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Are cancer registries a viable tool for cancer survivor outreach? A feasibility study

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Abstract

Purpose—Little is known about cancer survivors' receptivity to being contacted through cancer registries for research and health promotion efforts. We sought to: (1) determine breast and colorectal cancer (CRC) survivors' responsiveness to a mailed survey using an academic medical center's cancer registry; (2) assess whether responsiveness varied according to sociodemographic characteristics and medical history; and (3) examine the prevalence and correlates of respondents' awareness and willingness to be contacted through the state cancer registry for future research studies.

Methods—Stage 0–III breast and CRC survivors diagnosed between January 2004 and December 2009 were identified from an academic medical center cancer registry. Survivors were mailed an invitation letter with an opt-out option, along with a survey assessing sociodemographic characteristics, medical history, and follow-up cancer care access and utilization.

Results—A total of 452 (31.4%) breast and 53 (22.2%) CRC survivors responded. Willingness to be contacted through the state cancer registry was high among both breast (74%) and CRC (64%) respondents even though few were aware of the registry and even fewer knew that their information was in the registry. In multivariable analyses, tumor stage I and not having a family history of cancer were associated with willingness among breast and CRC survivors, respectively.

Conclusions—Our findings support the use of state cancer registries to contact survivors for participation in research studies.

Implications for cancer survivors—Survivors would benefit from partnerships between researchers and cancer registries that are focused on health promotion interventions.

Keywords

survivors; breast neoplasms; colorectal neoplasms; registries; recruitment

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1. Introduction

The US cancer survivor population is projected to grow from over 13 million survivors [1] in 2012 to approximately 18 million by 2020 [2]. Delivery of comprehensive survivorship care is necessary to prevent and reduce late effects as well as ensure long-term survival [3]. For breast and colorectal cancer (CRC) survivors who comprise one-third of the total cancer survivor population [4] and for whom specific surveillance guidelines have been developed, post-treatment screening is critical for early detection of new and recurrent cancer, improved survival, and decreased mortality [5–8].

Despite the benefits of post-treatment screening, studies consistently show that breast and CRC survivors do not adhere to recommended guidelines. Regardless of differences in study design (definitions of adherence, measurement, and tests), rates of mammography and colonoscopy among survivors are no better than screening rates in average-risk populations. Post-treatment screening rates for mammography range from 53–92% [9–18] and for CRC screening with colonoscopy, they range from 18–80% [19–26]. More importantly, rates decline over time, or tests are not done consecutively at recommended intervals for either mammography [10, 11, 27] or colonoscopy [6, 20, 25]. Adherence rates to follow-up office visits or other recommended tests for breast [28] or CRC [13, 23, 25] survivors are even lower.

Most post-treatment screening studies of breast and CRC survivors have been conducted within clinic settings in which survivors have access to healthcare; thus, little is known about whether adherence is a problem at the population-level. Cancer registries may represent a viable tool for measurement of post-treatment screening and early detection behaviors among the growing population of survivors. Registries may also provide opportunities to promote comprehensive survivorship care at a population-level by notifying survivors about the importance of following recommended guidelines. Historically, registries have collected data for cancer outcomes research with little direct patient contact [29]. Few have used registries for health promotion interventions with survivors, perhaps due to concerns regarding the best way to approach survivors given patient confidentiality laws and the potential for privacy violation [30].

Little is currently known about survivors' receptivity to being contacted through cancer registries for research and health promotion efforts. Accordingly, our study objectives were threefold: (1) determine breast and CRC survivors' responsiveness to a mailed survey using an academic medical center's cancer registry; (2) assess whether responsiveness varied according to sociodemographic characteristics and medical history; and (3) examine the prevalence and correlates of respondents' awareness and willingness to be contacted through the state cancer registry for future research studies. As this represents an exploratory study, no *a priori* hypotheses were made regarding correlates of willingness.

