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Recurrence risk perception and quality of life following treatment of breast cancer

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Abstract

Purpose Little is known about different ways of assessing risk of distant recurrence following cancer treatment (e.g., numeric or descriptive). We sought to evaluate the association between overestimation of risk of distant recurrence of breast cancer and key patient-reported outcomes, including quality of life and worry.

Methods We surveyed a weighted random sample of newly diagnosed patients with early-stage breast cancer identified through SEER registries of Los Angeles County & Georgia (2013–14) ~2 months after surgery ($N = 2578$, RR = 71%). Actual 10-year risk of distant recurrence after treatment was based on clinical factors for women with DCIS & low-risk invasive cancer (Stg 1A, ER+, HER2−, Gr 1–2). Women reported perceptions of their risk numerically (0–100%), with values ≥10% for DCIS & ≥20% for invasive considered overestimates. Perceptions of "moderate, high or very high" risk were considered descriptive overestimates. In our analytic sample ($N = 927$), we assessed factors correlated with both types of overestimation and report multivariable associations between overestimation and QoL (PROMIS physical & mental health) and frequent worry.

Results 30.4% of women substantially overestimated their risk of distant recurrence numerically and 14.7% descriptively. Few factors other than family history were significantly associated with either type of overestimation. Both types of overestimation were significantly associated with frequent worry, and lower QoL.

Conclusions Ensuring understanding of systemic recurrence risk, particularly among patients with favorable prognosis, is important. Better risk communication by clinicians may translate to better risk comprehension among patients and to improvements in QoL.

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Introduction

The long-term prognosis for women with a new diagnosis of ductal carcinoma in situ (DCIS, or stage 0) or early-stage invasive breast cancer with favorable biology is generally excellent [1, 2]. Studies have shown that initial management translates into a high likelihood of cure [2]. Only a small proportion of patients experience systemic recurrence of their cancer, which can lead to mortality from the disease. The likelihood of systemic recurrence after treatment for women with node negative, estrogen receptor-positive (ER) invasive breast cancer, and favorable tumor biology 5-year metastases-free survival rates is less than 2%; for those with DCIS, there is almost no chance of systemic recurrence [2–4]. Yet, understanding and interpreting risk, are challenging, and studies have found that many women with breast cancer significantly overestimate their risk of distant recurrence after treatment [5–8].

Importantly, overestimation of perceived risk of recurrence and associated fear of recurrence, may negatively contribute to long-term outcomes that are important for cancer survivors, such as quality of life (QoL) and ongoing worry. It may also motivate patients to prefer more extensive treatment and follow-up care [9, 10]. Prior work has identified an important link between overestimation of risk and lower scores on physical health assessments [5] and on fear of recurrence after treatment [7]. It may also motivate patients to prefer more extensive treatment and follow-up care [9, 10].

Furthermore, despite a rich literature in risk communication documenting different types of risk measurement, no studies have explicitly assessed whether it matters more if patients have an accurate numeric understanding of their risk or a more general descriptive comprehension (i.e., "gist" [11]) of their own risk of cancer spreading. While previous studies lend an important perspective on this issue from clinical samples, there have not been large population-based studies among racially/ethnically diverse samples on this issue.

Our study had two objectives. First, to evaluate correlates of overestimation of distant recurrence, measured both numerically and descriptively, in a diverse, contemporary, population-based sample of breast cancer patients with DCIS and early-stage invasive breast cancer. Second, to determine the association between overestimation of risk using two methods (numeric and descriptive) and the patient-reported outcomes of QoL and worry about recurrence.

