

Health Literacy and Cancer Risk Perception: Implications for Genomic Risk Communication

Noel T. Brewer, PhD, Janice P. Tzeng, BSPH, Sarah E. Lillie, MPH,
Alrick S. Edwards, BA, Jeffrey M. Peppercorn, MD, MPH, Barbara K. Rimer, DrPH

Background. As new genomic technology expands the number of medical tests available to physicians and patients, identifying gaps in our understanding of how best to communicate risk is increasingly important. We examined how health literacy informs breast cancer survivors' understanding of and meaning assigned to recurrence risks yielded by genomic tests. **Methods.** Study participants were posttreatment female breast cancer survivors (N = 163) recruited at a university breast cancer clinic. We assessed their health literacy (using REALM) and their interpretation of hypothetical recurrence risk results from a genomic test, presented in several verbal and numerical formats. Analyses controlled for women's objective recurrence risk, age, income, and race. **Results.** Women with lower health literacy gave higher mean estimates of recurrence risk for a hypothetical group of women with early-stage breast cancer than did women with

higher health literacy (52% v. 30%, $P < 0.001$). Women with lower health literacy also gave more variable estimates in this and several other tasks. When making chemotherapy decisions using risks presented in verbal formats, decisions by women with lower health literacy were less sensitive to the difference between low and high recurrence risk. Ease of understanding of risk formats differed by health literacy. **Conclusions.** Health literacy affected the meanings women assigned to recurrence risk when presented in certain formats. The greater variability in responding by women with lower health literacy supports the hypothesis that they have less precise mental representations of risk, but more research is needed to rule out other possible explanations. **Key words:** risk; relative risk; communication; decision making; Oncotype DX. (*Med Decis Making* 2009;29:157-166)

As the number of new medical tests increases, identifying gaps in our understanding of risk perception and risk communication is becoming increasingly important. One issue that has been little explored is the role that health literacy plays in how people understand and interpret risk. In the present article, we explore the correspondences

among health literacy, risk perception, and risk communication. We focus in particular on communicating recurrence risk derived from new genomic tests for breast cancer recurrence.

Evaluation of gene expression in breast cancer tumor samples now permits more accurate categorization of recurrence risk than standard clinical prognostic factors for patients with early-stage breast cancer.¹⁻³ One such test, Oncotype DX (Genomic Health, Redwood City, CA), analyzes 21 genes derived from an excised tumor to predict risk of recurrence for some patients with early-stage breast cancer. This test and others in development have important implications for risk communication and treatment decision making, including whether to have adjuvant chemotherapy. Patients with low recurrence risk may choose to avoid unnecessary treatments^{4,5} and, as a result, reduce potential overtreatment.

An interesting natural experiment in risk communication is happening in clinical care in the United States and Europe because commercially available recurrence risk tests are presenting results in different formats (as of summer 2008). MammaPrint (Agendia,

Received 18 January 2008 from the University of North Carolina, Chapel Hill, NC. Portions of the data reported in this article were presented at the 2006 meetings of the Society of Behavioral Medicine and the American Society of Preventive Oncology and at the 2008 meeting of the Society of Behavioral Medicine. Financial support for this study was provided in part by grants from the American Cancer Society (MSRG-06-259-01-CPPB) and the Lineberger Comprehensive Cancer Center. The funding agreements ensured the authors' independence in designing the study, interpreting the data, writing the report, and publishing it. Revision accepted for publication 15 July 2008.

Address correspondence to Noel T. Brewer, PhD, Department of Health Behavior and Health Education, Gillings School of Global Public Health, University of North Carolina, 325 Rosenau Hall, CB 7440, Chapel Hill, NC 27516; e-mail: ntba@unc.edu.

DOI: 10.1177/0272989X08327111

Huntington Beach, CA), a test developed in Holland and used in some clinical care in Europe, presents its recurrence risk estimate in simple verbal terms (e.g., “low risk”). In contrast, Oncotype DX, a test developed and used in clinical care in the United States, offers a complex sheet of risk data that includes a numerical recurrence risk estimate (e.g., “6% risk”) with a 95% confidence interval that is translated to a verbal descriptor (e.g., “low risk”). Given that these genomic tests are already in use, research is needed to understand better how patients interpret commonly used risk expressions.

Studies find wide variation in words different people use to describe a given numerical expression of risk and, similarly, a wide range of numbers used to describe an equivalent risk presented in a verbal format.^{6–13} Some research suggests that patients find numerical expressions more trustworthy¹⁴ and that they increase congruence in the treatment decisions reached by different physicians.¹⁵ Researchers have proposed several techniques to standardize risk language,^{10,16} but there remains no universally accepted language for matching risk numbers and words.

One important consideration in risk communication is health literacy,¹⁷ defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”¹⁸ Almost half of Americans have limited literacy skills,¹⁹ a concern because, for example, patients with lower health literacy have poorer comprehension of warning labels on prescription drugs.²⁰ Lower levels of health literacy are also associated with less knowledge about health and health care, poorer health outcomes, and increased risk of hospitalization.²¹ In the context of communicating recurrence risk, we have reported previously that breast cancer patients with lower health literacy, compared to those with higher health literacy, retained substantially less information about genomic recurrence risk testing, suggesting the potential of other difficulties that patients may experience in processing health information.²² It is natural to speculate that lower health literacy women may also have poorer understanding of risk information than higher health literacy women as well as different preferences for risk presentation format.

