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Recruitment of a population-based sample of young Black women with breast cancer through a state cancer registry

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Abstract

Purpose—Given that Black women remain underrepresented in clinical research studies, we sought to recruit a population-based sample of young Black women with breast cancer through a state cancer registry.

Methods—Demographic and clinical information on all Black women diagnosed with invasive breast cancer at or below age 50 between 2009–2012 in Florida was obtained through the state cancer registry. Survivors were invited to participate in the study through state-mandated recruitment methods. Participant demographic and clinical characteristics were compared using Chi-square tests for categorical variables and the two sample t-test for continuous variables to identify differences between: 1) consented participants versus all other eligible; and 2) living versus deceased.

Results—Of the 1647 young Black women with breast cancer, mean age at diagnosis was 42.5, with the majority having localized or regional disease, unmarried, privately insured, and employed. There were no significant differences in demographic and clinical variables between the 456 consented study participants versus the remaining 1191 presumed eligible individuals. Compared to potential participants, women determined to be deceased prior to recruitment (n=182) were significantly more likely to have distant disease and a triple negative phenotype. They were also significantly more likely to be unemployed, and uninsured or have public insurance (i.e., Medicaid or Medicare).

Conclusion—Our results demonstrate that recruitment of a population-based sample of breast cancer survivors through a state cancer registry is a feasible strategy in this underserved and underrepresented population. However, survival bias, which was observed due to the lag time between diagnosis and recruitment, is important to adjust for when generalizing findings to all young Black breast cancer patients.

Keywords

Breast cancer; Cancer Registry; African American women

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Conflict of interest - None

INTRODUCTION

Studying breast cancer in young Black women is particularly important given the increased incidence of and mortality rates from early onset breast cancer compared to the Caucasian population (1). Black women are typically underrepresented in research studies, in part due to challenges in recruitment (2,3). Successful approaches for reaching Black women have generally involved an element of personal communication at initial contact (4,5), particularly in the oncology care setting (6). However, these recruitment approaches are limited in the ability to generate a representative sample. Other sampling frames which may be used to recruit large numbers of participants include private or public health insurance plans, health care systems, or academic institutions; however, these methods lead to a systematic underrepresentation of Blacks who are more likely to be uninsured or have limited access to health services compared to non-Hispanic Whites (7).

In contrast to the afore mentioned recruitment approaches and sampling frames, the use of a state cancer registry represents a means by which to ensure representation of minority women from a wide sociodemographic profile including those who are uninsured and/or treated in the community at non-academic centers. Furthermore, the registry-based recruitment enables comparisons between demographic and clinical variables of participants versus non-participants and between living and deceased individuals to assess for potential response and survival bias. Prior efforts based in the United States (US) have recruited samples of breast cancer survivors through state cancer registries (8–10), yet none have focused solely on recruitment of young Black women nor compared participants and non-participants to assess sample representativeness specific to this racial strata.

The objectives of the current study were to: 1) evaluate the extent to which a sample of young Black women recruited through the Florida state cancer registry demonstrate similar demographic and clinical characteristics compared to all other Black breast cancer survivors within the sampling frame; and 2) explore survival bias that may result from this approach.

MATERIALS AND METHODS

Eligible participants were self-identified Black women diagnosed with invasive breast cancer at or below age 50 between the years 2009–2012 who were living in Florida at the time of diagnosis, alive at time of recruitment, and spoke English. Upon approval of the study protocol through the institutional review boards (IRB) of the University of South Florida and the Florida Department of Health (DOH), registry-based recruitment was initiated to a study focused on the etiology and outcomes of young Black women diagnosed with invasive breast cancer. The Florida State Cancer Registry released patient contact information, and available clinical (i.e., age at diagnosis, stage of diagnosis, histologic subtype) and demographic (i.e., county of residence, marital status, primary payor at diagnosis) information on all eligible participants and de-identified information on deceased Black women diagnosed with breast cancer during that time period. The lag time between diagnosis and availability of contact information from the registry ranged from 6–18

months. Additionally, Vital Records were searched for updated vital status information for those reported as living prior to recruitment.

Participants were recruited using previously described state-mandated recruitment methods (11), which consisted of 2 mailings, 3 weeks apart, including a 'telephone response card', which gave patients the option to either decline (i.e., indicating that they did not wish to be contacted by phone) or express interest in participation (i.e., indicating that they were interested in having the study team call them to follow-up). Information provided in the initial mailing included a study specific letter which indicated that the purpose of the study was: to find out why young African American women get certain types of breast cancer and how genetic, hormonal and lifestyle factors may be involved as well as to understand the impact of breast cancer on their quality of life. The letter also indicated that participation included: 1) completion of a questionnaire either by mail or telephone regarding health history and lifestyle factors; 2) speaking with a genetic counselor by phone to collect family history and discuss the chance that breast cancer might run in the family; and 3) collection of a saliva sample for genetic testing to evaluate for hereditary breast cancer predisposition.

