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Disparities in Barriers to Follow-up Care between African American and White Breast Cancer Survivors

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Abstract

Purpose—Despite recommendations for breast cancer survivorship care, African American women are less likely to receive appropriate follow-up care, which is concerning due to their higher mortality rates. This study describes differences in barriers to follow-up care between African American and White breast cancer survivors.

Methods—We conducted a mailed survey of women treated for non-metastatic breast cancer in 2009–2011, 6–24 months post-treatment (N=203). Survivors were asked about 14 potential barriers to follow-up care. We used logistic regression to explore associations between barriers and race, adjusting for covariates.

Results—Our participants included 31 African American and 160 White survivors. At least one barrier to follow-up care was reported by 62%. Compared to White survivors, African Americans were more likely to identify barriers related to out-of-pocket costs (28% vs. 51.6%, p=0.01), other

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CONFLICTS OF INTEREST

Authors, Nynikka R. A. Palmer, Kathryn E. Weaver, Sally P. Hauser, Julia A. Lawrence, Jennifer Talton, L. Douglas Case, and Ann M. Geiger all declare that they have no conflict of interest. We have full control of all primary data and agree to allow the journal to review the data if requested.

INFORMED CONSENT

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients included in this study.

This article was prepared while Drs. Geiger and Palmer were employed at Wake Forest School of Medicine. The opinions expressed in this article are the author's own and do not reflect the view of the National Institutes of Health, the Department of Health and Human Services, or the United States government.

healthcare costs (21.3% vs. 45.2%, $p=0.01$), anxiety/worry (29.4% vs. 51.6%, $p=0.02$), and transportation (4.4% vs. 16.1%, $p=0.03$). After adjustment for covariates, African Americans were three times as likely to report at least one barrier to care (OR=3.3, 95% CI=1.1–10.1).

Conclusions—Barriers to care are common among breast cancer survivors, especially African American women. Financial barriers to care may prevent minority and underserved survivors from accessing follow-up care. Enhancing insurance coverage or addressing out-of-pocket costs may help address financial barriers to follow-up care among breast cancer survivors. Psychosocial care aimed at reducing fear of recurrence may also be important to improve access among African American breast cancer survivors.

Keywords

barriers; follow-up care; health disparities; cancer survivor; breast cancer

INTRODUCTION

In 2012, there were 13.7 million cancer survivors in the United States, a population expected to grow to 18 million over the next decade [1]. Breast cancer survivors make up 22% of this population [2]. National guidelines, including the American Society of Clinical Oncology [3] and the National Comprehensive Cancer Network [4], strongly recommend women who have completed breast cancer treatment receive regular follow-up care and surveillance. This care includes early detection of recurrence and new primary cancers, to evaluate and monitor late and long-term effects from treatment, and provide ongoing physical and psychosocial support [5]. This includes a history, physical examination, mammography, pelvic examination with pap smear, coordination of care, and patient education regarding symptoms of recurrence.

Previous studies have reported breast cancer survivors under use surveillance mammography [6]; and compared to non-cancer controls, they are less likely to receive follow-up care, such as screenings for new primary cancers [7], screenings for other cancers (i.e., colonoscopy and pap test), and non-cancer related care (i.e., bone densitometry, cholesterol screening, and influenza vaccination) [8]. And many do not see a cancer specialist [9, 10]. More specifically, African American breast cancer survivors are less likely to receive necessary care after completing treatment compared to White survivors [6, 11–13]. Failure to receive follow-up care may contribute to delayed diagnosis and treatment of cancer or other comorbidities, reduced quality of life, and increased risk of disease and death. This is particularly concerning since African American women have a 41% higher breast cancer-specific mortality rate compared to White women [14].