Methods

Study population

The iCanCare Study, a large, diverse, population-based survey study of women with favorable prognosis breast cancer, accrued women ages 20–79 with newly diagnosed breast cancer (DCIS and stages I–II) as identified by rapid reporting systems from the Surveillance Epidemiology and End Results (SEER) registries of Georgia and Los Angeles County in 2013–2014. Black, Asian, and Hispanic women were oversampled in Los Angeles [12]. We selected 3880 of whom 249 women were later deemed ineligible due to having a prior cancer diagnosis or stage III or IV disease; residing outside the SEER registry area; being deceased, too ill or unable to complete a survey in Spanish or English. Of 3631 eligible women remaining, 1053 did not return mailed surveys, refused to participate or were lost to follow-up. Non-respondents did not differ significantly from respondents on key variables, including stage and race/ethnicity. Of 2578 patients who responded (71%) for this analysis, the following exclusions were made: 1388 because their actual risk of recurrence was higher than that for DCIS or our low-risk invasive cases, 165 because they did not have sufficient data to calculate actual risk, and 98 because they had bilateral disease. The resulting analytic sample was 927 women.

Data collection

Patients were sent surveys approximately 2 months after surgery. We provided a $20 cash incentive and used a modified Dillman method for patient recruitment, as done in prior work [12, 13]. All materials were sent in English and Spanish to those with Spanish surnames [12]. Survey responses were then merged with clinical data from SEER. The study was approved by the Institutional Review Boards of the University of Michigan, University of Southern California and Emory University and the Committee for the Protection of Human Subjects and the California Cancer Registry.

Questionnaire design and content

Patient questionnaire content was guided by a conceptual framework, research questions, and hypotheses. We chose established measures when available and developed new measures, when necessary, drawing from the literature and our prior research [14–16]. We used standard techniques to assess content validity, including review by survey design experts, cognitive pre-testing with patients, and pilot studies in selected clinic populations.

Measures

Actual risk of distant recurrence

We first created our analytic sample with highly favorable prognosis, and thus very low actual risk of distant recurrence, using stage, histology, and biology. Using SEER data, women were classified as having DCIS (stage 0) (with almost no risk of distant recurrence) or low-risk invasive breast cancer (with <10% actual risk of distant recurrence); stage 1A, ER+, HER2−, tumor grade 1–2, and either having a 21-gene assay test result of 0–10, or the result was not indicated [2, 3]. Actual risk was assessed following treatment (surgery, radiation, chemotherapy).

Overestimation of risk of distant recurrence

We assessed overestimation using both numeric and descriptive methods. In the survey, women were asked "*After receiving all the planned treatments*, what do you think is the chance that your cancer will spread to other parts of your body in 10 years?" and asked (1) to provide a numeric estimate on a scale from 0 to 100% and (2) to choose a descriptive risk category (very low, low, moderate, high, very high). For women with DCIS, we considered them to have overestimated risk numerically if they perceived a chance of distant recurrence of 10% or higher; for women with invasive cancer, overestimation was considered 20% or higher. These percent cutoffs were chosen by clinical experts to represent "substantial overestimation of risk of recurrence" as they are more than twice/double the percent of "actual risk of systemic recurrence" expected following treatment for these patients with highly favorable prognosis [2, 3]. For all women, if they indicated that their systemic risk of recurrence was moderate, high or very high, we considered them to have overestimated their risk descriptively.

To understand the independent and combined effects of numeric and descriptive discordant risk perception, we additionally combined the two risk measures into one 4-level categorical risk summary measure: (1) correct on both numeric and descriptive measure (N+, D+), (2) correct on numeric but overestimated descriptive (N+, D−), (3) correct on descriptive and overestimated on numeric (N−, D+), and (4) overestimated on both numeric and descriptive measures (N−, D−).

Quality of Life

Quality of life (QoL) was measured with the Patient-Reported Outcomes Measurement Information System (PROMIS) measure, providing Global Mental Health (GMH) and Global Physical Health (GPH) subscales. The PROMIS scales are validated QoL measures that have been widely used to assess patient-reported QoL in cancer [17, 18]. The 10-item scale is scored and standardized into the GMH and GPH. PROMIS scores are normalized to a mean of 50 with a standard deviation of 10. A score of <40 is considered a clinically meaningful decline/reduction in QoL. Following this scoring recommendation, for our analysis, scores of ≤40 for GPH and GMH were used to indicate low (worse) mental and physical health [17].