The present study examined how health literacy informs the way breast cancer survivors understand risk, especially when communicated in different formats. We hypothesized that women with higher health literacy would have a more precise notion of

what risk means. Based on this hypothesis, we predicted that women with higher health literacy would have less variability in the numbers and words they used to describe and interpret risk. We also predicted that women with higher health literacy would express better understanding of different risk formats than women with lower health literacy. Last, we expected that the effect of health literacy on risk format understandability would be stronger for some formats. We examined these hypotheses in a cross-sectional study of women previously treated for early-stage breast cancer, the group for whom Oncotype DX and other new recurrence risk tests were developed.

METHODS

Participants

Eligible participants were adult women who met the following criteria: English speaking, previously diagnosed with stage I/II primary breast cancer, completed surgery, and either had not received or had completed adjuvant chemotherapy. Patients who were currently receiving hormone therapy (tamoxifen) were eligible to participate in the study. Patients were excluded if they were non-English speaking or had a cancer recurrence, a life-threatening comorbid disease, a second primary cancer diagnosis, metastasis, or a history of serious psychiatric illness.

Procedures

Interviews were conducted between February and August 2005 at the University of North Carolina Breast Center. Eligible patients were mailed letters 2 weeks before their next scheduled appointments, inviting them to participate in the study. The letter included a form for patients to agree to be contacted at the Center during their regular appointments or to decline to participate. Patients who did not mail back the form were approached in the Center by trained research assistants and asked again to participate. Patients who agreed to participate received an oral and written introduction describing a new recurrence risk test that was roughly equivalent to Oncotype DX. For the exact text, see Lillie and others (2007), a paper that examines the relationship between health literacy and recall of test results and decision-making styles.²² They next completed a health literacy assessment and self-administered questionnaire. The Institutional Review Board of the

University of North Carolina approved the study protocol and materials. All participants provided written informed consent.

Measures

Health Literacy

We assessed health literacy using the Rapid Estimate of Adult Literacy in Medicine (REALM),²⁰ which requires people to read aloud 66 health-related words of increasing complexity. Any mispronunciation or skipping of a word counted as incorrect, in accordance with recommended scoring procedures.

Understanding Recurrence Risk

Estimating recurrence risk. Participants estimated how many of a hundred women just diagnosed with early-stage breast cancer would have their cancers recur in the next 5 years. They responded using a visual analog scale labeled from 0 to 100, and we converted their responses to percentages.

Interpreting own recurrence risk. Participants viewed a scenario in which they hypothetically had a “low” recurrence risk and another in which they hypothetically had a “high” recurrence risk. Women provided a percentage equivalent for each verbal risk term using a response scale labeled from 0% to 100% chance of recurrence.

Interpreting others’ recurrence risks. Two case vignettes about a fictitious person further explored word-percentage correspondence. The first case vignette described a woman as having either a “6%” or a “35%” risk for recurrence. Participants provided a verbal equivalent using a 5-point response scale labeled from “very low chance” to “very high chance” of recurrence with the midpoint labeled “moderate chance.” The second case vignette described the woman as having either a “low” or a “high” risk for recurrence. Participants provided a percentage equivalent using a response scale labeled from 0% to 100% chance of recurrence. Women received one of 2 randomly assigned combinations of the case vignettes: either “6%” risk in the first vignette followed by “high” risk in the second, or “35%” risk in the first vignette followed by “low” risk in the second.

Impact of recurrence risk results. In the case vignettes about a fictitious person, we asked whether respondents believed the patient should have

chemotherapy (response options: “no,” “maybe,” and “yes”).

Ease of Understanding Risk Communication Formats

Six questions assessed women’s beliefs about how easy it would be to understand recurrence risk presented in 6 formats. We presented the 6 risk communication formats using the following text:

- 1) Words showing your chances. Such as, “The chance that your cancer will recur is a low chance.”
- 2) Words comparing your chances to other women. Such as, “The chance that your cancer will recur is lower than the average woman with early stage breast cancer.”
- 3) Combination of percents and words. Such as, “The chance that your cancer will recur is 6%. This is a low chance.”
- 4) A pie chart or picture showing your chances of recurrence (no illustrations were used).
- 5) Numbers. Such as, “The chance that your cancer will recur is 6 in 100,” and (6) Percents. Such as, “The chance that your cancer will recur is 6%.”

Participants were randomly assigned to see only low risks (“low,” “6 in 100,” “6%,” etc.) or high risks (“high,” “35 in 100,” “35%,” etc.). Participants rated how easy it would be to understand each of these formats when describing chance of recurrence. Response options were “not easy,” “somewhat easy,” “moderately easy,” “very easy,” and “extremely easy.” Percentage equivalents were the midpoints for the low and high recurrence risk categories on the Oncotype DX printouts.

