

Retention and Use of Breast Cancer Recurrence Risk Information from Genomic Tests: The Role of Health Literacy

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Abstract

Background: New genomic technology now allows physicians to provide women with individualized and highly accurate breast cancer recurrence risk estimates that are a key factor in adjuvant (after surgery) therapy decisions. Because these genomic tests are so new, little is known about how well patients understand the tests and their results.

Method: We interviewed 163 stage I or II breast cancer patients at a routine follow-up appointment. We assessed their health literacy (using the Rapid Estimate of Adult Learning in Medicine) as well as their knowledge of and attitudes towards a genomic test that identifies risk of

recurrence in hormone receptor-positive, node-negative breast cancer (the OncoType Dx Recurrence Score).

Results: Women with lower health literacy recalled less of the information provided about the recurrence risk test than women with higher health literacy. Health literacy was not related to the amount of additional information women desired. Women with higher health literacy preferred to have a more active role in decisions about the test.

Implications: Health literacy may affect women's capacity to learn about the new genomic tests as well as their desire for informed participation in their medical care. (Cancer Epidemiol Biomarkers Prev 2007;16(2):OF1-7)

Introduction

Breast cancer is the most common cancer among women in the United States and the second leading cause of cancer death among women, behind lung cancer. In 2006, an estimated 212,920 women will be diagnosed with the disease, and 40,970 will die from the disease (1). A number of medical tests have been developed that concern breast cancer. For example, BRCA1/2 testing aims to identify inherited risk for breast cancer before it occurs. Routine mammography screening offers early identification of women who have breast cancer, allowing for earlier treatment and potentially saving lives (2). Recurrence risk estimation gives information on the chance that a breast cancer patient's tumor will recur by using a variety of prognostic indicators, including tumor size, progesterone receptor status, and estrogen receptor status. Recurrence risk information allows the patient and the physician to make an informed decision regarding the need for adjuvant treatments such as chemotherapy.

A number of genomic tests have been developed that help more accurately gauge risk of recurrence after a breast cancer diagnosis than conventional clinical risk indicators (3, 4). Although the genes in these tests may differ, they consistently identify poor-risk prognosis tumors based on biological variables (5) and are increasingly in clinical use. One of these, the OncoType Dx Recurrence Score, estimates the likelihood of a breast tumor recurring as distant metastasis in women with newly diagnosed early-stage estrogen receptor-positive, node-negative breast cancer who will be treated with tamoxifen (6). This test quantitatively analyzes multiple genes using RNA derived from an excised tumor. For the sake of simplicity, we refer to this new test as the "recurrence risk test," but we

acknowledge that there are several such tests under development, and that they are genomic improvements on existing techniques. Up to now, individualized information has not been available (7), and physicians and women have had to rely upon the best information available about groups of patients. The new recurrence risk test provides individualized risk estimates, or a recurrence score. The recurrence risk test may also correctly re-categorize women who were determined to be at high risk using existing risk indicators as being at low risk for recurrence. One limitation of the new tests is that their biological basis and implications for treatment are just now beginning to be well understood.

Personalized risk-for-recurrence estimates may inform treatment decisions, as patients with high risk for recurrence may choose different and more aggressive treatments, whereas patients with low risk-for-recurrence may avoid unnecessary treatments and the associated side effects and expense (3, 8). The important implication is that patients for whom the new recurrence risk test is suitable may be advised about the appropriate treatment for their individual cancers with greater accuracy. Thus, there may be less overtreatment: almost twice as many women have been treated with adjuvant therapy than may actually have needed it (9).

Information about risk for breast cancer recurrence from the new recurrence risk test should soon play a significant role in women's breast cancer treatment decisions. One study using data from existing risk indicators showed that reducing the risk of dying from breast cancer by even 0.5% to 1% would make adjuvant chemotherapy acceptable to patients (10). However, there are still relatively few studies that link between information provided to women and their treatment decisions.

