None	27(10.2)	29 (10.9)	
Missing 1			
Surveillance Mammography Barriers			
Any	64 (24.2)	30 (11.3)	0.238
None	128 (48.3)	43 (16.2)	
General Surveillance Knowledge (M+SD)	2.14 +0.81	2.08 +0.83	0.568
Missing 5			
Enabling			
Health insurance			
Yes	191 (72.1)	71(26.8)	0.127
No	1 (0.38)	2(0.75)	
Missing 1			
Family BC health history			
Yes	110 (41.5)	39(14.7)	0.570
No	82(30.1)	34 (12.8)	
Income (household)			

>$15,000	25(9.5)	6 (2.3)	
$15,000-<$35,000	33 (12.6)	7 (2.7)	0.297
$35,000-<$50,000	30 (11.4)	13 (4.9)	
$50,000-<$75,000	34 (12.9)	13 (4.9)	
>=$75,000	68 (25.7)	34 (12.9)	
Missing 3			
Financial Burden			
Yes	74 (27.9)	33 (12.5)	0.323
No	118 (44.5)	40(15.1)	
Employment			
Employed	99 (37.36)	43 (16.2)	0.284
Unemployed	93 (35.09)	30 (11.3)	
Missing 1			
Provider-Communicated Surveillance			
Yes	155 (58.5)	54 (20.4)	0.228
No	37 (13.9)	19 (7.2)	
Need			
Stage			
0	22 (8.3)	7(2.7)	0.894
I-II	122 (46.2)	47 (17.8)	
III-IV	47 (17.8)	19 (7.2)	
Missing 2			
Survivor Years			
<5 years since diagnosis	119 (44.9)	46 (17.4)	0.8767
5+ years since diagnosis	73 (27.6)	27 (10.2)	
Missing 1			
Surgery			
Lumpectomy	87(32.8)	5(1.9)	<.0001**
Mastectomy	105(39.6)	68(25.7)	
Chemotherapy			
Yes	147 (55.5)	58 (21.9)	0.615
No	45 (16.9)	15 (5.7)	
Endocrine Therapy			
Yes	48 (18.1)	21 (7.9)	0.532
No	144 (54.3)	52 (19.6)	
Radiation			
Yes	146 (55.1)	50 (18.8)	0.210
No	46 (17.4)	23 (8.7)	

* $p<0.05$; ** $p<0.01$

Table 8. Adjusted logistic regression results for survivor's surveillance mammography adherence odds ratios (OR) and 95% Confidence Intervals (CI)

	Adherence		
Variables	Adjusted OR	95% CI	p-value
Predisposing factors			
Age			
≥50	Ref.		
<50	0.71	(0.28-1.78)	0.464
Race-Communication			
White, Greater Communication	Ref.		
White, Lower Communication	1.79	(0.46-6.88)	0.392
Black, Greater Communication	0.97	(0.40-2.34)	0.950
Black, Lower Communication	0.16	(0.04-0.65)	0.010
Marital status			
Married	0.98	(0.40-2.35)	0.965
Single	Ref.		
Do you know your breast surveillance to follow?			
Yes	0.76	(0.23-2.50)	0.652
No	Ref.		
Surveillance Mammography Benefits			
Any	4.92	(2.16-11.21)	<0.001**
None	Ref.		
Surveillance Mammography Barriers			
Any	1.06	(0.48-2.33)	0.885
None	Ref.		
General Surveillance Knowledge (M+SD)	0.89	(0.49-1.63)	0.716
Enabling factors			
Health insurance			
Yes	24.12	(1.24-517.54)	0.041*
No	Ref.		
Family BC health history			
Yes	1.27	(0.61-2.64)	0.506
No	Ref.		
Income (household)			
>$15,000	4.86	(0.98-24.00)	0.051
$15,000-<$35,000	3.08	(0.80-11.87)	0.101

$35,000-<$50,000	0.89	(0.30-2.65)	0.844
$50,000-<$75,000	1.50	(0.52-4.27)	0.447
>=$75,000	Ref.		
Financial Burden			
Yes	0.57	(0.26-1.20)	0.141
No	Ref.		
Employment			
Employed	0.96	(0.44-2.07)	0.923
Unemployed	Ref.		
Need factors			
Stage			
0	Ref.		
I-II	0.71	(0.20-2.57)	0.612
III-IV	1.04	(0.26-4.11)	0.946
Survivor Years			
<5 years since diagnosis	1.03	(0.047-2.28)	0.925
5+ years since diagnosis	Ref.		
Surgery			
Lumpectomy	Ref.		
Mastectomy	0.04	(0.01-0.14)	<.0001**
Chemotherapy			
Yes	1.20	(0.44-3.28)	0.710
No	Ref.		
Endocrine Therapy			
Yes	0.62	(0.27-1.44)	0.276
No	Ref.		
Radiation			
Yes	0.52	(0.21-1.25)	0.147
No	Ref.		

* p<0.05; **p<0.01

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Chapter 5: Discussion

An estimate of 3.5 million breast cancer (BC) survivors in the U.S are at an increased risk for developing new and recurrent disease within the first five-years after treatment.[1,2,3]The National Comprehensive Cancer Network and American Society of Clinical Oncology recommend annual adherence to surveillance mammography for BC survivors. Surveillance mammography improves BC mortality by 39% through early detection of disease relapse. [4-7] Unfortunately, when compared to White women Black women have poorer rates of surveillance mammography, which may in part contribute to their suboptimal survival outcomes compared to all racial/ethnic groups of women in the U.S. [8-11] Factors associated with surveillance mammography include clinical and socio-demographic factors and relate to delivery system factors, [12-15] however these data have been limited for Black women.[16] The present study sought to fill this gap in the research by explicating psychosocial and healthcare delivery factors in Black women's adherence to surveillance mammography.

Guided by the Behavioral Model for Vulnerable Populations the goal of this mixed-methods approach study was to provide a better understanding of the complex interplay of *predisposing (e.g., sociodemographic) enabling (e.g., health insurance) and need factors (e.g., stage)* in adherence to surveillance mammography guidelines. The approach of the mixed-method design integrated both secondary and qualitative data to provide a multilevel examination of Black and White BC survivors surveillance mammography, through the following study aims:(1) Determine racial differences and influential factors in survivors breast cancer beliefs; (2) Evaluate the contribution of socioeconomic status, preceived health and health care access on adherence to surveillance mammography using BRFSS data; (3) Describe surveillance mammography experiences of survivors engaged in social media and determine predictors of adherence to

surveillance mammography among a diverse community-based cohort. Study aims were presented in a series of three original manuscripts aimed for peer-review submission at cancer survivorship journals.

To fill survivorship research gaps a central theme in each manuscript highlighted Black survivors' experiences. Manuscript 1 conducted a secondary analysis to examine racial differences in BC beliefs measured as perceived severity and susceptibility of a cancer recurrence, with three study hypotheses. Manuscript 2 evaluated adherence to surveillance mammography guidelines using a national secondary dataset to test two study hypotheses. Manuscript 3 integrated findings from four online focus groups that explored survivor's surveillance experiences and a survey that assessed two study hypotheses to determine predictors (e.g., knowledge, surveillance beliefs) of annual adherence to surveillance mammography. Overall, this study provides new insight on addressing racial disparities in surveillance mammography guidelines, to advance cancer prevention and control among BC survivors.