2. Methods

All stage 0–III breast and CRC survivors diagnosed between January 2004 and December 2009 (n=1,750; 1,510 breast, 240 CRC) and listed in an academic medical center cancer registry were identified. Duplicate survivors were removed in addition to a single male breast cancer case, resulting in a final recruitment sample of 1,680 survivors (1,441 breast, 239 CRC). All survivors were randomized based on gift card incentive (\$10, \$20, or entry into a lottery for a \$100 gift card). In July 2011, survivors were mailed an invitation letter that indicated the type and amount of the incentive along with a survey that assessed sociodemographic characteristics, medical history, and access and utilization of follow-up cancer care. Letters utilized a passive consent procedure and included an option to opt-out.

Responses were collected through March 2012. This study was approved by the institutional reviews boards of the University of Texas Health Science Center at Houston and UT Southwestern Medical Center/Simmons Cancer Center.

2.1. Measures

Outcome variables—We assessed breast and CRC survivors' response rates to the mailed survey. Awareness of the state cancer registry was assessed with two questions: whether they were aware of the state cancer registry and whether they were aware that their cancer information was listed in the state cancer registry. Survivors were also asked whether they would be willing to be contacted through the state cancer registry for future research studies.

Correlates—Sociodemographic variables included age, sex, race/ethnicity, incentive level, marital status, and education were obtained by self-report except in the following cases. If survivors' birth dates were missing or unclear, then birth date in the registry, was used to calculate age. If race/ethnicity differed between registry and self-report data, we used survivors' self-report.

Medical history variables examined included cancer type, tumor stage, years since diagnosis, family history of cancer, and whether the respondent saw a genetic counselor. The first three variables were obtained via registry data while the family history and genetic counselor variables were based on self-report. Tumor stage was classified according to American Joint Committee on Cancer, 6th edition [31].

Access and utilization of follow-up cancer care were assessed with four self-report variables: insurance status, whether follow-up care was received in 2010–2011, type of provider seen for follow-up care, and overall health status. Response categories for all variables are described in Table 1.

2.2. Data Analysis

We compared survey response rates for all breast and CRC survivors in the recruitment sample ($n=1,680$). In stratified analyses by cancer type, we examined whether responsiveness varied by sociodemographic and medical history correlates available in the registry ($n=1,441$ for breast, $n=239$ for CRC). We tested whether breast and CRC survey respondents differed on awareness of and willingness to be contacted for future research through the state cancer registry ($n=442$ for breast, $n=52$ for CRC). To examine correlates of willingness to be contacted, we stratified analyses by cancer type and used all of the correlates listed above. We used chi-square tests for all comparisons; statistical significance was based on $p < .05$.

To identify correlates of willingness that remained significantly associated in multivariable analyses, we ran logistic regressions in which all variables with a $p < .25$ [32] were included unless highly correlated with another covariate of interest (e.g., family history and genetic counselor visits).

3. Results

3.1. Survivors' Responsiveness to Contact from Academic Medical Center Cancer Registry

Breast cancer survivors had significantly higher survey response rates than CRC survivors (31.4% and 22.2%, respectively, Table 1). Approximately 22.2% of breast cancer survey respondents were in situ (stage 0) patients whereas all CRC survey respondents were diagnosed at stage I and higher. Within cancer type (breast and CRC), there were significant

differences in the characteristics of those who responded to the survey. Breast cancer survivors who were 50–64 years of age, non-Hispanic White, randomized to a \$20 incentive, diagnosed with a stage I tumor, and less than 5 years since diagnosis were more likely to respond to the survey (Table 1). Among CRC survivors, responsiveness only varied significantly by race/ethnicity, with CRC respondents largely of non-Hispanic White race/ethnicity.

3.2. Comparison of Breast and CRC Respondent Characteristics

Breast cancer respondents were more likely to be married/living with a partner in contrast to CRC respondents (67.1% vs. 48.1%; Table 1). Breast cancer respondents were more likely to report being diagnosed with a stage I tumor whereas CRC respondents were more likely to report a stage II diagnosis. Breast cancer respondents were also more likely to report: genetic counselor visits, private/VA insurance, receipt of follow-up care in 2010–2011, and an oncologist as the source for their follow-up care than were CRC respondents. Finally, breast cancer respondents were more likely to rate their overall health as “very good” whereas CRC respondents were more likely to rate their health as “good” to “fair/poor”.