Frequent worry about recurrence

We asked women to indicate on a 5-point scale how often they worried about the cancer coming back in the past month (not at all, a little, sometimes, a lot, almost always). For these analyses, those who indicated they worried at least sometimes were considered to have frequent worry.

Covariates

Covariates used in this analysis included patient demographics and clinical factors. We included age, race/ethnicity (White, Black, Latina, Asian, Other/Unknown), educational attainment (high school graduate or less, some college, or more), marital status (married/partnered vs. not), employment (employed, retired, unemployed), number of comorbid health conditions (none vs. 1 or more), and family history of breast cancer (none vs. 1 or more first degree relatives). Breast cancer treatment, including surgical treatment type (lumpectomy, unilateral mastectomy, bilateral mastectomy) and receipt of chemotherapy (yes/no), was also collected via survey. We controlled for patient factors that could confound QoL and worry by including patient report of being bothered by treatment side effects (yes/no) at the time of the survey and a measure of decisional anxiety. We further controlled for treatment (surgery type, radiation, and chemotherapy receipt).

Statistical analyses

We first calculated the proportion of women who overestimated their risk of distant recurrence using both the numeric and descriptive measures, as a whole and separately for women with DCIS and invasive cancer. Multivariable, weighted logistic regression was used to explore correlates of overestimation and to estimate the association between overestimation using both numeric and descriptive forms, and each PROMIS measure (physical and mental health) and frequency of worry, after adjustment for all covariates above. We further assessed the association between the combined overestimation measure and QoL.

Survey and SEER item non-response was low (<5%) for all covariates; however, to correct for the potential of bias due to missing data, values for missing items were imputed using sequential regression multiple imputation (SRMI) [19]. Five multiply imputed datasets were analyzed and model estimates were combined to account for additional uncertainty due to imputation. Results were compared between SRMI analyses and complete-case analyses for any meaningful differences. Odds ratios (OR) with 95% confidence intervals (CI) are reported for models, with *p*-values ≤0.05 considered significant. All statistical analyses incorporated weights to account for differential probabilities of sample selection and non-response. All analyses were performed using SAS version 9.4 (Cary, NC).

Results

Patient characteristics

The characteristics of the analytic sample ($N = 927$) are provided in Table 1. The mean age of patients was 63 (range 31–82). The diversity of the sample reflected the population-based sampling approach: 57.7% white, 17.7% black, 14.4% Latina, 7.5% Asian, and 2.7% other. Most reported being married (61.4%) and having some college or more education (71.6%). About two-thirds of patients were treated with lumpectomy (68.3%), and a minority (3.6%) reported having received chemotherapy at the time of the survey.

Overall, 30.4% of women with highly favorable prognosis substantially overestimated their risk of distant recurrence numerically, 14.7% descriptively, and 12.1% overestimated using both definitions. Among women with DCIS, 35.1% overestimated numerically, and 13.1% descriptively, while 24.3% of women with invasive cancer overestimated numerically and 16.7% descriptively (Fig. 1a).

About 10% of patients reported poor mental health and 18.2% poor physical health using PROMIS measures. About a third (30.8%) of women indicated that they worried about the cancer coming back "at least sometimes." (Fig. 1b).

Few demographic or clinical factors were consistently associated with overestimating risk both numerically and descriptively. Black (vs. white) patients were less likely to overestimate numerically (OR 0.47; 95% CI 0.29–0.76) but not descriptively. Those with more education more often overestimated numerically (OR 1.46; 95% CI 1.02–2.09). Women with a family history of breast cancer were more likely to overestimate both numerically (OR 1.45; 95% CI 1.03–2.04) and descriptively (OR 1.79; 95% CI 1.18–2.69). Finally, women who received bilateral mastectomy (vs. breast conservation) were significantly *less* likely to overestimate their risk of recurrence numerically (OR 0.46; 95% CI 0.28–0.76) (data not shown).