Study findings enhanced knowledge about survivor's health beliefs. Results indicated that clinical factors such as stage was an important need factor in survivors' beliefs about their cancer recurrence. Greater perceived susceptibility of a cancer recurrence was found among women diagnosed at stage II compared to stage I and III. Findings suggest women diagnosed with earlier stage cancer (II) vs. later stages have more concerns about their recurrences. Recurrence of cancer is a common late effect from a cancer diagnosis particularly among Black BC survivors compared to White counterparts, [8,17,18] yet there is limited research investigating the clinical impact from this concern among survivors.[19] Contrary to the current findings, one study observed racial differences in beliefs about cancer recurrence among a sample of BC survivors.[19] In this study, they reported that non-White women compared to White women were more likely to have lower ratings of

perceived susceptibility of a recurrence.[19] When measuring perceived risk of a cancer recurrence BC survivors with lower ratings of health literacy reported a higher mean of perceived risk to a recurrence, for a group of BC survivors diagnosed at earlier stages.[20] While measures were different from the current study, the mixed findings regarding survivors' cancer recurrence beliefs, may potentially be due to sample differences. Results from the current study were from an oversample of Black women that were 20 weeks out from primary treatment (surgery), married, highly educated, privately insured and had HR negative status and tumor size <2cm. More research concerning perceived susceptibility of a cancer recurrence is needed from other racial/ethnic and clinically diverse groups of BC survivors, to help fill research gaps.

Regarding survivors perceived severity beliefs, there are several influential factors to discuss. Lower satisfaction regarding finances in healthcare (enabling factor) and treatment utilization (need factor) were associated with greater severity beliefs in the sample. While treatment utilization (e.g., surgery, radiation, chemotherapy) was significantly associated with higher perceived severity beliefs in bivariate results, the effect diminished in multivariable analysis and was no longer significant. Prior work suggests that greater severity beliefs among BC survivors is linked with higher readiness for genetic counseling and supports higher treatment utiliztion.[21,22] One explanation why our results do not fully support this stance may be due to disparities reported in the sample. Black women vs. White women in the study were more likely to report lower levels of satisfaction concerning their healthcare finances, and higher levels of medical mistrust and healthcare discrimination. In multivariable analysis higher levels of perceived severity were among women with lower satisfaction regarding their financial aspects of healthcare. Black women compared to White women were more likely to report lower levels of satisfaction for their healthcare finances in the sample. Study findings suggest that finances play a role in BC survivor's

health beliefs and bring special attention to the financial concern's Black survivors face during cancer care delivery. Similarly, prior work indicate that Black survivors are more likely to report higher levels of financial distress,[23] higher rates (50%) of unemployment after a BC diagnosis in contrast to their White counterparts.[24]Secondly, financial concerns was a common health care barrier among survivors from qualitative findings. More research is needed to better address the financial burdens Black BC survivors face during their continuum of care, to better inform policy and financial resources.[8,18,25]

Although health beliefs are widely studied as a contributing predisposing factor in health care utilization, there has been limited research to observe the role health beliefs play in adherence related behaviors (e.g., surveillance, adjuvant endocrine therapy) among BC survivors.[26-28] This study helped to fulfil this gap in research by examining survivor's perceived barriers and benefits toward a mammogram and their beliefs about their overall health, as influential factors in surveillance mammography. Novel results from multivariable analysis indicated that women who perceived any benefit from a surveillance mammography were more likely to be adherent to surveillance mammography guidelines compared to women who did not perceive any benefits toward a mammogram. This finding supports the influential role that predisposing factors such as, mammography beliefs play in survivors' adherence to surveillance mammography guidelines. Although study results did not show any evidence related with perceived health and surveillance mammography, it is still important to further investigate survivor's health beliefs with their surveillance related behaviors and lifestyle changes. Future research should focus on describing the connection between health beliefs and other surveillance related behaviors such as clinical visits, to inform navigation strategies in the context of cancer survivorship.

Consistent with prior studies, socioeconomic status in terms of residential area within the U.S was found as an important predisposing factor in Black women's surveillance mammography behaviors. [29,30] Results indicated that Black women living in non-metropolitan residential areas were less likely to report adherence to surveillance mammography guidelines compared to their White counterparts living in non-metropolitan communities. One explanation from these findings relate to the socioeconomic racial disparities within U.S communities that contribute to the excess burden of morbidity and mortality for Black women living in the U.S [31-33] For example, a meta-analysis investigated the role of socioeconomic and health care access disadvantages on mortality among Black and White BC patients.[34] Unfortunately, after adjusting for stage, age, and socioeconomic status Black women still had significantly higher BC -specific and overall mortality rates compared to White counterparts.[34] These findings are in connection with other substantial data that report lower mammography use among women living in lower-income residential areas among the general population.[35,36]While there is compelling evidence for the role of socioeconomic status in BC disease morbidity/mortality, only a few studies have investigated area-levels of socioeconomic status on surveillance mammography among BC survivors, and have comparable results to ours.[29,30] The interaction that was found between race and residence in this study brings up new evidence and provides new insight on potential surveillance barriers within place of residence, such as transportation. Transportation was cited as a barrier to surveillance mammography in our online-focus groups. Prior studies also commonly reported transportation as a barrier to mammography screening among racial ethnic groups of women, but most of these data were among women without a history of BC.[37,38] The residential area finding deserves a deeper investigation to uncover access dynamics within specific geographic areas and structural barriers, such as systemic racism within Black survivors living environment. Moreover, the race-residence

effect raises an important issue in cancer survivorship regarding racial disparities in the neighborhood and built environment within the U.S.

Health care access was a key theme found in online focus groups and secondary analyses. Women commonly reported medical cost as a barrier for surveillance mammography in online focus groups. Similarly, secondary analyses indicated that health insurance coverage and access to see a doctor significantly predicted adherence to surveillance mammography. While health care access (e.g., access to see a doctor) was no longer significant when included in our multivariable model, that does not limit the importance of this enabling factor on adherence to surveillance mammography guidelines. For example, there is consistent research that support the association between the lack of health care access with lower mammography screening rates.[28 39,40 29,41,42] Prior work also suggest health care access factors (e.g., insurance type) are top barriers for Black women compared to White women, which contribute to Black women's poor mammographic surveillance rates.[8,18,43,44,45]There are several reasons why health care access diminished in multivariable results. Majority of women in the analytical sample were older, White, insured, retired from work, and were adherent to routine check-up. Given the wide range of access factors within health care, there is a further need to measure other access factors, such as the impact of having health care access over time, to address underinsured, low-income and uninsured survivors access related issues that relate to surveillance mammography.

Survivor years and surgery type were important need factors found in the current study. Concordant with prior studies women who underwent mastectomy compared to lumpectomy surgery were less likely to be adherent to surveillance mammography guidelines.[41,46,47] For the second need factor, women who were diagnosed $\leq$5 years vs. >5 years were more adherent to surveillance mammography guidelines. Study findings are consistent with prior research that

indicate short-term survivors are more likely to be adherent to surveillance mammography guidelines, when compared to long-term survivors no matter the time point definition.[41,46,48,49] There are several explanations for non-adherence to surveillance mammography, with regards to longer time elapsed from a BC diagnosis. Research suggest that short-term BC survivors have varying levels of intentions for screening vs. long-term survivors. [48] Another explanation may have been due to regular physical exams which, was found as a facilitator from our online focus groups. Other reports suggest that life-expectancy, enhanced provider-communication and provider recommendation play a big role in survivors surveillance decisions. [50,51]Taken together the consistent findings for longer time elapsed from diagnosis on non-adherence to surveillance mammography, future interventions should target survivors diagnosed >1 year.

