

Effect of oncologist-based counseling on patient-perceived breast cancer risk and psychological distress

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Women often seek reassurance from oncologists regarding their risk of developing breast cancer. Patient-perceived risk frequently is higher than calculated estimates of risk. We assessed perceived breast cancer risk, perceived *BRCA1/2* mutation carriage risk, and anxiety measured by the Brief Symptom Inventory-18 in 81 high-risk clinic patients before and immediately after risk counseling by an oncologist. Pre-counseling risk perceptions were much higher than calculated risk estimates. Perceived risk decreased significantly after counseling but continued to exceed calculated estimates and was correlated with pre-counseling perception. Post-counseling anxiety scores also declined but remained strongly correlated with pre-counseling anxiety scores and patient risk perceptions. Change in risk perceptions after counseling differed among physicians; change in anxiety levels did not. We conclude that oncologist-based counseling is effective in reducing anxiety despite persistent inaccuracy in patients' perceived risk of developing breast cancer.

Although one out of eight women will receive a breast cancer diagnosis over the course of her life,¹ this risk is distributed unevenly in the population, with higher risk being evident in women with clinically important mutations of tumor suppressor genes, a family history of breast cancer, or benign pathology known to predispose to future breast cancer development.²⁻⁸ Since the publication of the National Surgical Adjuvant Breast and Bowel Project (NSABP) P-1 study,⁹ there has been considerable interest in identifying patients at risk to assess prevention and early-detection options.

Increased public awareness of the risk of breast cancer development and the need for early detection does appear to motivate patients to undertake appropriate clinical evaluations.¹⁰⁻¹² Although anxiety can function as a motivator for women to seek these services,^{12,13} excess anxiety or emotional distress may interfere with adherence to appropriate screening recommendations, as well as with quality of life.^{1,14}

The well-described overestimation of personal risk of breast cancer development by women¹⁵⁻¹⁹ is complicated by an associated increase in psychologic distress in patients receiving high-risk counseling.¹⁸⁻²⁰ One overview indicated that such counseling results in increased accuracy in patient perception of risk of breast

cancer development and reduced anxiety.²¹ However, most studies evaluating high-risk counseling have been conducted in clinic settings employing genetic counselors, with the primary goal of the counseling often being to inform patients of *BRCA1/2* mutation risk in preparation for formal genetic testing. Little has been published regarding the counseling that oncologists or other physicians provide concerning more broadly defined risk of breast cancer development, such as risk meeting the eligibility requirements of the NSABP P-1 study in women considered at high risk on the basis of factors other than *BRCA1/2* mutation status.⁹ In this study, we attempted to ascertain the degree of effectiveness of oncologist-based counseling in improving the accuracy of patient risk perception and in reducing patient psychologic distress.

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Methods

Patients eligible for entry into the study were those referred for assessment of breast cancer development risk at a high-risk clinic at an ambulatory comprehensive breast center. Patients with a personal history of invasive breast cancer or ductal carcinoma in situ (DCIS) were excluded. Patients with lobular carcinoma in situ (LCIS) were eligible for participation. Patients were required to have a command of English sufficient to complete the study questionnaires. Breast center nursing staff explained the study to all eligible patients and obtained written informed consent from all patients prior to study entry. The study was reviewed and approved by the Institutional Review Board of Baystate Medical Center.

Consenting eligible subjects completed a standardized history intake form and specified their estimate of risk of developing an invasive or worrisome breast cancer. Patients then completed the Brief Symptom Inventory-18 (BSI-18); the BSI-18 is an 18-question self-reporting inventory that explores psychologic health employing a 5-point Likert scale designed to evaluate symptoms in three dimensions (depression, somatization, and anxiety), with results summed to report a Global Severity Index (GSI).²²

Each patient then met with the counseling oncologist, who completed the history-taking and performed a relevant physical examination. The session included a discussion of the oncologist's assessment of the patient's risk of breast cancer development and the general likelihood of risk of patient carriage of a critical *BRCA1/2* mutation. For patients with a risk of invasive breast cancer development of at least 1.7% over 5 years based on the modified Gail model, a validated risk-assessment tool based on personal and family characteristics and available as a computer program,⁴ a discussion of the value and possible

