

The impact of doctor–patient communication on patients’ perceptions of their risk of breast cancer recurrence

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Abstract

Purpose Doctor–patient communication is the primary way for women diagnosed with breast cancer to learn about their risk of distant recurrence. Yet little is known about how doctors approach these discussions.

Methods A weighted random sample of newly diagnosed early-stage breast cancer patients identified through SEER registries of Los Angeles and Georgia (2013–2015) was sent surveys about ~2 months after surgery (Phase 2, $N = 3930$, RR 68%). We assessed patient perceptions of doctor communication of risk of recurrence (i.e., amount, approach, inquiry about worry). Clinically determined 10-year risk of distant recurrence was established for low and intermediate invasive cancer patients. Women’s perceived risk of distant recurrence (0–100%) was categorized into subgroups: overestimation, reasonably accurate, and zero risk. Understanding of risk and patient factors (e.g.

health literacy, numeracy, and anxiety/worry) on physician communication outcomes was evaluated in multivariable regression models (analytic sample for substudy = 1295). **Results** About 33% of women reported that doctors discussed risk of recurrence as “quite a bit” or “a lot,” while 14% said “not at all.” Over half of women reported that doctors used words and numbers to describe risk, while 24% used only words. Overestimators (OR .50, CI 0.31–0.81) or those who perceived zero risk (OR .46, CI 0.29–0.72) more often said that their doctor did not discuss risk. Patients with low numeracy reported less discussion. Over 60% reported that their doctor almost never inquired about worry. **Conclusions** Effective doctor–patient communication is critical to patient understanding of risk of recurrence. Efforts to enhance physicians’ ability to engage in individualized communication around risk are needed.

Keywords Breast cancer · Physician communication · Risk perception · Worry about recurrence

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Introduction

Systemic recurrence of breast cancer is the most feared outcome after the diagnosis of early-stage breast cancer. Understanding personal risk of recurrence and its implications for treatment decisions and survivorship care is challenging for many women diagnosed with breast cancer. Several studies have found that a considerable number of women overestimate their risk of distant recurrence after treatment [1, 2], while others underestimate their risk [1]. The question is, how important is it for women to have a reasonably accurate understanding of their risk of distant recurrence?

A growing body of research suggests that misconceptions about risk are associated with less desirable behavior and health outcomes. Overestimation has been associated with preference for more extensive treatment than necessary [2], greater ongoing worry [3], a hypervigilance about symptoms resulting in unscheduled visits [4, 5], and worse quality of life [1]. In contrast, underestimation may lessen one's commitment to surveillance recommendations regarding mammography [6–8] and/or adhering to endocrine therapy [9].

Most breast cancer patients want to know about their risk of recurrence [10, 11], and many desire more information than they currently receive [10, 12, 13]. Although doctor–patient communication is the primary way that women with breast cancer learn about their risk, few studies have examined patient perceptions of how often doctors discuss risk and what approach is used in these discussions [14–16]. Importantly, in our previous study, most surgeons and medical oncologists report that they discuss risk with their patients [16]. There is no clear consensus on which approach to communicate risk yields greater patient understanding [15, 17–19], although most patients favor a simple format rather than a more complex report [15, 20].

Effectively shared decision-making can only be achieved if breast cancer patients understand their recurrence risk and how various treatments might influence it [16]. For some women, these discussions may be particularly challenging and require additional time and/or personalized approaches based on individual factors [21–23]. For example, less numerate women may require presentation of risk using formats that do not depend solely on numbers [19, 24, 25]. Women with low health literacy find discussions about risk challenging but are less likely to ask questions [23, 26, 27]. Unfortunately, many studies to date evaluating approaches to presenting risk information are limited by relatively small, non-diverse patient samples.

In addition, general anxiety about the cancer diagnosis and/or more specific worry about cancer recurrence have

been associated with greater inaccuracy in perceived risk of recurrence [10, 11, 28]. Worry about recurrence has been found to influence decisions in favor of more extensive surgery, such as CPM, even though there is no evidence that the procedure reduces systemic recurrence [2, 21]. What needs further study is whether doctor–patient communication about risk of recurrence varies among more vulnerable patient subgroups.

