

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

Megan C. Edmonds,¹ Sunny Jung Kim,² Matthew Wells,^{2,3} Bassam Dahman,² Vanessa B. Sheppard^{2,3}

Abstract

Annual surveillance mammography is a critical part of routine cancer care for breast cancer (BC) survivors; however, disparities exist with limited explanation of why Black BC survivors' experience the lowest national rates to surveillance mammography. In an oversample of Black survivors, we found that provider-communication about surveillance care significantly influenced receipt of annual surveillance mammography for Black survivors compared to White counterparts.

Purpose: The use of surveillance mammography following a breast cancer (BC) diagnosis is associated with early detection of disease relapse and increased overall survival; yet Black women compared to White women have the lowest surveillance mammography rates, with limited explanation. To further understand this racial disparity the present study examines the association of mammography beliefs, knowledge, and healthcare delivery factors on receipt of surveillance mammography among Black and White breast cancer survivors. **Methods:** This is a convergent parallel mixed method study design of an online survey and online focus groups among Black and White BC survivors (N = 266) recruited from community engagement. The online focus groups consisted of a series of theory-informed questions via social media platforms (eg Breastcancer.org, Quora, Reddit). An in-depth thematic analysis approach was used to extract themes from online focus group data. Bivariate (χ^2) and multivariable logistic regression analyses were conducted using the survey data to examine associated factors with receipt of a surveillance mammography within 12 months (yes vs. no). **Results:** 76% (n = 177) of women were Black, 62% were ≤ 5 years since diagnosis, 98% had health insurance, with an age range from 23 to 79 (mean = 55) years. 72% of the sample received a surveillance mammogram relative to 27%. Women more frequently received a surveillance mammogram if they reported perceived mammography benefits ($<.001$), underwent lumpectomy ($P < .001$) and had health insurance ($P = .04$). Black women without communication about surveillance care with providers had a lower likelihood of receiving a surveillance mammogram (OR:0.09,95% CI: 0.01-0.45, $P = .003$). Thematic findings from online focus groups included motivators for receipt of surveillance mammograms: physician recommendation, regular physical exams, and knowledge of recommended guidelines. Barriers of non-receipt of surveillance mammograms included: transportation, medical cost/financial barriers, feeling ignored from providers, and medical mistrust. **Conclusion:** Women may require more individualized information regarding their surveillance care to support routine guideline concordant follow-up. Patient-provider-communication is an integral part of Black survivors' surveillance care needs. Improving patient-provider communication for Black women's is necessary to address this group cancer care needs.

Clinical Breast Cancer, Vol. 000, No.xxx, 1–11 © 2022 Elsevier Inc. All rights reserved.

Keywords: Breast cancer, Black women, Surveillance care, Mammography, Survivorship

¹Division of General Internal Medicine, Icahn School of Medicine at Mount Sinai, New York, NY

²Department of Health Behavior and Policy, School of Medicine, Virginia Commonwealth University, Richmond, VA

³VCU Massey Cancer Center, Richmond, VA

Submitted: Feb 3, 2022; Revised: Aug 2, 2022; Accepted: Aug 21, 2022; Epub: xxx

Address for correspondence: Dr. Megan C. Edmonds, Icahn School of Medicine at Mount Sinai, Division of General Internal Medicine, 17 E 102nd St., New York, NY 10029, United States

Introduction

The American Society of Clinical Oncology (ASCO) and National Comprehensive Cancer Network (NCCN) recommend that breast cancer (BC) survivors receive annual breast cancer surveillance guidelines (eg, mammogram).^{1,2} Annual surveillance mammography,^{3,4} is associated with early detection of disease

E-mail contact: megan.edmonds@mounsinai.org

relapse, and decreases mortality by 39%.⁵⁻⁸ Unfortunately, evidence shows lower rates to surveillance mammography among Black and Hispanic women compared to their White counterparts (44% vs. 85%-75%).⁹⁻¹³ Data from several large retrospective studies also consistently found lower rates of surveillance mammography among Black BC survivors relative to White women.^{9,10,14-16} Black women's surveillance mammography rates are problematic as data show a higher cancer specific mortality among Black women who lacked surveillance during a 2-year surveillance period compared to Black women who received surveillance.^{17,18} 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.¹⁹ The Behavioral Model for Vulnerable populations,²⁰ conceptualize that health care utilization among vulnerable populations (eg cancer survivors) is an interplay of predisposing characteristics (demographics and knowledge), contextual and health care system factors. Guided by this conceptual framework, this study sought to observe the complex interplay of multifactorial predisposing (eg demographics, surveillance mammography beliefs/knowledge) enabling (eg provider communication) and need factors (survivor years) among Black and White survivors.^{8,21,22 19}

There is a strong causal relationship between women's mammography knowledge and beliefs (eg perceived benefits and barriers) and screening behaviors.²³⁻²⁵ Research studies among racial/ethnic minority women have shown that having perceived barriers (eg lack of transportation, fear of positive result, and cost) to a mammogram are significantly associated with the lower mammography screening behaviors.^{26,27} 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 mammography rates²⁸; 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.²⁹ This study seeks to delineate surveillance mammography beliefs and knowledge among a diverse sample of cancer survivors to further explicate how these psychosocial factors are related to this behavior, and to better inform future survivorship interventions.