This new test raises important issues about how to communicate with patients about their recurrence risks. Cancer patients prefer individualized risk estimates over those of a collective group (11); however, research has shown that cancer patients often have incorrect perceptions about their disease (12). Breast cancer patients often do not understand basic information about their prognosis, including their risk for recurrence (13). Many women even have difficulty understanding the basic concept of risk; some women greatly overestimate their risk for breast cancer (14), even after risk

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counseling (15). It is essential, then, that recurrence risk information is communicated clearly if such information is to contribute to informed decision making.

One potential reason for misunderstanding risk is low health literacy. The U.S. Department of Health and Human Services defines health literacy 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" (16). It has also been defined as the evolving skills that allow one to apply health concepts in new situations, to participate in dialogues about health and medicine, and to use health information to make informed choices that improve quality of life and reduce health risks (17).

Literacy and health outcomes are associated with one another; a systematic review found that people with low literacy had lower knowledge about health and healthcare, higher rates of hospitalization, poorer measures of general health, and more diagnoses of chronic illness (18, 19). Some researchers are concerned that existing health literacy instruments [REALM (20) and TOFHLA (21)] may measure literacy only but not domain-specific health literacy (22). Although there is no gold standard for measuring health literacy, the present measures of health literacy, though not ideal, appear from systematic reviews to be adequate proxies that predict significant health outcomes (18, 19). In the present study, we adopt a conceptualization of health literacy as indicating a fundamental capacity for processing information. In doing so, we consider its implications for health communication about this genomic recurrence risk test, the Recurrence Score.

In the context of genomic medicine, health literacy may affect patients' abilities to remember risk information and to use it as active participants in decisions about their medical care. The first outcome in the present study is the retention of information provided about the recurrence risk test. The retention of cancer information is associated with numeracy, literacy, psychological adjustment, and culture (23, 24), in addition to the heightened stresses inherent in medical encounters. Poor ability to retain information may be a barrier for receiving wanted information (25). Lower health literacy may impair the understanding of and retention of information about the test.

The second outcome, desire for medical information, has been examined in a number of studies of cancer patients. Determinants of desire for medical information have included younger age (26-28), female sex (28), being more affluent (29), being in the beginning stages of treatment (30), and having a more severe prognosis (27). Health literacy may be another determinant of the desire for risk and treatment information, as women with lower health literacy may prefer less additional, potentially confusing information.

Preference for active participation in decision making is the third outcome. Shared decision making occurs when the patient and the physician act as a team, sharing information and expressing their preferences, to make treatment choices (31). Although some research has found that breast cancer patients who seek medical information also prefer active involvement in making treatment decisions, it has been noted that there are differences between wanting more information and wanting to be actively involved in medical decisions (32). For the present study, we adopted the perspective that desire for medical information and desire for involvement in decision making are distinct constructs. Past studies have shown a preference for a more active part in decision making among younger (26, 33), Caucasian (34), and college-educated breast cancer patients (33). Research has shown that lower health literacy is associated with a preference for less active participation in health-related decisions, including for asthma care (35) and prostate cancer treatment (36). We posit that lower health literacy may be associated with a preference for

less active participation in decision making about the recurrence risk test.

We examined the relationship of health literacy to several indicators of breast cancer patients' information-processing styles and preferences. We predicted that women with higher health literacy would understand more information about the recurrence risk test shared with them at the beginning of the study and would desire more of such information than women with lower health literacy. We also predicted that women with higher health literacy would prefer a more active role in making the decision about getting the recurrence risk test and about incorporating the test results into their treatment decisions than women with lower health literacy. We examined these hypotheses in a cross-sectional study of women previously treated for early-stage breast cancer, the group for whom the new recurrence risk test was developed.

Materials and Methods

Participants and Procedure. Interviews were conducted between February 2005 and August 2005, with adult women previously diagnosed with stage I or II primary breast cancer who were patients at the University of North Carolina Breast Center. To decrease potential confusion with patients' own treatments and to maximize relevance of presented information, the study recruited only post-surgery and post-treatment patients who either did not receive neoadjuvant/adjuvant chemotherapy or had completed it. Patients who were currently receiving hormone therapy (tamoxifen) were eligible to participate in the study. Patients were excluded if they were not English speaking or had a life-threatening comorbid disease, a second primary cancer diagnosis, metastasis, or a history of serious psychiatric illness. Lastly, we interviewed only women who had not had a cancer recurrence either previously or during the present clinical visit to create a more homogenous group with respect to anxiety. Exclusion of patients from the study was open to the discretion of the treating physician, but, in practice, no patients were excluded under this provision.

