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CLINICAL TRIAL

What does risk of future cancer mean to breast cancer patients?

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Abstract

Purpose Newly diagnosed breast cancer patients greatly overestimate their risk of developing contralateral breast cancer (CBC). Better understanding of patient conceptions of risk would facilitate doctor–patient communication and surgical decision making. In this mixed methods study, we prospectively examined breast cancer patients' perceived risk of future cancer and the reported factors that drove their risk perceptions.

Methods Women age 21–60 diagnosed with breast cancer without a BRCA mutation or known distant metastases completed a study interview between surgical consult and surgical treatment. Participants completed a 12-item Perceived Risk Questionnaire, which assessed 10-year and lifetime risks of ipsilateral local recurrence, CBC, and distant recurrence. Patients provided qualitative explanations for their answers.

Results Sixty-three patients completed study interviews (mean age 50.3). Participants were primarily White (85.7%) and 90.5% had attended college. Patients estimated their 10-year risk of CBC as 22.0%, nearly 4 times the established 10-year risk. Women attributed their risk perceptions to "gut feelings" about future cancer, even when women knew those feelings contradicted medically established risk. Perceptions of risk also reflected beliefs that cancer is random and that risk for local recurrence, CBC, and distant recurrence are the same.

Conclusions Our findings point to the need for novel ways of presenting factual information regarding both risk of recurrence and of new primary cancers, as well as the necessity of acknowledging cognitive and affective processes many patients use when conceptualizing risk. By differentiating women's intuitive feelings about risk from their knowledge of medically estimated risk, doctors can enhance informed decision making.

Keywords Breast cancer · Risk · Contralateral prophylactic mastectomy · Patient education

Introduction

For most women diagnosed with invasive breast cancer or ductal carcinoma in situ, the estimated 10-year risk of developing a new cancer in the contralateral breast is approximately 6%. Risk of contralateral breast cancer (CBC) decreases to 0.2–0.5% per year (2–5% 10-year risk) after accounting for systemic therapy [1, 2]. However, breast cancer patients often overestimate their risk of developing cancer in the unaffected breast [3–5]. Newly diagnosed patients with early-stage disease perceived their 10-year risk of CBC to be 31.4%, on average [4]. Risk perceptions are important as an increasing number of patients with early-stage disease are choosing to undergo contralateral prophylactic mastectomy (CPM) [6–8], despite guidelines discouraging CPM for average risk women [1, 9], and the absence of added survival benefit of CPM over lumpectomy or single mastectomy for

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most women [10, 11]. Moreover, women who select CPM frequently indicate that a desire to decrease CBC risk was an important factor in their decision [12–14].

Although advances in risk prediction models have led to the development of more and better tools to calculate cancer risk, communicating risk to patients and assessing patient understanding of cancer risk remains challenging [15]. Risk communication is further complicated by the fact that future breast cancer is not a singular event. Rather, recurrence of the original cancer and development of contralateral cancer are distinct events with distinct probabilities [16–18]. Additional data are needed to understand how breast cancer patients comprehend the various risks that inform surgical decision making, such as risk of recurrence, risk of distant cancer, CBC risk, and 10-year versus lifetime risks of future cancer. In this mixed methods study, we assess breast cancer patients' risk perceptions and the reported factors that drove their risk perceptions.

Methods

Sample

Breast cancer patients were eligible for the study if they met the following inclusion criteria: female, age ≥ 21, with a diagnosis of breast cancer, who had decided on a surgical option to treat their breast cancer. Patients were excluded from the study if they had bilateral cancer, a known BRCA mutation, known metastases, prior chest radiation, prior surgical treatment of this breast cancer, prior breast cancer, had not decided on a surgery, or planned to undergo neoadjuvant therapy. A clinical research coordinator approached eligible women at the time of their surgical consult at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University. Interested women were enrolled in the study once they had chosen a surgical treatment for their cancer but prior to undergoing surgery. Targeted recruitment was used to ensure that approximately one-third of the sample intended to undergo CPM. The study occurred during 2014–2016 and was approved by the Northwestern University Institutional Review Board. Written informed consent was obtained from all study participants.

