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Research Article

Cancer Epidemiology, Biomarkers & Prevention

Accuracy of Perceived Risk of Recurrence Among Patients With Early-Stage Breast Cancer

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Abstract

Background: Accurate breast cancer recurrence risk perceptions might motivate health-promoting behaviors and alleviate undue anxiety. Although a few studies have examined early-stage breast cancer survivors' perceived risk of recurrence, none have assessed the accuracy of survivors' perceived risk of recurrence.

Methods: First primary ductal carcinoma *in situ* and early-invasive breast cancer survivors reported their perceived risk of recurrence during 6- and 12-month postsurgery interviews. We estimated the patients' 10-year risk of recurrence from published clinical trials, and for early-invasive breast cancer patients, risk of distant recurrence was based on their breast cancer–specific mortality calculated using *Adjuvant! Online*. Patients' perceived risk was compared with their calculated risk and categorized as "Accurate," "Underestimated," "Overestimated," and "Uncertain." Multinomial logit marginal effect models were fitted using Accurate as the reference.

Results: Only 17% of 531 patients accurately perceived their risk at 6 months, most of whom inaccurately perceived their risk at 12 months ($P = 0.0143$). Patients who were nonwhite [odds ratio (OR), 1.70; 95% confidence interval (95% CI), 1.12-2.56] and received radiation therapy (OR, 2.01; 95% CI, 1.07-3.77) were more likely to underestimate their risk. Patients with ductal carcinoma *in situ* (OR, 1.69; 95% CI, 1.08-2.70), lower social support (OR, 0.71; 95% CI, 0.53-0.95), and anxiety (OR, 1.58; 95% CI, 1.01-2.47) were more likely to overestimate their risk.

Conclusion: Few breast cancer survivors accurately perceived their risk of recurrence.

Impact: The accuracy of perceived risk may be increased by better physician-patient communications about their prognosis, provision of social support, and treatment for coexisting anxiety. *Cancer Epidemiol Biomarkers Prev; 19(3); 675–80. ©2010 AACR.*

Introduction

Early-stage breast cancer survivors are living longer but remain at risk of developing recurrence or new primary cancers after initial treatment (1). However, breast cancer patients often do not know their risk of recurrence. Perceived risk of recurrence has been positively correlated with cancer-specific worries (2) and anxiety (3) and could influence long-term adherence to follow-up care because engagement in health-promoting behaviors has been associated with one's perceived susceptibility of disease (4). Demographic and psychosocial factors as well as tumor characteristics and the treatment received could influence patients' recurrence risk perceptions (4-6). A few studies have reported on breast cancer patients' perceived risk of recurrence (3, 5, 6), but little is known about the accuracy of patients' risk perceptions. We sought to assess the accuracy of early-stage breast cancer patients' recurrence risk perceptions and identify the demographic, clinical, and psychosocial characteristics associated with the accuracy of their perceived risk.

Patients and Methods

Women with newly diagnosed first primary breast cancer (stages 0-IIA) at the Siteman Cancer Center and at Saint Louis University School of Medicine were invited to participate in a longitudinal quality-of-life study. The Institutional Review Boards at both institutions approved the study. Eligible participants were English speaking, had completed definitive surgical treatment,

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and were ages ≥40 y, as annual screening mammography is recommended for this age group (7) and ductal carcinoma *in situ* (DCIS) and small (<2 cm) tumors are commonly detected by mammography. Patients who had a prior history of breast cancer, received neoadjuvant chemotherapy, or showed cognitive impairment on the Orientation-Memory-Concentration Test (8) were excluded.

Measures

After consenting, patients completed computer-assisted telephone interviews 4 to 6 wk, 6 mo, and 1 y following their definitive surgery. We used validated measures of social support (9), anxiety (10), and comorbidity (11). We developed an eight-item measure of breast surgery–associated side effects (Supplementary Table), with higher scores indicating more severe side effects (Cronbach's $\alpha = 0.81$). We asked patients if they knew the type of breast cancer they had, expecting that recurrence risk perceptions would be lower in DCIS than early-invasive breast cancer (EIBC) survivors, and whether they had a family history of breast cancer (first-degree relatives). We also asked patients "What do you think the chances are that you will have this disease again someday?" to measure their perceived risk of recurrence, using a 0% to 100% scale (12). We defined "recurrence" broadly as a recurrence in the same breast or in other organs or a metachronous contralateral breast cancer. We categorized their responses into one of six groups: 0%, 1% to 9%, 10% to 24%, 25% to 49%, ≥50%, and uncertain (12). Breast cancer pathology and treatment data were abstracted from medical records.