Unfortunately, very little is known about why survivors may not receive follow-up care post-treatment. A population-based study by Weaver and colleagues found that cancer survivors are more likely to delay or forgo medical care because of cost compared to non-cancer controls [15]. In addition, two qualitative studies have reported several barriers to care for breast cancer survivors, including access to and availability of services, cost of service, travel issues, personal time constraints, lack of support, and lack of information about post-treatment follow-up care [16, 17]. Studies have yet to examine racial disparities

in perceived barriers to follow-up care among cancer survivors, a necessary step before designing programs that can address the unique needs of underserved cancer survivors and reduce racial disparities in long-term health after cancer. Therefore, this descriptive study was conducted to examine disparities in perceived barriers to follow-up care between African American and White breast cancer survivors.

METHODS

Study Design and Population

We conducted a cross-sectional study of women treated for breast cancer at the National Cancer Institute-designated Comprehensive Cancer Center at Wake Forest University (CCCWFU) in Winston-Salem, North Carolina. The Wake Forest University Institutional Review Board approved this study.

Women were eligible if they were diagnosed with first primary *in situ* or invasive breast cancer and received some or all of their treatment at CCCWFU from January 1, 2009, to November 30, 2011. In addition, women must have completed their cancer treatment six to 24 months previously. Women diagnosed with metastatic (stage IV) or unknown stage breast cancers were excluded because the nature of their care differs from that provided to survivors of earlier stage cancers. We also excluded women who were noted to be cognitively impaired or did not speak English.

Recruitment

We identified eligible women from the institutional cancer registry and confirmed treatment completion using medical records. Eligible women were invited to participate in the study through mailings and telephone calls. The first mailing included a cover letter introducing the study, a \$10 gas card, a 16 page survey, and a stamped, preaddressed return envelope. Non-respondents received a second mailing approximately two weeks later. We then made five attempts to reach non-respondents by telephone, offering those contacted the option to complete the survey by telephone or to receive a third mailing.

Study Variables

Our main outcome of interest was perceived barriers to follow-up care. Fourteen questions about barriers were asked, based on a prior NCI surveillance study [18] that asked cancer survivors about things that may have hinder them from getting cancer-related follow-up care. Additional problems were added to reflect barriers associated with rural residence [19], such as distance to care. Respondents were asked how much of a problem (no problem, somewhat of a problem, a big problem) has it been for them to get follow-up care after breast cancer because of 14 different reasons. See Figure 1 for a complete list of questions.

For modeling purposes, we created a dichotomous measure of reporting “any barrier to care” versus those who endorsed “no barriers,” where “any barrier” is defined as respondents answering any of the 14 barrier questions as “somewhat of a problem” or “a big problem.” Those who endorsed “no barriers” answered all 14 questions as “no problem.” Similarly, we created a second summary variable for three cost-related barriers (“your out-of-pocket

medical costs are too high,” “your insurance doesn’t cover it,” and “you cannot afford other costs associated with getting care”); we compared those who endorsed at least one cost-related barrier as somewhat or a big problem to those with none. Those missing responses for any of the cost-related barriers were excluded from analysis for this model (n=9).

We used self-report items from the Behavioral Risk Factor Surveillance System [20] to assess race, categorized as African American or White. Women were asked separately about their race (White, African American or Black, American Indian or Alaska Native, Asian, Native Hawaiian or other Pacific Islander, and Other), and ethnicity (not Hispanic or Latino/Hispanic or Latino). Zip code approximation of rural-urban commuting area (RUCA) codes [21] were used to define rural (RUCA 4–10) and urban (RUCA 1–3) residence, as done in previous studies [22–24]. We dichotomized marital status (currently married or living as married versus all others) and working full or part time (versus all others). Education was categorized into four categories (high school graduate or less; technical or vocational training, or some college; college graduate; and finished or some graduate work). Current insurance coverage consisted of four categories (none, private only, public only, and both private and public).

The cancer registry provided age at diagnosis (categorized as less than 50, 50 to 59, 60 to 69, and 70 years or older), if the patient had a recurrence or second primary cancer, and diagnosis date. The diagnosis date was used in combination with the date of survey completion to calculate the time from diagnosis to survey (6 to 17 months, 18 months to 23 months, 24 months or more).