Surveillance mammography is a complex behavior relating to the patient provider and system level factors; yet, data are lacking to explicate this behavior beyond the clinical and the demographic factors.^{9,10,21,30} Patient-provider communication is an essential process of cancer care delivery that improves women's initiation and adherence to adjuvant treatment.³¹⁻³³ 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.³² Similarly, another study found that frequent contact with the primary care physicians better predicted the use of mammography and improved breast cancer outcomes.³⁴ These findings support the importance of satisfaction in patient provider communication in promoting adherence behaviors^{35,36}; however, there has been limited work done on the relationship

between the patient-provider communication and receipt of follow-up surveillance mammography.³⁷

The underline premise of this convergent mixed methodological study design is to explain how the Behavioral Model of Vulnerable Population²⁰ constructs *predisposing* (eg demographics, mammography beliefs), (2) *enabling* (eg patient provider communication) and (3) *need factors* (eg years form diagnosis) influence BC survivor's receipt of surveillance mammography (Figure 1). We aim to explore BC survivor surveillance experiences (eg barriers and promoters) using breast cancer focused online platforms (eg breastcancer.org). This study will further advance our knowledge about survivor's receipt to annual mammograms, by highlighting BC survivors' perspectives and examining key factors (eg patient-provider communication) that are supported in adjuvant treatment adherence literature.

The survey data will test the following hypotheses:

H₁: Lower levels of provider communication will be associated with non-receipt of surveillance mammography and differ by race.

H₂: White race, and higher ratings of surveillance mammography benefits, and knowledge will be associated with receipt of surveillance mammogram.

Materials and Methods

Setting and Population

The Y-WE(WOMEN) SURVIVE BREAST CANCER Study³⁸ utilized mixed methods to examine surveillance mammography experiences among BC survivors engaged in social media. Women were recruited through multiple recruitment strategies: (1) virtual study ads on three social media platforms (Facebook, Instagram and Twitter), (2) sorority chapter emails listservs, and (3) community outreach engagement events at Massey Cancer Center Office of Health Disparities and Health Equity. Study ads included a link to our screening survey asking 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 (eg mastectomy, lumpectomy) before study participation (Figure 2). Study procedures were approved by Virginia Commonwealth University Institutional Review Boards.

Data Collection

Data were collected using a two-phase strategy: an online Qualtrics survey and online focus groups on three BC focused virtual platforms: Quora, Breastcancer.org, and Reddit.³⁹⁻⁴¹ Online focus group discussions were conducted publicly with 10 women on the three virtual platforms, guided with a moderator guide of questions about perceived knowledge, provider communication preferences, barriers, and promoters of adhering to breast surveillance guidelines (eg surveillance mammography). ME posted questions on the virtual platforms to facilitate online engagement and interaction with women over a 3-day period to allow flexibility in terms of participation consistent with other reports that utilized online focus group methods.⁴¹⁻⁴³ To simulate a focus group environment online, additional probes were posted subsequently to monitor and facilitate the communication with participants. Survivor's public engagement and discussions relating to their surveillance experiences on two 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. The survey link was embedded on study ads to recruit participants on Facebook, Instagram, and Twitter. Both the survey and online qualitative data were collected until saturation was achieved.

Survey Measures

Outcome Consistent with ASCO and NCCN recommended guidelines,³ surveillance mammography was measured with the question, “In the last 12-months did you have a mammogram?” with a yes versus 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).²⁴ 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 versus none.⁴⁴ Surveillance mammography knowledge included 2-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 4-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 $\geq \$75,000$), 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 sacrifice because of your cancer treatment, or the lasting effects of that treatment?” where responses were yes, versus 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 (eg financial burden) on a binary outcome and receipt of 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. The multivariable logistic regression model was adjusted for potentially confounded study variables (eg age, survival years, marital status, race, and health insurance) consistent with prior studies.^{10,45,46} Champion Scale items were recoded as any vs. none for logistic analysis interpretations.⁴⁴ Mean and mode imputation methods were used for study variables having 5 or more missing.⁴⁷ All statistical analyses were performed using SAS version 9.4

Online Focus Group Coding Procedure

Two trained coders (ME, MW) conducted a thematic analysis approach using grounded theory techniques.⁴⁸ Data included online focus group text from posts that ME 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.⁴⁹ In the initial

Figure 2 Survey flowchart of study participants.