Patient interview

Data were collected during an in-person or telephone interview in the period between surgical consult and surgery. Sociodemographic and clinical characteristics were obtained during the study interview and from the patient medical record. Perceived risk was measured with the Perceived Risk Questionnaire (PRQ), which was developed to assess risk perceptions in patients with DCIS and early-stage breast cancer [4, 19]. Our version of the PRQ contained 6 questions asking women to estimate their risk of breast cancer in the same breast, elsewhere in their body, or in their other breast in the next 10 years and in their lifetime. Questions were asked using a response scale from 0 to 100, where 0 = certain not to happen and 100 = certain to happen. To better understand how women evaluate and report risk, the interviewer asked each woman to explain how she arrived at her response for each question. Interviews were audio recorded and lasted approximately 40 min.

Analysis

Patients planning to undergo CPM were compared to those anticipating BCS or unilateral mastectomy (UM) on demographic and clinical characteristics. Chi-square tests or Fisher's exact tests were used for categorical variables, as appropriate; Mantel Haenszel Chi-square tests were used for ordinal variables; and two-sample *t* tests were used for continuous variables. Perceived risk scores were compared between surgical groups using analysis of variance (ANOVA) and its non-parametric equivalent, the Kruskal–Wallis test. In addition, individual patients' perceived risks were reviewed and the percentage of women who reported identical 10-year and lifetime risks or identical risk of recurrence, CBC, or distant recurrence was calculated. Finally, patients' comments about their risk perceptions were extracted from the interview transcripts and reviewed by two study team members. Key themes were identified using an inductive approach and all responses were coded for those themes.

Results

Sixty-three women completed study interviews, including 22 women planning to undergo CPM, 30 intending to undergo BCS, and 11 intending to have UM. Medical record review indicated that all but one patient underwent the surgery indicated at the time of the interview. Women planning to undergo CPM were significantly younger than women intending to undergo BCS or UM ($p = 0.05$) (Table 1). CPM patients were also significantly more likely to have estrogen receptor (ER)-positive or progesterone receptor (PR)-positive tumors ($p < 0.05$).

Perceived risk of future cancer

The average perceived 10-year risk of CBC was 22% (Table 1); perceived lifetime risk of CBC was 23%. Mean risk perception for CBC, local or distant recurrence did not differ significantly by surgery type. Nearly one-third of

Table 1 Patient demographics by anticipated surgery, $N=63$

	Full sample ($N=63$)	CPM ($N=22$)	BCS/unilateral mastectomy ($N=41$)	p value
Age (average)	50.3	48.3	51.4	0.05
Race				
Caucasian	54 (85.7%)	20 (90.9%)	34 (82.9%)	0.48
Non-Caucasian[a]	9 (14.3%)	2 (9.1%)	7 (17.1%)	
Education				0.75
High school or less	6 (9.5%)	2 (9.1%)	4 (9.8%)	
Some college/college degree	27 (42.9%)	11 (50.0%)	16 (39.0%)	
Advanced degree	30 (47.6%)	9 (40.9%)	21 (51.2%)	
Has children	42 (66.7%)	16 (72.7%)	26 (63.4%)	0.58
Family history[b]	13 (20.6%)	4 (18.2%)	9 (22.0%)	1.00
Histology				0.66
DCIS	20 (31.8%)	6 (27.3%)	14 (34.2%)	
IDC	37 (58.7%)	13 (59.1%)	24 (58.5%)	
ILC/Unknown/other	6 (9.5%)	3 (13.6%)	3 (7.3%)	
Tumore size, median(range)[c]	1.5 (0.2–5.6)	1.3 (0.2–4.5)	1.7 (0.2–5.6)	0.13
ER positive	55 (87.3%)	22 (100.0%)	33 (80.5%)	0.04
PR positive	53 (84.1%)	22 (100.0%)	31 (75.6%)	0.01
Grade				0.28
Grade 1	19 (30.2%)	7 (31.8%)	12 (29.3%)	
Grade 2	31 (49.2%)	13 (59.1%)	18 (43.9%)	
Grade 3	13 (20.6%)	2 (9.1%)	11 (26.8%)	
	Mean (SD)	Mean (SD)	Mean (SD)	
10 year perceived risk 0–100%				
Contralateral breast cancer	22.0% (26.0)	14.7% (24.4)	25.7% (25.9)	0.11
Ipsilateral local recurrence	21.0% (26.0)	16.1% (25.6)	23.5% (25.7)	0.28
Distant recurrence	20.0% (21.0)	19.2% (16.4)	19.7% (24.0)	0.93
Lifetime perceived risk 0–100%				
Contralateral breast cancer	23.0% (27.0)	15.6% (24.5)	27.4% (28.3)	0.10
Ipsilateral local recurrence	24.0% (27.0)	18.6% (27.7)	26.4% (26.8)	0.28
Distant recurrence	22.0% (22.0)	23.8% (18.5)	20.9% (23.7)	0.60

[a]The non-Caucasion group included 6 African American and 3 Asian women

[b]Family history is defined as one or more first-degree relatives diagnosed with breast cancer

[c]Median size of tumor based upon the largest tumor for the current diagnosis. Sixty patients had valid tumor information

the sample reported a 10-year CBC risk of 30% or higher ($n=18$, 28.6%).