Demographics

The questionnaire assessed age, race, education, marital status, and financial status; missing age or race information were collected from medical records. Based on patients’ medical histories, we calculated participants’ 10-year objective breast cancer recurrence risks using Adjuvant! Online (www.adjuvantonline.com), a validated tool that provides objective risk estimates based on clinical parameters.^{23,24}

Data Analyses

Health literacy–related differences in means of percentage and verbal scales used to describe recurrence risks were analyzed using *t* tests, and differences in variances were examined using Levene tests for equality of variance. When variances were

unequal, we report the unequal variance-adjusted (and more conservative) *t* statistics and *P* values. To control for effects of patients' age, income, race, and objective breast cancer recurrence risk, we first conducted linear regressions using these variables to predict the percentage or verbal risk estimate and output the residual that was used in the *t* tests and Levene tests described previously. Analyses do not control for time since diagnosis, marital status, and education because these variables were generally unrelated to the outcome measures in preliminary analyses. Other outcomes were analyzed using analyses of covariance (ANCOVAs) that controlled for the same covariates. We examined the effect of health literacy (lower or higher) and test result magnitude (low or high risk) on interest in chemotherapy using 2×2 between-subjects ANCOVAs conducted separately for percentage and verbal risk formats. We examined the effect of health literacy on ease of understanding risk communication formats using a 2×6 mixed ANCOVA with format as a within-subjects factor. Controlling for both having received chemotherapy and objective breast cancer recurrence risk is conceptually problematic because chemotherapy treatment decisions weigh recurrence risk so heavily. For this reason, we chose to control for recurrence risk only, as it is more central to our research questions about understanding risk information than is patients' previous decision about chemotherapy. All statistical analyses were performed using SPSS 15.0 (Chicago, IL). Statistical tests were 2-tailed, and the critical α was .05.

RESULTS

Of 231 patients contacted, 165 completed the study (see Lillie and others 2007, for detailed analysis of nonresponders).²² Because 2 participants completed surveys but did not complete health literacy assessments, their data were not used in analyses presented in this article. Hence, we report findings based on 163 participants. Mean age was 59 years (SD, 10.6; range, 36–87). Most women identified themselves as white (86%) or African American (12%). Participants generally had high levels of education (53% were college graduates), and most were married or living as married (73%). The majority (66%) described their finances as having spare money after paying their bills, and a small minority (6%) reported having difficulty paying their bills. The women were an average of 4 years' postdiagnosis

of breast cancer. The median 10-year recurrence risk score from Adjuvant! Online was 28%.

The average health literacy score was 63.6 (range, 30–66). As is common in the literature,^{25,26} we dichotomized health literacy scores to create higher health literacy (63 and above, $n = 125$) and lower health literacy (below 63, $n = 38$) groups. Classification according to reading levels that correspond to health literacy scores yielded the following groups: 4th to 6th grade, $n = 4$ (3%); 7th to 8th grade, $n = 15$ (9%); and high school, $n = 144$ (88%).

Typical Recurrence Risk

Given the scenario about a hypothetical sample of 100 women described as newly diagnosed with early-stage breast cancer, patients estimated that an average of 35 women (35%) would have their cancer recur in the next 5 years. Women with lower health literacy gave *higher* estimates of recurrence risk for the hypothetical group of 100 women than did women with higher health literacy (averages = 52% v. 30%, $P = 0.01$) (Table 1). Women with lower health literacy also offered more *variable* estimates than women with higher health literacy ($P < 0.001$).

Low and High Recurrence Risk

Tables 1 and 2 show numbers and words patients used to describe recurrence risk. They said low risk terms represented lower risk than high risk terms, as one might expect. Women interpreted the term "low chance" similarly when the risk referred to them and to another woman in a hypothetical vignette (20% and 21%, on average, respectively). Women also interpreted "high chance" similarly for themselves and others (58% and 64%, on average, respectively). Women saw a "6% chance" most commonly as being a "very low chance" and a "35% chance" as a "moderate chance" (Table 2).

Women with lower health literacy gave more variable interpretations of recurrence risks described in words (Table 1). When interpreting risks described as being their own, women with lower health literacy used higher numbers to describe "low chance," but this difference did not reach statistical significance. However, women with lower health literacy had greater variability in the numbers they used to interpret "low chance" of recurrence than women with higher health literacy ($P = 0.02$). Similarly, although health literacy was unrelated to the average numbers they used to describe "high" recurrence risk, women

Table 1 Effect of Health Literacy on Interpretation of Recurrence Risk

	Overall, Mean (SD, range [%])	N	Lower Health Literacy, Mean	Higher Health Literacy, Mean	P	Lower Health Literacy, SD	Higher Health Literacy, SD	P
Typical recurrence risk ^a	35% (.22, 0–100)	158	52%	30%	0.01	.27	.17	<0.001
Interpreting low- and high-risk words ^b								
“Low chance,” self	20% (.17, 0–100)	163	24%	19%	0.44	.23	.15	0.02
“High chance,” self	58% (.22, 0–100)	162	57%	58%	0.72	.27	.20	0.05
“Low chance,” other	21% (.17, 3–82)	78	32%	17%	0.05	.21	.14	0.008
“High chance,” other	64% (.17, 20–96)	79	66%	64%	0.22	.16	.17	0.33
Interpreting low- and high-risk percentages ^c								
“6% chance,” other	1.5 (.60, 1–3)	80	1.6	1.5	0.73	.71	.57	0.14
“35% chance,” other	3.1 (.59, 2–5)	78	3.1	3.2	0.53	.64	.58	0.64