Controlling for all covariates, patients who overestimated their risk numerically had higher odds of reporting frequent worry (OR 2.87; 95% CI 1.90–4.33) than those who did not overestimate. These women were also more likely to report poor physical health (OR 1.90; 95% CI 1.11–3.26). Women who overestimated their risk descriptively more often reported frequent worry (OR 3.16; 95% CI 1.87–5.35) and lower mental health (OR 2.52; 95% CI 1.24–5.08), but were no more likely to report worse physical health. The covariates significantly ($p < 0.05$) associated with poor physical health, poor mental health, and more frequent worry are included in Table 2.

The point estimates and 95% confidence intervals for the association between the 4-category risk perception measure described above and frequent worry are presented in Fig. 2. As it is apparent from the figure, in adjusted analysis, there is a nearly linear association between risk perception and frequent worry. Compared to women who correctly reported both numeric and descriptive risk (N+, D+), N−, D+ women were 3.2 times as likely to have frequent worry, N+, D− women were 6.2 times as likely, and those who overestimated on both measures (N−, D−) were 8.4 times as likely to have frequent worry.
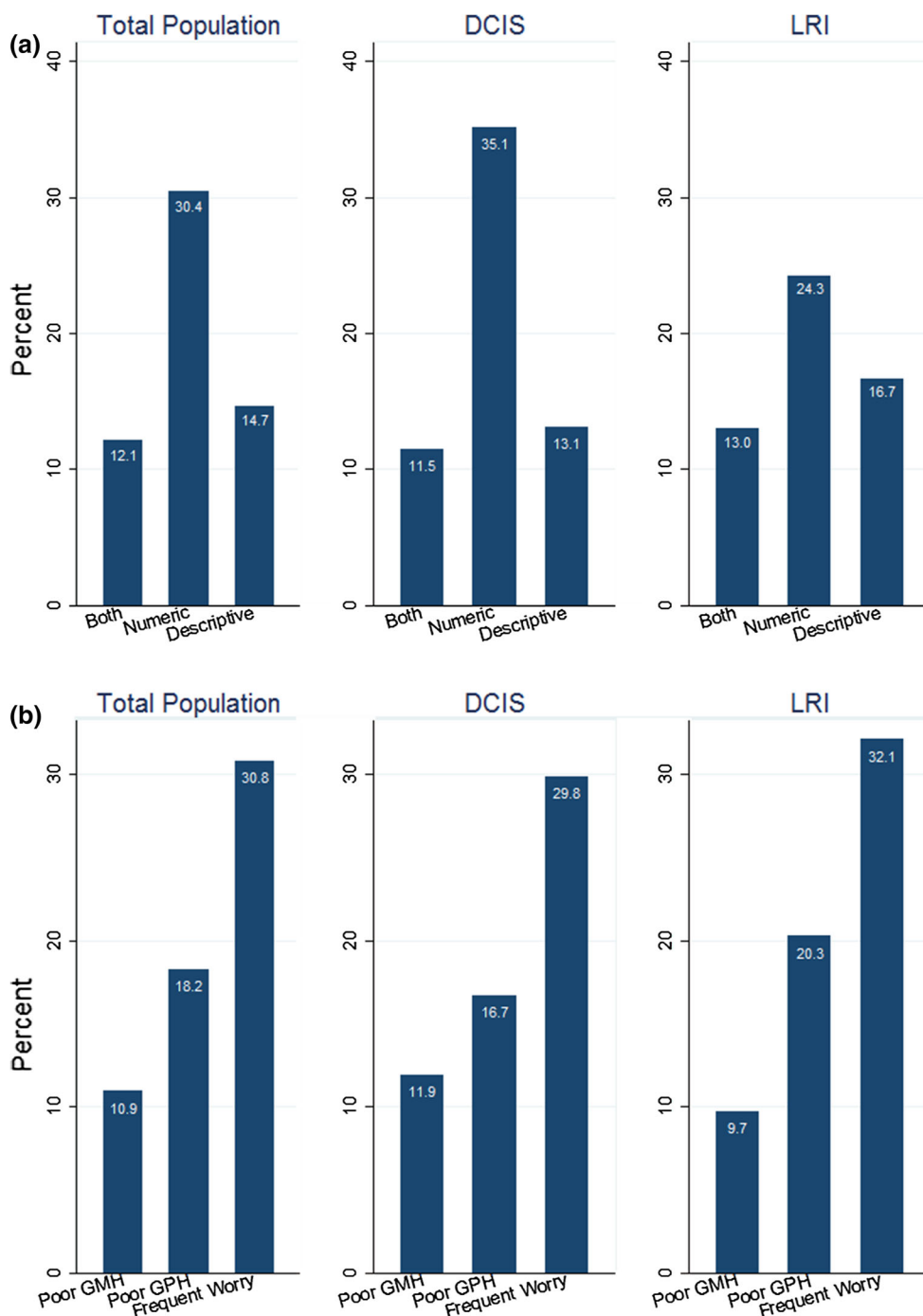
Discussion