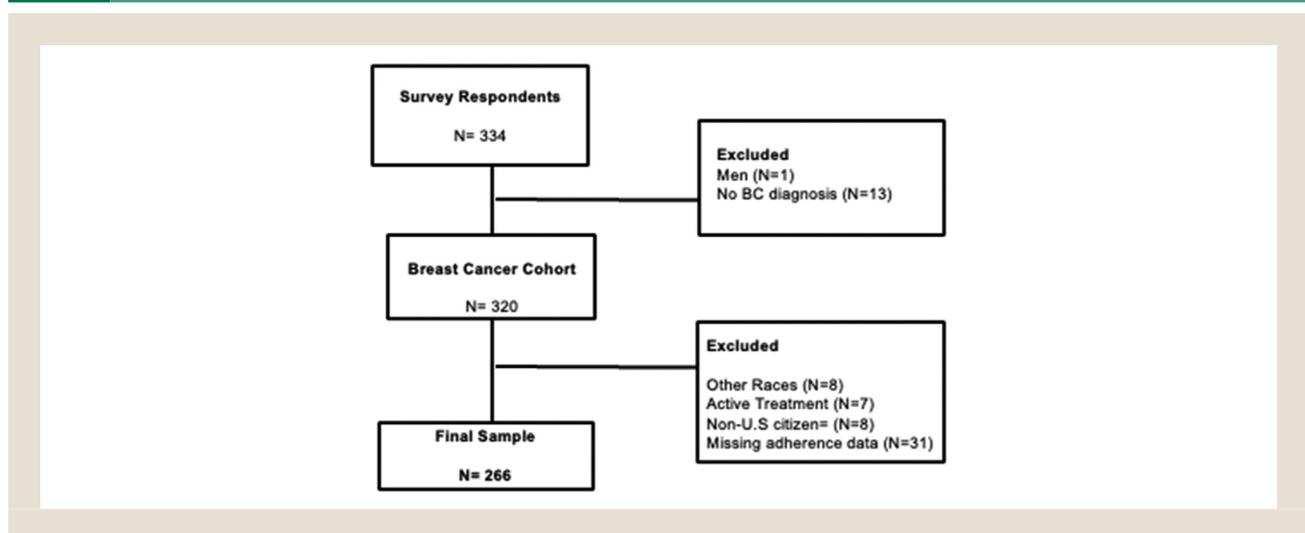
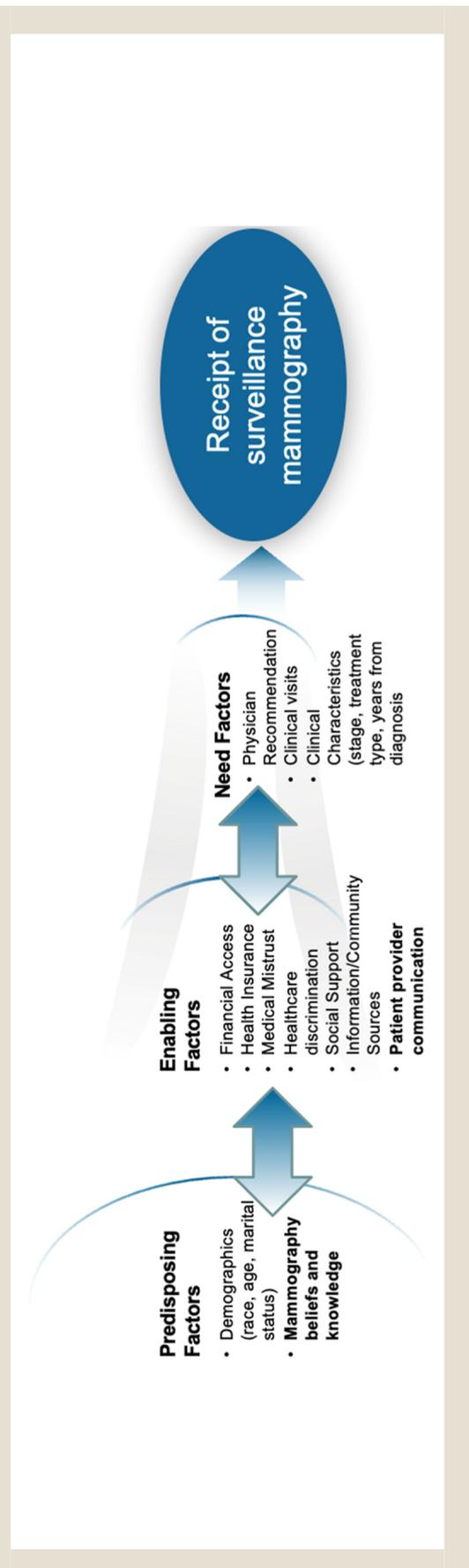


Figure 1 Behavioral Model for Vulnerable Populations.



coding scheme, dimensions from the theoretical framework were used as priori codes to guide the scheme of coding, and the research question (eg 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 online 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 online 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.⁵⁰ 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 codes in the table to closely reflect the theoretical constructs and research question and to find emergent themes inductively.^{48,49} This technique was used to eliminate bias and to gauge consistency across the team.⁵¹ Codes were then deciphered amongst the coders for consensus.

Results

Survey Data

Sixty seven percent ($n = 177$) of our study sample were Black and 33% ($n=88$) were White. Among our sample 52% were married, employed (53%), had health insurance (98%), a family history of breast cancer (56%) and a mean age of 55 years ($SD = 10.67$). Table 1 describes predictors of surveillance mammography by predisposing, enabling, and need characteristics from a total of 266 BC survivors. 72% of survivors had a surveillance mammography (in the last 12 months) compared to 27% women who did not receive one. For predisposing factors, women who reported any surveillance mammography benefits (85%) compared to women who did not report any benefits (14%) were more likely to receive a surveillance mammography ($P < .0001$; H_2). Among need factors, women who received a type of mastectomy (54%) versus a lumpectomy (45%) was associated with receiving a surveillance mammography ($P < .0001$). While insignificant in data analysis, it is important to note the following: 63% of survivors who were 50 years and below did not receive a surveillance mammogram; survivors who did receive a surveillance mammography were more informed about their breast surveillance guidelines from their provider (80%vs.19%; enabling factor) had more general surveillance knowledge ($m = 2.14$ vs. $m = 2.08$; predisposing factor), and had higher receipt of radiation (76%;need factors), compared to women who did not receive a surveillance mammogram.