Eligible patients were mailed letters 2 weeks before their next scheduled appointments, inviting them to participate in the study. The letter included a form allowing patients to agree to be contacted at the Clinic during their regular appointments or to decline to participate. Patients who did not mail back the form were approached in the Clinic and asked again to participate. Patients who agreed to participate were provided with an oral and written introduction to the recurrence risk test (text shown in Appendix) that was written at the 7th grade reading level (according to the Fry Readability Scale; ref. 37). Their health literacy levels were assessed, and then they completed self-administered questionnaires. In one case, the entire questionnaire was read aloud to a participant with poor eyesight. The study protocol and materials were approved by the Institutional Review Board of the University of North Carolina at Chapel Hill. Written informed consent was obtained from all participants.

Measures

Health Literacy. Health literacy was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM; ref. 20), a widely used measure. Participants were asked to read aloud 66 health-related words of increasing complexity. Any mispronunciation or skipping of a word was counted as incorrect, in accordance with recommended scoring procedures. Patients accepted this assessment of health literacy, and none voiced discomfort with it.

Respondents were categorized as having either lower health literacy or higher health literacy, based on their scores on the

REALM. Because our study participants had relatively high REALM scores (mean = 63.6; range, 30-66), we were unable to use the traditional four category health literacy classification that groups participants by grade level. Had we used this scoring, our sample would break down into the following health literacy groups: "3rd grade and below," $N = 0$ (0%); "4th to 6th grade," $N = 4$ (2.5%); "7th to 8th grade," $N = 15$ (9.2%); "high school," $N = 144$ (88.3%). As has been done in the literature, we instead dichotomized REALM scores to create two health literacy groups (38, 39). We dichotomized at the mean; scores >63 were classified as higher health literacy ($n = 125$), and scores ≤ 63 were classified as lower health literacy ($n = 38$).

Retention of Information about the Recurrence Risk Test. Participants were asked seven true or false questions that tested their understanding of the material previously given in printed form and read aloud to them by the interviewer. The items and the correct answers (true = T, false = F) were as follows: "The test may help women avoid unneeded treatment and side effects" (T); "The test tells how likely a breast cancer is to recur" (T); "The test results are based on the genes of the tumor" (T); "The test helps women decide about chemotherapy" (T); "The test helps women decide about surgery" (F); "The test is done before the patient has surgery" (F); and "The results of the test are always correct" (F). Participants' responses were coded for accuracy. A "don't know" response option was also included; these responses were coded as incorrect.

Desire for Additional Health Information. Participants were asked how much information they wanted about the following seven topics: how the test results might affect the treatment that the doctor recommends; the different treatments available; the accuracy of the test compared with other medical tests for breast cancer recurrence; how breast cancer grows differently depending on the recurrence risk test results; how genes affect breast cancer; what genes are and how they work; and how scientists developed the test. Response options were "just the basics," "a moderate amount," and "a lot." For the statistical analyses, we collapsed the first two response options ("just the basics" and "a moderate amount") for each question because so few women answered using the first category.

Preference for Active Participation in Decision Making. Participants were asked two questions about the degree to which they would want to be involved actively in making decisions about their medical care. The first question asked about getting the recurrence risk test; the second asked about using the test results in choosing a treatment. Both questions used a response scale adapted from Degner et al.'s Control Preferences Scale (40) and had the following response options: "I prefer to leave the decision to my doctor"; "I prefer that my doctor makes the decision, but seriously consider my opinion"; "I prefer that my doctor and I share responsibility for deciding"; "I prefer to make my own decision after seriously considering my doctor's opinion"; "I prefer to make my own decision regardless of my doctor's opinion." As is common in the literature, the first two response options were collapsed in data analyses and designated a "passive" decision style, and the last two response options were collapsed and designated an "active" decision style (41, 42).