In this large, diverse, population-based sample of newly diagnosed and treated breast cancer patients with favorable prognosis, we found that nearly a third (30.4%) overestimated the numeric risk of systemic recurrence to be more than twice their actual risk. A unique finding relative to prior work was that numeric overestimation was more common than descriptive or "gist" overestimation (14.7%). Particularly striking was that almost a third of women with DCIS, who have almost no chance of systemic recurrence, believed their risk to be at 10% or higher.

This study confirms prior research showing that many women diagnosed with breast cancer, including DCIS, do not have an accurate understanding of the likelihood of their cancer spreading systemically [5–8]. However, our study substantially extends this literature to a diverse, population-based sample and by assessing patients' understanding of two different measures of risk perception; a numeric (number-based) and a descriptive (word-based) measure. While we did not find a consistent set of demographic or clinical factors associated with a tendency to overestimate risk using either measure, one factor, having a family history of breast cancer, was associated with both types of overestimation. We conclude that no assumptions should be made about the ability of patients to comprehend their risk, but that patient understanding of their familiar risk may contribute to their assessment of their own risk.

Table 1 Demographic and clinical characteristics among patients with favorable prognosis breast cancer ($N = 927$)

Characteristic	N or mean	Percent or minimum–maximum	Weighted percent or weighted mean
SEER site			
Los Angeles County	491	53.0	51.8
Georgia	436	47.0	48.2
Age at survey administration	63.3	31.2–82.4	62.8
Race/ethnicity			
Non-Hispanic White	478	51.6	57.7
Non-Hispanic Black	168	18.1	17.7
Hispanic	175	18.9	14.4
Asian	81	8.7	7.5
Missing	25	2.7	2.7
Education			
High school or less	273	29.4	27.4
At least some college	645	69.6	71.6
Missing	9	1.0	1.0
Marital status			
Married/partnered	566	61.1	61.4
Not partnered	349	37.7	37.0
Missing	12	1.3	1.5
Employment status			
Employed	363	39.2	40.8
Retired	329	35.5	34.7
Unemployed	212	22.9	22.1
Missing	23	2.5	2.3
Breast cancer stage			
DCIS (0)	429	46.3	45.0
Low-risk invasive	498	53.7	55.0
Comorbidities			
None	644	69.5	70.0
One or more	279	30.1	29.7
Missing	4	0.4	0.3
Family history of breast cancer			
No	702	75.7	74.3
Yes	225	24.3	25.7
Surgical treatment			
Breast conserving surgery	634	68.4	68.3
Unilateral mastectomy	170	17.0	17.0
Bilateral mastectomy	131	14.1	14.4
Missing	4	0.4	0.4
Chemotherapy at time of survey			
No	884	95.4	95.9
Yes	33	3.6	3.0
Missing	10	1.1	1.1
Current symptom bother			
No	665	71.7	72.8
Yes	243	26.2	24.9
Missing	19	2.1	2.4
Decisional axiety scale	2.5	1–5	2.5
Missing	18	1.9	1.9