Note: Case vignettes presented risks for hypothetical patients with early stage breast cancer. Means are unadjusted, and *P* values are from analyses controlling for age, income, race, and patients' own objective breast cancer recurrence risk. Response scale for average recurrence risk was a visual analog scale.

a. Response scale ranged from 0 to 100 women and was converted to 0% to 100%.

b. Response scale ranged from 0% to 100%.

c. Response scale for words ranged from 1 (not at all) to 5 (completely).

Table 2 Words Patients Used to Describe Numerical Recurrence Risks

Recurrence Risk Description	N	Patients' Interpretations				
		Very Low Chance	Low Chance	Moderate Chance	High Chance	Very High Chance
Provided to patients						
“6% chance”	80	52%	42%	5%	0%	1%
“35% chance”	78	0%	10%	68%	21%	1%

Note: Data are percentages of patients using each term. Risks were presented in case vignettes about hypothetical patients with breast cancer. Patients' interpretations did not differ by level of health literacy.

with lower health literacy gave more variable estimates for “high” recurrence risk than women with higher health literacy ($P = 0.05$).

These effects of health literacy were partially corroborated by results from the hypothetical case vignettes about others' risks described in words. When describing other women's results, lower literacy women described “low chance” for recurrence using higher percentages, on average, than higher literacy women ($P = 0.05$). Women with lower health literacy also had greater variability in the numbers they used to describe “low chance” of recurrence than women with higher health literacy ($P = 0.008$). Lower and higher literacy women used equivalent percentages on average to describe “high chance.”

The words women selected to describe “6%” and “35%” chance of recurrence did not differ by health literacy level (Table 1).

Impact of Test Results

When recurrence risks were described using percentages, women more strongly endorsed chemotherapy if the magnitude of recurrence risk was high than low (2.7 v. 1.6, $F_{1,154} = 70.76$, $P < 0.001$). However, women with higher health literacy were more sensitive to recurrence risk when making chemotherapy decisions than women with lower health literacy (interaction, $F_{1,154} = 5.86$, $P = 0.02$) (see Figure 1A). Higher health literacy women less

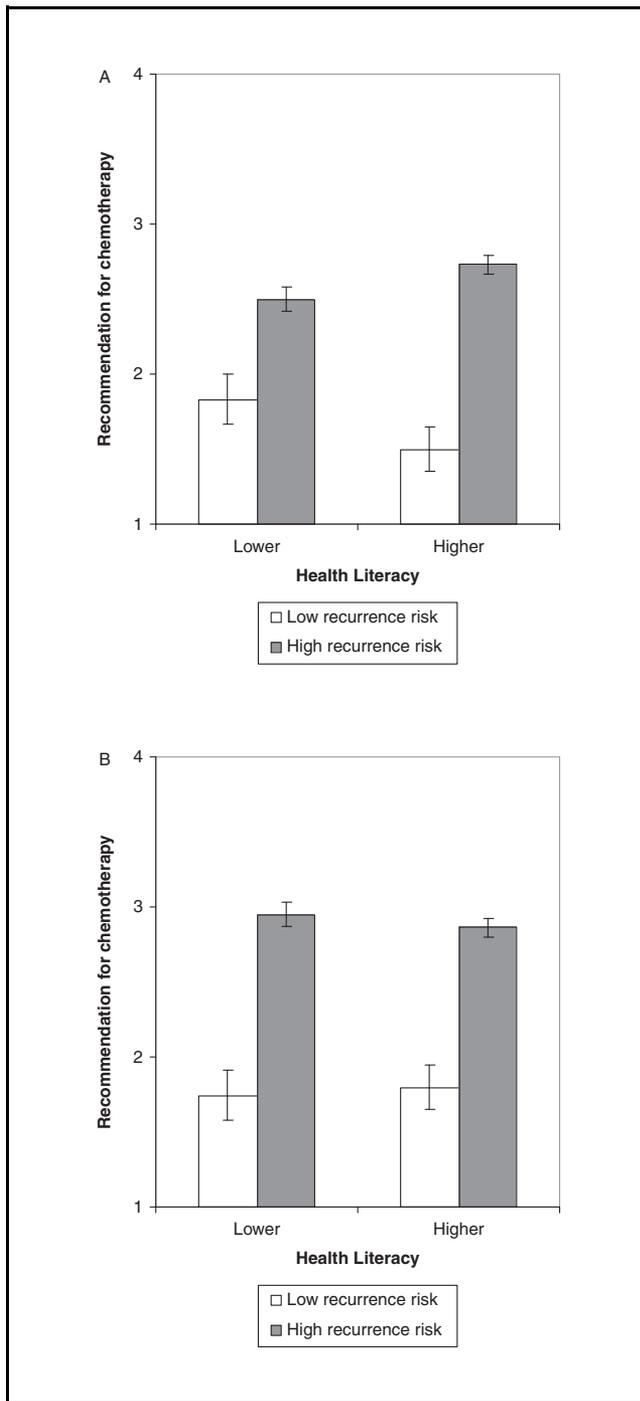


Figure 1 (A) Percents: The effects of health literacy and recurrence risk magnitude on recommendations for chemotherapy, when recurrence risk was described in percentages. (B) Words: The effects of recurrence risk magnitude on recommendations for chemotherapy, when recurrence risk was described in verbal terms. Means are unadjusted. Analyses control for patients' age, race, income, and objective recurrence risk. Bars depict standard errors.