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).^{10,45,46} When testing study hypothesis 1, a significant interaction was found between a combi-

Table 1 Characteristics of Black and White BC Survivors by Surveillance Mammography, Unadjusted N = 266.

Variables	Surveillance		Mammography	P-value
	Yes	No	No	
	N (%)	N (%)		
	192(72.2)	73 (27.4)		
<i>Predisposing factors</i>				
Age				
≥50	53(27.6)	27(36.9)		.158
<50	136(70.8)	46(63.0)		
Race				
White	64(33.3)	24 (32.9)		.943
Black	128 (66.7)	49 (67.1)		
Marital status				
Married	97 (50.5)	43 (58.9)		.222
Single	95 (49.5)	30 (41.1)		
Do you know your breast surveillance to follow?				
Yes	149 (77.6)	54 (73.9)		.803
No	38 (19.8)	15 (20.5)		
Surveillance Mammography Benefits				
Any	165 (85.9)	44 (60.3)		<.0001 ^b
None	27(14.1)	29 (39.7)		
Surveillance Mammography Barriers				
Any	64 (33.3)	30 (41.1)		.238
None	128 (66.7)	43 (58.9)		
General Surveillance Knowledge (M+SD)	2.14 +0.81	2.08 +0.83		.568
<i>Enabling factors</i>				
Health insurance				
Yes	191 (99.5)	71(97.3)		.127
No	1 (0.5)	2(2.8)		
Family BC health history				
Yes	110 (57.3)	39(53.4)		.570
No	82(42.7)	34 (46.6)		
Income (household)				
>\$15,000	25(13.0)	6 (8.2)		
\$15,000-<\$35,000	33 (17.8)	7 (9.6)		.297
\$35,000-<\$50,000	30 (15.6)	13 (17.8)		
\$50,000-<\$75,000	34 (17.7)	13 (17.8)		
≥\$75,000	68 (35.4)	34 (46.6)		
Financial Burden				
Yes	72 (37.5)	34 (46.5)		.177
No	120 (62.5)	39(53.4)		
Employment				
Employed	99 (51.6)	43 (58.9)		.284
Unemployed	93 (48.4)	30 (41.1)		
Provider-Communicated Surveillance				
Yes	155 (80.7)	54 (73.9)		.228
No	37 (19.3)	19 (26.0)		
<i>Need factors</i>				
Stage				
0	22 (11.5)	7(9.6)		.894
I-II	122 (63.5)	47 (64.4)		
III-IV	47 (24.5)	19 (26.0)		
Survivor Years				
≤5 years since diagnosis	119 (61.9)	46 (63.0)		.8767
5+ years since diagnosis	73 (38.0)	27 (36.9)		

(continued on next page)

Table 1 (continued)

	Surveillance Yes	Mammography No	
Surgery			
Lumpectomy	87(45.3)	5(6.8)	<.0001 ^b
Mastectomy	105(54.7)	68(93.2)	
Chemotherapy			
Yes	147 (76.6)	58 (79.5)	.615
No	45 (23.4)	15 (20.5)	
Hormonal Therapy			
Yes	48 (25.0)	21 (28.8)	.532
No	144 (75.0)	52 (71.2)	
Radiation			
Yes	146 (76.0)	50 (68.5)	.210
No	46 (23.9)	23 (31.5)	

^a $P < .05$;

^b $P < .01$.

nation of race and provider communication ($P = .039$), 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 receiving a surveillance mammography in our adjusted model ($P < .001$, Table 2).

Enabling factors. Health insurance coverage was a predictor of receiving a surveillance mammogram. Survivors who reported health insurance coverage versus not had a higher likelihood of meeting annual surveillance mammography guidelines (OR: 24.12; 95% CI:1.24-517.54).

Need factors. Surgical treatment remained significant in our adjusted model, survivors who had a mastectomy had a decreased odd of receiving 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 detail were less likely to receive a surveillance mammogram (OR:0.09, 95% CI: 0.01-0.45) when compared to White counterparts. Online Focus Group Data

Barriers to Recommended Surveillance Mammography and Follow-up visits

10 women participated in online discussions posted on (Quora, Breastcancer.org, and Reddit). Guided by Behavioral Model for Vulnerable Populations,²⁰ data coding revealed several themes. Women commonly reported feeling ignored from physicians (enabling), limited access to transportation (enabler), financial burden (enabler) 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 receipt of 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 and or having a physician recommendation (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*

Table 2 Adjusted Logistic Regression Results for Survivor's Receipt of Surveillance Mammography Odds Ratios (OR) and 95% Confidence Intervals (CI).