Fig. 1 a Overestimation of risk of distant recurrence (numeric, descriptive, and both) in women with favorable prognosis breast cancer (weighted). [†]The denominator population is those answering the risk perception questions. *Description* describes the proportion of patients who overestimated using descriptive, numeric, and both types of measurement of risk in the population. **b** Distribution of Low general mental health (GMH), general physical health (GPH), and frequent worry about recurrence in women with favorable prognosis breast cancer (weighted). [†]The denominator population is those answering the QoL questions. *Description* describes the proportion of patients with QoL scores of low general mental health, general physical health, and frequent worry about recurrence

Our findings reflect the difficulty of communicating complex risk information (e.g., distant metastatic recurrence versus new primary) in a situation that is emotionally charged and affectively driven [20].

Our study revealed associations between overestimation and reduced physical and mental health, using validated PROMIS QoL measures, and more frequent patient self-reported worry about recurrence. Our results are consistent

Table 2 Multivariable adjusted logistic regression odds ratios for poor mental health, poor physical health and frequent worry

Characteristic	Odds ratio, weighted, with 95% confidence interval		
	Poor mental health	Poor physical health	Frequent worry
Age			
+1 year increase	0.99 (0.96–1.02)	1.01 (0.99–1.04)	0.97 (0.95–0.99)**
Race/ethnicity			
Non-Hispanic White	REF	REF	REF
Non-Hispanic Black (vs. non-Hispanic White)	0.60 (0.31–1.15)	1.78 (1.01–3.15)*	1.09 (0.66–1.80)
Hispanic (vs. non-Hispanic White)	1.33 (0.59–3.00)	1.48 (0.77–2.84)	0.75 (0.44–1.27)
Asian (vs. non-Hispanic White)	1.22 (0.44–3.37)	2.60 (1.14–5.92)*	1.09 (0.61–1.94)
Education			
Some college or more vs. high school or less	1.76 (0.95–3.26)	3.18 (1.99–5.09)^	1.34 (0.88–2.06)
Employment status			
Retired vs. employed	2.31 (1.21–4.43)*	2.38 (1.32–4.31)**	1.32 (0.84–2.06)
Unemployed vs. employed	2.49 (1.20–5.17)*	2.04 (1.16–3.61)*	0.82 (0.50–1.34)
Marital status			
Not married/partnered vs. married/partnered	2.44 (1.41–4.20)**	1.18 (0.75–1.86)	0.95 (0.66–1.35)
Breast cancer stage			
Low-risk invasive vs. DCIS	0.67 (0.37–1.22)	1.06 (0.69–1.65)	1.57 (1.10–2.25)*
Family history of breast cancer			
Yes vs. no	0.52 (0.28–0.97)*	1.12 (0.72–1.74)	1.05 (0.69–1.61)
Comorbidities			
1 or more vs. none	3.42 (2.02–5.81)^	2.90 (1.89–4.44)^	1.00 (0.66–1.50)
Current symptom bother			
Yes vs. no	2.36 (1.44–3.87)^	6.04 (3.98–9.18)^	1.30 (0.89–1.90)
Decisional anxiety scale			
+1 point increase	2.14 (1.54–2.97)^	1.14 (0.88–1.46)	1.70 (1.37–2.11)^
Descriptive overestimation			
Yes vs. no	2.52 (1.24–5.08)*	1.56 (0.84–2.91)	3.16 (1.87–5.35)^
Numeric overestimation			
Yes vs. no	1.36 (0.72–2.56)	1.90 (1.11–3.26)*	2.87 (1.90–4.33)^

Controlling for: site, surgical treatment, chemotherapy receipt

* $p < 0.05$, ** $p < 0.01$, ^ $p < 0.001$

with other work showing an association between overestimation and reduced physical health [5]. However, our study further suggests that how overestimation is expressed may influence outcomes. For example, while we found that numeric overestimation was more common, descriptive overestimation had an independent influence on outcomes. While others have found that providing numbers is important for risk comprehension [21], our study suggests that having a "gist" understanding is also very important. As a whole, these results underscore the need to ensure that women accurately understand their risk of systemic recurrence following treatment, in a general way, as well as numerically.

