Cancer Surveillance Behaviors and Psychosocial Factors Among Long-Term Survivors of Breast Cancer:

Cancer and Leukemia Group B 79804

Mira L. Katz, PhD[1], **Kathleen A. Donohue, MA**[2], **Catherine M. Alfano, PhD**[1], **Jeannette M. Day, MS**[2], **James E. Herndon II, PhD**[2], and **Electra D. Paskett, PhD**[1]

[1]Ohio State University Comprehensive Cancer Center and College of Public Health, Columbus, Ohio

[2]Cancer and Leukemia Group B Statistical Center, Duke University Medical Center, Durham, North Carolina

Abstract

BACKGROUND—Little is known about cancer surveillance (mammography, clinical breast examination, and pelvic examination) behaviors in long-term (9–16 years) breast cancer survivors. This report describes the relation of these behaviors to demographic and clinical characteristics, psychological symptoms, body satisfaction, and social support.

METHODS—Survivors who had participated in Cancer and Leukemia Group B treatment Trial 8541 completed a survey that included questions on breast cancer surveillance and pelvic examination, psychological well being, body satisfaction, and social support.

RESULTS—The participation rate was 78% and included 245 breast cancer survivors. Survivors (n = 107; 44%) reported completing breast cancer surveillance (mammography and clinical breast

examination) and completing pelvic examination (n = 162; 68%) within recommended guidelines. There were no significant associations between breast cancer surveillance and breast cancer anxiety, depression, stressful life events, body satisfaction, social support, or demographic characteristics. Survivors within recommended guidelines for pelvic examinations were younger (*P* = .05), married (*P* = .003), had health insurance (*P* = .004), and had lower depression scores (*P* = .005) than survivors who underused or overused pelvic examination. In addition, survivors within recommended pelvic examination guidelines had significantly lower levels of breast cancer anxiety (*P* = .03) compared with survivors who underused pelvic examination.

CONCLUSIONS—Many long-term breast cancer survivors were not within recommended cancer surveillance guidelines. Private health insurance was associated with following recommendations for pelvic examinations, although such a relation did not exist for breast cancer surveillance. The results of this study have implications for the development of educational programs to improve cancer surveillance among the growing population of long-term breast cancer survivors.

Keywords

cancer survivorship; cancer surveillance; cancer screening; breast cancer

In the United States, over 2.4 million breast cancer survivors live with an increased risk for recurrence and second cancers, such as cancer of the contralateral breast or endometrial cancer.[1] To address this increased risk, national professional organizations have developed cancer surveillance guidelines and recommend that breast cancer survivors receive annual surveillance that includes evaluation of the breasts (mammography and clinical breast examinations) and gynecologic examination.[2–4] Previous studies have documented the prevalence of breast cancer surveillance among breast cancer survivors.[5–11] In general, these studies have documented the rates of mammography within recommended guidelines in the range of 60% to 92% among patients within 1 year after completing treatment or among breast cancer survivors within a few years after their diagnosis.[5–11] Breast cancer survivors who were most likely not to be within recommended surveillance guidelines were women who were older, not married, from a minority population, diagnosed at a later stage, had comorbidities, and were further in time from their original diagnosis.

Although there is increasing information available about the rates of cancer surveillance among breast cancer survivors, little is known about surveillance in long-term survivors (>5 years postdiagnosis) and the psychological well being and social support issues that may affect compliance with recommended surveillance guidelines among this group of survivors. This is important because previous studies have indicated that psychological distress may prevent adherence to recommended surveillance guidelines (breast and cervical) among healthy women and women who have an increased risk of breast cancer.[12–15] The objective of this study was to investigate the use of recommended breast cancer surveillance and pelvic examinations among a group of long-term (9–16 years) breast cancer survivors and examine how compliance with these surveillance behaviors may be associated with demographic characteristics and with psychological symptoms, body satisfaction, and social support.