TABLE 1

Patient characteristics

Characteristic	Value
Mean age, years (range)	44.6 (21–75)
Mean weight, kg (range)	73.9 (47–129)
Mean body mass index, kg/m ² (range)	27.7 (18.6–44.0)
Mean age at menarche, yr (range)	12.4 (9–17)
Patients with children, n (%)	55 (68)
Mean age at first birth, yr (range)	24.7 (16–40)
Patients with first-degree relatives with breast cancer, n (%)	55 (68)
Mean number of first-degree relatives with breast cancer (per patient with involved first-degree relative)	1.23
Race, n (%)	
White	70 (86.4)
Black	4 (5)
Hispanic	4 (5)
Asian	2 (2.5)
American Indian	1 (1.2)
Past psychiatric history, n (%)	13 (16.0)
Depression	10 (12.3)
Bipolar disorder	2 (2.5)
Psychosis	2 (2.5)
Postmenopausal, n (%)	28 (34.5)
Current tobacco use, n (%)	11 (13.6)
Current alcohol use, n (%)	47 (58)
Health insurance, n (%)	
Commercial	61 (75.6)
Medicaid	10 (12.2)
Medicare	5 (6)
No insurance/free care	5 (6)
Patients with breast biopsies, n (%)	43 (53)
Mean number of biopsies (per patient undergoing biopsy)	1.49
Patients with a history of risk-associated histology, n (%)	25 (31)
Atypical hyperplasia	21 (26)
Lobular carcinoma in situ	8 (9.9)
Mean <i>BRCA1/2</i> mutation probability, % (range)	8.4 (0–99)
Mean Gail model 5-year breast cancer risk, % (range)	2.7 (0–11.2)
Mean Gail model lifetime breast cancer risk, % (range)	23.2 (3.9–57.3)

complications of hormone prevention (including participation in the Study of Tamoxifen and Raloxifene [STAR]) was undertaken.

Patients were told of their risks of developing breast cancer, as assessed by the modified Gail model, by phrasing similar to the following: “Your personal chances of developing a breast cancer over the next 5 years

are _____%, or one in _____, and for a lifetime, _____%, or one in _____. Put another way, your chance of *not* getting breast cancer over the next 5 years is _____%. These figures are based on a statistical model that creates estimates of risk, based on women with your risk factors.”

For patients with LCIS, the quoted risks of invasive breast cancer were 5%

over 5 years and 15% over a lifetime.²³ Information regarding the probability of a critical *BRCA1/2* mutation, based on published tabular estimates,²⁴ was shared with the patient in a similar fashion. Prior to departing the breast center, patients again provided their assessment of risk of breast cancer development and *BRCA1/2* mutation carriage, as well as repeated BSI-18.

Statistical analysis

Risk perceptions were evaluated by converting patient responses to a percentage if reported as a proportion. Post-counseling risk perception in excess of Gail model estimates was used to assess the impact of counseling. Individual patient BSI-18 raw scores for each of the three dimensions and the GSI were converted to T-scores based on a linear transformation that yields standardized scores while adjusting for sex differences in a normative community population.^{22,25}

Data consisting of continuous variables were analyzed using Student's *t* test (paired or unpaired, as appropriate for normally distributed data), Wilcoxon's test, Spearman's correlation, or simple ordinal logistic regression. Multivariate models were constructed by forward stepwise regression²⁶; all relevant variables were considered for inclusion. Analysis was assisted by a computer program (JMP version 5.0.1a, SAS, Cary, NC). All *P* values reported are two-sided.

Results

Eighty-one patients were enrolled in the study. Their mean age was 44.6 years, with a range of 21–75 years. Other patient characteristics are summarized in Table 1. Table 2 shows the *P* values for univariate and multivariate measures of risk perception, as well as univariate measures of anxiety.

Pre-counseling findings

Patient risk perceptions. The mean patient perception of 5-year risk of developing breast cancer, 33.1%, far

exceeded the calculated mean Gail model estimate of 2.7% ($P < 0.0001$). No correlation was found between pre-counseling patients' perception of 5-year risk and their calculated risk ($r_s = -0.058$; $P = 0.68$). Similar differences were found for lifetime risk of developing breast cancer. Patients also overestimated their likelihood of carrying a *BRCA1/2* mutation (mean difference compared with tabular estimates 31.6%; $P < 0.0001$); however, a correlation was found between pre-counseling patient perceptions and clinic estimates ($r_s = 0.32$; $P = 0.007$).