Variables	Adjusted OR	Surveillance Mammography 95% CI	P-Value
<i>Predisposing factors</i>			
Age			
≥50	Ref.		
<50	0.71	(0.28-1.78)	.464
Race-communication			
White, Greater communication	Ref.		
White, Lower communication	1.79	(0.46-6.88)	.392
Black, Greater communication	0.97	(0.40-2.34)	.950
Black, Lower communication	0.16	(0.04-0.65)	.010
Marital status			
Married	0.98	(0.40-2.35)	.965
Single	Ref.		
Do you know your breast surveillance to follow?			
Yes	0.76	(0.23-2.50)	.652
No	Ref.		
Surveillance mammography benefits			
Any	4.92	(2.16-11.21)	<.001 ^b
None	Ref.		
Surveillance mammography barriers			
Any	1.06	(0.48-2.33)	.885
None	Ref.		
General surveillance knowledge (M+SD)	0.89	(0.49-1.63)	.716
<i>Enabling factors</i>			
Health insurance			
Yes	24.12	(1.24-517.54)	.041 ^a
No	Ref.		
Family BC health history			
Yes	1.27	(0.61-2.64)	.506
No	Ref.		
Income (household)			
> \$15,000	4.86	(0.98-24.00)	.051
\$15,000-<\$35,000	3.08	(0.80-11.87)	.101
\$35,000-<\$50,000	0.89	(0.30-2.65)	.844
\$50,000-<\$75,000	1.50	(0.52-4.27)	.447
≥\$75,000	Ref.		
Financial Burden			
Yes	0.57	(0.26-1.20)	.141
No	Ref.		
Employment			
Employed	0.96	(0.44-2.07)	.923
Unemployed	Ref.		
<i>Need factors</i>			
Stage			
0	Ref.		
I-II	0.71	(0.20-2.57)	.612
III-IV	1.04	(0.26-4.11)	.946
Survivor Years			
<5 years since diagnosis	1.03	(0.047-2.28)	.925
5+ years since diagnosis	Ref.		
Surgery			

(continued on next page)

Table 2 (continued)

Variables	Adjusted OR	Surveillance Mammography 95% CI	P-Value
Lumpectomy	Ref.		
Mastectomy	0.04	(0.01-0.14)	<.0001 ^b
Chemotherapy			
Yes	1.20	(0.44-3.28)	.710
No	Ref.		
Endocrine Therapy			
Yes	0.62	(0.27-1.44)	.276
No	Ref.		
Radiation			
Yes	0.52	(0.21-1.25)	.147
No	Ref.		

^a $P < .05$;^b $P < .01$.

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 breastcancer.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 no new themes were found, however we found similar themes that provided new insight in our current themes. These included: (1) continuity of care (enabler), (2) worry about recurrence (predisposing), and (3) medical mistrust (enabler),

which fits within the context of our prior theme (feeling ignored by providers) and (4) 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."

Discussion

Receipt of surveillance mammography guidelines is linked with better survival outcomes among BC survivors. Explanations for not receiving surveillance guidelines are lacking outside of sociodemographic and clinical factors. In this study, we sought to determine theory guided determinants of surveillance behaviors and explored surveillance mammography experiences among a racial diverse sample of BC survivors. In adjusted multivariable 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 surveil-

lance 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 surveillance mammography behaviors were related with their ratings of provider-communication about their surveillance guidelines. Black women who reported lower communication with their provider were found to have a lower likelihood of receiving a surveillance mammogram. Given the lack of data on provider-communication in the surveillance context, our finding extends possible explanations for Black women's lower rates of surveillance mammograms.⁹⁻¹³ 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, relative to their White counterparts.³² Reports have also indicated the important role the patient-provider relationship play, in making breast cancer treatment decisions especially for Black women.^{32,33,52} One explanation why Black survivor's reported lower ratings may be from receiving less communication with their providers, and feeling ignored from their providers when they had an issue, and having more unaddressed barriers compared to their White counterparts (24% vs. 14%, respectively), which was cited as barriers across our online focus groups and survey data. 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 post-treatment, 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 communication and coordination between patients and providers in the surveillance setting,^{31,53-56} which may enhance the quality of survivorship information given to racial minority BC survivors.

Health insurance coverage was an important enabling factor for surveillance mammography in both our qualitative and quantitative findings. The lack of health insurance among BC survivors is consistently associated with not receiving a surveillance mammogram.^{10,11,57} Our findings are aligned with prior research and suggest health insurance coverage is in part, a buffer for women's receipt of breast cancer surveillance guidelines. While, having health insurance is historically linked with better health care utilization in survivors,^{58,59} 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.⁶⁰ Similarly, other studies report lower treatment adherence for public insurance holders vs. being privately insured.^{61,62} The persistent relationship between non-receipt to a surveillance mammogram and 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 from 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 survivor's use of cancer care delivery.

Mammography beliefs were an important predisposing factor for survivor's receipt of a mammogram. Women who reported any mammography benefits were more likely to have a mammogram in the last 12 months compared to women who did not report beliefs about mammography benefits. This finding is consistent with prior research in the general population of women, that support the independent association between mammography benefits and mammography screening.^{24,44,63} 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 receive a surveillance mammogram 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 receipt of surveillance mammography. These findings are consistent with an earlier study of Black BC survivor's surveillance mammography experiences.⁶⁴ 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 (eg 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 many limitations to acknowledge. The use of online data collection presented several weaknesses including self-reported data and not knowing the response rate, which may have resulted in response biases. The use of our online focus groups lacked group cohesion which may be better achieved in real-time in-person focus groups. Additionally, sociodemographic and clinical factors were not collected from online focus group participants. Clinical characteristics were also not confirmed from medical records using histology reports, nor did we control for first or second recurrent cancers from survey participants. Lastly, BC survivors' breast surgical type may include other options beyond lumpectomy and mastectomy, thus our results lacked the type of mastectomy such as, bi-lateral mastectomy, and whether women received a reconstruction which limits the context of our findings.