Statistical Analysis

Descriptive statistics (n, %) were calculated for participant characteristics and barriers to care. Bivariate associations comparing African American versus Whites were evaluated using chi-square tests. To evaluate barriers to care, we first calculated descriptive statistics (n, %) for each barrier, combining “somewhat of a problem” and “a big problem” versus “no problem.” We then looked at the association between each barrier and race using chi-square tests. Using endorsement of 1) any barrier and 2) any cost-related barriers as outcome variables, logistic regression was used to assess the associations with sociodemographic and clinical characteristics, both in unadjusted and adjusted models. For all logistic regression analyses, odds ratios (ORs) and 95% confidence intervals (CIs) were reported. We conducted all statistical analyses using SAS version 9.3 (SAS Institute, Cary, NC), and $p < 0.05$ were considered statistically significant.

RESULTS

We sent surveys to 328 women (16 of whom were later deemed ineligible because they denied a history of breast cancer or reported treatment in the past 6 months); 237 responded (76%) and 203 agreed to participate and completed the survey (65%). Due to small cell sizes, we did not consider ethnicity and excluded 1 American Indian/Alaska Native, 2 people who identified as “Other” race, and 6 with missing race information. We also excluded 3 participants who were missing 4 or more of the 14 barriers questions, leaving a final sample size of 191 for analyses.

Study respondent characteristics by race are shown in Table 1. The majority of breast cancer survivors were White (84%), over the age of 50 years (78%), and had at least some college education (77%). Compared to White survivors, African American survivors were less likely to be married ($p<0.01$), have higher education ($p=0.038$) and health insurance ($p<0.001$).

Overall, 61.8% of survivors reported at least one barrier to follow-up care and 36.8% reported at least one cost-related barrier (see Table 2). The most common barriers identified were *going to the doctor makes you feel anxious or worried* (33%), *out-of-pocket medical costs are too high* (31.9%), *cannot afford other costs associated with getting care, like gas/travel or lost wages* (25.1%), and *insurance doesn't cover it* (21.7%).

African Americans were more likely to report at least one barrier (80.6% vs. 58.1%, $p=0.018$) and at least one cost-related barrier (58.6% vs. 32.7%, $p=0.0079$) compared to White survivors. Racial differences were noted for several barriers to care (see Table 2). African American survivors were more likely to identify the following barriers, compared to White survivors: *out-of-pocket medical costs are too high* (51.6% vs. 28.0%, $p=0.01$), *cannot afford other costs associated with getting care* (45.2% vs. 21.3%, $p=0.01$), *going to the doctors makes you feel anxious or worried* (51.6% vs. 29.4%, $p=0.02$), and *don't have transportation to get to a doctor* (16.1% vs. 4.4%, $p=0.03$). However, White survivors were more likely to identify distance to travel to get to a doctor as a barrier, compared to African Americans (18.8% vs. 3.2%, $p=0.03$).

Results of the logistic regression model for any barrier to follow-up care showed race was significantly associated with barriers to follow-up care in both unadjusted and adjusted models (Table 3). After adjustment, African American survivors were 3.29 times more likely (95% CI: 1.06–10.13) to report any barrier to follow-up care than White survivors. No other variables were significantly associated with reporting at least one barrier.

In the cost-related barriers model, African Americans were 2.92 times more likely (95% CI: 1.29–6.58) to report cost-related barriers to follow-up care than White survivors, but the effect of race was not significant in the adjusted model.

DISCUSSION

Our study examined the prevalence of 14 self-reported barriers to follow-up care among breast cancer survivors and potential differences by race. Over half of the survey respondents reported at least one barrier to follow-up care; the most common were anxiety or fear and financial concerns. Many cancer survivors experience fear and anxiety related to follow-up care [25] and previous reports have found associations between delaying care and fear of detecting cancer and anticipated sequelae [26, 27]. Studies have also found that 10–20% of cancer survivors delay or forgo medical care because of cost, with minority survivors at greater risk [28–30]. Similarly, a cross-sectional study of cancer survivors found that those who reported cancer-related financial problems were more likely to delay or forgo medical care [29].