strongly endorsed chemotherapy when risk was low and more strongly endorsed chemotherapy when risk was high. When recurrence risks were presented in word format, all women again more strongly endorsed chemotherapy if risk was high than low (2.9 v. 1.8, $F_{1,155} = 113.79, P < 0.001$), but health literacy had no main effect or interaction (Figure 1B).

Ease of Understanding Risk Communication Formats

Of 6 risk communication formats, the verbal comparison (e.g., “The chance your breast cancer will recur is lower than the average woman with early stage breast cancer.”) received the lowest ease of understanding ratings, and the combined percent + word format (e.g., “The chance your cancer will recur is 6%. This is a low chance.”) received the highest ratings (Figure 2). Averaged across all formats, women with lower health literacy expressed lower ease of understanding than women with higher health literacy ($F_{1,152} = 10.10, P = 0.002$). Health literacy and risk communication format interacted in unadjusted analyses ($F_{5,760} = 2.83, P = 0.02$). The effect remained after controlling for age and actual recurrence risk but not after also adjusting for race and income ($F_{5,760} = 0.89, P = 0.49$). Post hoc tests showed that women with lower health literacy did not find any one risk format easier to understand than another ($F_{5,150} = 1.74, P > 0.13$). In contrast, women with higher health literacy said some formats were easier to understand than others ($F_{5,610} = 20.74, P < 0.001$). As shown in Figure 2, they expressed the best understanding of the combined percent + word format while finding the verbal comparison format least understandable; the remaining formats were seen as intermediate (and equivalent to one another).

DISCUSSION

As genomic tests become more common in clinical settings, it is increasingly important to understand how patients interpret and use the risk information such tests provide. Study participants gave highly variable interpretations of risk information provided in the survey, a finding that was exacerbated by health literacy. Women with higher health literacy gave lower and less variable risk estimates when interpreting “low chance” and were more sensitive to numerical recurrence risks when making hypothetical chemotherapy treatment decisions. They also found most risk communication