Conclusions

Findings from this study indicate the importance of receiving patient-provider communication, perceiving mammography benefits and having health insurance coverage regarding surveil-

lance 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-receipt to surveillance mammography.

Clinical Practice Point

What is already known about this subject?

- Annual surveillance mammography is recommended for early detection of recurrent cancer for breast cancer survivors.
- Health care access and provider recommendation influences receipt of surveillance mammogram.
- Evidence shows national rates of surveillance mammography are lower for Black women.
- What are the new findings?
- Breast cancer survivors' beliefs about mammography benefits were associated with surveillance mammography regardless of race
- Higher rates of surveillance mammography were associated with provider-communication about surveillance guidelines for Black women
- How might it impact on clinical practice in the foreseeable future?
- Patient-provider communication about surveillance care is essential during cancer care delivery for breast cancer patients and further supports surveillance receipt of surveillance care.

HIP

Annual receipt of surveillance mammography, are recommended for breast cancer survivors, for early detection of recurrence and to reduce breast cancer mortality; however, evidence shows Black women report lower receipt of a mammogram compared to other racial groups of women. Our study examined the factors of psychosocial and healthcare delivery to help explicate Black women's surveillance mammography behaviors rates. Data analysis included 266 Black and White women, with Black women comprising a slight majority of the sample. Surveillance mammography was higher among Black women with provider communication about surveillance. Survivors frequently received surveillance care when reporting perceived mammography benefits, regardless of race. Healthcare delivery factors of provider communication around surveillance may be an important targeted area of clinical practice for Black women's surveillance care needs.

Declaration of Competing Interest

Authors have no conflicts of interest to disclose.

Funding

Research was supported in part by the National Cancer Institute of the National Institutes of Health under Award Number P30CA177558; and Virginia Commonwealth University Massey Cancer Centered Shared Resource supported with funding from NIH-NCI Cancer Center Support Grant P30 CA016059

Acknowledgments

The authors are grateful for study participants who took the time to participate in online focus groups and/or the online survey. We also appreciate the willingness of survivor advocates and advocacy groups who helped with recruitment Natasha Ewa from I-Thrive Therapy and Wellness, Ann-Marie Swatson and other board members from Painted Pink non-profit organization and Lara Aiyegbusi from Victorious 23. We also want to acknowledge and thank our media specialist Farrin Hymon who designed our social media study ads and played a key role in the study branding.

Disclosure

The authors have stated that they have no conflicts of interest.

References

1. Khatcheressian JL, Hurley P, Bantug E, et al. Breast cancer follow-up and management after primary treatment: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol*. 2013;31(7):961–965.
2. Saslow D, Boetes C, Burke W, et al. American Cancer Society guidelines for breast screening with MRI as an adjunct to mammography. *CA Cancer J Clin*. 2007;57(2):75–89.
3. Runowicz CD, Leach CR, Henry NL, et al. American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline. *J Clin Oncol*. 2016;34(6):611–635.
4. Monticciolo DL, Newell MS, Hendrick RE, et al. Breast Cancer Screening for Average-Risk Women: Recommendations from the ACR Commission on Breast Imaging. *J Am Coll Radiol: JACR*. 2017;14(9):1137–1143.
5. Houssami N, Ciatto S, Martinelli F, Bonardi R, Duffy SW. Early detection of second breast cancers improves prognosis in breast cancer survivors. *Ann Oncol: official journal of the European Society for Medical Oncology*. 2009;20(9):1505–1510.
6. Lu WL, Jansen L, Post WJ, Bonnema J, Van de Velde JC, De Bock GH. Impact on survival of early detection of isolated breast recurrences after the primary treatment for breast cancer: a meta-analysis. *Breast Cancer Res Treat*. 2009;114(3):403–412.
7. Doubeni CA, Field TS, Ulcickas-Yood M, et al. Patterns and predictors of mammography utilization among breast cancer survivors. *Cancer*. 2006;106(11):2482–2488.
8. Medicine Io, Council NR. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: The National Academies Press; 2006.
9. Ruddy KJ, Sangaralingham L, Freedman RA, et al. Adherence to guidelines for breast surveillance in breast cancer survivors. *Journal of the National Comprehensive Cancer Network : JNCCN*. 2018;16(5):526–534.
10. Keating NL, Landrum MB, Guadagnoli E, Winer EP, Ayanian JZ. Factors related to underuse of surveillance mammography among breast cancer survivors. *J Clin Oncol*. 2006;24(1):85–94.
11. Field TS, Doubeni C, Fox MP, et al. Under utilization of surveillance mammography among older breast cancer survivors. *J Gen Intern Med*. 2008;23(2):158–163.
12. Carcaise-Edinboro P, Bradley CJ, Dahman B. Surveillance mammography for Medicaid/Medicare breast cancer patients. *J Cancer Surviv: Res and practice*. 2010;4(1):59–66.
13. Advani P, Advani S, Nayak P, et al. Racial/ethnic disparities in use of surveillance mammogram among breast cancer survivors: a systematic review. *J Cancer Surviv: Res and practice*. 2021.
14. Erim AE, Schellhase KG, Sparapani R, Nattinger AB. Effect of model of care delivery on mammography use among elderly breast cancer survivors. *Breast Cancer Res Treat*. 2006;96(3):293–299.
15. Advani PS, Ying J, Theriault R, et al. Ethnic disparities in adherence to breast cancer survivorship surveillance care. *Cancer*. 2014;120(6):894–900.
16. Mandelblatt JS, Lawrence WF, Cullen J, et al. Patterns of care in early-stage breast cancer survivors in the first year after cessation of active treatment. *J Clin Oncol*. 2006;24(1):77–84.
17. Nurgalieva ZZ, Franzini L, Morgan R, Vernon SW, Liu CC, Du XL. Surveillance mammography use after treatment of primary breast cancer and racial disparities in survival. *Med Oncol (Northwood, London, England)*. 2013;30(4):691.
18. De La Cruz LM, Shulman LN. Under surveillance: impact of race and socioeconomic status on post-treatment breast cancer imaging. *Ann Surg Oncol*. 2018;25(6):1456–1457.
19. Murphy CC, Bartholomew LK, Carpentier MY, Bluethmann SM, Vernon SW. Adherence to adjuvant hormonal therapy among breast cancer survivors in clinical practice: a systematic review. *Breast Cancer Res Treat*. 2012;134(2):459–478.
20. Gelberg L, Andersen RM, Leake BD. The Behavioral Model for Vulnerable Populations: application to medical care use and outcomes for homeless people. *Health services Res*. 2000;34(6):1273–1302.
21. DeSantis CE, Ma J, Gaudet MM, et al. Breast cancer statistics, 2019. *CA: Cancer J Clin*. 2019.