Demographics. The questionnaire assessed age, race, marital status, and financial status. We evaluated financial status using the question "without giving exact dollars, how would you describe your household's financial situation right now?" Response options were "after paying bills, you still have enough money for special things you want"; "you have enough money to pay the bills, but little spare money to buy extra or special things"; "you have money to pay the bills, but only because you have cut back on things"; and "you are

having difficulty paying the bills, no matter what you do" (43). The first two response options were collapsed to create a "sufficient" financial status category, and the last two response options were collapsed to create a "limited" financial status category. In cases when patients offered incomplete age or race information, it was collected from medical records.

Statistical Analyses. Logistic regressions examined the relationship of demographic characteristics and health literacy level. A logistic regression model adjusted for multiple observations within subjects examined the relationship of health literacy and retention of information given to participants about the recurrence risk test. A logistic regression model adjusted for multiple observations within subjects examined the relationship between health literacy and desire for information about each of the seven topics presented to participants. Linear regressions assessed the relationship between health literacy and preferences for active decision making about getting the recurrence risk test done and about using the test results to inform treatment. Analyses were adjusted for age, race, and marital status. We report the one case where adjusting changed the finding. Analyses were not adjusted for education because health literacy and education are closely related conceptually (22) and were not adjusted for financial status because race and financial status were colinear [odds ratio (OR), 3.53; 95% confidence interval (95% CI), 1.17-10.67; $P = 0.03$]. Two-tailed tests were used for all analyses, and $P < 0.05$ was the criterion for statistical significance.

Results

Participants. As shown in Fig. 1, of 339 eligible patients, 108 could not be contacted. Of the patients contacted, 65 declined to participate, either via mail ($n = 48$) or at the clinic ($n = 17$). The response rate was 72% (166 of 231). Because one participant consented but did not actually participate in the survey, her data could not be included. Because two participants completed the surveys but did not complete the health literacy assessment, their data were not used in the data analyses presented in this study. Hence, we report findings based on 163 participants, or 48% of eligible participants.

The mean age of participants was 59 years (SD, 10.6; range, 36-87). Participants were generally well educated; only 3% did not graduate from high school, and 53% were college graduates. Racial groups self-identified primarily as Caucasian or White (86%), with African American or Black as the largest minority group (12%). Most participants were married or living as married (73%) and had children (84%). Slightly more than half the participants worked for pay (56%), and only 4% reported not having health insurance. In addition, the majority of the participants reported having spare money after paying their bills (66%), with a small minority reporting having

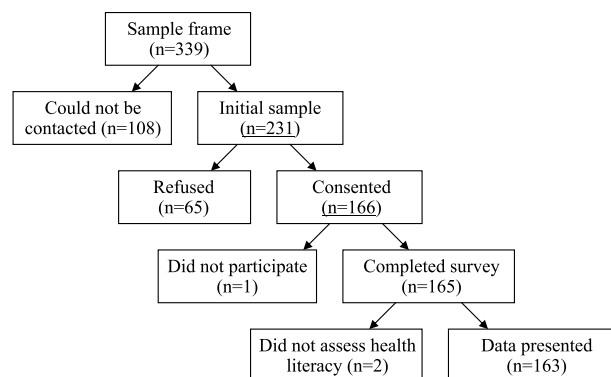


Figure 1. Recruitment flow chart.

difficulty paying their bills (6%). The women were an average of 4 years after diagnosis. Although no women reported having had the recurrence risk test, 13% reported having heard of it. As noted previously, the average score on the REALM was 63.6 (range, 30-66), which translates to a high school reading ability and the ability to read most patient education materials using the traditional REALM interpretation.

Demographic characteristics and their relationships to health literacy are summarized in Table 1. Four demographic variables were related significantly to health literacy. White women had higher health literacy than women who were not White (OR, 6.71; 95% CI, 2.67-16.89; $P < 0.001$), and married women had higher health literacy than unmarried women (OR, 2.37; 95% CI, 1.08-5.21; $P = 0.03$). Women with post-high school degrees (e.g., technical, associates, college, MD, etc.) had higher health literacy than women without such degrees (OR, 1.18; 95% CI, 1.08-1.49; $P < 0.001$), and women with sufficient finances had higher health literacy than women with limited finances (OR, 1.11; 95% CI, 1.03-1.47; $P < 0.001$).

Retention of Information about the Recurrence Risk Test.