We observed that African American breast cancer survivors were more likely to report barriers to care, even after accounting for various sociodemographic and clinical

characteristics. Initially, it appeared this may be due to the high prevalence of cost-related barriers, but there were no significant differences for financial barriers by race after controlling for covariates. Anxiety and fear of recurrence may be an important barrier for African American breast cancer survivors. A study by Peek and colleagues [31] found that African American women were afraid to get screened for breast cancer because they: (1) feared the results, (2) had previous negative experiences with the health care system, (3) had fatalistic views about cancer, and (4) used denial of symptoms as a coping mechanism. While these findings were specific to breast cancer screening, African American breast cancer survivors may have similar feelings and views regarding follow-up care, despite or because of their cancer experience.

Cost-related barriers were the most frequently reported barriers. Cancer can impose a significant financial burden on patients and their families, and many survivors continue to deal with the consequences long after treatment ends [32]. A study by Ramsey and colleagues [33] found that cancer survivors were more than twice as likely to file bankruptcy as people without a history of cancer. Even with health insurance, patients incur out-of-pocket expenses, such as copayments and deductibles. For those who are uninsured or underinsured, the burden can be even greater. The Patient Protection and Affordable Care Act (ACA) shows promise in expanding health insurance coverage [34]. However, it does not cover the indirect cost of care, for example lost wages and costs associated with inability to afford other costs associated with healthcare, which was one of the top five barriers identified in this study. It will be important to examine the impact the ACA will have on healthcare costs for cancer survivors.

There are several notable strengths in this study. First, we elected to focus on women with breast cancer because they constitute almost one-fourth of the cancer survivor population [1]. Second, we used well-established questions from national surveys. Finally, the overall response rate was 65%, which is excellent for this type of survey [35].

This study has several limitations. African American women had slightly lower response rates and small sample size. If non-respondents were also more likely to report barriers, we may have underestimated the prevalence of self-reported barriers to care among these women. The cross-sectional design also precluded us from examining longitudinal patterns of follow-up care use. Furthermore, our sample was from a single NCI-designated Comprehensive Cancer Center located in the Southeast, and results may not generalize to women with breast cancer in other settings. Despite these limitations, our results provide a foundation for identifying the barriers and potential needs of women with breast cancer, which is critical to facilitate appropriate follow-up care among cancer survivors, particularly minority and underserved survivors.

Barriers to follow-up care can be addressed through several approaches. First, addressing financial issues should be an integral part of cancer survivorship care programs. Second, patient navigators or facilitated support groups can be an important resource for cancer survivors with a variety of issues and concerns [36], particularly underserved minority survivors [37]. A qualitative study examining African American breast cancer survivors' psychosocial needs found peer-based support may be a culturally salient resource for

African American women, providing health information and navigation, comfort and support, and economic and functional relief [37]. Third, psychosocial interventions show promise in reducing anxiety, depressive symptoms, overall distress, and improving quality of life [38], which may promote appropriate follow-up care use among survivors. Studies have indicated peer counseling [39], communication coaching [40], use of imagery [41], and mindfulness-based stress reduction [42] show promise in improving psychosocial outcomes, particularly anxiety and distress, among breast cancer survivors. And lastly, individualized survivorship care plans are a promising approach to addressing low compliance with following-up care and surveillance recommendations among African American breast cancer survivors [43].

In conclusion, African American breast cancer survivors are more likely to report barriers to cancer-related follow-up care. Assessing cancer survivors' barriers to follow-up care may help identify specific patients at risk for not complying with recommended follow-up care and specific barriers to target for future interventions. Future studies should assess if survivors' reported barriers are associated with delay or forgone medical care, specifically cancer-related care and potential impact on survivors' health outcomes.

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- How much of a problem has it been for you to get follow-up care after breast cancer because of the following reasons?**
- 1) Your out-of-pocket medical costs are too high
 - 2) Your insurance doesn't cover it
 - 3) You cannot afford other costs associated with getting care (like gas/travel or lost wages)
 - 4) You don't know a good doctor
 - 5) You don't know which doctor you are supposed to see for care
 - 6) You have too many doctors to see
 - 7) You don't know how frequently you need to be seen
 - 8) You find it too difficult to schedule an appointment
 - 9) Going to the doctor makes you feel anxious or worried
 - 10) You have to travel too far to get to a doctor
 - 11) You don't have transportation to get to a doctor
 - 12) You don't have time to go to the doctor
 - 13) Going to the doctor inconveniences your family
 - 14) Child care is a problem
 - 15) Are there any other reasons it has been challenging to get cancer-related follow-up care? What are these?