22. DeSantis CE, Ma J, Goding-Sauer A, Newman LA, Jemal A. Breast cancer statistics, 2017, racial disparity in mortality by state. *CA: Cancer J Clin.* 2017;67(6):439–448.
23. Russell KM, Champion VL, Skinner CS. Psychosocial factors related to repeat mammography screening over 5 years in African American women. *Cancer nursing.* 2006;29(3):236–243.
24. Champion VL, Monahan PO, Springston JK, et al. Measuring mammography and breast cancer beliefs in African American women. *J Health Psychol.* 2008;13(6):827–837.
25. Rafie C, Ayers A, Cadet D, Quillin J, Hackney MH. Reaching Hard to Reach Populations with Hard to Communicate Messages: Efficacy of a Breast Health Research Champion Training Program. *J Cancer Educ: the official J American Association for Cancer Education.* 2015;30(3):599–606.
26. Miller BC, Bowers JM, Payne JB, Moyer A. Barriers to mammography screening among racial and ethnic minority women. *Soc Sci Med (1982).* 2019;239.
27. Alexandraki I, Mooradian AD. Barriers related to mammography use for breast cancer screening among minority women. *J Natl Med Assoc.* 2010;102(3):206–218.
28. Chan DN, So WK. A systematic review of randomised controlled trials examining the effectiveness of breast and cervical cancer screening interventions for ethnic minority women. *Eur J Oncol Nurs.* 2015;19(5):536–553.
29. Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *J Gen Intern Med.* 2012;27(5):520–526.
30. Freedman RA, Keating NL, Partridge AH, Muss HB, Hurria A, Winer EP. Surveillance Mammography in Older Patients With Breast Cancer—Can We Ever Stop?: A Review. *JAMA oncology.* 2017;3(3):402–409.
31. Sheppard VB, Adams IF, Lamdan R, Taylor KL. The role of patient-provider communication for black women making decisions about breast cancer treatment. *Psychooncology.* 2011;20(12):1309–1316.
32. Sheppard VB, Isaacs C, Luta G, et al. Narrowing racial gaps in breast cancer chemotherapy initiation: the role of the patient-provider relationship. *Breast Cancer Res Treat.* 2013;139(1):207–216.
33. Mandelblatt JS, Sheppard VB, Hurria A, et al. Breast cancer adjuvant chemotherapy decisions in older women: the role of patient preference and interactions with physicians. *J Clin Oncol.* 2010;28(19):3146–3153.
34. Roetzheim RG, Ferrante JM, Lee JH, et al. Influence of primary care on breast cancer outcomes among Medicare beneficiaries. *Ann Fam Med.* 2012;10(5):401–411.
35. Sutton AL, He J, Edmonds MC, Sheppard VB. Medical Mistrust in Black Breast Cancer Patients: Acknowledging the Roles of the Trustor and the Trustee. *J Cancer Educ: the official J American Association for Cancer Education.* 2018.
36. Sheppard VB, Oppong BA, Hampton R, et al. Disparities in breast cancer surgery delay: the lingering effect of race. *Ann Surg Oncol.* 2015;22(9):2902–2911.
37. Royak-Schaler R, Passmore SR, Gadalla S, et al. Exploring patient-physician communication in breast cancer care for African American women following primary treatment. *Oncol Nurs Forum.* 2008;35(5):836–843.
38. Sheppard VB, Sutton A, Holmes E, et al. Recruitment of African Americans into Cancer Clinical Research: Strategies and Outcomes. *J Urban Health: bulletin of the New York Academy Med.* 2021;98(2):149–154 Suppl.
39. Richard B, Sivo SA, Ford RC, et al. A Guide to Conducting Online Focus Groups via Reddit. *Int J Qual Methods.* 2021;20.
40. Stewart DW, Shamdasani PN. *Focus groups: Theory and practice.* 20. Thousand Oaks, California: Sage publications; 2014.
41. Stewart K, Williams M. Researching online populations: the use of online focus groups for social research. *Qualitative Research.* 2005;5(4):395–416.
42. Kenny AJ. Interaction in cyberspace: an online focus group. *J Adv Nurs.* 2005;49(4):414–422.
43. Reinsner SL, Randazzo RK, White-Hughto JM, et al. Sensitive Health Topics With Underserved Patient Populations: Methodological Considerations for Online Focus Group Discussions. *Qual Health Res.* 2018;28(10):1658–1673.