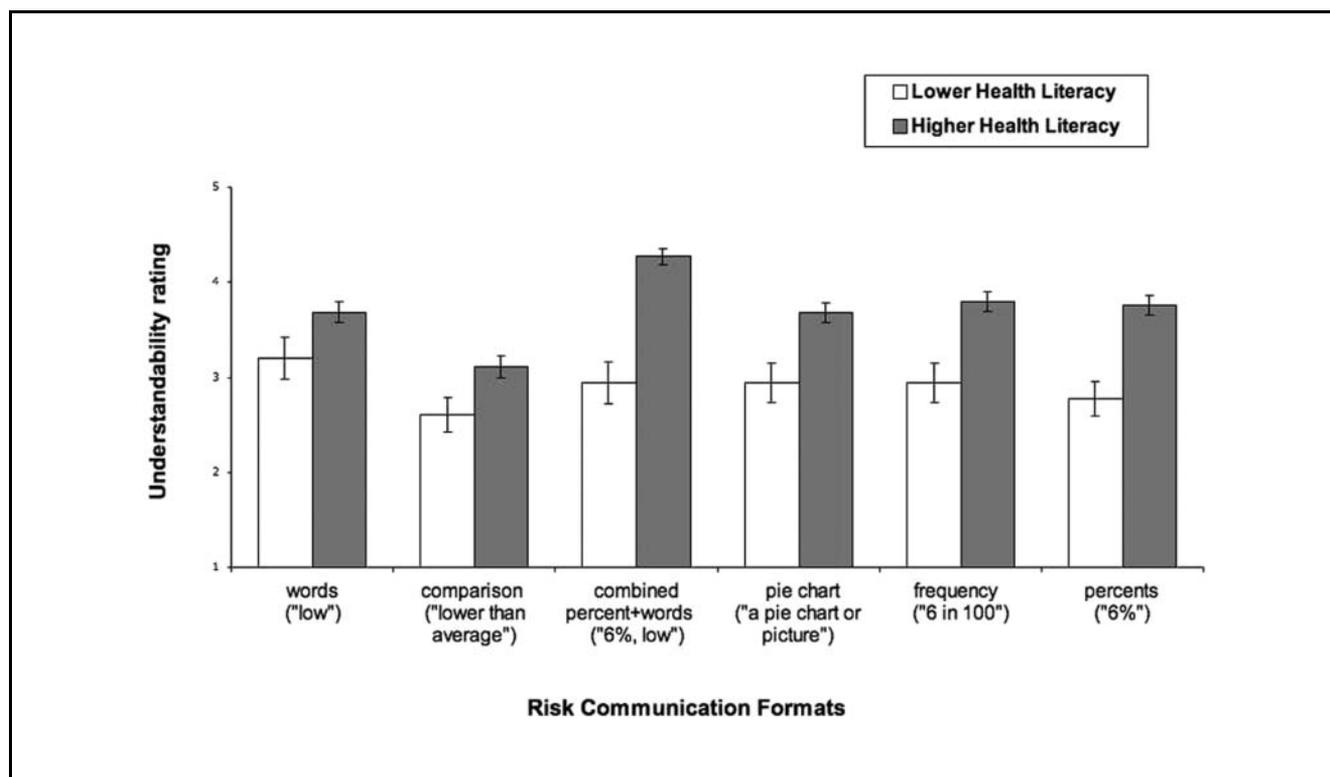


Figure 2 The effects of health literacy on self-reported understandability of recurrence risk presented in 6 different formats. Bars depict standard errors.

formats easier to understand than the lower health literacy women. Health literacy did not affect most interpretations of the term “high chance” and chance described in percentages.

The simplest summary of our findings is that health literacy often matters when talking about risk, but an explanation of the exact pattern of findings in our study is more elusive. Our a priori hypothesis was that women with lower health literacy had less precise mental representations of risk. This is consistent with our findings of the greater variability of many risk estimates and in the lower understandability of most risk formats. However, we have a harder time making sense of why the effect of health literacy was more pronounced for low than high risks and why there were mean (not just variance) differences in risk estimates.

Our data cannot fully rule out several other hypotheses. We discuss one in particular: perhaps lower literacy women were more likely to guess. They may have been less engaged by the survey for whatever reason and, as a result, invested less mental energy in giving thoughtful answers.²⁷ This account

does well in explaining the mean differences in numerical risk estimates, which tended to regress toward 50% among the lower literacy women and did not regress when estimates were fairly close to 50%. Similarly, guessing would lead to higher variances in estimates. It explains the different perceived understandability of the risk formats and the lack of differences in perceived understandability across formats among low literacy women, if one assumes that lower health literacy women were aware that they were guessing.

A related finding from recent work by Bruine de Bruin and others is that those with less education—and by extension, presumably those with lower literacy—use the “50%” response category more often, apparently to indicate a best guess or not knowing the answer.²⁸ However, in our study, women infrequently responded 50%. More importantly, the few 50% responses were not more common among lower health literacy women’s responses (data not shown).

Neither the guessing nor the fuzzy representation hypotheses can explain why health literacy did not affect translation of percentages to verbal expressions

of risk. We suspect that this task may have been an especially easy one for participants to complete. Previous studies have found that discriminating among risk presented numerically is easier than discriminating among equivalent verbal risk expressions.^{6,29,30} This would mean there was less need for guessing or less impact of imprecise mental representations.

A particularly interesting finding is the effect of health literacy on women's endorsements of chemotherapy. Our findings were consistent with the fuzzy representation hypothesis, suggesting that women were less sure what the percentages meant. The guessing hypothesis also does well because guessing would dampen the sensitivity of chemotherapy recommendations to risk magnitude, making recommendations of lower health literacy women more similar in both low- and high-risk vignettes. However, neither hypothesis can explain why risks described in percentages were interpreted more variably by those with lower health literacy, but verbal risk descriptors were not. We again speculate that verbal risk phrases such as "low chance" have clear and widely known implications for treatment that percentage risk terms may not have. In other words, in the task of deciding about chemotherapy, words used to describe risk may be easier to make use of than percentages.

Taken together, the findings suggest that words may have less precise risk meanings than numbers,³¹ but they may convey more meaning that is relevant to treatment decisions.^{17,32} One of the prime clinical implications of this study is that physicians should summarize numerical data with verbal risk terms to facilitate collaborative decision making with patients. This conclusion also is supported by data in the area of risk communication that patients prefer risk be described using both verbal and numerical terms.^{33,34}

We turn now to discussing other specific study findings in greater detail. Our findings demonstrate that health literacy affects variability in numbers used to interpret verbal ("low" or "high") descriptors of risk. This association existed even after controlling for age, income, race, and actual recurrence risk. These results offer a partial explanation for the wide variation in the numbers people use to describe a given verbal risk phrase,⁶⁻¹³ but there are likely to be many other factors contributing to this variability.

Contrary to our expectation, health literacy was not associated with variability in verbal phrases women used to describe recurrence risk presented to them in percentages ("6%" or "35%"). Women may have found this an easier task to complete, regardless

of health literacy level, because they were given only 5 response options to choose from, compared to the potentially 100-point visual analog scales that participants used to assign numerical meaning to verbal recurrence risks. Whatever the reason, it remains possible that health literacy would influence the words that people choose to represent a given risk number if they were allowed an open-ended format.

Lower health literacy women found all but one risk format harder to understand than did higher literacy women. Furthermore, women with lower health literacy did not find any format to be easier to understand, while women with higher health literacy preferred combined percent + word formats. While it is important to make health communications as clear as possible for everyone,³⁵ these data lead us to suggest that test makers, clinicians, and health educators should be especially attentive to patients' health literacy levels when communicating results from tests that yield risk information.