If no response to the initial mailing was received within 3 weeks of the second mailing, a study team member contacted the patient by phone to explain the study and determine interest in participation. In those willing to participate, written informed consent was secured through mailing the informed consent to all potential participants who expressed interest in the study. Study coordinators then reviewed the consent form and answered participants' questions over the telephone. The participants then signed the consent form and returned it in a postage paid envelope provided to them. In addition, study participation included completion of medical records release, study questionnaires and a genetic consultation during which time risk assessment and counseling for inherited breast cancer were completed. Following the genetic consultation, a saliva sample was collected for DNA extraction and *BRCA* testing was performed.

Demographic and clinical characteristics were summarized using descriptive statistics, including means, standard deviations, and frequencies, for the following groups: 1) all presumed eligible survivors; 2) those known to be deceased prior to or within their respective recruitment wave; and 3) subgroups consisting of those who consented versus all other eligible survivors. Comparisons were made using Chi-square tests for categorical variables and the two sample t-test for age at diagnosis to assess for differences between: 1) consented participants versus all other eligible; and 2) living versus deceased. All statistical tests were 2-sided and considered statistically significant at a level of $p = 0.05$.

RESULTS

Of the 1,886 Black women reported to the cancer registry with invasive breast cancer diagnosed in 2009–2012, 182 were determined to be deceased prior to or within one week after attempting active telephone recruitment (Figure 1). In those eligible according to cancer registry data, 57 were deemed ineligible primarily due to lack of English speaking ($n=24$) and failure to self-identify as Black ($n=15$). After exclusion of those ineligible, 1647 young Black women were presumed or confirmed to meet eligibility criteria and were

included in the sampling frame, of whom 456 were consented between June 2011 to June 2014. Of the remaining 1191 presumed eligible women, contact was established in 426 of them. A total of 182 declined participation and the remaining 244 either expressed interest but failed to consent or were undecided at the time the study was closed to recruitment. Thus, among the 882 women in whom contact was established, 51.7% consented to the study and 20.6% declined.

Among women in the sampling frame, the mean age at diagnosis was 42.5, and the majority had localized or regional disease, and were unmarried, privately insured, and employed at the time of diagnosis (as summarized in Table 1). There were no statistically significant differences in demographic or clinical characteristics between the 456 who consented to the study compared to the remaining living women in the sampling frame.

Comparisons between those in the sampling frame and the 182 women known to be deceased revealed several statistically significant differences (Table 2). The deceased group demonstrated higher proportions with distant disease and a triple negative phenotype. They were also more likely to be unemployed and uninsured or have public insurance (i.e., Medicaid or Medicare).

DISCUSSION

Our results suggest that recruitment through a state cancer registry is a feasible means of enrolling a large population-based sample of recently diagnosed Black breast cancer survivors, who represent the overall sampling frame with respect to available clinical and demographic variables. Furthermore, the survival bias in our sample included an overrepresentation of breast cancer patients with early stage and less aggressive (non-triple negative) disease. Additionally, survivors tended to have higher socioeconomic status indicators, such as private insurance and employment.

Recruitment of Black women through US-based state cancer registries is generally more challenging compared to recruitment of non-Hispanic White women. For example, results of the Carolina Breast Cancer Study (CBCS) (12, 13), reported that contact rates were lowest among young Black women despite the use of a rapid ascertainment system implemented to contact patients soon after diagnosis. More recently, two population-based studies used state cancer registries in Michigan and Pennsylvania to evaluate access to genetic services in breast cancer survivors, however minority representation was limited in both (14, 15). Specifically, the Michigan study of women diagnosed with breast cancer below age 50, reported that response rates were much lower in Blacks (35.8%) compared to Whites (64.0%) (14). Consequently, there was underrepresentation of Blacks among participants (8.3%) compared to non-participants (21.3%). Similarly, the Pennsylvania study had underrepresentation of Blacks, which comprised 10% of the population, but only 6% of study participants (15). Despite the challenges in recruitment of Black breast cancer survivors, our findings demonstrate that state cancer registry based recruitment remains a highly feasible means to enroll a large representative sample of this “hard to reach” population.