Patient-centered communication is an important enabling factor in cancer care delivery care. [52-54] Research indicates that having adequate communication and coordination between patients and providers, [25,55-58] is linked with better clinical outcomes and healthcare experiences among BC survivors.[29,41] For example, a study reported that frequent visits with a primary care physician before BC diagnosis predicted the use of mammography and improved breast cancer outcomes. Reports also suggest when compared to White counterparts' Black patients are more likely to have lower patient-provider communication and participation in their care; however it is unknown whether racial differences exist during the surveillance period.[59] To fill this gap we investigated racial differences in provider communication as research supports higher ratings of provider communication has shown to improve adherence related behaviors (e.g., adjuvant treatment, mammography screening).[42] In the current study a joint association between race and patient-provider communication significantly influenced adherence. Specifically, Black women with lower ratings of communication with their providers had lower adherence compared to their White

counterparts. This is a new finding regarding surveillance mammography. Our results are consistent with earlier studies that found racial variations in provider communication levels. [60]Potential explanations for this finding may result from survivors feeling ignored form their providers, which was a commonly reported barrier in online-focus groups. This finding calls for more clinical interventions to support patient-centered provider communication and interaction to enhance surveillance mammography adherence among racial/ethnic minority survivors.

Strengths, Limitations and Future Directions

This study has numerous strengths. First, this study uses a multifaced framework to guide selection of influential factors on adherence to surveillance mammography. Most studies lack a comprehensive theoretical framework to contextualize surveillance related behaviors, such as mammography.[49,50,61,62] Secondly, the mixed method approach utilized a variety of data sources (e.g., surveys, online-focus groups), which provided a robust examination to better understand surveillance behaviors among survivors. Another strength was the online recruitment approach to engage with BC survivors from racial/ethnic diverse groups. With the rise of technological advancements, social media platforms serve as optimal opportunities to rapidly reach and engage larger populations. [63,64] The online approach exceeded study expectations and proved that even during a historic pandemic, women are accessible to reach through online engagement. Lastly, findings identified modifiable predictors (e.g., beliefs, patient-provider communication) that can help to mitigate non-adherence rates to surveillance mammography among Black BC survivors.

While there are several strengths, there are limitations to note. Analyses was limited to Black and White women across three datasets, which limited our interpretation for other racial/ethnic groups of women. Thus, findings from this study are not generalizable to all BC survivors. Another limitation is around the adherence measurement. This study measured adherence as yes vs. no to

meeting ASCO/NCCN nationally recommended surveillance mammography guidelines. This measurement does not fully capture factors that may influence women who delay their surveillance mammogram due to health service delays, inability to pay, lack of transportation etc. Lastly, while this study solely focused on surveillance mammography, (the highest recommendation for early stage detection), triple negative breast cancer (TNBC) subtypes are more challenging to detect mammographically compared to non-TNBC.[65] Considering Black women are more likely to present with TNBC subtypes there is a need for an improved evaluation of breast surveillance guidelines (e.g., MRI) specifically for this group.[66,67]

This study provides multiple points of future directions within cancer survivorship research. Breast surveillance guidelines encompass more than mammography screening, future works should focus on receipt to other guidelines such as, clinical follow-up visits and chest-wall exams, to help narrow down priority groups. More research is needed to better understand the impact of late effects from BC treatment such as lymphedema and other side effects, that may influence adherence to surveillance guidelines. Because Black women are more likely to have more health care barriers throughout their continuum of care compared to White women, [4,8,18,43,44,68] a better understanding of Black survivor's management of late effects are needed in the literature. Future studies should also capture other measures of adherence to surveillance mammography such as, group-based trajectories and longitudinal measures to fully understand optimal points of intervention for non-adherence among BC survivors. This study helped to identify the role of socioeconomic disparities and health care system factors driving role in surveillance mammography racial disparities. Interventions are needed to enhance patient-centered communication following treatment, during the enhanced time for breast surveillance guidelines. Future work should also focus their interventions within disadvantaged groups of Black women

living in lower income residentials areas, to help address current disparities. More research is also needed for a better evaluation of other important risk factors for late-stage diagnosis in BC survivors. Knowing risk factors for late-stage diagnosis is critical and may help equalize disparities in BC morbidity and survival outcomes among Black BC survivors. [69] There is also a need for a comprehensive evaluation of surveillance guidelines and cancer care delivery models during the survivorship phase, to help identify structural barriers such as, financial barriers, systemic racism within the delivery system, and other missed opportunities to address cancer health disparities.[70] Lastly, more research should partner with breast health advocates to refine and enhance engagement of survivors, to optimize targeted intervention development to improve surveillance. [7,45]

Implications for Clinical Practice

This study provides robust implications for cancer prevention and control practice. There are several national level cancer screening programs such as CDC National Breast and Cervical Early Detection that have effectively improved mammography screening rates among low-income, uninsured and underinsured women;[71] and yet none of these programs have been adapted for BC survivors. Expanded funding and implementation of these navigation programs are needed among BC survivors to increase adherence to routine mammography screening.[71] Incorporating individualized screening criteria's within a primary care delivery model may encourage organizational navigation and promotion of breast surveillance guidelines for patients with a history of BC. This individualized screening system should also be developed through community and advocacy partnerships to build community trust within the delivery system. Policy expansion in health insurance coverage plans is also warranted to reduce health care access barriers in the receipt of surveillance mammography, among BC survivors. Expansion in health insurance

coverage plans should consider all breast surveillance and testing guidelines for new and recurrent disease, such as MRI. Given that breast cancer is often detected by a woman initially and later confirmed through biopsy; in a scenario where a woman with a BC history has already received her mammogram and discovers a new lump within the same year, there should be no financial barriers or additional cost or delay for patients to receive multiple surveillance. Such consideration may help to reduce access barriers and can translate to refining the current surveillance guidelines developed by NCCN and ASCO. Specifically, revising breast surveillance guidelines to better detect TNBC subtypes will aid in improving early-stage detection among Black BC Survivors diagnosed with TNBC. [65]Results from this study also introduced new strategies to engage BC survivors in research through social media. With the rise of technological advancements, social media is often a preferred tool to seek health-information. In the context of cancer survivorship, the use of social media (e.g., cancer blogs, support groups) is commonly used as an online community for BC survivors.[72] Moreover, this presents an optimal opportunity to leverage communication through social media-based technology for future survivor navigation interventions. Utilizing emerging health technologies and social media may enhance survivorship delivery outreach and engagement to help facilitate wider dissemination of BC survivorship materials and behavioral interventions.

Conclusion

Non-adherence to recommended surveillance mammography is a risk factor for late-stage detection of new and recurrent disease and cancer-related death among BC survivors. This was the first mixed method approach to examine racial disparities in adherence to surveillance mammography among Black and White BC survivors. Results from this study help to fill gaps in research to explain surveillance disparities. First, we identified modifiable predictors (e.g., beliefs,

patient-provider communication) of non-adherence, that should be considered to mitigate the poor rates of surveillance mammography among Black BC survivors. Secondly, this study captured multiple relationships (e.g., healthcare delivery and psychosocial) with adherence to surveillance mammography, which provided new insight on socioeconomic disparities in cancer care delivery during the surveillance period. Finding also offer evidence that support the use of community and social media as a tool for engaging BC survivors in research, which may aid in tackling health inequities among Black BC survivors via community collaborations and novel communication strategies.