Because the numerical response scales used to describe verbal risks were bounded at 0 and 100, one could be concerned that answers closer to 0 would have less variability. The specific pattern of our findings gives us confidence that, even if scaling explains a portion of our findings, our results also depict the effect we hypothesized. Health literacy-associated variance differences were larger for the 2 variables that also had health literacy-associated mean differences (consistent with the variance constraint explanation). However, 2 other variables showed variance differences but not mean differences. These latter 2 variance effects appeared to be slightly smaller, suggesting some other effect is present in addition to health literacy, perhaps related to scaling. The presence of the difference in variances even when the means were equivalent lends credence to our proposed fuzzy representation hypothesis.

The study has several limitations. First, although we measured health literacy using a well-validated measure, other measures of this construct exist. Also, we did not assess numeracy, a type of health literacy that has obvious relevance to understanding and using numerical risk information.³⁶⁻³⁹ Because the average health literacy score was relatively high (63.6 out of a maximum score of 66), fewer patients were categorized as lower than higher health literacy. Although significant differences were observed between the 2 groups, these limitations warrant further examination with more diverse samples. Dichotomizing the health literacy variable may lead to different conclusions than data for a population that more fully represented

the full continuum of health literacy. We studied a proxy population that was not actually using the recurrence risk test. We believe this decision was defensible given that the test, at the time of the study, was not available for clinical use. Using this proxy population allowed us to quickly gather data just before the test moved into clinical use. Proxy studies were also used in the early days of genetic testing before validated tests were available.^{40,41} The sample of breast cancer patients is one for whom these issues are very real, and the health literacy differences should generalize to other patients. The order of the hypothetical vignettes was not counterbalanced, although we believe order effects do not explain our findings. The hypothetical nature of the exercises may yield different findings than an actual clinical encounter would. Although self-reported ease of understanding is an important outcome, it is distinct from an objective accuracy measure, an approach that should be pursued in future studies.

The findings of the present study suggest that health literacy affects how patients understand risk information. When presenting complex information or making difficult decisions, clinicians should take special care with lower health literacy patients. Although a great deal is known about the relationship of health literacy to use of clinical services and clinical outcomes,²¹ additional research is needed to map the extent to which health literacy affects risk communication and treatment decision making in actual clinical settings. In addition, there are individual difference variables such as dispositional optimism, health locus of control, and spirituality that may potentially relate to perceptions of recurrence risk. These are all topics for future studies.

ACKNOWLEDGMENTS

We thank Ellen Peters for the inspiration for this article and for suggesting the guessing hypothesis as an interesting alternative explanation for our findings. We also thank Edward Morrill and Suzanne O'Neill for their help in planning and conducting the study; the interviewer team for their help with data collection; Lisa Carey, Claire Dees, Beth Fogel, and other physicians and nurses of the University of North Carolina Breast Center for their assistance; and Rob Hamm and 2 anonymous reviewers for their helpful comments on an earlier version of the article. Most importantly, we thank the women who participated in this study.

REFERENCES

1. Buyse M, Loi S, van't Veer L, et al; TRANSBIG Consortium. Validation and clinical utility of a 70-gene prognostic signature for women with node-negative breast cancer. *J Natl Cancer Inst.* 2006;98:1183–92.
2. Foekens JA, Atkins D, Zhang Y, et al. Multicenter validation of a gene expression-based prognostic signature in lymph node-negative primary breast cancer. *J Clin Oncol.* 2006;24:1665–71.
3. Paik S, Shak S, Tang G, et al. A multigene assay to predict recurrence of tamoxifen-treated, node-negative breast cancer. *N Engl J Med.* 2004;351:2817–26.
4. van't Veer LJ, Dai H, van de Vijver MJ, et al. Gene expression profiling predicts clinical outcome of breast cancer. *Nature.* 2002;415:530–6.
5. Cleator S, Ashworth A. Molecular profiling of breast cancer: clinical implications. *Br J Cancer.* 2004;90:1120–4.
6. Biehl M, Halpern-Felsher BL. Adolescents' and adults' understanding of probability expressions. *J Adolesc Health.* 2001;28:30–5.
7. Bryant GD, Norman GR. Expressions of probability: words and numbers. *N Engl J Med.* 1980;302:411.
8. Budescu DV, Wallsten TS. Processing linguistic probabilities: general principles and empirical evidence. In: Busemeyer J, Medin DL, Hastie R, eds. *Decision Making from a Cognitive Perspective.* New York: Academic Press; 1995.
9. Budescu DV, Wallsten TS. Dyadic decisions with numerical and verbal probabilities. *Organ Behav Hum Decis Process.* 1990;46:240.
10. Dhami MK, Wallsten TS. Interpersonal comparison of subjective probabilities: toward translating linguistic probabilities. *Mem Cognit.* 2005;33:1057–68.
11. Reagan RT, Mosteller F, Youtz C. Quantifying meanings of verbal probability expressions. *J Appl Psychol.* 1989;74:433–42.
12. Wertz DC, Sorenson JR, Heeren TC. Clients' interpretation of risks provided in genetic counseling. *Am J Hum Genet.* 1986;39:253–64.
13. Witteman CL, Renooij S, Koele P. Medicine in words and numbers: a cross-sectional survey comparing probability assessment scales. *BMC Med Inform Decis Mak.* 2007;7:13.
14. Gurmankin AD, Baron J, Armstrong K. Intended message versus message received in hypothetical physician risk communications: exploring the gap. *Risk Anal.* 2004;24:1337–47.
15. Timmermans D. The roles of experience and domain of expertise in using numerical and verbal probability terms in medical decisions. *Med Decis Making.* 1994;14:146–56.
16. Witteman C, Renooij S. Evaluation of a verbal-numerical probability scale. *Int J Approx Reason.* 2003;33:117.
17. Reyna VF. How people make decisions that involve risk: a dual-processes approach. *Curr Dir Psychol Sci.* 2004;13:60.
18. US Department of Health and Human Services. *Healthy People 2010: Understanding and Improving Health and Objectives for Improving Health.* Washington (DC): US Department of Health and Human Services; 2006.
19. Kutner M, Greenberg E, Jin Y, Boyle B, Hus Y, Dunleavy E. *Literacy in Everyday Life: Results from the 2003 National Assessment of Adult Literacy (NCES 2007-480).* Washington (DC): National Center for Education Statistics; 2007.

20. Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Fam Med*. 1993;25:391-5.
21. Dewalt DA, Berkman ND, Sheridan S, Lohr KN, Pignone MP. Literacy and health outcomes: a systematic review of the literature. *J Gen Intern Med*. 2004;19:1228-39.
22. Lillie SE, Brewer NT, O'Neill SC, et al. Retention and use of breast cancer recurrence risk information from genomic tests: the role of health literacy. *Cancer Epidemiol Biomarkers Prev*. 2007;16:249-55.
23. Olivotto IA, Bajdik CD, Ravdin PM, et al. Population-based validation of the prognostic model ADJUVANT! for early breast cancer. *J Clin Oncol*. 2005;23:2716-25.
24. O'Neill SC, Brewer NT, Lillie SE, et al. Women's interest in gene expression analysis for breast cancer recurrence risk. *J Clin Oncol*. 2007;25:4628-34.
25. Fortenberry JD, McFarlane MM, Hennessy M, et al. Relation of health literacy to gonorrhea related care. *Sex Transm Infect*. 2001;77:206-11.
26. Lindau ST, Tomori C, Lyons T, Langseth L, Bennett CL, Garcia P. The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multiethnic cohort of women. *Am J Obstet Gynecol*. 2002;186:938-43.
27. Krosnick JA. Response strategies for coping with the cognitive demands of attitude measures in surveys. *Appl Cogn Psychol*. 1991;5:213-36.
28. Bruine de Bruin W, Fischhoff B, Millstein SG, Halpern-Felsher BL. Verbal and numerical expressions of probability: "it's a fifty-fifty chance." *Organ Behav Hum Decis Process*. 2000;81(1):115-31.
29. Behn RD, Vaupel JW. *Quick Analysis for Busy Decision Makers*. New York: Basic Books; 1982.
30. von Winterfeldt D, Edwards W. *Decision Analysis and Behavioral Research*. Cambridge: Cambridge University Press; 1986.
31. Erev I, Cohen BL. Verbal versus numerical probabilities: efficiency, biases, and the preference paradox. *Organ Behav Hum Decis Process*. 1990;44:1.
32. Reyna VF, Lloyd FJ, Whalen P. Genetic testing and medical decision making. *Arch Intern Med*. 2001;161:2406.
33. Rimer BK, Sugarman J, Winer E, Bluman LG, Lerman C. Informed consent for BRCA1 and BRCA2 testing. *Breast Dis*. 1998;10:99-114.
34. Wallsten TS, Budescu DV, Zwick R, Kemp SM. Preferences and reasons for communicating probabilistic information in numerical or verbal terms. *Bull Psychon Soc*. 1993;31:135-8.
35. Hamm RM, Bard DE, Hsieh E, Stein HF. Contingent or universal approaches to patient deficiencies in health numeracy. *Med Decis Making*. 2007;27(5):635-7.
36. Lipkus IM, Samsa G, Rimer BK. General performance on a numeracy scale among highly educated samples. *Med Decis Making*. 2001;21:37-44.
37. Peters E, Hibbard J, Slovic P, Dieckmann N. Numeracy skill and the communication, comprehension, and use of risk-benefit information. *Health Aff (Millwood)*. 2007;26:741-8.
38. Schwartz LM, Woloshin S, Black WC, Welch HG. The role of numeracy in understanding the benefit of screening mammography. *Ann Intern Med*. 1997;127:966-72.
39. Sheridan SL, Pignone M. Numeracy and the medical student's ability to interpret data. *Eff Clin Pract*. 2002;5:35-40.
40. Smith KR, Croyle RT. Attitudes toward genetic testing for colon cancer risk. *Am J Public Health*. 1995;85:1435-8.
41. Lerman C, Daly M, Masny A, Balshem A. Attitudes about genetic testing for breast-ovarian cancer susceptibility. *J Clin Oncol*. 1994;12:843-50.