MATERIALS AND METHODS

Participants

Participants were recruited into the current study (Cancer and Leukemia Group B [CALGB] 79804) from among 1572 patients with unilateral breast cancer who participated in a chemotherapy treatment trial (CALGB 8541) from 1985 to 1991.[16] At the beginning of the

current study, 314 women were alive, disease-free, and had their treating physician's approval to be contacted for participation. The surveys were returned by 245 women (78%). CALGB 79804 participants did not differ from CALGB 8541 survivors who were alive but did not participate, except that more whites versus nonwhites (*P*<.0001) agreed to participate in the current study. Of the 245 participants who completed surveys, 241 participants (98.4%) provided data on breast cancer surveillance, and 239 participants (97.6%) provided data on pelvic examination and were included in the analyses presented here.

Procedures

CALGB 79804 was approved by the institutional review board at each participating institution. Patient registration and data collection were managed by the CALGB Statistical Center. The patient's addresses, phone numbers, and disease status (alive and disease-free) were confirmed, and the patient's treating physicians were contacted for permission to approach the patients about the current study. A consent form and questionnaire were mailed to each eligible participant along with a postage-paid return envelope. Nonrespondents were contacted by telephone; and, if necessary, the consent form was returned by mail, and the survey was conducted by telephone (n = 8 respondents).

Measures

Demographic and clinical variables—Patient information was obtained from the CALGB 8541 database, including demographic characteristics, health insurance status, surgery type, estrogen receptor status, radiation therapy, original treatment arm (low-dose, standard-dose, or intensive-dose adjuvant chemotherapy), and date of treatment.

Cancer surveillance—Breast cancer surveillance and pelvic examination use were assessed by asking participants to report how many times in the past year they had the following examinations: mammogram (defined for participants as 'a special x-ray of the breast to detect breast cancer'), physical examination of the breast or breasts by a physician, and pelvic examination ('internal examination of the female organs') by a physician. Responses to each cancer surveillance item were categorized as zero times, 1 time, 2 times, 3 times, >3 times, or unknown.

Survivors were determined to be within recommended guidelines according to National Comprehensive Cancer Network (NCCN) recommendations.[4] Breast cancer surveillance was categorized as either complied with recommended guidelines (1 mammogram and 1 clinical breast examination in the past year) or did not comply with recommended guidelines (either >1 mammogram and/or >1 clinical breast examination in the past year or did not complete a mammogram or did not complete a clinical breast examination in the past year). Pelvic examination was categorized as either complied with recommended guidelines (1 pelvic examination in the past year) or did not comply with recommended guidelines (more than 1 pelvic examination in the past year or did not complete a pelvic examination in the past year).

Psychological symptoms—*Breast cancer anxiety* was assessed with a modified form of the Breast Cancer Anxiety and Screening Behavior Scale, a 21-item reliable and valid scale that assesses the intrusive and avoidant thoughts related to breast cancer as well as fear of recurrence.[17] We used 14 of the items on that scale that were relevant to breast cancer survivors and omitted 7 items that were relevant only to high-risk women or to breast cancer screening. Higher scores indicated more frequent breast cancer anxiety.

Depressive symptoms during the past week were measured with the Center for Epidemiologic Studies Depression Scale 20-item short form total score.[18] Higher scores indicated worse depression symptomology.

Stressful life events were assessed with the 11-item Life Events Scale[19] adapted from the Social Readjustment Rating Scale[20] to measure the occurrence of a variety of potentially stressful life events as well as the perceived emotional impact of the event. These events were not related to the diagnosis of breast cancer but reflected general stressful events (ie, spousal death, job loss, etc). Higher scores on this scale represented a worse burden of stressful life events.

Body satisfaction was assessed with the summed 10-item Self-Concept Scale, which assesses participants' satisfaction with different body areas and their weight.[21] With this scale, higher scores indicated greater body satisfaction.

Social support was measured with the 20-item Medical Outcomes Study Social Support Survey[22] total score. Higher scores indicated greater perceived social support.