Table 1 presents how each patient's individualized risk of recurrence was determined. For DCIS patients receiving breast-conserving surgery (BCS), the 10-y risk of recurrence, including local and distant recurrence and contralateral breast cancer, was estimated based on results of randomized trials (13-15). Regardless of type of adjuvant therapy, the risk of recurrence was estimated to be 7% for DCIS patients receiving mastectomy (16, 17). For EIBC patients receiving mastectomy, the 10-y risk of local recurrence was derived from a meta-analysis of 25 randomized trials (1). Because postmastectomy adjuvant systemic therapy does not significantly influence the risk of local recurrence (1), we did not consider adjuvant systemic therapy in the estimation of risk of local recurrence after mastectomy. For EIBC patients receiving BCS, the 10-y estimated risk of local recurrence varied with types of adjuvant therapy received and nodal status (1). The 10-y risk of distant recurrence among EIBC patients was estimated using *Adjuvant! Online*, a Web-based program that predicts 10-y risks of mortality and recurrence (based on age at diagnosis, tumor size, tumor grade, number of positive nodes, estrogen receptor status, and comorbidity) and the benefit of systemic adjuvant therapy for EIBC patients (18). The annual risk of contralateral breast cancer was estimated to be 0.6% for EIBC patients who had an intact contralateral breast (19) and 0.1% for EIBC patients who underwent bilateral mastectomy (20). The estimated 10-y risk of recurrence was a sum of estimates of local recurrence, distant recurrence, and contralateral breast cancer. The *Adjuvant!*-derived proportional risk reductions were used to estimate the efficacy of adjuvant systemic therapy on all types of recurrence (18).

Calculated estimated risks of recurrence were categorized as 1% to 9%, 10% to 24%, 25% to 49%, and ≥50%, corresponding to these categories of patients' perceived risk.

Statistical Analysis

We contrasted patients' perceived risk-of-recurrence categories with their calculated risk categories, creating four accuracy-of-perceived-risk categories: underestimated (perceived < calculated risk), accurate (patient's perceived risk fell in the same category as her calculated risk), overestimated (perceived > calculated risk), or uncertain (patients reported not knowing their risk).

Bowker's test of symmetry was used to evaluate the within-subject change in the accuracy of perceived risk from 6 to 12 mo after surgery. We performed multinomial logistic regression analyses with a generalized logit link function to evaluate independent risk factors of each inaccurate-risk-perception category using accurate as the reference category.

The generalized estimating equations method (SAS procedure PROC GENMOD) was used to model the log odds of each of overestimation, underestimation, and uncertain categories over a follow-up period as a function of a series of potential predictors, including age at diagnosis, race, education, marital status, family history of breast cancer, cancer stage, type of surgery, radiotherapy, chemotherapy, adjuvant hormone therapy, breast surgery side effects, knowledge of one's type of breast cancer, social support, and anxiety. We report odds ratios (OR) with 95% confidence intervals (CI). Statistical analyses were done using SAS 9.1. Two-sided P values of <0.05 were considered statistically significant.

Results

Of 772 eligible patients, 549 (71%) completed the baseline interview 4 to 6 weeks after surgery; of these 549, 537 (98%) completed the 6-month postsurgery interview, and 527 (96%) completed the 12-month postsurgery interview. A larger proportion of participants than nonparticipants were white (80% versus 64%, $P < 0.001$), with no significant differences in age, cancer stage, or type of surgery between participants and nonparticipants.

Because patients had not completed adjuvant chemotherapy and radiotherapy until 6 months postsurgery, the accuracy of patients' recurrence risk perceptions was assessed at the 6- and 12-month interviews. We excluded two patients with subsequent contralateral breast cancer from analysis. Due to insufficient medical record information about type of adjuvant hormone therapy, tumor size, or nodal status, we could not calculate individualized risk for 17 patients at 6-month follow-up

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and for 7 patients at 12-month follow-up. Because the generalized estimating equation method copes with missing observations by using all available data, the analysis included 531 patients whose perceived risk could be assessed at either or both the 6- and 12-month follow-up. Characteristics of the sample are shown in Table 2. Of 344 patients with BCS, 21(6.1%) did not receive radiotherapy.