3.3. Respondents’ Willingness to be Contacted through the State Cancer Registry

Among breast cancer survey respondents, willingness to be contacted through the state cancer registry for future research studies was high (74.4%) even though few were aware of the registry (15.8%) and even fewer knew that their information was in the registry (13.1%; Figure 1). Similarly, 63.5% of CRC respondents indicated willingness to be contacted through the state cancer registry, while only 17.3% reported awareness of the registry and 13.5% reported knowledge of being listed in the registry.

Factors significantly associated at $p < 0.25$ with willingness in univariable analyses differed for breast and CRC respondents (Table 2). Among breast cancer respondents, willingness was associated with younger age, being married or living with a partner, more formal education, being diagnosed with a lower stage tumor, and seeing a genetic counselor. Among CRC respondents, those reporting a family history of cancer were less willing to be contacted as were those who saw a genetic counselor, whereas receiving follow-up care in 2010–2011 was positively associated.

In the multivariable model for breast cancer respondents, only lower tumor stage remained associated with willingness (Table 2). In the multivariable model for CRC, only family history of cancer remained associated with willingness.

4. Discussion

Our response rate of 31.4% for breast cancer survivors was in the range reported by other studies using state and hospital-based cancer registries where response rates ranged from 9–83% [33–39]. In our CRC sample, 22.2% responded; other CRC studies reported response rates ranging from 23–47% [39–41]. Our response rate is likely at the low end of the range because we mailed the survey only once while other studies employed varying combinations of time- and resource-intensive methods such as physician notification and/or permission prior to participant mailings; participant opt-in feature; follow-up mailings and phone calls; and re-querying of registry databases for updated participant contact information [33–38, 40, 41].

Consistent with some previous research [34, 36], we found that younger (compared to older) and non-metastatic (compared to metastatic) breast cancer survivors and non-Hispanic White (compared to non-White) breast and CRC survivors were more likely to respond. We also observed that randomization to a \$20 gift card incentive (compared to \$10 and \$100

lottery) significantly increased breast cancer survivors' responsiveness to our mailed survey. Because only a few cancer registry studies to date have examined correlates of responsiveness [34–36, 40], additional research is warranted in order to identify specific subgroups of survivors who may require more targeted recruitment efforts. Moreover, given that our documented impact of incentives on responsiveness differs from the non-significant findings observed in similar albeit few studies, [39] further research is needed that explores the optimal denomination of incentive required to encourage survivors' responsiveness to recruitment through cancer registries.

Breast cancer survivors reported better follow-up cancer care access and utilization compared to CRC survivors. One potential explanation is the well-established breast cancer advocacy movement which has drawn intense public, scientific, and legislative attention to the need for breast cancer screening, diagnosis, and treatment as well as funding for these types of care [42–44]. In contrast, CRC has been notably under-represented in advocacy efforts despite being the second most common cancer in both women and men [45]. It may be that breast cancer survivors are more connected to the health care system prior to diagnosis (e.g., through annual screening mammograms), a pattern that persists into survivorship. Alternatively, greater follow-up care utilization may reflect breast cancer survivors' increased frequency of recommended follow-up care compared to that of CRC survivors. More frequent contact with the system may translate into increased cancer care. Gender differences may also explain the observed differences by cancer site, although we were unable to explore this given small cell sizes and low statistical power.