Individual trends in risk perceptions

To better understand how women understand various risks, we first identified whether women differentiated 10-year and lifetime risk. For each cancer risk (i.e., ipsilateral local recurrence, distant recurrence, or CBC), between 78% and 84% of respondents reported identical 10-year and lifetime risk. Next, we assessed whether women differentiated their risks of ipsilateral local recurrence, distant recurrence, or CBC. Perceived risk of cancer in the same breast and perceived risk of CBC were most likely to be identical, with 63.5% ($n=40$) of the sample reporting identical 10-year risks of CBC and cancer in the same breast. Perceived 10-year risk of ipsilateral local recurrence and 10-year risk of distant recurrence were least likely to be identical, with 36.5% ($n=23$) of the women reporting the same risks. Finally, we evaluated whether any individual women viewed *all risks* as identical. Over one quarter of the sample (18 women, 28.6%) reported the same risk perception for all 6 risk questions (i.e., identical 10-year and lifetime risks of ipsilateral local recurrence, CBC, and distant recurrence).

Qualitative data on risk perceptions

When asked how they arrived at their risk estimates, about 1 in 6 participants spontaneously referred to risk information received from physicians. More often, women's responses reflected their own beliefs about cancer, or indicated a lack of awareness of differing risks for ipsilateral, contralateral, and distant recurrence. Women's explanations for their risk estimates revealed that many women, particularly women planning to undergo CPM, reported their perceived post-treatment risk. Additionally, what is considered a "low" risk may be different for patients. Each of these themes is discussed in more detail below.

- *Risk as feeling* Women frequently referenced gut feelings, optimism, and pessimism to explain their risk estimate. Moreover, women often acknowledged that these feelings about risk did not align with medical estimates of risk. For example, a BCS patient who reported a 70% 10-year ipsilateral recurrence risk said, "I'm just a pessimist and I always think the worst is going to happen, so I put it pretty high. It's not on any scientific basis". A mastectomy patient who indicated that she had a 100% lifetime chance of developing CBC said, "One hundred, yes. I'm certain even though I know the statistics don't show, don't prove that. That's how I feel". Optimism prompted women to report lowered risk perceptions, although less dramatically. For example, a BCS patient who reported a 5% 10-year ipsilateral recurrence risk said, "My doctor told me 5–10% risk, but I went with the low end—positive thinking". A CPM patient who reported a 15% risk of 10-year distant recurrence noted, "These are all kind of estimated low because I'm trying to remain positive". A lumpectomy patient who reported a 5% chance of recurrence said, "I don't necessarily think that it's going to come back in me…You know how you have like that inner feeling that something's good or something's bad? I just have that feeling…that it's not coming back. But I can't say zero because that's not logical".
- *Cancer as random* Eleven women in the sample reported a 50% risk for at least one of their responses. Underlying these responses was a belief that cancer was random or unpredictable. For example, according to one CPM patient, "I think it's (ipsilateral recurrence) a hit or miss, 50/50". Another CPM patient who perceived she had a 50% risk for every type of future cancer explained, "I don't know because…zero (means) it certainly will not happen and we don't know that. Is it absolutely going to happen? No. So I don't know". Women's reflections on their choice of reporting 50% risk also highlight a prevailing belief that once a woman is diagnosed with cancer, her body will produce more cancer. A BCS patient said, "Well, I think that my left breast is related to my right one…I think there's a 50/50 chance the left one might (get cancer) too". Another BCS patient who believed she has a 50% chance of all types of future cancer said, "I don't have (cancer) anywhere in the family. So the fact that I have it right now, you know, there's a good 50/50 percent chance that it will come back".
- *All cancer risk is the same* We reviewed the qualitative data from women who reported the same risk for every cancer to better understand how they arrived at their expressed risk estimates. In some cases, women reported receiving ipsilateral risk information from their doctors and applied that knowledge to all types of future cancer, often while stating that they were not sure of the other risks. In other cases, women believed that we possess one risk for cancer, regardless of location or timeframe, as evidenced by comments such as "These questions all seem the same to me". "I don't see how it would be high or lower in my lifetime (vs. in 10 years)". "I applied the same reasoning (for every question)".
- *Perceived post-treatment risk* Despite completing the risk measure prior to treatment, many women reported their perceived post-treatment risk. This tendency was particularly noticeable for CPM patients. Thirty-six percent of women intending to undergo CPM stated that their 10-year risk of CBC was zero, with the reason that they would no longer have breasts provided as their rationale for their perception.
- *The meaning of "low" estimates* Some women reported risks well over the actual estimated risk of future cancer, yet considered themselves to be low risk. For example, a lumpectomy patient, who indicated that she had a 20% chance of recurrence, stated: "Everything is in God's hands…that's why I put the low number". A CPM patient who reported a 20% lifetime CBC risk noted, "It's a low number, but still a possibility". Another CPM patient, who reported a 20% risk of 10-year and lifetime ipsilateral breast cancer said, "I know (the risk) is not zero, but it's not 100 either and so I went on the low end of the scale".