Statistical Analysis

Descriptive statistics were used to describe participants' characteristics by breast cancer surveillance and pelvic examination use during the past year. The association between categorical variables and cancer screening was assessed using the Fisher exact test.[23] The relation between screening and age was analyzed using analysis of variance, and the relation between screening and 'time since enrollment' was analyzed using the Kruskal-Wallis test[24] because of non-normality of the data. Analysis of covariance models adjusted for age, relationship status, and private insurance status were used to generate adjusted means for psychological symptoms, body satisfaction, and social support for patient subgroups defined by breast cancer surveillance and pelvic examination use. All statistical tests were 2-sided, and the level of significance set at 5%. Statistical analyses were performed by statisticians at the CALGB Statistical Center (K.A.D., J.E.H., and J.M.D.).

RESULTS

Breast cancer survivors who participated in this study (n = 245 women) had a mean age of approximately 62 years. On average, the survivors were greater than 12 years since enrollment in the CALGB treatment trial (range, 9.3–16.4 years).

Cancer Surveillance Behaviors

Overall, 107 participants (44%) reported compliance to breast cancer surveillance recommendations. There were no significant differences in demographics or clinical characteristics for breast cancer survivors who did and did not comply (underused and overused) with recommended breast cancer surveillance (Table 1). Of those who did not comply (n = 134; 56%) with the NCCN-recommended guidelines for breast cancer surveillance, 102 women (76%) completed more surveillance and 32 women (24%) completed less surveillance than recommended. There was a trend (*P* = .07) for breast cancer survivors who completed more than the recommended breast cancer surveillance to be more likely to have health insurance compared with survivors who completed less than the recommended breast cancer surveillance.

Completing a pelvic examination within recommended guidelines was reported by 162 breast cancer survivors (68%). There were significant differences in mean age, health insurance, and marital status between breast cancer survivors who did and did not comply with recommended guidelines for pelvic examination. Survivors who reported undergoing a

pelvic examination within recommended guidelines were younger (*P* = .05), more likely to have health insurance (*P* = .004), and more likely to be married (*P* = .003) compared with breast cancer survivors who were not within recommended guidelines for pelvic examination (Table 2). Of those who did not comply (n = 77; 32%) with the NCCN-recommended guidelines for pelvic examination, 19 women (25%) completed more than an annual pelvic examination and 58 women (75%) did not complete an annual pelvic examination as recommended.

Relation Between Psychological Symptoms, Body Satisfaction, and Social Support by Cancer Surveillance Behaviors

Mean psychological well being scores, adjusted for age, marital status, and insurance coverage, are listed in Table 3 for survivors stratified by surveillance compliance with recommended guidelines. For breast cancer surveillance, there were no significant differences between women who did and did not comply (underuse and overuse) with recommended guidelines and breast cancer anxiety, depression, body satisfaction, or social support. There was a trend (5.03 vs 6.93; *P* = .08) for fewer life events among women who were within recommended guidelines compared with women who underused breast cancer surveillance.

Survivors who were within recommended guidelines for pelvic examination had significantly lower breast cancer anxiety (0.78 vs 0.93; *P* = .03), less depression (9.29 vs 12.78; *P* = .005), and had a trend for fewer life events (4.95 vs 6.27; *P* = .008) compared with survivors who had completed less than the recommended annual pelvic examination. In addition, breast cancer survivors who were within recommended guidelines for pelvic examination had less depression (9.29 vs 12.88; *P* = .005) compared with survivors who completed more than the recommended annual pelvic examination. The scores for breast cancer anxiety (0.78 vs 0.92) and stressful life events (4.95 vs 6.26) among those who completed more than an annual pelvic examination did not reach statistical significance because of the small number of survivors (n = 19) compared with survivors who were within recommended guidelines for pelvic examination. For pelvic examination use, there were no significant differences between women who did and did not comply (underuse and overuse) with recommended guidelines and body satisfaction or social support.