Importantly, our analysis included a unique assessment of patient report of their personality as it relates to "general anxiety" when making decisions (not specific to breast cancer treatment). This trait was significantly and independently associated with QoL and frequent worry, supporting the concept that patients who are more naturally anxious may also be more likely to overestimate recurrence risk and worry. These findings suggest that ideally patient–provider communication would include the assessment and management of underlying anxiety related to decisions as well as communication of risk information using gist and numeric approaches. It is important to note that even when controlling for decisional anxiety, overestimation remained independently associated with frequent worry.

Little is known about underlying reasons why women have difficulty understanding this recurrence risk. In prior work by our team, over 80% of surgeons and oncologists reported that they *do* discuss risk of recurrence with breast cancer patients—most often using descriptive terms [22].
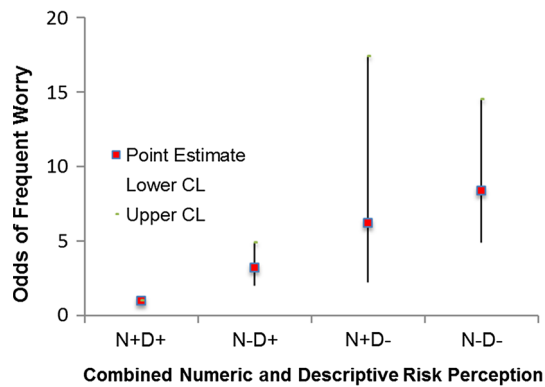
Fig. 2 Association between combined risk perception measure and frequent worry. †Controlling for all covariates. (−) indicates overestimation of risk N: numeric, D: descriptive; +: correct (did not overestimate), −: incorrect (did overestimate). *Description* describes the odds ratios for the association between the combined numeric/descriptive measure on frequent worry

The current study suggests that despite prior clinician reports, not all patients comprehend risk of recurrence. Several factors may contribute, including low patient numeracy, or clinicians more focused on discussing risk among patients presenting with higher recurrence risk. Importantly, prior work also showed that despite discussing risk, many oncologists and surgeons reported lack of confidence in identifying women who are frequent worriers and in managing worry about recurrence with their patients [23]. Our results suggest that clinicians should consider both as important avenues for intervention. Efforts to educate providers about how to effectively convey risk information to their patients using principles of patient centered communication across patients of diverse backgrounds and literacy levels are needed [24, 25]. In fact, research suggests effective communication of uncertainty, including risk information, translates into higher decision satisfaction on the part of patients [26]. Effective patient–provider communication around risk of recurrence would benefit from further studies examining the dimensions of the communication process most closely aligned with patient understanding.

Strengths of this study include a large, diverse sample, clinical information to determine actual recurrence risk, a high participation rate, and use of weighting and multiple imputation methodology. However, the study has some limitations. Patients lived in two geographic regions, so may not represent all U.S. breast cancer patients. Although we had detailed clinical information from SEER to determine actual risk, it is possible that patients perceived additional factors influencing their risk that were not assessed. Finally, associations observed in the study are not necessarily causal.

Implications

Our results suggest strategies to improve patient experiences and outcomes. First, in addition to providing numbers, clinicians could focus attention on describing risk in general verbal terms as well as in numeric terms; doing both may prove easier than conveying specific numeric risk estimates particularly to patients with lower numeracy skills. Second, assessing anxiety and worry across the care trajectory, from diagnosis through the survivorship period, may help identify women who would benefit from support services to manage worry. There is a clear need to improve approaches to convey risk information to patients as well as assess and manage patient anxiety about the cancer diagnosis and its treatment. Areas for intervention include clinician skill-building in risk communication and patient decision tools that present risk information in comprehensible ways practice. These types of interventions are needed to improve risk comprehension among patients and, if effective, may translate into better quality of life for patients with breast cancer.

Invitae, Ambry Genetics, GeneDx, and Genomic Health. All the other authors have no conflict to disclose.

Ethical standards All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study through their return of a completed survey.

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