To address these gaps, this paper has three major objectives: (1) to characterize patients' perceptions of doctor–patient discussions about risk of recurrence in a large, diverse population-based sample of women with early stage invasive breast cancer, (2) to determine if the amount of discussion, approach used, and/or assessment of worry during the communication effort are associated with patient understanding of risk, and (3) to determine whether doctors' approaches to communicating risk and addressing worry vary by the patient's personal factors.

Methods

Study population

The iCanCare Study, a large, diverse, population-based survey study of women with favorable prognosis breast cancer, accrued women aged 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 from July 2013 to August 2015. Black, Asian, and Hispanic women were oversampled in Los Angeles [29]. In Phase 2 of the study, we selected 3930 women, of whom 258 women were later deemed ineligible due to a prior cancer diagnosis or stage III or IV disease; residing outside the SEER registry area; or being deceased, too ill, or unable to complete a survey in Spanish or English. Of the 3672 eligible women, 2502 (68%) patients responded, and 1172 did not return mailed surveys or refused to participate. Of 2502 women, 1207 did not meet eligibility criteria for this substudy due to the following: 444 had DCIS, 555 had a clinically estimated recurrence risk higher than our definition for “intermediate risk invasive” and 141 had insufficient data to calculate risk. The resulting analytic sample was 1295 women.

Data collection

Patients were sent surveys approximately 2 months after surgery. The median time between surgical path and receipt of the survey was 8 months. We provided a \$20 cash incentive and used a modified Dillman method for

patient recruitment, as done in prior work [29, 30]. All materials were sent in English and Spanish to those with Spanish surnames [29]. Survey responses were 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 [31–33]. We used standard techniques to assess content validity, including expert review, cognitive pre-testing, and pilot studies in clinic populations.

Measures

Primary outcome The doctor–patient communication items regarding risk included: (1) how much your doctor discussed risk of recurrence (5-pt Likert scale, “not at all” to “a lot”), (2) if the discussion included words only, numbers only, or both, and (3) how often the doctor asked about worry about the cancer coming back (5-pt Likert scale, “almost never” to “almost always”).

Primary correlates The primary correlates included patient perceived risk of systemic recurrence and personal factors known to influence understanding of risk (i.e., numeracy, health literacy, general worry, worry about recurrence).

Patient perceived risk of recurrence

Determining actual risk of systemic recurrence From the analytic sample for women with invasive disease, we classified women as having relatively “low actual risk” (<10%) or “intermediate actual risk” (<20%) of distant recurrence, using stage, histology, and biology. Using SEER, actual risk was estimated following treatment (surgery, radiation, chemotherapy). Women were classified as low risk if SEER data indicated stage IA, ER+, HER2–, tumor grade 1–2, and Oncotype DX either not done or recurrence score 0–10. Women were classified as intermediate risk if SEER data indicated stage IA, ER+, HER2–, tumor grade 1–2, and Oncotype DX recurrence score >10; or stage IA, ER+, HER2–, and tumor grade 3+; or stage IB or IIA, ER+, HER2–, with any tumor grade and any Oncotype DX status.

Patients’ perceived risk of systemic recurrence Women were asked to give a numeric estimate from 0 to 100: “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?” For women with “low-risk” invasive cancer, overestimation was defined as 20% or higher. For women with “intermediate-risk” invasive, overestimation was defined as 30% or higher. These percent cutoffs were chosen by clinical experts to represent “substantial overestimation” of risk of recurrence as they were considerably higher than the “clinically estimated risk” of systemic recurrence expected following treatment for these patients with favorable prognosis [34, 35]. For all women with invasive disease, if they indicated that the chance of their cancer spreading to other parts of their bodies was 0%, we considered them to perceive “zero risk” of recurrence.

Numeracy and health literacy

Numeracy was assessed with an item: “How often do you find numerical information to be useful” (5-pt scale “never” to “very often”) [36, 37]. Health literacy was measured by an item: “How often do you have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy” (5-pt scale “never” to “always”) [38, 39].

General worry and worry about recurrence

The “general worry” measure asked women on a scale 1–10, “all things considered, I feel that I almost never worry” to “almost always worry.” Worry specific to breast cancer recurrence was assessed by asking women, “in the past month, how often have you worried about your cancer coming back” (5-pt scale “almost never” to “almost always”) [11].