The fact that most breast and CRC respondents were willing to be contacted through the state cancer registry despite being unaware of it and unaware that their information was in the registry was noteworthy. Because awareness is low, survivorship research studies that recruit through registries should provide an introduction to the mission and purpose of state cancer registries. Research is needed to identify effective methods of educating and reassuring cancer patients about registries, including their purpose, type of data collected, potential for being contacted, and the safeguards in place to protect their privacy [30]. Researchers should also determine the best time to inform patients about the registry (e.g., at the time of or shortly following diagnosis or as a precursor to research recruitment [34, 46]). Our finding that, in contrast to breast cancer survivors, CRC survivors with a family cancer history were less willing to be contacted through the registry than those without a family history is not readily explained. It is possible that CRC survivors with a family history are concerned about intrusions into the privacy of family members who may not want this information disclosed. This explanation is consistent with our finding that willingness was lower among CRC survivors who had seen a genetic counselor. Additional research is needed to understand this differential pattern of association between breast and CRC survivors' family cancer history and willingness.

Our study had some limitations. There was a small available pool of CRC survivors from which to recruit resulting in a small sample of CRC respondents. Because our sample was drawn from an academic medical center cancer registry of largely non-Hispanic White patients with access to health care, our findings may have limited generalizability. Self-selection is another possible limitation; non-respondents to the survey differed from respondents on several characteristics for both breast and CRC survivors. We also did not compare self-report of follow-up cancer care access and utilization to data in the electronic medical record. Despite the fact that willingness to be contacted through the state cancer registry was high among survey respondents, it remains unknown whether these individuals would follow through with participation. Future studies should assess concordance between survivors' willingness to be contacted and their actual study participation. Finally, among the stage 0 (in situ) breast cancer patients recruited for this study, a handful opted out

because they reported not being diagnosed with cancer; others chose to respond but specified on the survey that they only had precancerous cells. These responses suggest that this subgroup may not self-identify as a cancer survivor. Researchers should be careful when describing and extending study invitations to in situ patients. Additional research is needed on how to best communicate their greater risk for breast cancer compared to the general population and the importance of continued surveillance.

Conclusion

Cancer registries have historically focused solely on collecting patient data; however, the opportunity exists for registries to help conduct health promotion interventions with survivors. Our finding that approximately two-thirds of survivors were willing to be contacted through the state cancer registry for research participation illustrates this unmet opportunity. Working with state registries for recruitment is cost effective both in terms of time and staff effort [36, 47] and may provide researchers with a method to disseminate efficacious health behavior interventions to survivors when funding has ended [36]. Moreover, recruitment of racially and ethnically diverse population-based samples is necessary to generalize findings to the larger survivor population [36, 47], an aspect which has been lacking in survivorship research given its predominant focus on clinic or hospital-based samples.

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Fig. 1.

Awareness of and willingness to be contacted through the state cancer registry for future research among breast and CRC survey respondents contacted through an academic medical center cancer registry in 2011, $p > .05$

Sociodemographics, medical history, and access and utilization of follow-up cancer care of breast and CRC survivors listed in an academic medical center cancer registry and survey respondents.

Table 1

Variables	Breast Registry Sample (n=1,441)				CRC Registry Sample (n=239)				Comparison Breast & CRC Respondents				
	Respondents		Non-respondents		p-value ^a		Respondents		Non-respondents		p-value ^b		p-value ^c
	n ^e	%	n ^e	%	n ^e	%	n ^e	%	n ^e	%			
Overall	452	31.4	989	68.6			53	22.2	186	77.8			
Sociodemographics													
Age (y)						0.004						0.896	0.252
49	63	13.9	210	21.2			5	9.4	16	8.6			
50–64	228	50.4	443	44.8			22	41.5	72	38.7			
65+	161	35.6	336	34.0			26	49.1	98	52.7			
Female sex							31	58.5	92	49.5		0.246	
Race/ethnicity						0.000						0.001	0.924
NH White	336	74.3	555	56.1			40	75.5	82	44.1			
NH Black	65	14.4	223	22.5			8	15.1	45	24.2			
Hispanic	37	8.2	150	15.2			3	5.7	39	21.0			
Other/unknown	14	3.1	61	6.2			2	3.8	20	10.8			
Incentive						0.002						0.145	0.140
\$10	145	32.1	329	33.3			12	22.6	68	36.6			
\$20	176	38.9	298	30.1			19	35.8	60	32.3			
\$100 lottery	131	29.0	362	36.6			22	41.5	58	31.2			0.006
Marital status ^d													
Married/living with partner	300	67.1					25	48.1					
Other	147	32.9					27	51.9					0.121
Education ^d													
<HS/HS diploma/GED	78	17.4					14	29.8					
Some college/tech degree	140	31.3					16	34.0					
Bachelor's degree	138	30.8					9	19.2					