Women with lower health literacy answered an average of 76% of the questions correctly, whereas women with higher health literacy answered an average of 90% of the questions correctly (OR, 2.82; 95% CI, 1.31-6.07; $P < 0.01$). We also found an effect of format: whether the correct answer to the item was true or false had a significant effect on the accuracy of response for women overall. Women were less likely to answer correctly when the correct answer was false; 77% of women answered all of the true items correctly, but 57% of women could answer all of the false items correctly (OR, 2.62; 95% CI, 1.58-4.32; $P < 0.001$). There was no interaction of health literacy and format (see Fig. 2).

Desire for Additional Health Information. In general, women desired a great deal of further information related to the recurrence risk test, as shown in Fig. 3. The topic for which women wanted the most information was treatment: over 90% of women wanted a lot of information about both how the test

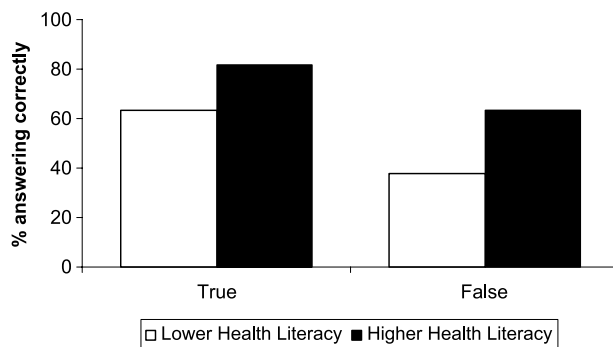


Figure 2. The percentage of women correctly answering all questions about the recurrence risk test. Women were less likely to answer correctly if they had lower health literacy or when the correct answer was false. The two factors did not interact.

results might affect the treatment that the doctor recommends and the different treatments available. The topic for which women wanted the least amount of information was how scientists developed the test, although there was still an interest; almost half (49%) wanted a lot of information. The desire for additional information related to the recurrence risk test did not differ significantly by health literacy (OR, 1.33; 95% CI, 0.67-2.62; $P = 0.41$) perhaps due to limited variability in the dependent variable.

Preference for Active Participation in Decision Making.

Women's desires to be actively involved in both the decision to have the recurrence risk test done and in treatment decisions based on test results differed by health literacy level (see Fig. 4A and B). Women with higher health literacy indicated a preference for more active participation in the decision to *get the recurrence risk test* than did women with lower health literacy. The finding was statistically significant in our unadjusted analysis [$F(1,144) = 4.77, P = 0.03$]; however, after adjusting for age, race, and marital status, the finding dropped to marginally significant [$F(1,144) = 3.59, P = 0.06$]. The majority of higher health literacy women (58%) reported a preference for active decision making (reporting either that the decision should be all or mostly their decision), whereas 41% of lower health literacy women reported this preference. The majority of lower health literacy women preferred shared decision making (47%), while also expressing interest in passive decision making (12%). Thirty-nine percent of higher health literacy women reported a preference for shared decision making, whereas only 3% of women reported a preference for passive decision making.

Similarly, women with higher health literacy indicated they preferred active participation in the decision to *use the results* of the recurrence risk test to make treatment decisions more than women with lower health literacy [$F(1,144) = 18.56, P < 0.001$]. Half the women with higher health literacy (50%) reported preferring active decision-making styles for use of the test results. In contrast, 26% of lower health literacy women reported a preference for active decision making. Although lower and higher health literacy women were similarly interested in shared decision making (40% and 45%, respectively), lower health literacy women reported an interest in passive decision making (34%) that higher health literacy women did not have (6%).

Our results show a larger effect of health literacy on decision-making preferences for use of the recurrence risk test results to inform care than for being tested in the first place. This was confirmed by a significant interaction of health literacy and the dependent variables in a repeated measures ANCOVA [$F(1,144) = 9.37, P = 0.003$].