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APPENDICIES

APPENDIX 1

Greetings,

My name is Megan Edmonds and I am a Social and Behavioral Health doctoral student at Virginia Commonwealth University in Richmond, VA. Breast cancer survivorship and addressing cancer disparities has been a focal point of my research experiences in graduate school. Currently, I am recruiting Black and White breast cancer survivors who have completed definitive treatment to participate in an online research study "Y-WE SURVIVE". The study will consist of a >10 minute survey assessing participants' experiences barriers with obtaining mammography screenings. There is also online discussions you can participate in for further discussion about this topic. The goal of the project is to expand knowledge around women's barriers, attitudes and beliefs on adhering to mammography screening and follow up care.

Description: Y-WE SURVIVE is seeking Black and White breast cancer survivors who and are willing to participate in a study examining the attitudes, beliefs and barriers of adhering to routine mammography screenings.

Time: Participants will be asked to complete a >10-minute questionnaire
Exploring their attitudes, beliefs, and demographic factors

Screening: To determine eligibility, participants must identify as a black or white female, ≥21 years old or older, have been diagnosed with breast cancer, and have completed breast cancer treatment.

Sign Up: To enroll in the study, please go the survey link:
https://qtrial2019q1az1.qualtrics.com/jfe/form/SV_a2CU3v8tasNzN2d
If eligible, you will be then directed to the main study survey. Before starting the survey, participants will be given more information about the research study via the information sheet.

If you have any questions or would like any additional information, please contact me at edmondsm2@vcu.

Best,

Megan Edmonds, MPH
Doctoral Student
Virginia Commonwealth University

APPENDIX 2

Online Focus Group
Moderator Guide

Barriers→ Adherence Behavior

Please Note: Regarding comments on this post, researchers at Virginia Commonwealth University will use your comments below for RESEARCH purposes to learn about breast cancer survivors views on the mammography screening and follow-up care. By commenting on this post, you are giving permission to have your responses used in the research study. If you do not wish to be included in the research, do not comment on this post. Leaving comments and participating is completely voluntary, and we will NOT collect your name or any other identifying information. If you want to share your thoughts, experiences, and concerns anonymously, click "" to go to our online survey. Your responses will be kept confidential with researchers at Virginia Commonwealth University.

Questions about this project can be directed to:

Megan Edmonds, MPH
Doctoral Student
(edmondsm2@vcu.edu) 804-453-8210

Sunny Jung Kim, PhD
Assistant Professor
(Sun.Jung.Kim@vcuhealth.org)

Breast cancer survivors! We'd like to understand your thoughts about routine screening after breast-conserving surgery/treatment. Please respond if you are ≥21 and have been diagnosed with breast cancer and completed definitive treatment

Intro: Adherence to mammography screening in breast cancer survivors may reduce late diagnosis of secondary cancers; however, some women may underutilize recommended screening guidelines. We often hear that breast cancer survivors experience a range of barriers that prevent them from following and adhering to suggested guidelines. To better promote this preventative health behavior in survivors specifically, we'd like to conduct a research study to further understand the drivers ("facilitators) and barriers for why women of all racial/ethnic backgrounds do not adhere to follow-up regimens and related information.

Breast Surveillance Guidelines: If you had breast-conserving surgery or mastectomy, it is recommended that you get a physical examination 6 months posttreatment (e.g., surgery, radiation), and a mammogram 12 months then yearly thereafter. It is also recommended that survivors perform monthly breast self-examinations, and a physical examination (clinical breast self-examination [every 3 to 6 months for 3 years, then every 6 to 12 months for the next 2 years, then annually].

Highlighted text were the actual questions posted on virtual platforms

ASCO Surveillance Guidelines	
Recommendation: History and physical	
(a) individualize clinical follow-up care based detailed cancer-related history on age, specific diagnosis, and treatment protocol as recommended by the treating oncology team	✓ Physical examination ✓ Every 3-6 post-treatment for first 3 years ✓ Every 6-12 ✓ Annually thereafter
Recommendation: Screening breast for local recurrence or a new primary breast cancer	
(a) Should refer women who have received a unilateral mastectomy for annual mammography on the intact breast and for those with lumpectomies an annual mammography of both breasts	✓ Mammography
(b) Should not refer for routine screening with MRI of the breast unless the patient meets high risk	✓ MRI

American Society of Clinical Oncology (ASCO)

Parent Focus Group Post 1)

- What comes to mind when you think about breast surveillance guidelines following breast cancer treatment?
    - *PROBE: Were you aware of these guidelines?*
    - *PROBE: Are there any barriers or concerns you have face that delayed you from screening?*
    - *PROBE: Are there any key emotions about follow-up care (physical exams, mammograms) you wish to share?*
- Do you receive routine yearly mammograms?
    - *PROBE: If not what prevents you?*
    - *Were there any barriers to prevent you from receiving your screening within your first-year after completion of treatment? What obstacles or constraints would make it challenging to meet this recommendation?*
- Did you receive a physical examination (clinical breast exam) within 3-6 months after completing treatment?
    - *PROBE: If not, why not?*
- Do you perform monthly breast self-examination?
    - PROBE: If not why not?

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Sunny Jung Kim, PhD
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Literature: It is important to communicate with your oncologist or primary doctors during and after breast cancer treatment surgery and/or radiation). Higher satisfactory levels in a patient provider communication involves a woman's needs, values, and preferences. Benefits from adequate patient provider communication are characterized by higher participation in care, more effective discussions about prognosis, and symptom management.

Parent Focus Group Post 2)

Where have you received information about breast cancer surveillance guidelines (mammogram, MRI)?

- *PROBE: If you haven't received information, where would you like to receive information regarding your breast cancer surveillance guidelines (e.g., screening and follow-up exams)?*
- *PROBE: Describe what type of information you would like to receive regarding your survivorship care?*
- *PROBE: What format would you like to get this information (e.g., text, email, phone call?)*

- What were your concerns post-breast cancer treatment?
- Describe the communication barriers between you and your oncologist or primary care physician about your survivorship care needs?
  - *PROBE: Do you prefer to visit your oncologist or your primary care provider to discuss your survivorship care needs?*
  - *PROBE: Do you discuss your values and preferences related to your care to your oncologist and/or primary care provider?*
  - *PROBE: Do any barriers come to mind when you think of engaging with your oncologist or primary doctors to discuss follow-up recommendations such as breast imaging screening?*

Facilitators→ Adherence Behavior

Please Note: Regarding comments on this post, researchers at Virginia Commonwealth University will use your comments below for RESEARCH purposes to learn about breast cancer survivors views on the mammography screening and follow-up care. By commenting on this post, you are giving permission to have your responses used in the research study. If you do not wish to be included in the research, do not comment on this post. Leaving comments and participating is completely voluntary, and we will NOT collect your name or any other identifying information. If you want to share your thoughts, experiences, and concerns anonymously, click "" to go to our online survey. Your responses will be kept confidential with researchers at Virginia Commonwealth University.