Figure 1.
Barriers to Follow-up Care Questions

Table 1

Characteristics of study participants, stratified by race

	Total n=191		African American n=31		White n=160		p-value
	N	(%)	N	(%)	N	(%)	
Age at diagnosis (yrs)							0.55
<50	42	(22.0)	9	(29.0)	33	(20.6)	
50-59	66	(34.6)	12	(38.7)	54	(33.8)	
60-69	52	(27.2)	6	(19.4)	46	(28.8)	
70+	31	(16.2)	4	(12.9)	27	(16.9)	
Residence at survey							0.15
Rural	71	(37.2)	8	(25.8)	63	(39.4)	
Urban	120	(62.8)	23	(74.2)	97	(60.6)	
Marital Status*							<0.01
Married/living together	129	(67.9)	12	(40.0)	117	(73.1)	
Not married	61	(32.1)	18	(60.0)	43	(26.9)	
Education							0.04
High school or less	44	(23.0)	12	(38.7)	32	(20.0)	
Some college/technical/vocational	57	(29.8)	4	(12.9)	53	(33.1)	
College graduate	46	(24.1)	6	(19.4)	40	(25.0)	
Some/finish graduate school	44	(23.0)	9	(29.0)	35	(21.9)	
Employment							0.34
Full-time or part-time	89	(46.6)	12	(38.7)	77	(48.1)	
Other	102	(53.4)	19	(61.3)	83	(51.9)	
Insurance*							<0.01
None	11	(5.8)	7	(22.6)	4	(2.5)	
Private	116	(61.1)	13	(41.9)	103	(64.8)	
Public	15	(7.9)	6	(19.4)	9	(5.7)	
Both private and public	48	(25.3)	5	(16.1)	43	(27.0)	
Time since diagnosis							0.53
< 18 months	59	(30.9)	7	(22.6)	52	(32.5)	
18 months - < 2 years	52	(27.2)	10	(32.3)	42	(26.3)	

	Total n=191		African American n=31		White n=160		p-value
	N	(%)	N	(%)	N	(%)	
2 + years	80	(41.9)	14	(45.2)	66	(41.3)	

* missing observations

Table 2

Reported barriers to follow-up care, stratified by race

	Total n=191		African American n=31		White n=160		p-value
	N	(%)	N	(%)	N	(%)	
Out-of-pocket medical costs are too high ^a	60	(31.9)	16	(51.6)	44	(28.0)	0.01
Insurance doesn't cover it ^a	40	(21.7)	8	(27.6)	32	(20.6)	0.41
Cannot afford other costs associated with getting care ^a	48	(25.1)	14	(45.2)	34	(21.3)	0.01
Don't know a good doctor	12	(6.4)	2	(6.7)	10	(6.3)	0.94
Don't know which doctor you are supposed to see for care	19	(9.9)	3	(9.7)	16	(10.0)	0.96
Too many doctors to see	27	(14.1)	7	(22.6)	20	(12.5)	0.14
Don't know how frequently you need to be seen	30	(15.7)	7	(22.6)	23	(14.4)	0.25
Find it too difficult to schedule an appointment	13	(6.8)	1	(3.2)	12	(7.5)	0.39
Going to the doctor makes you feel anxious or worried	63	(33.0)	16	(51.6)	47	(29.4)	0.02
Have to travel too far to get to a doctor	31	(16.2)	1	(3.2)	30	(18.8)	0.03
Don't have transportation to get to a doctor	12	(6.3)	5	(16.1)	7	(4.4)	0.03
Don't have time to go to the doctor	23	(12.1)	4	(13.3)	19	(11.9)	0.82
Going to the doctor inconveniences your family	18	(9.4)	2	(6.5)	16	(10.0)	0.54
Child care is a problem	4	(2.1)	0	-	4	(2.5)	0.38
<u>Across all 14 barriers</u>							0.02
At least one barrier is somewhat/big problem	118	(61.8)	25	(80.6)	93	(58.1)	
<u>Across 3 cost barriers ^a</u>							0.01
At least one cost barrier is somewhat/big problem	67	(36.8)	17	(58.6)	50	(32.7)	

Note: Numbers shown present barriers reported as somewhat or a big problem.