Discussion and conclusions

We examined perceived risk of future cancer following surgical consult among a sample of women diagnosed with unilateral breast cancer. Given the growing rates of CPM, we were particularly interested in women's perceptions of their risk of developing CBC. On average, our sample reported their 10-year risk of CBC to be 22%, nearly four times the actual 10-year estimated risk for most women. This misperception is consistent with prior work showing breast cancer patients overestimated their perceived risk of future cancer [3–5].

Our data demonstrate that even if breast cancer patients have accurate risk knowledge (i.e., awareness and understanding of medically estimated, objective risk [20–24]), they may rely on their risk beliefs (i.e., affective, personal beliefs or intuitions about risk [20–25]) when evaluating their personal risk. Risk counseling has been shown to bring risk beliefs closer to accurate risk estimates [26, 27]. Thus, future work is needed to evaluate the feasibility and success of attempting to align breast cancer patients' risk beliefs with accurate risk information. Tools to elicit patients' risk knowledge *and* risk beliefs would aid in identifying women who need further education about cancer risk to support informed decision making, and women whose decisions may be motivated by incorrect risk beliefs.

Our data also reveal how the meaning of numeric estimates varies for patients, as is demonstrated by patients in our sample who considered a 20% 10-year risk of future cancer to be a "low" risk. Some research suggests that numeric information will have a greater impact on patients if it is tied to affective verbal qualifiers (e.g., "high") to aid patients with evaluating information [25, 28, 29]. Additional work is needed to test these ideas in cancer patient education [30].

Notably, some women underreported their risk. Upon further analysis, we identified that these women, who were reporting 0% risk, appeared to be reporting on their perceptions of risk post-surgery. Thirty-six percent of women intending to undergo CPM stated that their 10-year risk of CBC was zero, providing the rationale that they would no longer have breasts. Reports of zero risk may explain the lower average perceived risk of our CPM group compared to the rest of our sample. This trend among CPM patients may also explain why our sample had lower average perceived risk than prior studies with a smaller proportion of CPM patients [4]. Measures which clearly specify the reference period of the risk perception (i.e., current risk versus risk after completing treatment) are needed.

Finally, our data demonstrate a tendency for breast cancer patients to think of risk as one-dimensional. The majority of patients did not differentiate 10-year and lifetime cancer risk. Nearly two-thirds of this sample reported identical risks of ipsilateral local recurrence and CBC. One in four women viewed all future cancer risks identically. Because we did not observe the surgical consultations, we do not know what risk information was provided to patients. For women with a unilateral breast cancer diagnosis, surgeon discussions may reasonably focus on ipsilateral recurrence risk. Distant risk might only be discussed in general terms as the patient's pathology report would not be available at the surgical consult. Thus, we do not assume that our participants all received detailed risk information. However, as patients are increasingly requesting CPM, a growing number of surgical consults likely include discussions of CBC risk. Given the limited awareness of how risk varies by type of future cancer, even in this sample of highly educated women, there is an opportunity to introduce patients to more nuanced conceptions of risk. To this end, clinicians need tools to help them communicate risk and understand how patients process quantitative risk information [31]. As is shown by these data, beneath the surface of a patient's quantitative risk perception, are feelings, beliefs, and gaps in knowledge; addressing these underlying factors will help to ensure that patients are informed about their cancer.

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Compliance with ethical standards

Conflict of interest All authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human subjects were in accordance with the ethical standards of the Northwestern University Institutional Review Board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Informed consent Informed consent was obtained from all individual participants included in the study.

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