Additional covariates

Sociodemographic covariates included age, race/ethnicity (White, Black, Latina, Asian, Other/Unknown), educational attainment (high school graduate or less, some college, or more), and family history of breast cancer (none vs. >1 first degree relative). Clinical covariates included SEER stage, recurrence risk group, breast cancer treatment (lumpectomy; unilateral mastectomy; bilateral mastectomy), receipt of radiation (yes/no), receipt of chemotherapy (yes/no), and presence of comorbid health conditions (none vs. >1).

Table 1 Sample characteristics of women with invasive breast cancer ($n = 1295$)

Variables	Weighted % ^a
Sociodemographic factors	
Age	
Under 50	14
50–65	43
65 and over	43
Race	
Asian	9
Non-hispanic White	60
Non-hispanic Black	15
Latina	14
Education	
High school diploma or less	29
Some college or more	69
Family history	
No family history of BRCA	76
1 or more family history of BRCA	24
Clinical factors	
SEER stage	
I	75
II	25
Surgery type	
Lumpectomy	67
Unilateral mastectomy	16
Bilateral mastectomy	15
Radiation therapy	
No	34
Yes	64
Chemotherapy	
No	79
Yes	18
Comorbidities	
None	69
1 or more	31
Patient factors—manageable	
Understanding recurrence risk	
Zero risk	27
Reasonably accurate	51
Overestimation	21
Health literacy (needs help with written materials)	
Never/rarely	75
Sometimes	13
Often/always	11
Numeracy (finds numbers useful)	
Never/rarely	17
Sometimes	40
Often/very often	40

Table 1 continued

Variables	Weighted % ^a
Worry in general	
Almost never worry	38
Sometimes worry	43
Almost always worry	18
Worry about recurrence	
Almost never/rarely	60
Sometimes	24
Often/almost always	13

^a These percentages do not add up to 100% due to missingness

Statistical analyses

First, we calculated descriptive statistics on the distribution of patient factors and doctor–patient communication measures. We then fit multivariable regression models to the three doctor–patient communication outcomes: (1) whether the doctor discussed the risk of cancer recurrence (yes/no); (2) the approach used to discuss risk (none/words only/numbers only/both); and (3) whether the doctor asked the patient about their worry about recurrence (almost never vs at least some). Patient understanding of systemic recurrence risk was categorized as zero risk/reasonably accurate/overestimation compared to clinically estimated risk. To examine whether each patient “personal” factor is an independent predictor of the first and third outcomes, we fit separate logistic regression models, while controlling for sociodemographic and clinical factors. To examine the association of the doctor–patient communication approach (none/words/numbers/both) with the accuracy of patient risk perception (zero risk, reasonably accurate, overestimation), a generalized logit model was used, while adjusting for sociodemographic and clinical factors. Based on this model, a patient’s predicted probability for each reported communication approach was calculated for their respective risk perception group when assuming site of Emory, age <50, white, no college, no family history of breast cancer, no comorbidities, low clinically estimated risk of recurrence, stage I, no radiation or chemotherapy, and lumpectomy treatment). As a sensitivity analysis, a linear regression was performed to examine whether the amount of physician communication was associated with how accurately patients understood their risk of distant recurrence. All regression models adjusted for sociodemographic and clinical factors. All statistical analyses incorporate weights to account for differential probabilities of sample selection and non-response. Weighting allows statistical inferences to be more representative of the target population and reduces potential bias due to non-response. All analyses used SAS software, Version 9.4 (SAS Institute, Cary, NC).