44. Miller AM, Champion VL. Attitudes about breast cancer and mammography: racial, income, and educational differences. *Women & health.* 1997;26(1):41–63.
45. Teyssir J, Gegechkori N, Wisnivesky JP, Lin JJ. Racial disparities in surveillance mammography among older breast cancer survivors. *Breast Cancer Res Treat.* 2019;176(2):461–467.
46. Breslau ES, Jeffery DD, Davis WW, Moser RP, McNeel TS, Hawley S. Cancer screening practices among racially and ethnically diverse breast cancer survivors: results from the 2001 and 2003 California health interview survey. *J Cancer Surviv: Res Pract.* 2010;4(1):1–14.
47. Zhang Z. Missing data imputation: focusing on single imputation. *Ann Transl Med.* 2016;4(1):9.
48. Strauss A, Corbin, J. *Basic qualitative research: Techniques and procedures for developing grounded theory.* Thousand Oaks, CA: Sage; 1998.
49. Bernard H, Wutich, A., Ryan, G. *Analyzing Qualitative Data: Systematic Approaches.* 2010.
50. Watkins DC, Gioia D. *Mixed Methods Research.* New York, NY: Oxford University Press; 2015.
51. Watkins DC, Allen JO, Goodwill JR, Noel B. Strengths and weaknesses of the Young Black Men, Masculinities, and Mental Health (YBMen) Facebook project. *Am J Orthopsychiatry.* 2017;87(4):392–401.
52. Ashton CM, Haidet P, Paterniti DA, et al. Racial and ethnic disparities in the use of health services: bias, preferences, or poor communication? *J Gen Intern Med.* 2003;18(2):146–152.
53. Canzona MR, Garcia D, Fisher CL, Raleigh M, Kalish V, Ledford CJ. Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives. *Patient Educ Couns.* 2016;99(11):1814–1820.
54. Moreno PI, Ramirez AG, San-Miguel-Majors SL, et al. Unmet supportive care needs in Hispanic/Latino cancer survivors: prevalence and associations with patient-provider communication, satisfaction with cancer care, and symptom burden. *Support Care Cancer: official journal of the Multinational Association of Supportive Care in Cancer.* 2018.
55. Brennan ME, Butow P, Spillane AJ, Boyle F. Patient-reported quality of life, unmet needs and care coordination outcomes: Moving toward targeted breast cancer survivorship care planning. *Asia Pac J Clin Oncol.* 2016;12(2):e323–e331.
56. Poon EG, Haas JS, Louise-Puopolo A, et al. Communication factors in the follow-up of abnormal mammograms. *J Gen Intern Med.* 2004;19(4):316–323.
57. Flores EJ, Lopez D, Miles RC, et al. Impact of Primary Care Physician Interaction on Longitudinal Adherence to Screening Mammography Across Different Racial/Ethnic Groups. *J Am Coll Radiol: JACR.* 2019;16(7):908–914.
58. Coughlin SS. Social determinants of breast cancer risk, stage, and survival. *Breast Cancer Res Treat.* 2019;177(3):537–548.
59. Wu XC, Lund MJ, Kimmick GG, et al. Influence of race, insurance, socioeconomic status, and hospital type on receipt of guideline-concordant adjuvant systemic therapy for locoregional breast cancers. *J Clin Oncol.* 2012;30(2):142–150.
60. Sabatino SA, Thompson TD, Richardson LC, Miller J. Health insurance and other factors associated with mammography surveillance among breast cancer survivors: results from a national survey. *Medical care.* 2012;50(3):270–276.
61. Sheppard VB, He J, Sutton A, et al. Adherence to Adjuvant Endocrine Therapy in Insured Black and White Breast Cancer Survivors: Exploring Adherence Measures in Patient Data. *J Manag Care Spec Pharm.* 2019;25(5):578–586.
62. Farias AJ, Du XL. Association Between Out-Of-Pocket Costs, Race/Ethnicity, and Adjuvant Endocrine Therapy Adherence Among Medicare Patients With Breast Cancer. *J Clin Oncol.* 2017;35(1):86–95.
63. Fouladi N, Pourfarzi F, Mazaheri E, et al. Beliefs and behaviors of breast cancer screening in women referring to health care centers in northwest Iran according to the champion health belief model scale. *Asian Pac J Cancer Prev: APJCP.* 2013;14(11):6857–6862.
64. Thompson HS, Littles M, Jacob S, Coker C. Posttreatment breast cancer surveillance and follow-up care experiences of breast cancer survivors of African descent: an exploratory qualitative study. *Cancer Nurs.* 2006;29(6):478–487.