Variables	Breast Registry Sample (n=1,441)				CRC Registry Sample (n=239)				Comparison Breast & CRC Respondents	
	Respondents		Non-respondents		Respondents		Non-respondents		p-value ^b	p-value ^c
	n ^e	%	n ^e	%	n ^e	%	n ^e	%		
Graduate degree	92	20.5			8	17.0				
Medical history										
Tumor stage ^e									0.298	0.000
0	81	22.2	147	18.3	0	0.0	6	3.4		
I	137	37.5	271	33.7	11	20.8	46	26.3		
II	114	31.2	265	32.9	26	49.1	66	37.7		
III	33	9.0	122	15.2	16	30.2	57	32.6		
Years since dx									0.632	0.300
<5 y	313	69.2	580	58.6	33	62.3	109	58.6		
5+ y	139	30.8	409	41.4	20	37.7	77	41.4		
Family cancer history ^d	132	29.2			14	28.0				0.859
Saw genetic counselor ^d	139	31.7			7	14.9				0.017
Access & utilization										
Insurance status ^d										0.010
Private/VA	298	67.0			21	44.7				
Medicare/Medigap/Medicaid	108	24.3			19	40.4				
County/none	39	8.8			7	14.9				
Received care in 2010–2011 ^d	403	89.2			39	73.6				0.001
Provider seen ^d										0.000
No one	48	10.6			14	26.4				
PCP	12	2.7			8	15.1				
Oncologist	313	69.3			25	47.2				
Both PCP & oncologist	79	17.5			6	11.3				
Overall health ^d										0.000
Excellent	61	13.7			5	9.8				
Very good	167	37.6			8	15.7				

Variables	Breast Registry Sample (n=1,441)				CRC Registry Sample (n=239)				Comparison Breast & CRC Respondents	
	Respondents		Non-respondents		Respondents		Non-respondents		p-value ^b	p-value ^c
	n ^e	%	n ^e	%	n ^e	%	n ^e	%		
Good	159	35.8			19	37.3				
Fair/poor	57	12.8			19	37.3				

CRC, colorectal; y, years; NH, non-Hispanic; HS, high school; GED, general equivalency diploma; tech, technical; VA, Veterans Affairs; PCP, primary care provider

^aP-value reflects comparisons between breast respondents and non-respondents and variables of interest.

^bP-value reflects comparisons between CRC respondents and non-respondents and variables of interest.

^cP-value reflects comparisons between breast and CRC respondents and variables of interest.

^dThese variables were ascertained by the survey; thus, data are only available for survey respondents.

^eMissing values ranged from 0 for most variables to 184 for tumor stage of breast non-respondents. Tumor stage was only collected consistently beginning in 2006.

Table 2

Distribution of characteristics and multivariate logistic regression models of breast and CRC survey respondents' willingness to be contacted through the state cancer registry for future research.

Variables	Willingness to be contacted ^a				Multivariate Models ^b			
	Breast (n=442)		CRC (n=52)		Breast (n=353) ^c		CRC (n=49) ^c	
	n ^d	%	n ^d	%	OR (95% CI)		OR (95% CI)	
Overall willingness	329	74.4	33	63.5				
Sociodemographics								
Age (y)								
49	54	90.0	3	60.0			2.96 (0.99–8.85)	
50–64	170	74.9	14	66.7			0.94 (0.54–1.63)	
65+	105	67.7	16	61.5			Reference	
Sex								
Female			20	64.5				0.848
Male			13	61.9				
Race/ethnicity					0.959		0.630	
NH White	244	74.2	27	67.5				
NH Black	47	73.4	3	42.9				
Hispanic	27	77.1	2	66.7				
Other/unknown	11	78.6	1	50.0				
Incentive					0.619		0.823	
\$10	108	75.0	7	58.3				
\$20	121	72.0	11	61.1				
\$100 lottery	100	76.9	15	68.2				
Marital status					0.080		0.585	
Married/living with partner	229	77.1	16	66.7			1.59 (0.93–2.72)	
Other	97	69.3	16	59.3			Reference	
Education					0.008		0.548	
<HS/HS diploma/GED	48	65.8	7	53.9			Reference	
Some college/technical degree	94	68.1	9	56.3			0.82 (0.41–1.67)	