DISCUSSION

This study determined the prevalence of adherence to cancer surveillance (mammography, clinical breast examination, and pelvic examination) behaviors within recommended guidelines among long-term breast cancer survivors and the association of these behaviors with demographic and clinical characteristics, psychological symptoms, body satisfaction, and social support. On average, participants in this study were 12 years (range, 9–16 years) postentry into a chemotherapy treatment trial. Over half of the women (56%) self-reported not undergoing breast cancer surveillance within NCCN-recommended guidelines, and 32% of the women did not comply with the NCCN-recommended guidelines for pelvic examination. Of those who did not comply, 24% underused and 76% overused breast cancer surveillance, and 75% underused and 25% overused recommended annual pelvic examination. These findings are similar to previous studies that were conducted among women closer in time to cancer treatment and documented that many breast cancer survivors are not undergoing recommended cancer surveillance.[5–11] Thus, our findings may have implications for survival among this growing population of long-term breast cancer survivors.[25]

The current study, however, did not confirm the findings of previous studies that reported the lack of breast cancer surveillance among survivors who were older, unmarried, or from a

minority population.[5–11] The findings in the current study may be because of the limited number of older, unmarried, and minority women participating in the current study. In addition, the design of the original treatment study did not allow for a comparison of surveillance among participants who were diagnosed at a later stage of disease or based on physician specialty for follow-up after treatment.[5–11]

There were significant differences in demographic characteristics for women who reported having a pelvic examination within recommended guidelines compared with women not within guidelines in this study. Younger women and married women were more likely to be within recommended pelvic examination guidelines. In addition, women who lacked private health insurance were more likely not to comply with guidelines for receiving a pelvic examination. These findings are similar to studies reporting the completion of Papanicolaou (Pap) testing among women in the general population.[26–30]

To our knowledge, this is the first report examining the compliance of long-term breast cancer survivors to cancer surveillance and how compliance to these surveillance behaviors may be associated with psychological symptoms, body satisfaction, and social support. We were surprised that there were no significant psychosocial variables associated with breast cancer surveillance, because survivors report considerable cancer-related stress and anxiety,[31,32] and stress has been associated with screening among women at high risk for breast cancer.[13] There was a trend for more stressful life events among survivors who underused breast cancer surveillance, but there was no trend for breast cancer anxiety. It is possible that breast cancer-related stress and anxiety are not associated with breast cancer surveillance among long-term survivors (mean, 12 years after diagnosis).

This study, however, indicated that long-term breast cancer survivors who followed recommended guidelines for pelvic examination had significantly lower levels of breast cancer anxiety and depression and fewer reported stressful life events than survivors who did not comply with recommended annual pelvic examination. This result may reflect the breast cancer survivors' concern that their cancer has spread to a different body organ or site or another, unmeasured factor (eg, provider recommendation).[33]

The results of this study add to the increasing literature focusing on the need for interventions to promote continued cancer surveillance among long-term breast cancer survivors. Many long-term breast cancer survivors do not comply (underuse and overuse) with current surveillance recommendations for breast and pelvic examinations. Barriers to cancer surveillance may be at the patient, provider, or system level. These issues highlight the importance of physician-patient communication to avoid the known fragmented care that is received by many cancer survivors after the conclusion of their cancer treatment.[2] Although many of the cancer screening barriers in cancer survivors may be similar to the screening barriers identified in noncancer patients, future educational programs to improve surveillance in cancer survivors may benefit from addressing psychosocial and health-related quality-of-life issues associated with a specific cancer diagnosis and the fear of recurrence in this specific population.

Limitations of this study include its cross-sectional design, the reliance on self-report of cancer surveillance, and the generalizability of the findings to all populations, because many of women in this study were white, insured, and had some college education. Women in this study were categorized by NCCN guidelines to assess their compliance with cancer surveillance guidelines. If a woman was instructed by her healthcare provider to receive screening examinations on a different schedule because of symptoms or a family/personal history or if a woman was evaluated by multiple healthcare providers, then that information was not available. Another limitation was that it is known that the self-report of cancer

screening within a specific timeframe differs from a medicals record review, especially for cervical cancer screening examinations.[34,35] In addition, women had participated in a clinical cancer treatment trial and, thus, may have had access to more cancer-related health information. Future studies should investigate cancer screening behaviors in survivors using a prospective design with outcomes measured by a medical records review.

Despite these limitations, the current study provides a unique contribution to the existing literature by reporting the prevalence of cancer surveillance behaviors and its relation to the psychosocial well being of long-term breast cancer survivors. The results from this study have implications for the development of educational programs to improve cancer surveillance in this growing population. Because physician recommendation is the single most predictive facilitator to improve cancer screening rates among women in the general population,[27,33,36] it also may be an important facilitator among breast cancer survivors. Developing patient-level educational programs directed at improving knowledge and activating survivors to communicate with their healthcare providers about cancer surveillance may prove useful in the future to reduce cancer mortality in this population of survivors.