Results

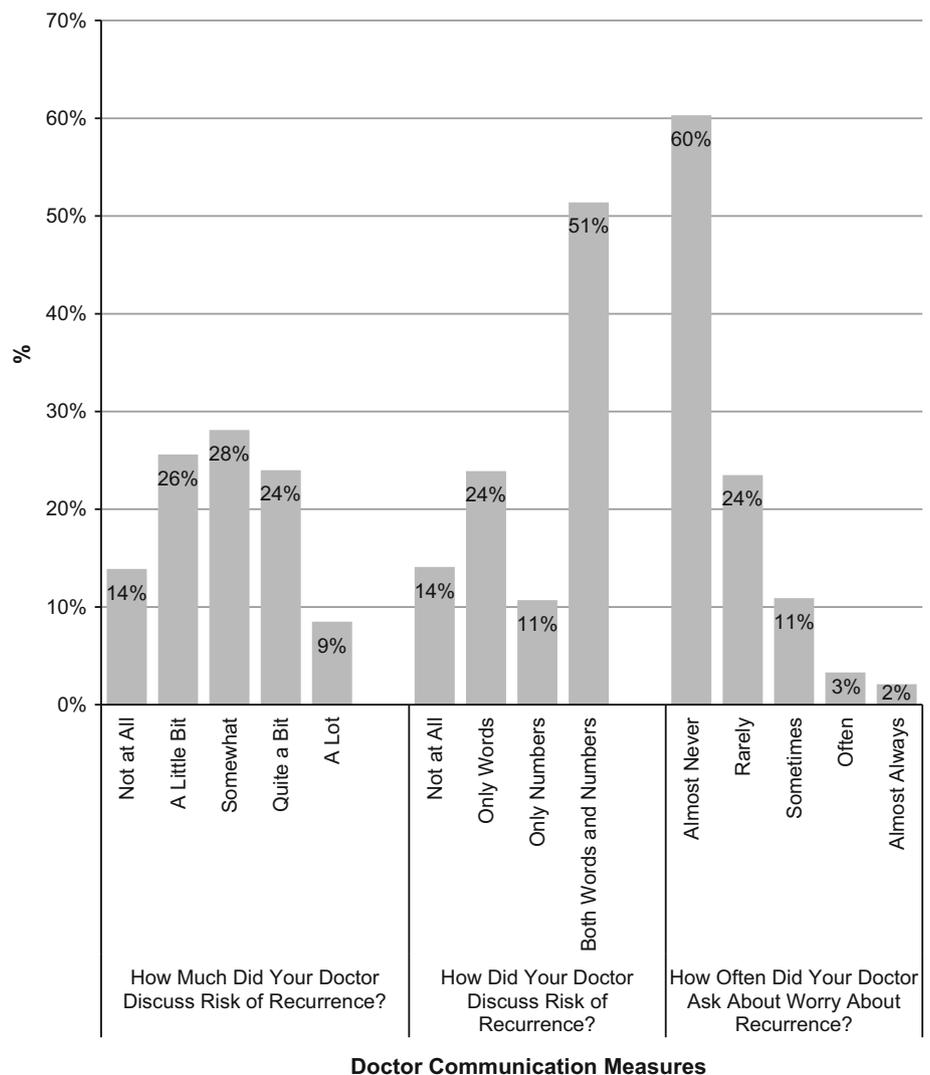
Table 1 presents the sample characteristics. Approximately 86% of patients were over the age of 50, 38% were non-white, 69% had achieved some college education, and 76% had no family history of breast cancer. With regard to clinical factors, 75% were SEER stage I, 67% had a lumpectomy, 64% had radiation therapy, and 18% had chemotherapy. About 27% of patients reported “zero risk” of distant recurrence, while 21% overestimated their risk. About one quarter (24%) of women reported at least sometimes needing help with written material, and 17% reported low numeracy. In terms of worry, about 61 reported that they considered themselves “worriers” at least some of the time, and about 37% reported that they worried specifically about cancer recurrence from “sometimes” to “almost always.”

Figure 1 demonstrates the distribution of the doctor–patient communication measures about risk. With regard to

how much their doctor discussed the chance of cancer coming back, 33% reported “quite a bit” or “a lot,” 14% “not at all” and 26% responded “a little bit.” In terms of how the doctor discussed risk, 24% of patients reported their doctor used “only words” 11% said “only numbers” and 51% reported their doctor used “both words and numbers.” Over 60% of patients reported that their doctors “almost never” asked of worry about recurrence, with an additional 24% responding “rarely.”

Figure 2 displays the association between each primary patient correlate and patients’ perception of whether their doctor discussed risk of recurrence. Specifically, patients who overestimated their risk and those who perceived zero risk of recurrence were significantly less likely to report having had any kind of discussion with their doctors about risk [OR 0.50 (0.31–0.81) for overestimation; OR 0.46 (0.29–0.72) for zero risk]. When we looked more specifically at whether how much the doctor discussed risk

Fig. 1 Distribution of doctor–patient communication measures about risk of recurrence