Variables	Willingness to be contacted ^a				Multivariate Models ^b			
	Breast (n=442)		CRC (n=52)		Breast (n=353) ^c		CRC (n=49) ^c	
	n ^d	%	p-value ^e	n ^d	%	OR (95% CI)	OR (95% CI)	
Bachelor's degree	108	79.4		7	77.8	1.04 (0.49–2.21)		
Graduate degree	77	83.7		6	75.0	2.30 (0.91–5.80)		
Medical history								
Tumor stage			0.166					
0	54	66.7		0	0.0	Reference		
I	106	79.7		7	63.6	2.07 (1.07–4.01)		
II	85	75.2		14	56.0	1.35 (0.70–2.63)		
III	22	68.8		12	75.0	1.17 (0.47–2.94)		
Years since diagnosis			0.556					
<5 y	231	75.2		22	68.8			
5+ y	98	72.6		11	55.0			
Family cancer history			0.723					
No	233	74.0		27	75.0	Reference		
Yes	96	75.6		4	30.8	0.19 (0.04–0.83)		
Saw genetic counselor			0.008					
No	209	71.3		27	67.5	Reference		
Yes	114	83.2		3	42.9	1.27 (0.68–2.37)		
Access & utilization								
Insurance status			0.878					
Private/VA	219	75.0		14	66.7			
Medicare/Medigap/Medicaid	77	72.6		11	61.1			
County/none	27	73.0		4	57.1			
Follow-up care in 2010–2011			0.656					
No	37	77.1		7	50.0	Reference		
Yes	292	74.1		26	68.4	1.25 (0.75–2.08)		
Type of provider seen			0.918					
No one	36	76.6		7	50.0			
PCP	8	66.7		6	75.0			

Variables	Willingness to be contacted ^a				Multivariate Models ^b			
	Breast (n=442)		CRC (n=52)		Breast (n=353) ^c		CRC (n=49) ^c	
	n ^d	%	p-value ^e	n ^d	%	p-value ^f	OR (95% CI)	OR (95% CI)
Oncologist	228	74.5		16	66.7			
Both PCP and oncologist	57	74.0		4	66.7			
Overall health			0.986			0.722		
Excellent	44	73.3		3	75.0			
Very good	124	75.6		5	62.5			
Good	116	74.4		13	68.4			
Fair/poor	41	74.6		10	52.6			

CRC, colorectal; y, years; NH, non-Hispanic; HS, high school; GED, general equivalency diploma; VA, Veterans Affairs; PCP, primary care provider

^aNon-respondents to the willingness question (n = 10 for breast, n = 1 for CRC) were excluded from analyses.

^bVariables associated with willingness in univariable analyses (p<.25) were entered into multivariable models unless highly correlated with other variables. Shaded cells reflect those variables not entered into multivariable models.

^cBreast and CRC sample size was further reduced by 89 and 3, respectively, due to missing values on variables of interest.

^dMissing values ranged from 0 for most variables to 62 for tumor stage.

^eReflects univariable comparisons between breast respondents' willingness (no, yes) to be contacted and variables of interest.

^fReflects univariable comparisons between CRC respondents' willingness (no, yes) to be contacted and variables of interest.

^gReflects univariable comparison between willingness (no, yes) to be contacted and cancer type (breast, CRC).

OR, odds ratio; CI, confidence interval.