Table 1. The 10-y cumulative risk estimates of local and distant recurrence and contralateral breast cancer among women with early-stage breast cancer at 6 mo after definitive breast surgery by cancer stage (references shown in parentheses)

	No. of our patients	Local recurrence	Contralateral breast cancer	Local recurrence + contralateral breast cancer	Distant recurrence
Patients with DCIS					
BCS alone	4	33% (15)	5% (15)		3% (15)
BCS + radiation therapy	40	16% (15)	7% (15)		2% (15)
BCS + tamoxifen	7			32% (14)	1%*
BCS + radiation therapy + tamoxifen	49			14% (13, 14)	1% (13)
Mastectomy	69	1% (17)	5% (16)		1% (17)
Patients with EIBC and negative nodes					
BCS alone	4	44% (1)	6% (19)		14%†
BCS + radiation therapy	32	15% (1)	6% (19)		7%†
BCS + systemic adjuvant therapy	17	25%‡	6% (19)		7%†
BCS + radiation therapy + systemic adjuvant therapy	159	8%§	6% (19)		5%†
Mastectomy alone	92	8% (1)	6%‖ (19)		7%†
Mastectomy + radiation therapy	7	3% (1)	6%‖ (19)		7%†
Patients with EIBC and positive nodes					
BCS alone	0	61%¶	6% (19)		–**
BCS + radiation therapy	0	18%††	6% (19)		–**
BCS + systemic adjuvant therapy	2	34%‡	6% (19)		30%†
BCS + radiation therapy + systemic adjuvant therapy	12	8%§	6% (19)		13%†
Mastectomy alone	13	28% (1)	6%‖ (19)		13%†
Mastectomy + radiation therapy	3	8% (1)	6%‖ (19)		11%†

NOTE: The 10-y cumulative risk estimates were calculated as 1 – (1 – annual risk estimates)[10], in which the annual risk estimates were derived from the literature cited or from the calculations specified in the following footnotes.

*The risk of distant recurrence was estimated based on the annual risk estimate of distant recurrence in DCIS patients who received BCS alone and proportional risk reductions after radiation therapy (18%) and after radiation therapy plus tamoxifen use (79%).

†The risk was estimated based on the annual risk of one's breast cancer–specific mortality that was calculated using *Adjuvant! Online* and was adjusted by a weighting factor (1.6 for estrogen receptor (ER)-positive cases, 1.1 for ER-negative cases, and 1.4 for unknown ER status; ref. 18). For analysis, comorbidity scores of 0, 1, 2, 3, 4, and ≥5 corresponded to the categories used in *Adjuvant! Online*, namely perfect health, minor problems, average for age, major problems (+10), major problems (+20), and major problems (+30), respectively.

‡The mean value of individualized risk estimates that were calculated using the following equation: annual risk after BCS plus systemic adjuvant therapy = annual risk after BCS alone × (1 – proportional risk reduction due to systemic adjuvant therapy). The proportional risk reduction due to each type of chemotherapy and adjuvant hormone therapy was obtained from the *Adjuvant! Online* program.

§The mean value of individualized risk estimates that were calculated using the following equation: annual risk after BCS plus radiation therapy and systemic adjuvant therapy = annual risk after BCS plus radiation therapy × (1 – proportional risk reduction due to systemic adjuvant therapy).

‖The risk estimates were 1% for patients with bilateral mastectomy (Herrinton et al., 2005).

¶The risk of 17% that was obtained from the literature (Clarke et al., 2005) was added to the risk estimates due to positive nodes (44% + 17% = 61%).

**No risk estimate was presented because no patient was in that group (n = 0).

††The risk of 3% that was obtained from the literature (Clarke et al., 2005) was added to the risk estimates due to positive nodes (15%+3% = 18%).

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Figure 1 shows the participants' perceived risk of recurrence at the 6-month interview and their calculated risk of recurrence. At that time, 17% accurately perceived their risk, 44% underestimated their risk, and 21% overestimated their risk. This pattern of recurrence risk perceptions changed 6 months later ($P = 0.0143$); 66% of 87 patients with accurate risk perceptions at the 6-month interview inaccurately perceived their risk and only 17% of patients with inaccurate risk perceptions at the 6-month interview accurately reported their risk at 12 months.