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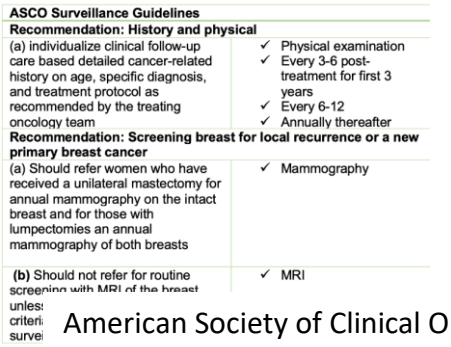
Sunny Jung Kim, PhD
Assistant Professor
(Sun.Jung.Kim@vcuhealth.org)

Adherence to follow-up regimens is key for better breast cancer treatment outcomes. We often hear that some breast cancer survivors do an excellent job on tracking and following up with the recommendations. We'd like to understand what motivates them to adhere to the recommended regimens.

Breast Surveillance Guidelines: If you had breast-conserving surgery or mastectomy, it is recommended that you get a physical examination 6 months posttreatment (e.g., surgery, radiation), and a mammogram 12 months then yearly thereafter. It is also recommended that survivors perform monthly breast self-examinations, and a physical examination (clinical breast self-examination [every 3 to 6 months for 3 years, then every 6 to 12 months for the next 2 years, then annually].



ASCO Surveillance Guidelines	
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Recommendation: Screening breast for local recurrence or a new primary breast cancer	
(a) Should refer women who have received a unilateral mastectomy for annual mammography on the intact breast and for those with lumpectomies an annual mammography of both breasts	✓ Mammography
(b) Should not refer for routine screening with MRI of the breast unless criteri surve	✓ MRI

American Society of Clinical Oncology (ASCO)

Parent Focus group 3)

- What motivates you to perform annual follow-up mammography screening?
  - *PROBE: What/who helps support your plans to get screened?*
  - *PROBE: Are you reminded to perform your screening annually?*
  - *PROBE: What helps relax you when you receive a mammogram?*
  - *PROBE: Do you follow annual breast imaging guidelines mentioned above?*

- What motivates you to follow up with physical examination guidelines mentioned above?
  - *PROBE: What/who helps support your plans to get screened?*
  - *PROBE: Are you reminded to perform your screening annually?*
  - *PROBE: What helps relax you when you receive a mammogram?*
  -
- What motivates you to perform self-breast exams?
  - *PROBE: Can you describe how often you do these?*
  - *PROBE: Who taught you how to perform a self-breast exam?*

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Parent Focus Group 4)

- Are you motivated to engage in detailed discussion with your oncologist/primary doctor?
    - *PROBE: What supports this motivation for you?*
    - *PROBE: Who do you prefer to keep in contact with about your remission concerns?*
- Describe what helps you adhere to your annual mammogram and follow-up visit with your provider?
    - *PROBE: What supports your engagement with your oncologist or primary doctor?*
      PROBE: Would you prefer a reminder text, call, or email about your mammogram appointment?
- Describe what information is helpful your oncologist/primary care provider give you?
    - *PROBE: What resources are supportive to your care needs?*

APPENDIX 3

Priority Factors in Surveillance Mammography

Survey Flow

Standard: Block 1 (1 Question)
Block: clinical questions (54 Questions)

Page Break

Start of Block: Block 1

Q41 **VCU IRB NO: HM20015818 Y-WE SURVIVE BREAST CANCER RESEARCH PROJECT INFORMATION SHEET**

PURPOSE OF THE STUDY

This research project is being conducted by PhD Candidate Megan Edmonds from Virginia Commonwealth University in Richmond, VA. The purpose of this study is to explore attitudes and beliefs on adherence to surveillance mammography and follow up care among breast cancer survivors. You are being asked to participate in this study because you identify as woman, ≥21 years old or older, been diagnosed with breast cancer and completed primary surgery.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you agree to participate in this online survey, you will be asked questions about your demographics and breast cancer follow-up experience. We ask that you read our survey questions and provide your responses/comment(s). We expect this survey to take less than 20 minutes. The survey records will be kept **confidential and secure**. Your name and contact information will not be used in any presentation or paper written about the study results. All digital data will be destroyed when their use is no longer needed but not before a minimum of five years after data collection.

VOLUNTARILY PARTICIPATION

Your participation in this study is completely voluntarily. The information we learn by your participation may help us to better inform programs for breast cancer survivors' women adherence to routine screening post breast cancer diagnosis.

Compensation

Participation in this study includes an electronic gift card. If you wish to receive the gift card please read at the end of the survey and click the link to provide your email address, that you would like the gift card sent to.

Questions about this project can be directed to:

Megan Edmonds, MPH PhD Candidate
edmondsm2@vcu.edu

Vanessa Sheppard, PhD Associate Professor
Vanessa.Sheppard@vcuhealth.org

The study staff named above is the best persons to call for questions about your participation in this study.

Clicking “Next” to begin the study indicates your consent to participate in this study. You may print a copy of this information for your records.

End of Block: Block 1

Start of Block: clinical questions

Have you been diagnosed with breast cancer?

- ○ Yes (1)
- ○ No (2)

Skip To: End of Survey If breast = 2

sex What is your sex?

- ○ Male (1)
- ○ Female (2)

Skip To: End of Survey If sex = 1

X→

Years since diagnosed?

- ○ less than 1 year (1)
- ○ 1-2 years (2)
- ○ 3-4 years (3)
- ○ 5 years (4)
- ○ More than 5 years (5)

What stage were you diagnosed?

- ○ 0 (1)
- ○ I-II (2)
- ○ III-IV (3)

Did you complete your breast cancer surgery?

- ○ Yes (1)
- ○ No (2)

Skip To: surgery_type If finished_treatment = 1

Which breast surgical treatment did you have?

- ○ Lumpectomy (1)
- ○ Mastectomy (2)
- ○ OTHER (SPECIFY) (3) _____

Did you complete Chemotherapy?

- ○ Yes (1)
- ○ No (2)

Did you complete Radiation?

- ○ Yes (1)
- ○ No (2)

Did you complete Hormonal Therapy?

- ○ Yes (1)
- ○ No (2)

Years since end of treatment?

- ○ Less than a year (1)
- ○ 1-2 years (2)
- ○ 3-4 years (3)
- ○ 5 years (4)
- ○ More than 5 years (5)

Are you currently being treated for cancer- that is, are you actively receiving chemotherapy, radiation, or hormonal therapy for your cancer?

- ☐ Yes (1)
- ☐ No (2)

Page Break

Which one of these groups would you say best represents your race?

- White (1)
- Black or African American (2)
- American Indian or Alaska Native (3)
- Asian (4)
- Native Hawaiian or Pacific Islander (5)
- Other (6)

Thinking about members of your family living in this household, what is your combined annual income, meaning the total pre-tax income from all sources earned, in the past year?

- Less than $10,000 (1)
- $10,000 to under $15,000 (2)
- $15,000 to under $20,000 (4)
- $20,000 to under $35,000 (5)
- $35,000 to under $50,000 (6)
- $50,000 to under $75,000 (7)
- $75,000 to under $100,000 (8)
- $100,000 to under $200,000 (9)
- $200,000 or more (10)

What is your current occupational status? Please mark all that apply.

- ○ Employed (1)
- ○ Unemployed (2)
- ○ Homemaker (3)
- ○ Student (4)
- ○ Retired (5)
- ○ Disabled (6)
- ○ OTHER (please describe) (7) _____

What is your five-digit residential ZIP CODE (Enter number only. e.g., 23981)

_____

What is your age? (Enter a whole number between 18 and 110).

_____

Please tell me which situation from the list best describes your marital status?