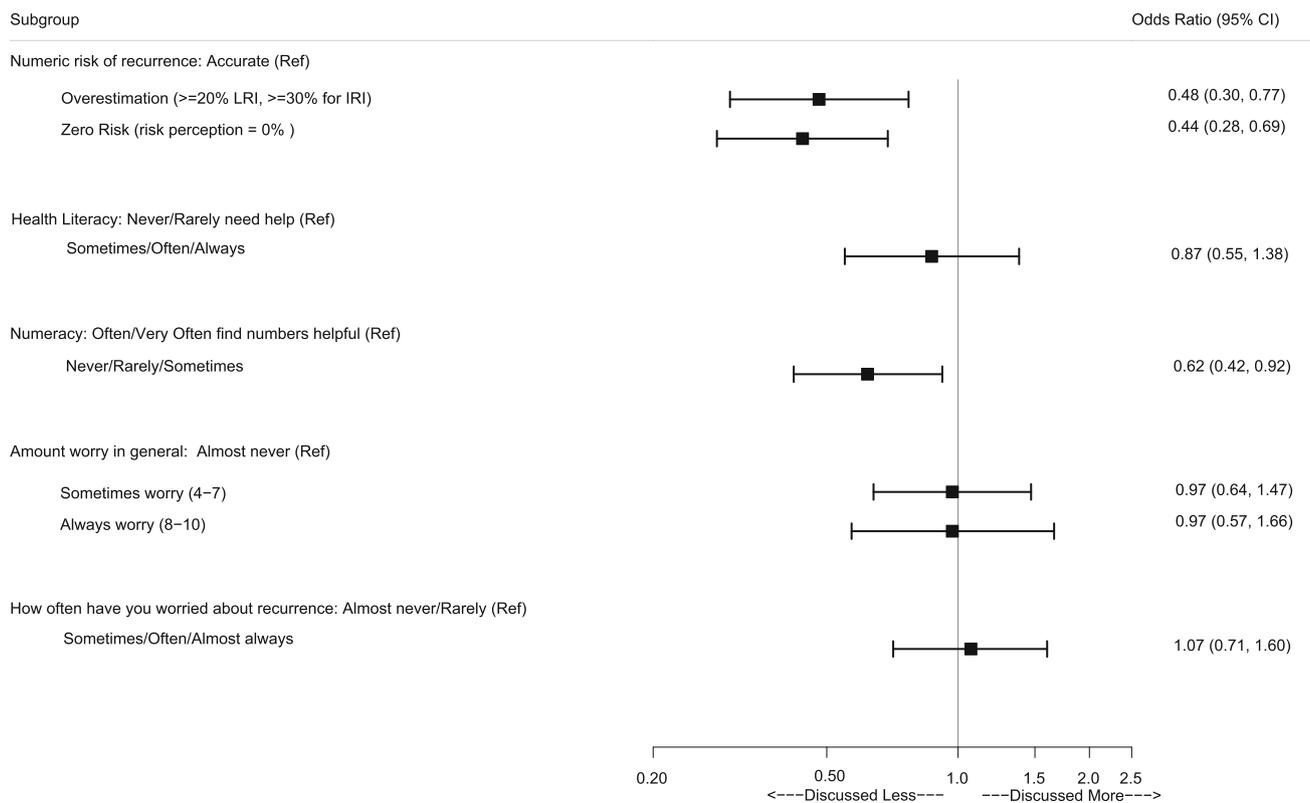


Fig. 2 Association between each primary patient correlate and patients' perception of whether their doctor discussed risk of recurrence. *Ref* not at all. A separate logistic regression model is fit for each patient correlate, while controlling for age, race/ethnicity,

educational attainment, and family history of breast cancer, SEER stage, recurrence risk group, breast cancer treatment, receipt of radiation, receipt of chemotherapy, and presence of comorbid health conditions

mattered, the linear regression showed that more discussion was significantly associated with more patients having reasonable accuracy of distant recurrence risk (vs. not). Patients who reported low numeracy also reported less discussion around cancer recurrence [OR 0.64 (0.43–0.95)]. Other personal factors (e.g. health literacy and/or patient worry) were not significantly associated with patient perception of whether their doctor discussed recurrence risk.

Figure 3 displays the predicted probability of physicians using each approach to discuss risk with their patients according to the accuracy of patients' risk perception. Patients who had misperceptions about their risk of recurrence were more likely to report that their physicians did not discuss cancer recurrence at all and less likely to report their physicians discussed risk using “both words and numbers” or “only numbers.” Note that among patients who had a reasonably accurate understanding of their numeric risk, only 4% reported that their doctor did not discuss risk, while 73% said their doctor used either “numbers only” or “both words and numbers.”