To evaluate factors associated with overestimation, underestimation, and uncertain categories, three multinomial logit marginal effects models with repeated measures were fitted separately using accurate as the reference category (Table 2). Patients with a diagnosis of DCIS, lower social support, and greater anxiety were

Table 2. Multivariable analysis of factors associated with each of three categories of inaccurate perception of risk of recurrence in women with early-stage breast cancer, using accurate as the reference category of response

	n	Overestimated		Underestimated		Uncertain	
		OR	95% CI	OR	95% CI	OR	95% CI
Race							
White	428	1.00		1.00		1.00	
Nonwhite	103	0.59	0.34-1.01	1.70	1.12-2.56	1.02	0.59-1.78
Education							
High school or lower	163	1.00		1.00		1.00	
Some college or higher	368	0.82	0.55-1.20	1.25	0.90-1.74	1.00	0.61-1.63
Marital status							
Nonmarried/nonpartnered	209	1.00		1.00		1.00	
Married/partnered	319	1.17	0.77-1.76	0.93	0.65-1.32	1.01	0.64-1.60
Family history of breast cancer							
No	386						
Yes	122	1.36	0.94-1.98	1.05	0.77-1.44	0.78	0.50-1.23
Cancer stage							
Early Invasive breast cancer	352	1.00		1.00		1.00	
DCIS	179	1.76	1.11-2.79	0.59	0.39-0.89	0.70	0.40-1.25
Type of surgery							
BCS	344	1.00		1.00		1.00	
Mastectomy	187	0.99	0.46-2.15	1.09	0.57-2.07	0.59	0.23-1.53
Radiation therapy							
No	190						
Yes	341	0.61	0.28-1.31	2.01	1.07-3.77	0.67	0.27-1.64
Chemotherapy							
No	401						
Yes	130	1.16	0.70-1.91	0.81	0.51-1.28	1.23	0.69-2.18
Adjuvant hormone therapy							
No	189						
Yes	338	1.22	0.83-1.80	0.95	0.67-1.35	0.71	0.32-1.80
State anxiety (BAI ≥10 in the past week)							
No	423						
Yes	108	1.58	1.01-2.47	0.63	0.41-1.01	1.06	0.58-1.94
Having knowledge of type of breast cancer							
Yes	366						
No	164	0.77	0.51-1.17	1.16	0.81-1.65	1.69	1.04-2.77
	Mean (SD)						
Age at diagnosis	58 (11)	0.98	0.96-1.00	1.01	0.99-1.02	1.04	1.02-1.06
Side effects of breast surgery	1.5 (0.6)	1.18	0.85-1.63	0.91	0.66-1.26	1.10	0.66-1.81
Social support	4.4 (0.7)	0.71	0.53-0.95	1.02	0.82-1.28	1.44	0.88-2.38

Abbreviation: BAI, Beck Anxiety Inventory.

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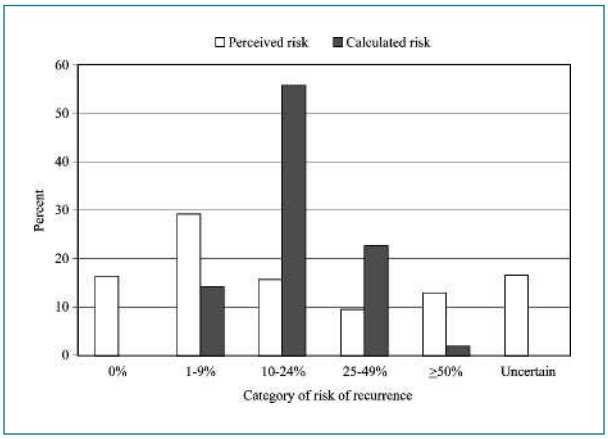

Figure 1. Distributions of early-stage breast cancer patients' perceived risk of recurrence and individualized calculated risk of recurrence at 6 mo after definitive surgical treatment.

more likely to overestimate their risk. Patients who were nonwhite (92% of whom were African-American) and who underwent radiotherapy were more likely to underestimate their risk. Knowledge of type of breast cancer was not significantly associated with overestimating or underestimating one's risk.

Older patients and patients who did not know their type of breast cancer were more likely to be uncertain about their risk.

Discussion

To our knowledge, this is the first study to evaluate the accuracy of breast cancer survivors' recurrence risk perceptions by comparing their perceived risk with individualized recurrence risk estimates based on the results of randomized clinical trials and calculations using *Adjuvant! Online*. Only 17% of patients accurately perceived their risk of recurrence at the 6-month follow-up, most of whom inaccurately reported their risk 6 months later.