- ○ Married or living as married (1)
- ○ Divorced (2)
- ○ Separated (3)
- ○ Widowed (4)
- ○ Single (never married) (5)
- ○ OTHER (SPECIFY) (6) _____
- ○ DON'T KNOW/UNSURE (7)

What is the highest grade or year of school you completed?

- ○ Less than 1st grade (1)
- ○ Grades 1 through 8 (elementary) (2)
- ○ Grades 9 through 11 (some high school) (3)
- ○ Grade 12 or GED (high school graduate) (4)
- ○ Some college but no degree (5)
- ○ Diploma or certificate from a vocational technical, trade or business school beyond high school level (6)
- ○ Associate degree in college-Occupational/vocational program (7)
- ○ Associate degree in college- Academic program (8)
- ○ Bachelors degree (For example: BA, AB, BS) (9)
- ○ Master's degree (10)
- ○ Professional School degree (For example MD, DDS, DVM, LLB, JD) (11)
- ○ Doctorate degree (For example: PhD, EdD (12)
- ○ OTHER (SPECIFY) (13) _____
- ○ DON'T KNOW/UNSURE (14)

Were you born in the United States?

- ○ Yes, inside of the United States (1)
- ○ No, outside of the United States (write in name of country) (2) _____

Do you currently have health insurance coverage?

- ○ Yes (1)
- ○ No (2)

Skip To: insurance_type If health_insurance = 1

Skip To: surveillance If health_insurance = 2

What type of health insurance do you have?

- ○ Public (1)
- ○ Private (2)

Page Break

X→

In the last year (12 months) have you had a? (Check all that apply)

- ☐ Mammogram (1)
- ☐ MRI (2)
- ☐ CT Scan (3)
- ☐ Breast self examination (4)
- ☐ Physical Exam (5)

Display This Question:

If surveillance = 1

And surveillance = 2

And surveillance = 3

And surveillance = 4

And surveillance = 5

How often do you have what you selected in the previous question?

- ☐ Every 3-6 months (1)
- ☐ Every 6 months (2)
- ☐ Every 12 months (3)
- ☐ OTHER (SPECIFY) (5) _____

Skip To: Knowledge If surveillance_freq = 1

Are you aware of what breast surveillance guidelines you need to follow ?

- ○ Yes (1)
- ○ No (2)
- ○ Other (3) _____

How would you rate your knowledge regarding breast cancer surveillance recommendations for breast cancer survivors in general?

- ○ Very High (1)
- ○ High (2)
- ○ Low (3)
- ○ Very Low (4)

Where have you received information about breast cancer surveillance guidelines (mammogram, MRI)? (Click all that apply)

- ☐ Oncologist (1)
- ☐ Primary care provider (2)
- ☐ Family and friends (3)
- ☐ Newspaper/magazines (4)
- ☐ Radio/TV (5)
- ☐ Online cancer information sources (American Cancer Society, National Cancer Institute) (6)
- ☐ Online support groups (Facebook Groups for breast cancer survivors) (7)
- ☐ OTHER (please specify) (8)

_____

- ☐ Not received any information (9)

Skip To: Knowledge If surv_Information = 8

Please rate your preference of how you would like to receive information regarding your breast cancer surveillance guidelines (e.g., screening, follow-up exams) (Please rank your preference)

_____ Face to Face from Medical professional (4)
_____ Video Conferencing from Medical professional (6)
_____ Phone call (7)
_____ Email (8)
_____ Text message (9)
_____ Mobile app (10)
_____ OTHER (11)

Did your doctor or any healthcare provider discuss with you the need for regular follow-up care and monitoring after completing your treatment?

- ○ Discussed it with me in detail (1)
- ○ Briefly discussed it with me (2)
- ○ Did not discuss it at all (3)
- ○ I don't remember (4)

Following your breast cancer treatment when was your next follow-up visit?

- ○ Less than 6 months (1)
- ○ 6 months (2)
- ○ Less than 12 months (3)
- ○ 12 months (4)
- ○ OTHER (SPECIFY) (5) _____

Have you ever delayed a mammogram or follow-up visit with your doctor until you were able to obtain insurance/benefits?

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Page Break

Have anyone in your family been diagnosed with breast cancer?

- ○ Yes (1)
- ○ No (2)

Skip To: Q15 If family_BC = 1

Please specify your relation to the relative (e.g.,mother, grandmother)

_____

Did you have the social support you needed after completion of breast cancer treatment to guide you with your follow-up care?

- ○ Yes (1)
- ○ No (2)

Please elaborate what might have got in the way with your follow-up care (e.g., depression, stress, racial discrimination or racism in medical establishment)

_____

Have you ever felt like a doctor or nurse was not listening to what you were saying

- ○ Yes (1)
- ○ No (2)
- ○ If yes, please describe your experience (3)

_____

Of the persons listed, with whom did you prefer to discuss your follow-up care after completing treatment with the most?

- ○ Surgeon (1)
- ○ Medical Oncologist (2)
- ○ Oncology Nurse (3)
- ○ OTHER (4) _____

Rate your communication with (person from above) on a scale of 0-10, ten being the highest level of communication (for example frequency and depth of conversation)

- ○ 1 (1)
- ○ 2 (2)
- ○ 3 (3)
- ○ 4 (4)
- ○ 5 (5)
- ○ 6 (6)
- ○ 7 (7)
- ○ 8 (8)
- ○ 9 (9)
- ○ 10 (10)

Rate your overall trust with (person form above) on a scale of 0-10, ten being the highest level of trust

- ○ 1 (1)
- ○ 2 (2)
- ○ 3 (3)
- ○ 4 (4)
- ○ 5 (5)
- ○ 6 (6)
- ○ 7 (7)
- ○ 8 (8)
- ○ 9 (9)
- ○ 10 (10)

How likely is it that 'Having a mammogram would help me find a breast cancer recurrence early'?

- ○ Very Likely (1)
- ○ Likely (2)
- ○ Unlikely (4)
- ○ Very Unlikely (5)

How likely is it that 'Having a mammogram could help me find another breast lump before it is big enough to feel'?

- ○ Very Likely (1)
- ○ Likely (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

How likely is it that 'Having a mammogram will decrease my chances of dying from breast cancer'?

- ○ Very Likely (1)
- ○ Likely (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

How likely is it that 'Getting a mammogram would be inconvenient for me'?

- ○ Very Likely (1)
- ○ Likely (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

How likely is it that 'I would not get a mammogram because my doctor already examines my breasts'?

- ○ Very Likely (1)
- ○ Likely (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

How likely is that 'Being afraid of finding another breast lump would keep me from having a mammogram'?

- ○ Very Likely (1)
- ○ Likely (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

How likely is it that 'Not being able to afford a mammogram would keep me from having one'?

- ○ Very Likely (1)
- ○ Likely (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

How likely is it that 'Other health problems would keep me from having a mammogram'?

- ○ Very Likely (1)
- ○ Likely (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

How likely is it that 'I will not have time to have a mammogram'?

- ○ Very Likley (1)
- ○ Likley (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

How likely is it that 'Worrying about a recurrence would keep me from having a mammogram'?

- ○ Very Likely (1)
- ○ Likely (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

How likely is that 'I find it difficult to remember to make an appointment for a mammogram'?

- ○ Very Unlikely (1)
- ○ Likely (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

How likely is it that 'Forgetting my appointment would keep me from getting a mammogram'?