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Table 1

Demographic and Clinical Characteristics of Study Participants by Breast Cancer Surveillance (N=241)

| | Breast Cancer Surveillance: No. of Patients (%)[*] | | |
| | Within Guidelines, n = 107 | Not Within Guidelines, n = 134 | |
Characteristic		Underused, n = 32	Overused, n = 102
Age, y			
30–49	12 (11)	3 (9)	8 (8)
50–59	30 (28)	14 (44)	34 (33)
60–69	45 (42)	8 (25)	37 (36)
70	20 (19)	7 (22)	23 (23)
Mean±SD	62.8 (9.8)	61.6 (10.0)	61.3 (9.8)
Race			
White	103 (96)	28 (88)	95 (93)
Other	4 (4)	4 (13)	7 (7)
Education, y			
0–12	62 (58)	15 (47)	43 (42)
13–16	33 (31)	10 (31)	39 (38)
17–70	8 (7)	3 (9)	14 (14)
Income, $ US			
<$20,000	21 (20)	4 (13)	17 (17)
$20,000–$44,999	30 (28)	10 (31)	27 (27)
$45,000–$79,999	29 (27)	6 (19)	17 (17)
$80,000	14 (13)	5 (16)	25 (25)
Health insurance	103 (96)	27 (84)	102 (100)
Private	87 (81)	22 (69)	87 (85)
Medicare	45 (42)	11 (34)	40 (39)
Medicaid	6 (6)	2 (6)	4 (4)
None	4 (4)	4 (13)	0 (0)
Not reported	1 (1)	0 (0)	0 (0)
Marital status			
Single	7 (6)	2 (6)	6 (6)
Married/living as married	67 (68)	21 (69)	71 (70)
Separated/divorced/widow	33 (26)	8 (25)	25 (25)
Surgery type			
Mastectomy	88 (82)	27 (84)	74 (73)
Breast conservation	19 (18)	5 (16)	28 (27)
Estrogen receptor status			
Negative	32 (30)	11 (34)	33 (32)
Positive	72 (67)	19 (59)	65 (64)
Borderline	2 (2)	1 (3)	2 (2)
Radiation therapy			
No	86 (80)	27 (84)	71 (71)

	Breast Cancer Surveillance: No. of Patients (%)[*]		
	Within Guidelines, n = 107	Not Within Guidelines, n = 134	
Characteristic		Underused, n = 32	Overused, n = 102
Yes	20 (19)	5 (16)	30 (29)
Treatment arm: CALGB 8541			
Low dose	30 (28)	15 (47)	28 (27)
Standard dose	43 (40)	8 (25)	40 (39)
Intensive dose	34 (32)	9 (28)	34 (33)
Time since CALGB 8541 enrollment, y			
Mean±SD	12.431.9	12.631.6	12.231.8
Range	9.5–16.4	9.3–15.9	9.3–16.2

SD indicates standard deviation; CALGB, Cancer and Leukemia Group B.

[*] Frequencies may not add up to the sample size total because of missing data.

Table 2

Demographic and Clinical Characteristics of Study Participants by Pelvic Examination Use (n=239)