Many prior US-based efforts (including the three studies cited above (12, 14,15)) have not consistently reported on comprehensive demographic and clinical comparisons between participants and non-participants or between living and deceased individuals.. In contrast, a German cohort study of various cancer types reported that having population-based cancer registry data for both participants and non-participants was important to demonstrate recruitment of a generalizable sample (16). These results are similar to our findings which demonstrate the generalizability of our sample of living Black breast cancer survivors according to available demographic and clinical characteristics. This finding bolsters our confidence in using data from participants to make inferences about all young Black breast cancer survivors in Florida. However, statistical adjustments may be necessary to account for differences between the survivors and deceased if conclusions based on participants' data are to be generalized to all young Black women with breast cancer. For example, the proportion of young black women with triple negative breast cancer would be underestimated if relying solely on participant data because the proportion of triple negative cancer among those who are deceased is much higher.

Prior efforts suggest that state cancer registries represent an invaluable method to recruit large numbers of participants compared to community-based efforts. For example, an Australian study compared recruitment of breast cancer patients through a state-based cancer registry to a community awareness program (17). Findings indicated that only 16% of participants recruited through the registry actively refused participation, similar to our findings. Furthermore, community-based recruitment was much more difficult and labor-intensive yielded fewer participants when compared to registry-based recruitment. Similarly, community-based recruitment through an African American sorority to enhance participation in cancer genetics research also demonstrated very limited accrual (18). An older U.S.-based study also suggested recruitment through the Wisconsin Cancer Registry was a highly efficient means to recruit a large number of breast cancer survivors for clinical research (10). These findings reiterate that access to a large state cancer registry with a diverse population was instrumental in our ability to successfully recruit a sizeable sample of young Black women with breast cancer.

Although state cancer registries represent an important and effective strategy to recruit large samples of participants, this method also poses unique challenges. First, most registries have a recruitment protocol that is exclusively or largely focused on mailed contact, sometimes only after treating physician "approval". Some also allow for telephone follow up calls after a set number of mailings. However, these protocols largely limit opportunities to integrate face-to-face personal communication at first contact, particularly among "hard to reach" minority populations such as Black women (19). Furthermore, allowable procedures for research recruitment through registries vary by state, with the majority allowing active follow-up, with an opt-out approach, (20) analogous to that used in our study. However, the active follow-up strategy used most frequently is for investigators to secure passive consent from physicians, in contrast to our Florida-based protocol which did not require physician notification before recruitment (20). Interestingly, prior studies to evaluate patient perspectives on research recruitment through cancer registries have indicated a preference to be directly contacted by researchers to determine interest in study participation as was done in our study, rather than checking with treating physicians first (20, 21). Ultimately, it is not

surprising that variability in recruitment protocols of state cancer registries greatly impacts participation rates, with higher rates associated with more contact intensity (22). These prior studies suggest that our state mandated protocol was instrumental in our ability to recruit a population-based sample of young Black breast cancer patients, given that multiple contacts were allowed including follow-up by mail and phone and the ability to actively consent, unless the individual opted out of any contacts.

Other factors which likely contributed to our recruitment success include our efforts to target recruitment materials developed and refined through our prior studies, our statewide outreach efforts to raise awareness about inherited breast cancer in Black women (as outlined on our website: www.bgreatinitiative.com), and ongoing guidance on recruitment strategies from our longstanding community-academic partnership with our community advisory panel (23–26). Consistent with previous studies (27–29), this academic-community partnership was likely instrumental in the recruitment success achieved by the study team.

Finally, given that there was an average lag of 6–18 months between breast cancer diagnosis and availability of contact information from the cancer registry, survival bias in our sample is not surprising. Specifically, our results demonstrate that eligible living women in our sampling frame were significantly different from those in the population who were deceased. As expected, the deceased group demonstrated higher proportions with distant and/or triple negative aggressive disease phenotype. They were also more likely to be unemployed and uninsured or have public insurance (i.e., Medicaid or Medicare), all of which may be considered surrogates of lower socioeconomic status (SES). This observation is consistent with prior data from other populations demonstrating indicating that a significant association between SES and breast cancer survival remains even after controlling for other clinical and demographic factors, co-morbidities, and treatment (30, 31). One means to mitigate survival bias include the development of a rapid ascertainment mechanism as developed in the CBCS efforts (12–13), which is currently unavailable through our Florida state cancer registry.

There were a number of strengths in the current study, including the culturally-sensitive approach used to optimize participant recruitment methods and materials, and the large sample size of young Black breast cancer survivors recruited to the study. Another strength was our registry-based study design which allowed us to compare participants and non-participants, enabling us to demonstrate the recruitment of a representative sample of eligible living women (based on available clinical and demographic variables) and to compare our sampling frame with those in the population who were deceased. Despite these strengths, there remain some limitations, including the reliance on self-identification as Black and the exclusion of non-English speakers, which were the most common reasons for ineligibility. Also, we were unable to confirm that all those presumed eligible actually were and it is likely that some of them were also non-English speakers or did not self-identify as Black. Other limitations include the incomplete data for certain variables, particularly employment status and triple negative status. Data on triple negative status was incomplete because the registry did not begin systematically collecting information on HER2 receptor status until 2010, later in the study period. Although the proportion of missing data were similar among the participants and non-participants, receptor status was less likely to be

known among the deceased. It is possible that the proportion of triple negative cancer could differ even more between the living and deceased. Finally, even though our sample of participants appears to be similar to the non-participants, there could be some differences between these groups on other variables, such as cancer family history, that are not captured in the registry data.