Current age, age at menarche, postmenopausal status, tobacco or alcohol use, and presence of risk-associated histology were not associated with patient perceptions of their 5-year risk of developing breast cancer. However, patients with a history of psychiatric disorders had a significantly higher pre-counseling 5-year risk perception than those without such a history (52.3% vs 30.0%; $P = 0.004$), as did patients with Medicaid coverage versus those without (48.3% vs 31.4%; $P = 0.06$). Increased risk perception was significantly correlated ($r_s = 0.30$; $P = 0.009$) with increased body mass index (BMI). Patients who were younger when their first child was born had significantly higher 5-year risk perceptions ($r_s = -0.50$; $P = 0.0003$) and higher impressions of risk of carrying a *BRCA1/2* mutation than those who were older ($r_s = -0.31$; $P = 0.03$).

Stepwise multivariate analysis revealed that increased pre-counseling 5-year patient perceptions of risk were associated with increased pre-counseling anxiety T-scores ($P = 0.0004$), increased BMI ($P = 0.01$), and greater number of first-degree relatives with breast cancer ($P = 0.02$).

BSI-18 and GSI results. Similar results were found on all three subscales of the BSI-18 and GSI. Consequently, only the findings on the anxiety subscale, which demonstrated higher values overall compared with the other two scales, are reported here.

Younger patients exhibited greater anxiety levels ($r_s = -0.34$; $P = 0.002$), in general and a trend toward greater anxiety among those who were younger at the birth of their first child ($r_s = -0.24$; $P = 0.08$). Patients with a past psychiatric diagnosis also reported significantly more anxiety (mean T-score, 62.0 vs 52.7 without such a history; $P = 0.001$), as did patients diagnosed with LCIS (mean T-score, 62.1 vs 53.4; $P = 0.02$) and those covered by Medicaid (59.9 vs 53.8 for other health insurance options; $P = 0.06$). Patients with higher pre-counseling 5-year risk perceptions also reported greater pre-counseling anxiety levels ($r_s = 0.35$; $P = 0.002$); similar results were seen for lifetime risk and *BRCA1/2* mutation carriage perceptions.

Patient post-counseling perceptions

Patient risk perceptions. After counseling, patient 5-year risk perceptions decreased significantly (–11.5%; $P < 0.0001$) but remained significantly higher than calculated estimates based on the Gail model (mean difference, 18.7%; $P < 0.0001$). Despite the reduction in risk perception after counseling, 5-year risk perceptions before and after counseling were highly correlated ($r_s = 0.67$; $P < 0.0001$), and no association was found between patient post-counseling risk perceptions and modified Gail model estimates ($r_s = 0.02$; $P = 0.84$). Similar data were determined for lifetime risk perceptions. Patient perceptions of carrying a *BRCA1/2* mutation were likewise significantly reduced by counseling (mean difference, 18.9%; $P < 0.0001$), and pre-counseling and post-counseling perceptions were also correlated ($r_s = 0.54$; $P < 0.0001$). However, post-counseling perceptions and clinic estimates of the risk of *BRCA1/2* mutation carriage were correlated ($r_s = 0.50$; $P < 0.0001$), in line with the pre-counseling findings.

Patients with a past psychiatric diagnosis continued to have significantly greater perceptions of 5-year risk in

TABLE 2

Summary of P values for variables evaluated for patient-perceived 5-year risk and anxiety*