- ○ Very Likely (1)
- ○ Likely (2)
- ○ Unlikely (3)
- ○ Very Unlikely (4)

Have you or your family had to make any kinds of financial sacrifices because of your cancer, your treatment, or the lasting effects of that treatment?

- ○ Yes (1)
- ○ No (2)
- ○ If yes, please describe your financial experiences (4)

_____

Skip To: Q58 If financial_burden = 1

What information did your oncologist or cancer provider share with you about your follow-up care?

_____

_____

_____

_____

_____

Please describe your experience with barriers such as (e.g., transportation, fear, trust, stress, waiting time) with receiving a mammogram or visiting your provider? There is no right or wrong answers, just your opinion.

_____

_____

_____

_____

_____

The following questions are about your follow-up care doctor. Please tell us if your follow-up care doctor has offered the following suggestions, as well as your concerns with follow-up care.

	Yes (1)	No (2)
Has your follow-up care doctor educated and counseled you about the signs and symptoms of breast cancer recurrence? (7)	○	○
Have you ever been concern about your cancer diagnosis impact on your health insurance (8)	○	○
Is time availability and busyness (i.e. work, schedule, family life, etc.) a concern for your follow-up care (9)	○	○
If you are suspected of potential hereditary risk factors, has your follow-up care doctor offered genetic counseling? (10)	○	○
Has your follow-up care doctor counseled you on how to prevent/reduce the risk of lymphedema? (Lymphedema refers to swelling that generally occurs in one of your arms or legs.) (11)	○	○
Do you ever fear the results of your annual exams or follow-up physician visits (12)	○	○
Is your religion/spirituality such as prayer a source of support for you with your follow-up care? (14)	○	○
Has your follow-up care doctor educated you on potential cardiac risk factors, and when to report relevant symptoms? (15)	○	○
Has your follow-up care doctor assessed you for distress, depression and/or anxiety? (16)	○	○

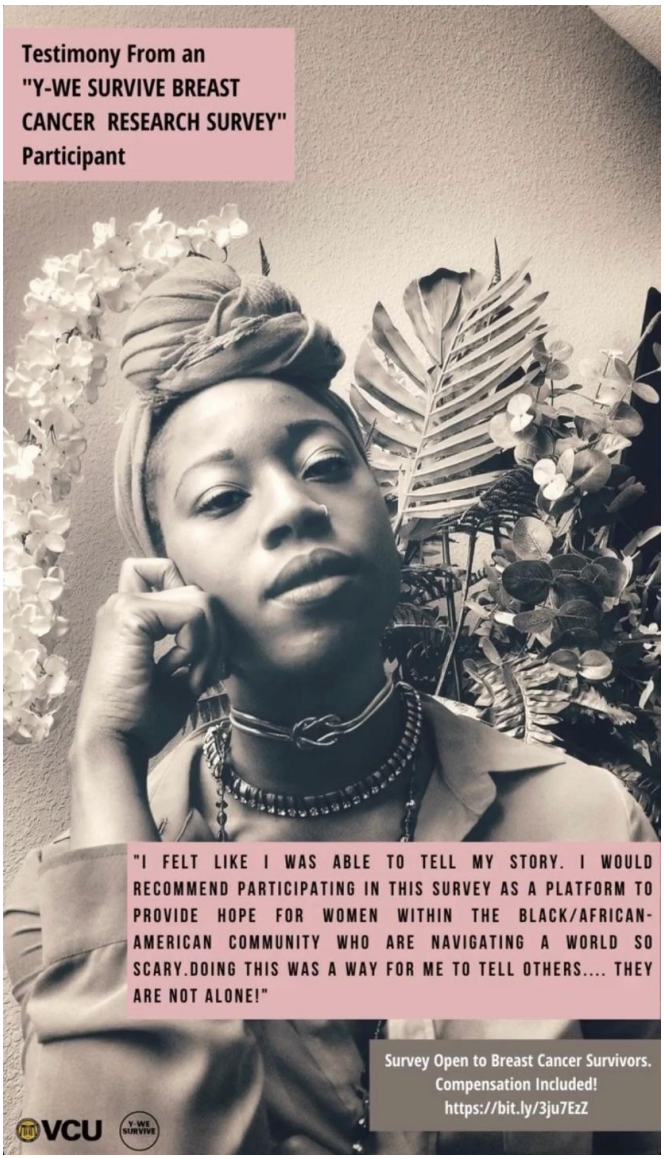
Has your follow-up care doctor asked you about your symptoms to assess for musculoskeletal symptoms, including pain? (18)	○	○
Has your follow-up care doctor assessed you for body image/appearance concerns and offered the option of adaptive devices (e.g. breast prostheses, wigs)? (19)	○	○
Has your follow-up care doctor assessed your information needs related to breast cancer and its treatment, side effects, other health concerns and available support services? (17)	○	○