^a cost-related barriers

Table 3

Associations of Any Barrier to Follow-up Care among Breast Cancer Survivors (n=191)

	Unadjusted		Adjusted	
	OR	95% CI	OR	95% CI
Race				
White	reference		reference	
African American	3.00	1.17–7.72	3.29	1.06–10.13
Residence at survey				
Urban	reference		reference	
Rural	0.92	0.5–1.68	1.26	0.63–2.49
Age at Diagnosis				
< 50	reference		reference	
50–59	0.51	0.22–1.22	0.50	0.19–1.31
60–69	0.36	0.15–0.89	0.46	0.15–1.37
70+	0.38	0.14–1.03	0.40	0.1–1.55
Marital Status				
Married/living together	reference		reference	
Not married	1.92	0.99–3.72	1.68	0.78–3.62
Education				
Some/Completed Graduate School	reference		reference	
College Graduate	1.45	0.6–3.53	1.63	0.63–4.27
Some College/Technical/Vocational School	0.91	0.4–2.05	1.26	0.52–3.09
<= High School Graduate/GED	0.57	0.24–1.34	0.55	0.2–1.49
Employment				
Full or part time	reference		reference	
Other	0.76	0.42–1.37	1.12	0.5–2.51
Health Insurance Coverage				
Both Public and Private	reference		reference	
Private	1.92	0.97–3.78	1.46	0.57–3.76
Public	2.17	0.65–7.32	1.72	0.42–7.05
None	10.87	1.29–91.67	4.89	0.46–52.21
Time Since Diagnosis				
>= 2 years	reference		reference	
18 months to < 2 years	0.96	0.47–1.97	0.89	0.4–1.96
< 18 months	0.94	0.47–1.88	0.98	0.45–2.13

Table 4

Associations of Cost Barriers to Survivorship Care among Breast Cancer Survivors (n=182)

	Unadjusted		Adjusted	
	OR	95% CI	OR	95% CI
Race				
White	reference		reference	
African American	2.92	1.29–6.58	2.46	0.93–6.56
Residence at survey				
Urban	reference		reference	
Rural	1.12	0.6–2.09	1.88	0.91–3.89
Age at Diagnosis				
< 50	reference		reference	
50–59	0.77	0.35–1.73	1.02	0.41–2.59
60–69	0.76	0.33–1.75	1.40	0.48–4.14
70+	0.41	0.14–1.16	0.75	0.18–3.11
Marital Status				
Married/living together	reference		reference	
Not married	1.70	0.89–3.23	1.29	0.59–2.81
Education				
Some/Completed Graduate School	reference		reference	
College Graduate	1.06	0.45–2.53	1.25	0.47–3.28
Some College/Technical/Vocational School	1.04	0.46–2.37	1.58	0.62–4.01
<= High School Graduate/GED	0.81	0.33–2.01	0.65	0.22–1.96
Employment				
Full or part time	reference		reference	
Other	0.75	0.41–1.38	0.83	0.36–1.92
Health Insurance Coverage				
Both Public and Private	reference		reference	
Private	2.05	0.92–4.56	2.04	0.71–5.83
Public	4.80	1.35–17.08	4.82	1.14–20.43
None	28.77	3.21–257.9	31.01	2.67–360.5
Time Since Diagnosis				
>= 2 years	reference		Reference	
18 months to < 2 years	0.80	0.38–1.68	0.75	0.33–1.73
< 18 months	0.79	0.39–1.61	0.76	0.33–1.72