Nonwhite patients were more likely than white patients to underestimate their risk of recurrence. The role of higher perceived risk in motivating screening mammography in women without a history of breast cancer (21) suggests that underestimating one's risk of recurrence might contribute to being less likely to receive posttreatment surveillance mammography in African-American patients compared with white survivors (22).

Although DCIS patients generally have a lower risk of recurrence after treatment and only ~1% die from breast cancer (17), DCIS patients were more likely than EIBC patients to overestimate their risk of recurrence. DCIS patients seem to lack awareness about their better prognosis relative to EIBC. The similarity in treatment options for DCIS and most stage I patients might explain DCIS patients' overestimation of their risk. Although physicians review recurrence risk benefits of treatment options with patients before surgery, they seldom provide actual risk assessments.

Breast cancer survivors often feel uncertain about treatment and the future. Social support is important in helping breast cancer survivors cope with disease uncertainty and maintain a good quality of life (23). Consistent with the literature, we found that patients with greater availability of support were less likely and patients reporting greater anxiety were more likely to overestimate their risk of recurrence.

Interestingly, patients who received radiotherapy were more likely to underestimate their risk of recurrence. Radiotherapy is the standard of care for patients who receive BCS to reduce the chance of local recurrence. Patients who received radiotherapy might believe they had less severe disease and thus were at lower risk for recurrence after completing treatment or they might view radiotherapy as having a greater benefit in reducing their risk of recurrence than it actually has.

This study has limitations. Our sample did not include patients age <40 years, the age group at greatest risk for recurrence (24); therefore, we cannot generalize our findings to this younger age group. Because *Adjuvant! Online* has limited ability to estimate risks of local recurrence and contralateral breast cancer and there is a paucity of clinical trials about the potential effects of tumor pathology and age at diagnosis on local recurrence and contralateral breast cancer risks, our literature-based method to individualize our patients' risk of recurrence was limited. Additionally, we were unable to consider the contributions of BRCA1/2 germline mutations to patients' risk of recurrence. Inclusion of these factors in our risk estimates (had they been available) might have altered the accuracy of patients' calculated risk of recurrence. Validating our calculated estimates against patients' actual risk of recurrence remains to be seen. Next, a larger proportion of participants than nonparticipants were white, possibly resulting in selection bias. Nonwhite participants were younger than nonwhite nonparticipants, and younger patients tended to overestimate their risk. Therefore, the age difference between nonwhite participants and nonwhite nonparticipants did not seem to bias our findings because nonwhite participants were more likely than white participants to underestimate their risk. Finally, comparisons of survivors' estimated 10-year cumulative risk with their perceived lifetime risk might have led more patients to be categorized as overestimating their risk. However, because 89% of first recurrences identified from a 20-year follow-up of EIBC patients had occurred within the first 10 years after the initial diagnosis (25), our assumption that the estimated 10-year cumulative risk of recurrence approximates the estimated lifetime risk is likely valid.

In conclusion, most of our patients inaccurately perceived their risk of recurrence, although most knew the type of breast cancer they had. Accurate recurrence risk perceptions might be achieved by educating patients

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about their prognosis and how the types of breast cancer and various treatments affect their risk of recurrence, providing social support, and identifying and treating coexisting anxiety. Therefore, this study could provide insight into designing interventions to promote more accurate risk perceptions in breast cancer survivors, which could have implications for psychological and behavioral outcomes (e.g., becoming overly anxious or not adhering to recommended follow-up care).

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

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Cancer Epidemiology, Biomarkers & Prevention

Correction: Accuracy of Perceived Risk of Recurrence among Patients with Early-Stage Breast Cancer

In this article (1), which was published in the March 2010 issue of *Cancer Epidemiology, Biomarkers & Prevention*, the last sentence of the Results section of the abstract incorrectly reported the odds ratio and 95% confidence interval as "(OR, 1.69; 95% CI, 1.08-2.70)" for patients with ductal carcinoma *in situ*. The correct sentence should read "Patients with ductal carcinoma *in situ* (OR, 1.76; 95% CI, 1.11-2.79), lower social support (OR, 0.71; 95% CI, 0.53-0.95), and anxiety (OR, 1.58; 95% CI, 1.01-2.47) were more likely to overestimate their risk."

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