End of Block: clinical questions

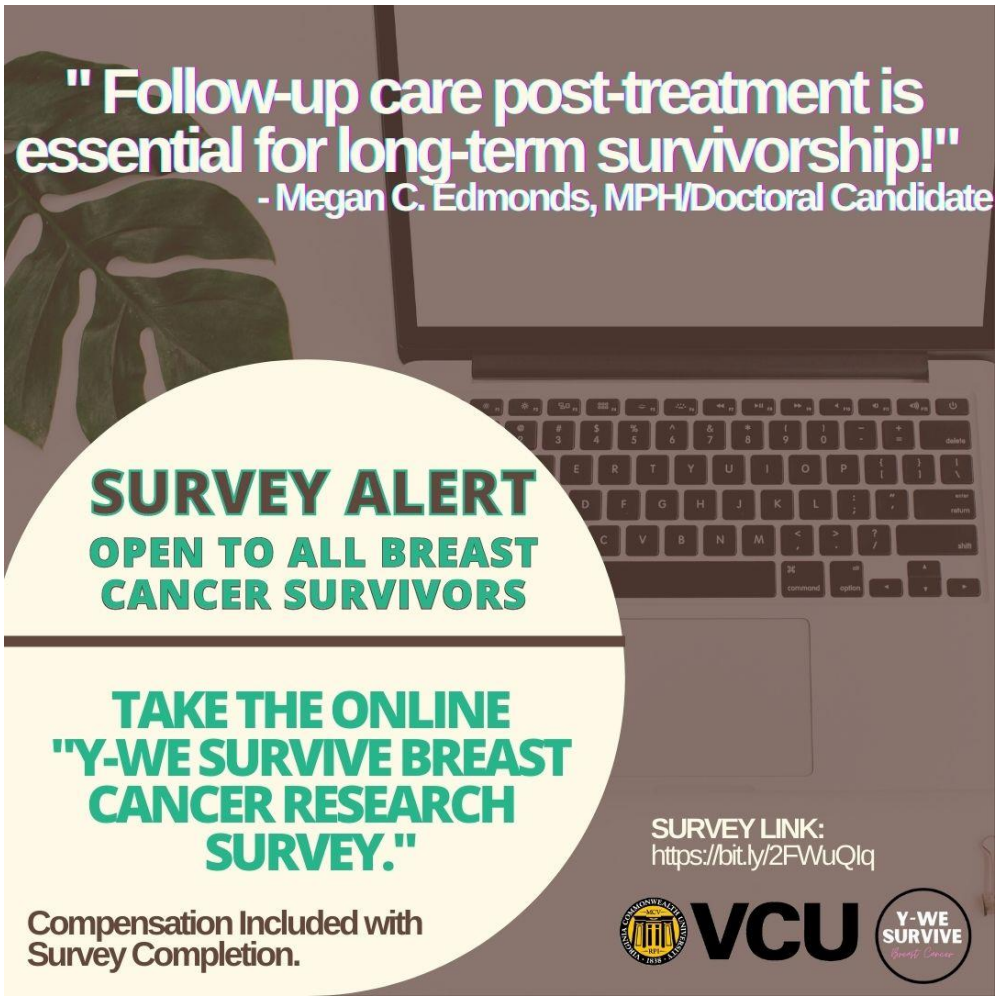
APPENDIX 4

Study Ad 1

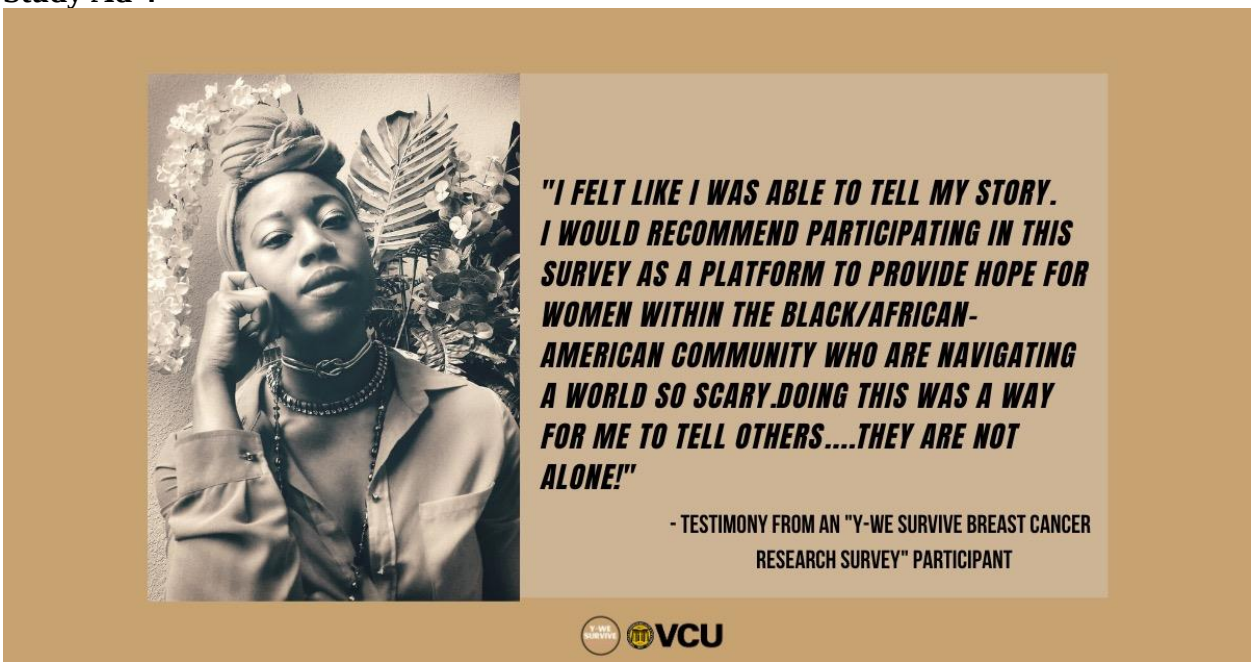
Study Ad 2


Testimony From an
"Y-WE SURVIVE BREAST
CANCER RESEARCH SURVEY"
Participant
"I FELT LIKE I WAS ABLE TO TELL MY STORY. I WOULD RECOMMEND PARTICIPATING IN THIS SURVEY AS A PLATFORM TO PROVIDE HOPE FOR WOMEN WITHIN THE BLACK/AFRICAN-AMERICAN COMMUNITY WHO ARE NAVIGATING A WORLD SO SCARY.DOING THIS WAS A WAY FOR ME TO TELL OTHERS.... THEY ARE NOT ALONE!"
Survey Open to Breast Cancer Survivors.
Compensation Included!
https://bit.ly/3ju7EzZ
VCU
Y-WE SURVIVE

Study Ad 3



Study Ad 4



Study Ad 5

Vita

Megan Christina Edmonds was born on December 25, 1991 in Dayton, Ohio. Megan graduated from Stivers School for the Arts in Dayton, Ohio in 2010. As a graduating senior in high school Megan was awarded the Gates Millennium Scholarship, which has covered all of her tuition and fees for all of her degrees. She received her Bachelor of Arts in Psychology from Spelman College and her Master of Public Health from the University of Michigan with a concentration in Health Behavior and Health Education. Following her Master of Public Health, she pursued her PhD at Virginia Commonwealth School of Medicine. During her years of doctoral training, she has published research articles in health disparities and cancer survivorship journals, presented her research at numerous national level conferences. Just recently she was awarded an NCI Geographic Management of Cancer health Disparities Program Region 1 grant to examine racial disparities in breast cancer survivor's follow-up care, which helped to support the primary data collection of her dissertation. From this work she intends to continue to support efforts to improve the quality of follow-up care among breast cancer survivors.

Peer-Reviewed Publications

1. **Edmonds MC**, Sutton AL, He J, Perera RA, Sheppard VB. Correlates of Adjuvant Therapy Attitudes in African American Breast Cancer Patients [published online ahead of print, 2020 Mar 17]. *J Natl Med Assoc*. 2020;S0027-9684(20)30030-4. doi:10.1016/j.jnma.2020.02.006
2. Sutton, A.L., He, J., Tanner, E., **Edmonds, M.C.,** Henderson, A., Hurtado de Mendoza, A., & Sheppard, V.B. (2019). Understanding medical mistrust in Black women at risk of BRCA 1/2 mutations. Journal of Health Disparities Research and Practice.
3. Sheppard, V.B, Jun, H, Sutton, A, Cromwell, L, Adunulin, G, Salgado, T, Tolsma, D, Trout, M, Robinson, B, **Edmonds, M.C.,** Bosworth, H, Tadesse, M. Adherence to Adjuvant Endocrine Therapy in Insured Black and White Breast Cancer Survivors: Exploring Adherence Measures to Patient Data. Journal of Managed Care & Specialty Pharmacy 2018.
4. Sutton A, Jun H, **Edmonds, M.C.,** Sheppard V.B. Medical Mistrust in Black Breast Cancer Patients: Acknowledging the Roles of the Trustor and Trustee. J Cancer Educ, 2018
5. Sheppard, V .B, deMendoza, A.H, He,J, Jennings, Y ., **Edmonds, M.C.** Oppong, B.A., Tadesse, M.G. Initiation of Adjuvant Endocrine Therapy in Black and White Women with Breast cancer. Clin Breast Cancer, 2017
6. **Edmonds, M.C.,** Sutton A, Cummings, Y, Sheppard, V.B. Engaging Women from Racial/Ethnic Diverse Backgrounds to Provide Biospecimens Research: Opportunities to Improve Women's Health. Journal of Women's Health, *In Press*
7. Sheppard V.B.... **Edmonds, M.C**... The Role of Race and Patient-reported Symptoms in Regimen Adherence to Adjuvant Endocrine Therapy: A Report from the Women's Hormonal Initiation and Persistence Study. Cancer Epidemiology, Biomarkers & Prevention, *In Press*