Figure 4 shows the relationship between each primary correlate and patient perception of whether their doctor asked about worry concerning the cancer coming back.

While patients who overestimated their cancer risk showed no association with the doctor asking about worry of recurrence, patients whose perceived risk was zero were significantly more likely to report that their physician almost never asked about worry [OR 0.58 (0.42–0.81)]. Patients who reported some general worry were more likely to report their doctor asking about worry, although this was not significant for patients who reported almost always worry. Similarly, respondents who worried specifically about recurrence at least sometimes were significantly more likely to report that their physicians asked about worry [OR 2.31 (1.75–3.05)]. While not statistically significant, patients who had low health literacy were more likely to report that their doctors asked about worry [(OR 1.24 (0.89–1.72)].

Discussion

In this large, diverse, population-based sample of newly diagnosed women with invasive breast cancer, patients' perceptions of how often their physicians communicated about systemic recurrence risk were associated with the accuracy of patients' perception of risk. Women who

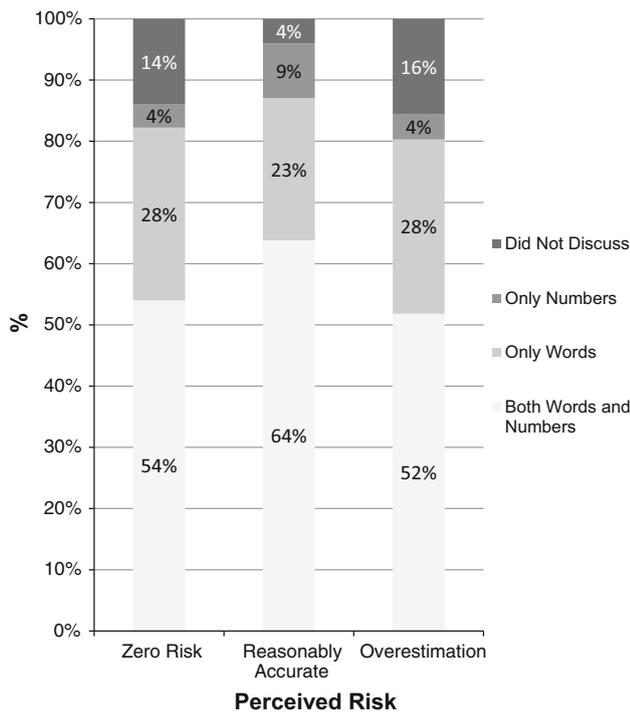


Fig. 3 Predicted probability of doctors using various approaches when discussing risk according to patients' understanding of their risk of recurrence. A generalized logit model was used to examine the association of the doctor–patient communication approach (none/words/numbers/both) with the accuracy of patient risk perception (zero risk, reasonably accurate, overestimation), while adjusting for sociodemographic and clinical factors. Based on this model, a patient's predicted probability for each reported communication approach was calculated for their respective risk perception group when assuming site of Emory, age <50, white, no college, no family history of breast cancer, no comorbidities, low clinically estimated risk of recurrence, stage I, no radiation or chemotherapy, and lumpectomy treatment

perceived they had zero risk of recurrence or overestimated their risk were less likely to report discussions of risk. Almost 15% of women reported that their doctor never discussed risk, and these women were the least likely to have a reasonable understanding of their numeric recurrence risk. Given the negative outcomes associated with misperceptions about risk [7, 40], our findings substantiate the importance of doctor–patient communication efforts around risk of recurrence as it relates to decisions about treatment and breast cancer survivorship behaviors. Patients who overestimate their risk may be more vulnerable to pursuing aggressive testing and treatment even when there is no evidence-based rationale for such choices [2, 7, 21]. In addition, women who perceive no chance of recurrence may be less likely to adhere to survivorship recommendations including symptom surveillance, regular follow-up, and adjuvant endocrine therapy that plays an essential role in reducing distant recurrence risk [6–9].