Variable	Before counseling			After counseling [†]		
	Patient-perceived risk		Anxiety [‡]	Patient-perceived risk		Anxiety [‡]
	Univariate	Multivariate	Univariate	Univariate	Multivariate	Univariate
Age	0.53		0.002	0.69		0.003
Race	0.30		0.55	0.52		0.09
Non-white race	0.17		0.32	0.47		0.25
Menarche	0.24		0.60	0.60		0.68
Menopausal status	0.39		0.59	0.54		0.43
Number of affected first-degree family members	0.10	0.02	0.13	0.78		0.13
Risk histology [§]	0.32		0.46	0.65		0.63
Lobular carcinoma in situ	0.25		0.02	0.36		0.06
Tobacco use	0.32		0.13	0.97		0.51
Alcohol use	0.55		0.62	0.85		0.50
Body mass index	0.009	0.01	0.92	0.02		0.35
Psychiatric diagnosis	0.004		0.001	0.04		0.009
Pre-counseling anxiety [‡]	0.002	0.0004	–	–		< 0.0001
Post-counseling anxiety [‡]			–	0.004		–
Age at birth of first child	0.10		0.08	0.002		0.004
Health insurance (all types)	0.23		0.41	0.39		0.23
Medicaid	0.06		0.06	0.06		0.08
Gail model risk estimate	0.68		0.24	0.84		0.18
Patient-perceived risk	–	–	0.002			
Pre-counseling patient-perceived risk				< 0.0001	< 0.0001	0.008
Post-counseling patient-perceived risk				–	–	0.004
Counseling oncologist				0.01	0.003	0.38

* Values shown in **boldface type** are significant at a P value < 0.05 or better.

[†] Risk is assessed as amount in excess of Gail model estimate.

[‡] Brief Symptom Inventory-18 anxiety subscale

[§] Lobular carcinoma in situ or atypical hyperplasia

excess of Gail model estimates (31.6% vs 16.2%; P = 0.04), as did those with an earlier first childbirth ($r_s = -0.43$; P = 0.002) or greater BMI ($r_s = 0.26$; P = 0.02). Medicare-covered patients also continued to have significantly greater excess risk perceptions compared with those who had other or no coverage (32.9% vs 16.6%; P = 0.06).

The degree to which patients exhibited differing levels of change in risk perception was markedly influenced by the oncologist performing the consultation, with mean changes in 5-year risk perception from pre- to post-counseling ranging from -4.6% to -29.4% (P = 0.005) among different oncologists. Consequently, the degree of excess post-counseling 5-year risk perception also differed considerably among oncologists, ranging

from a mean of 20.3% to 42.7% (P = 0.01). Patients' lifetime breast cancer risk perceptions similarly varied from one oncologist to the next, but no individual physician effect was found for patient perceptions of *BRCA1/2* mutation carriage.

Multivariate analysis of excess 5-year risk perceptions demonstrated that pre-counseling risk perception (P < 0.0001) and counseling physician (P = 0.003) were independently associated variables.

BSI-18 results. Anxiety T-scores decreased significantly after counseling (mean change, -4.2; P < 0.0001). Despite this decrease, post-counseling scores were strongly correlated with pre-counseling scores ($r_s = 0.84$; P < 0.0001) as well as with patient perceptions of risk both before ($r_s =$

0.31; P = 0.008) and after ($r_s = 0.33$; P = 0.004) counseling. Patients with a psychiatric history continued to have much higher anxiety subscale T-scores than those without such a background (57.9 vs 49.0; P = 0.009), but both groups demonstrated the same degree of post-counseling improvement. Younger age ($r_s = -0.32$; P = 0.003) and younger age at first childbirth ($r_s = -0.39$; P = 0.004) also were associated with post-counseling anxiety. Race, postmenopausal status, type of health insurance, and counseling oncologist were not associated with post-counseling anxiety.

Discussion

As in other studies, patients in the current trial expressed perceptions of their risk of breast cancer develop-

ment that far exceeded risk estimates based on the modified Gail model. Immediately after counseling, patient estimates were significantly reduced but still exceeded the calculated risks. Importantly, post-counseling risk perceptions did not correlate with the Gail model estimates shared during the counseling session that had taken place a short time before; rather, post-counseling perceptions were strongly associated with pre-counseling risk perceptions. Although patients also overestimated their risk of carrying a *BRCA1/2* mutation, patient estimates did correlate with the estimated risk of carriage calculated by the clinic, suggesting that patients did perceive a clear link between the number, and perhaps age, of family members who were affected by breast cancer.

The fact that the individual counseling oncologist affected the degree of reduction in excess risk perception is a unique finding. Others have suggested establishing guidelines to create counseling consistency among genetic counselors after finding that differing communication styles led to different patient anxiety outcomes.^{27,28} No data documenting differences in effectiveness among counseling physicians with presumed differing styles have been published. Future work should consider not only that different individuals will yield differing counseling results but also the development of strategies for achieving improved performance of those who provide counseling.