Characteristic	Pelvic Examination: No. of Patients (%)[*]		
	Within Guidelines (n=162)	Not Within Guidelines, n=77	
		Underused, n=58	Overused, n=19
Age, y			
30–49	18 (11)	2 (3)	2 (11)
50–59	49 (30)	22 (38)	5 (26)
60–69	70 (43)	15 (26)	6 (32)
70	25 (15)	19 (33)	6 (32)
Mean±SD; P=.05[†]	61.5 (9.5)	64.4 (9.6)	65.7 (10.9)
Race			
White	153 (94)	55 (95)	17 (89)
Other	9 (6)	3 (5)	2 (11)
Education, y[‡]			
0–12	75 (46)	30 (52)	13 (68)
13–16	57 (35)	19 (33)	6 (32)
17–70	18 (11)	7 (12)	0 (0)
Income, $ US			
>$20,000	22 (14)	15 (26)	3 (16)
$20,000–$44,999	45 (28)	15 (26)	7 (37)
$45,000–$79,999	34 (21)	13 (22)	5 (26)
$80,000	35 (22)	7 (12)	2 (11)
Health insurance; P=.004[§]	160 (99)	52 (90)	18 (95)
Private insurance	142 (88)	40 (69)	14 (74)
Medicare	58 (36)	28 (48)	9 (47)
Medicaid	8 (5)	2 (3)	1 (5)
None	2 (1)	6 (10)	0 (0)
Not reported	0 (0)	0 (0)	1 (5)
Marital status; P=.003[‡]			
Single	7 (4)	6 (10)	0
Married/living as married	120 (74)	28 (48)	12 (63)
Separated/divorced/widowed	35 (22)	24 (41)	7 (37)
Surgery type			
Mastectomy	127 (78)	47 (81)	14 (74)
Breast conservation	35 (22)	11 (19)	5 (26)
Estrogen receptor status			
Negative	56 (35)	13 (22)	6 (32)
Positive	100 (62)	43 (74)	12 (63)
Borderline	4 (2)	1 (2)	0
Radiation therapy			
No	123 (76)	46 (79)	14 (74)

	Pelvic Examination: No. of Patients (%)[*]		
	Within Guidelines (n=162)	Not Within Guidelines, n=77	
Characteristic		Underused, n=58	Overused, n=19
Yes	37 (23)	12 (21)	5 (26)
Treatment arm: CALGB 8541			
Low dose	49 (30)	20 (34)	4 (21)
Standard dose	57 (35)	23 (40)	11 (58)
Intensive dose	56 (35)	15 (26)	4 (21)
Time since CALGB 8541 enrollment, y[//]			
Mean±SD	12.431.8	12.431.8	11.931.6
Range	9.3–16.4	9.3–16.2	9.7–15.9

SD indicates standard deviation; CALGB, Cancer and Leukemia Group B.

[*] Frequencies may not add up to the sample size total because of missing data.

[†] The *P* value for this characteristic was calculated using an analysis of variance.

[‡] The *P* value calculation excludes missing data.

[§] The *P* value for this characteristic was calculated using a 2-sided Fisher exact test. Insurance coverage was categorized as 'have private insurance' versus 'do not have private insurance.'

[//] The *P* value for this characteristic was calculated using Kruskal-Wallis test.

Table 3

Psychological Symptoms, Body Satisfaction, and Social Support by Breast Cancer Surveillance and Pelvic Examination Use

Variable	Psychological Symptoms, Body Satisfaction, and Social Support: Mean±SD				
	Breast Cancer Anxiety	Depression	Stressful Life Events	Body Satisfaction	Social Support
Breast cancer surveillance*	n=230; P=.73	n=240; P=.32	n=239; P=.08	n=238; P=.47	n=241; P=.20
Recommended (n=107)	0.85±0.42	11.52±8.6	5.03±4.5	24.79±7.7	76.21±20.9
Underused (n=32)	0.81±0.41	13.53±8.8	6.93±5.4	24.03±7.4	69.05±25.8
Overused (n=102)	0.90±0.50	11.61±8.3	5.61±4.2	25.82±7.3	74.63±19.2
Pelvic examination*	n=230; P=.03	n=238; P=.005	n=237; P=.08	n=236; P=.58	n=239; P=.21
Recommended (n=162)	0.78±0.42[a]	9.29±7.5[a]	4.95±3.9	25.88±7.5	78.81±18.1
Underused (n=58)	0.93±0.48[b]	12.78±9.6[b]	6.27±5.4	24.41±7.7	74.38±22.6
Overused (n=19)	0.92±0.58[a,b]	12.88±8.6[b]	6.26±5.3	25.62±6.0	71.90±29.3

SD indicates standard deviation.

Results after controlling for age, marital status, and insurance coverage (categorized as "have private insurance" versus "do not have private insurance").

[a–b] difference: $p < .05$.