The approach used by physicians to describe risk was also associated with patients' level of understanding of numeric risk. Among those who had a reasonably accurate understanding of their numeric risk of distant recurrence, almost two-thirds (64%) reported that their doctor used a combination of words and numbers, while only 23% of these women reported the doctor used only words. While the advantages of verbal communication include that it allows for easier and more natural discussion about risk and may better capture a person's emotions [17], the disadvantage is the variability inherent in interpretation of terms such as “unlikely,” “rare,” and “low risk” [17]. Numeric communication has the appeal of more precision, and providing a standard of reference, but needs to be supplemented with other representations, particularly for women with low numeracy [19]. Overall, these findings suggest that for women to understand their numeric risk, some combination of words and numbers may present the most ideal approach. Note that in our previous study, 88% of medical oncologists compared to 47% of surgeons reported using numerical estimates when discussing risk [16].

This study also assessed whether doctor–patient communication varied by patient factors known to make some discussions more challenging. Women with low numeracy were less likely to report physicians' discussions about risk of recurrence. Previous studies have demonstrated that low numeracy is a predictor of lower comprehension of risk [37] and recommend spending additional time with low numerate patients explaining risks and benefits [41] and using risk presentation formats that are easier to evaluate in order to reduce the amount of cognitive effort involved [42–44]. Risk communication strategies might include verbal translations and/or graphical displays along with numbers to increase the likelihood of understanding these messages [45]. Unfortunately, we did not find that women with low health literacy received any more communication about risk than those with higher literacy. Previous studies suggest that women with low health literacy express more unmet information needs [46], and may benefit from strategies such as encouraging question asking, or using “teach back” techniques (asking patients to describe what they just heard in their own words) [47, 48].

Even though anxiety and worry have been associated with misperceptions of risk [28], a majority (60%) of patients reported that physicians “almost never” asked if they were worried about recurrence. Anxiety and worry about recurrence definitely influence women during the treatment decision-making process [49], and well into survivorship [11]. Whether correction of risk estimates alone will result in less worry is uncertain [14]. In a Cochrane review (2013) on the value of personalized risk communication, the authors concluded that incorporating personalized risk estimates increases knowledge, may