Counseling seemed to be effective in reducing—although not necessarily eliminating—anxiety irrespective of a past psychiatric diagnosis. Despite a clear association between the degree of improvement in risk perception and the individual oncologist performing the counseling, similar associations between the extent of amelioration of anxiety levels and counseling physician were not discovered. This finding, coupled with the observation that post-counseling risk

perceptions, albeit improved, bore no clear relationship to actual Gail model estimates, suggests that the counseling goals of patient education and reduction of psychologic stress are imperfectly linked.

We did not measure the impact of counseling according to educational level or socioeconomic status of the patients (although healthcare insurance did not appear to be an independently associated variable in pre- and post-counseling changes in perceived risk), nor did we attempt to evaluate and categorize individual patient coping styles. Although these factors have been shown to be important in determining the degree of benefit patients derive from counseling,²⁹ such factors may be less easily ascertained, quantified, and incorporated into routine clinical practice.

Clinical features that are easily ascertained include a history of psychiatric disorder. Patients with such a history had significantly higher anxiety T-scores both before and after counseling than did patients without such a history, but counseling resulted in an equivalent decrease in T-scores for both groups. Discovering patients with greater levels of anxiety after counseling may afford the opportunity for more intensive therapy and may support additional counseling specifically tailored to patient needs. Although the BSI-18 proved to be a convenient, unobtrusive data-collection tool that can be easily implemented in the clinic setting, identifying patients with a psychiatric history might prove equally effective.

Many challenges remain in communicating the risk of breast cancer development to patients. Physicians appear to have incomplete success in aligning risk perceptions with calculated risk but, nevertheless, seem to be reasonably effective in reducing anxiety. The ability of counseling oncologists to alter patient risk perceptions varies, but these differences do not appear to have an impact on

their ability to provide reassurance. With the results of the STAR trial³⁰ resulting in additional therapeutic options—and more widely available genetic testing leading more women to contemplate their breast cancer risk and consider seeking physician-based counseling and risk management—more rigorous and uniform approaches to patient education on breast cancer risk and to identification and management of associated anxiety are needed.

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Commentary

Anxiety in high-risk or already diagnosed cancer patients: recognizing and treating external and internal sources

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The paper by Dr. Mertens and colleagues demonstrates that patients seen for high-risk breast cancer consultation have a significant level of anxiety. This study demonstrates that detailed information alone does not fully address patients' anxieties.

As a therapist focused on cancer counseling for the past 20 years, I am often asked by oncologists, why anxiety is so resistant to the clinical data provided and reassurances offered by physicians and staff. As with depression, anxiety and worry spring from both external and internal sources. The external source of anxiety can indeed be reduced and managed by oncologists giving information to a patient about her diagnosis and by offering reassurances. Successfully progressing through treatment, good test results, and an optimistic prognosis can allay these anxieties for patients by reducing the external threat.

However, the internal sources of

worry and anxiety are more resistant to influence from you and your staff, precisely because they develop and are fed *inside* by the emotions and experiences of the patient. Each patient must learn how to manage and address these internal fears and uncertainties, perhaps with the help of a trained psychosocial counselor. If these anxieties and fears are preexisting and reinforced through past experience, or strongly based on closely held beliefs, patients may need help acquiring new skills and restructuring their cognitive assumptions. In this way, they can learn to manage and mitigate the internal sources of their fears.

Making changes

The cognitive-behavioral approach to treating anxiety involves changing both behaviors and ways of thinking. To this end, a therapist can help teach and support ways to challenge and change perceptions, false beliefs, undermining behaviors, and unproductive coping mechanisms. For example,

a patient who believes that cancer is a "death sentence"—even in the face of a good prognosis—may not adhere to treatment or may even refuse it. By changing the message a patient gives herself, she can usually effectively relieve her anxiety and make better choices. Some patients require medications to fully benefit from counseling and commit to change.

If you see that your patient remains anxious, even though she has learned the facts about her risk, you should refer her to a trained counselor to effectively relieve the internal sources of anxiety. To provide a truly comprehensive approach to high-risk cancer counseling, care should be coordinated among the oncologist, primary care doctor, therapist, and/or psychiatrist. Together, these practitioners can find the best type and duration of medication for the anxious patient.

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