In summary, our findings indicate that state cancer registries represent a feasible means by which a large representative sample of young living Black breast cancer survivors may be recruited for clinical research studies. However, the lag time between diagnosis and contact results in survival bias; thus it is important to account for this when trying to generalize to the population of all young Black women with breast cancer (living and deceased). Using these recruitment methods, studies can inform future research efforts to reduce health disparities faced by underserved and understudied Black women with breast cancer.

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Figure 1. Breakdown of the population, sampling frame, participants, and non-participants

^a Includes those who died prior to or within one week after attempting active telephone recruitment

^b Includes 24 non-English speaking, 15 who did not self-identify as Black, and 5 who reported not having invasive breast cancer.

Table 1

Clinical and Demographic Comparisons

	Deceased Versus Living			Consented Versus Other Presumed Eligible		
	Deceased N=182	Living N=1647	P-value	Consented N=456	Other Eligible N=1191	P-value
Mean age at Diagnosis (SD)	42.5 (5.9)	42.5 (6.3)	0.98	42.1 (6.05)	42.6 (6.4)	0.13
Stage at Diagnosis (n (%))						
Localized	26 (14.3)	810 (49.2)	<0.001 **	239 (52.4)	571 (47.9)	0.09
Regional	61 (33.5)	684 (41.5)		187 (41.0)	497 (41.7)	
Distant	84 (46.2)	116 (7.0)		22 (4.8)	94 (7.9)	
Unstaged	11 (6.0)	37 (2.2)		8 (1.8)	29 (2.4)	
Histologic Subtype (n (%))						
Ductal	140 (76.9)	1323 (80.3)	<0.001 **	359 (78.6)	964 (80.9)	0.32
Lobular	2 (1.1)	73 (4.4)		27 (5.9)	46 (3.9)	
Mixed	4 (2.2)	113 (6.9)		30 (6.6)	83 (7.0)	
Other/Unknown	36 (19.8)	138 (8.4)		40 (8.8)	98 (8.2)	
ER/PR/HER2 Receptor Status Known (n (%))	77 (42.3)	1067 (64.8)	<0.001 **	300 (65.7)	767 (64.4)	0.60
Receptor Status (n (%))						
Triple-negative	41 (53.2)	266 (24.9)		80 (26.7)	186 (24.3)	0.41
Not triple-negative	36 (46.8)	801 (75.1)	<0.001 **	220 (73.3)	581 (75.7)	
Marital Status (n (%))						
married (including common law)	70 (38.5)	697 (42.3)	0.48	179 (39.3)	518 (43.5)	0.21
not married	107 (58.8)	919 (55.8)		270 (59.2)	649 (54.5)	
unknown	5 (2.7)	31 (1.9)		7 (1.5)	24 (2.0)	
Insurance at Diagnosis (n (%))						
Not Insured	24 (13.2)	161 (9.8)	<0.001	47 (10.3)	114 (9.6)	0.88
Private Insurance	71 (39.0)	954 (57.9)		257 (56.4)	697 (58.5)	
Medicaid	55 (30.2)	265 (16.1)		75 (16.4)	190 (16.0)	
Medicare	15 (8.2)	66 (4.0)		21 (4.6)	45 (3.8)	
Other Insurance	13 (7.1)	177 (10.7)		51 (11.2)	126 (10.6)	
Unknown	4 (2.2)	24 (1.5)		5 (1.1)	19 (1.6)	

	Deceased Versus Living			Consented Versus Other Presumed Eligible		
	Deceased N=182	Living N=1647	P-value	Consented N=456	Other Eligible N=1191	P-value
Employment at Diagnosis (n (%))						
Unemployed	21 (14.8)	184 (11.2)	0.004 *	52 (11.4)	132 (11.1)	0.81
Employed	88 (48.4)	1007 (61.1)		283 (62.1)	724 (60.8)	
Unknown	67 (36.8)	456 (27.7)		121 (26.5)	335 (28.1)	
Metropolitan (n (%))	169 (92.9)	1581 (95.9)	0.05 *	438 (96.1)	1143 (96.5)	0.94

* <0.05
** <0.001