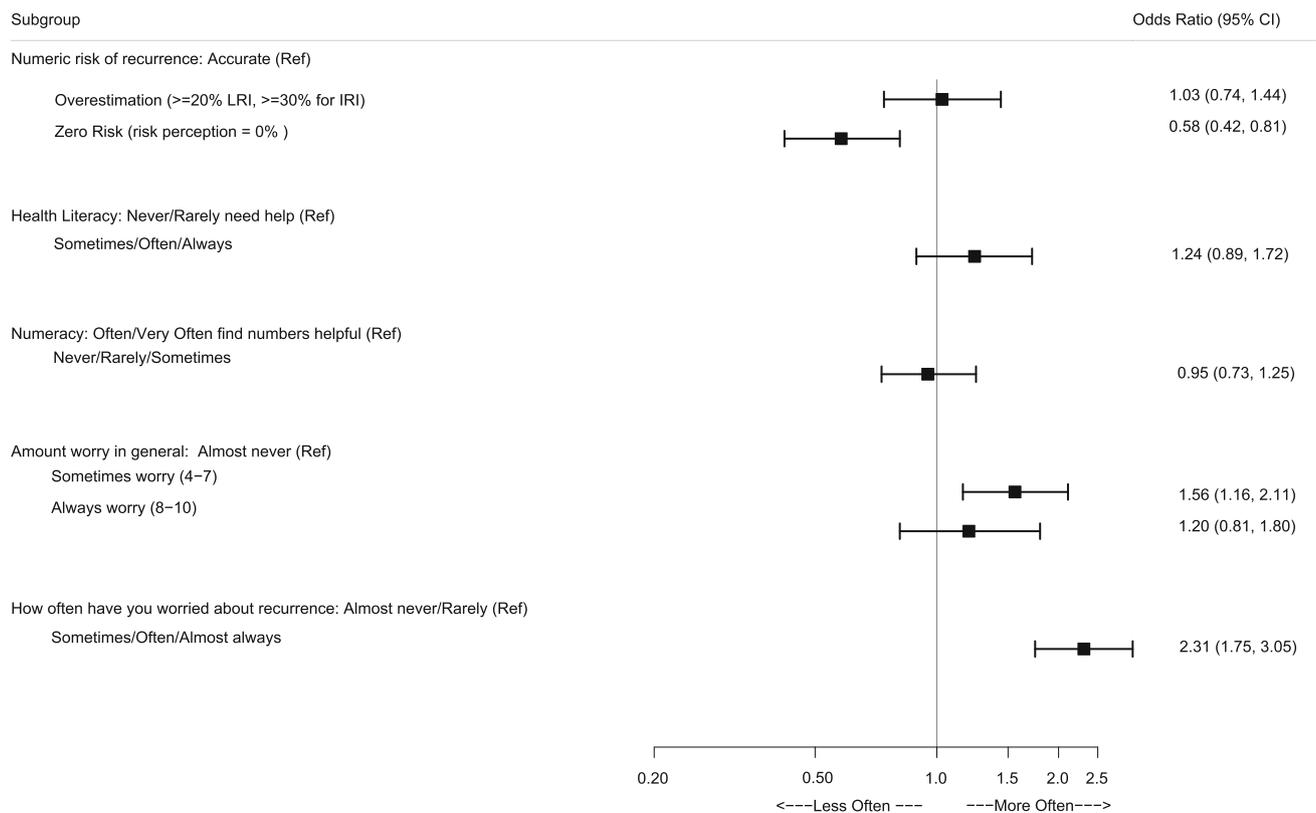


Fig. 4 Association between each primary correlate and patient perception of whether their doctor asked if they were worried about their cancer coming back. Ref almost never. A separate logistic regression model is fit for each patient correlate, while controlling for

age, race/ethnicity, educational attainment, and family history of breast cancer, SEER stage, recurrence risk group, breast cancer treatment, receipt of radiation, receipt of chemotherapy, and presence of comorbid health conditions

increase accuracy of risk, and may enhance informed choices, but may not significantly affect an individual's anxiety [14, 50]. However, identifying women who are anxious or worry about recurrence and simultaneously managing their worry with supportive care while correcting misconceptions about recurrence risk seems like a reasonable approach [21, 24, 51]. Our findings do suggest that physicians are more likely to inquire about worry among women who themselves report the most worry. Notably, many oncologists and surgeons report lack of confidence in managing worry about recurrence with their patients [12, 24].

Further studies might focus on physician education and skill building in risk communication and management of worry [52]. Evaluation of innovative physician education interventions that employ multiple modes of delivery (web and face-to-face) as well as multi-faceted approaches (e.g. modeling, framing of risk, feedback [50, 53]) are needed to identify best practices in communication of health risk across diverse populations. Further research involving patients might focus on better understanding of factors that influence women's perceptions of risk, and the mistakes they make when evaluating their personalized vulnerability

regarding recurrence [40]. Supplementing physician communication with patient decision tools as well as utilizing other medical personnel in the communication process seems like promising directions [14, 19, 50]. Longitudinal studies are also needed to monitor whether survivor behaviors vary over time among women who overestimate their risk or perceive zero risk of recurrence.

Strengths of this study include a large, diverse sample, clinical information to determine actual recurrence risk, a high participation rate, and use of weighting. However, the study has some limitations. Doctor–patient communication around risk was captured with patient perceptions and is subject to recall. The communication measures asked about “your doctors” and did not capture risk discussions by other health care personnel. In addition, we did not have an “uncertain” or “don't know” category in our numeric risk items [1]. Patients lived in two geographic regions, so findings may not represent all USA 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

Risk of systemic cancer recurrence is a difficult concept to communicate to patients particularly in the emotionally charged setting of a new cancer diagnosis [10]. Our results emphasize the importance of doctor–patient communication about risk and suggest further strategies that may improve patient understanding. Physicians should communicate risk information using a combination of approaches, usually including both words and numbers, and possibly supplemented with easy-to-understand written materials. Assessing patient numeracy may be helpful, and developing communication strategies that low numerate patients can understand would likely be a valuable starting point for discussions of recurrence risk with most patients. In addition, assessing anxiety and worry across the care trajectory from diagnosis through survivorship may identify women who would benefit from supportive services to manage worry. Further studies need to test additional strategies to communicate risk to vulnerable and diverse populations. Physicians must be sensitive to personal characteristics of their patient population in deciding on approaches and formats used to communicate risk.

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Compliance with ethical standards

Conflicts of interest Allison Kurian has received research funding for work performed outside of the current study from MyriadGenetics, Invitae, Ambry Genetics, GenDx, and Genomic Health. No other authors have conflicts of interests to report.

Ethical approval 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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