Table 1. Demographic characteristics of participants

	Lower health literacy (n = 38), n (%)	Higher health literacy (n = 125), n (%)	OR (95% CI)
Race			
Non-White	13 (57)	10 (43)	—
White	25 (18)	115 (82)	6.71 (2.67-16.89)*
Education			
No degree †	24 (48)	26 (52)	—
Degree	13 (12)	95 (88)	1.18 (1.08-1.49)*
Marital status			
Not married	15 (35)	28 (65)	—
Married	21 (18)	94 (82)	2.37 (1.08-5.21) ‡
Children			
No	5 (21)	19 (79)	—
Yes	32 (24)	101 (76)	0.83 (0.29-2.40)
Employed			
No	21 (30)	49 (70)	—
Yes	16 (18)	72 (82)	1.93 (0.92-4.06)
Financial status			
Limited	11 (69)	5 (31)	—
Sufficient	26 (18)	115 (82)	1.11 (1.03-1.47)*
Health insurance			
Not insured	3 (50)	3 (50)	—
Insured	34 (22)	118 (78)	3.47 (0.67-17.98)
Mean age (SD)	58.8 (10.9)	59.7 (10.6)	1.09 (0.76-1.58)

NOTE: ORs are based on unadjusted logistic regressions.

* $P < 0.001$.

†Degrees included associate, technical, bachelors, graduate, medical, law, or other advanced degrees.

‡ $P < 0.05$.

Discussion

We examined the role health literacy plays in the retention of and desire for information about one of the new genomic recurrence risk tests. We also investigated the effect of health literacy on desire for active participation in two decisions: the decision to get the recurrence risk test and to use the test results to inform treatment. Consistent with predictions, health literacy was associated with greater retention of information and preference for active decision making. However, contrary to our expectation, health literacy was not associated with the desire for more information about the recurrence risk test.

Our findings show that health literacy affects retention of information about the breast cancer recurrence risk test. This result parallels previous findings that numeracy and literacy are associated with the retention of cancer information (23, 24). This is important because it indicates that the retention of breast cancer risk for recurrence information is sensitive to individuals' capacity for processing information; patient-oriented educational materials about the recurrence risk test must compensate for this effect. These data lead us to suggest that clinicians and health educators should be concerned about patients' health literacy levels when discussing the genomic recurrence risk tests.

Participants' strong desires for additional information about the recurrence risk test did not vary by health literacy level. Although this finding was surprising in some ways, it is consistent with past research. Women, particularly those being treated for breast cancer, have been found to have a high desire for information about cancer recurrence (specifically the risk for recurrence and how to tell if a cancer has recurred) that does not differ by demographics, such as race, level of education, or level of income (29, 44). It is possible, though, that the very high scores on the desire for information items in the present study may be one reason we did not detect a difference by health literacy. The finding suggests that patient education materials should not avoid presenting recurrence information. Rather, they should include it, even emphasize it, to provide women with the information they want. Clinicians should take note of the importance that breast cancer patients place on information about recurrence of breast cancer and how recurrence risk affects treatment. At the same time, the desire for additional information does not guarantee the comprehension of basic information provided. It is noteworthy

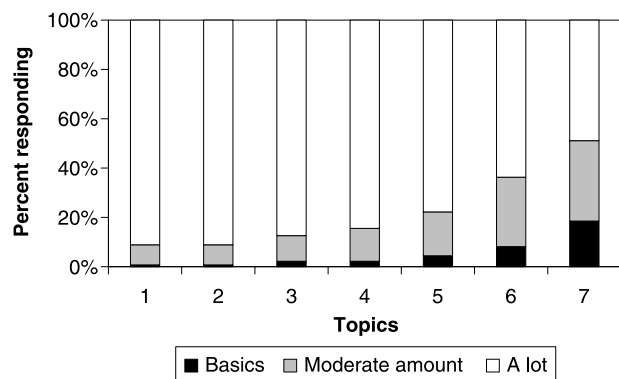


Figure 3. Amount of additional information about the recurrence risk test women desired. *Topic 1*, how the test results might affect the treatment that the doctor recommends. *Topic 2*, the different treatments available. *Topic 3*, the accuracy of the test compared with other medical tests for breast cancer recurrence. *Topic 4*, how breast cancer grows differently depending on the recurrence risk test results. *Topic 5*, how genes affect breast cancer. *Topic 6*, what genes are and how they work. *Topic 7*, how scientists developed the test.

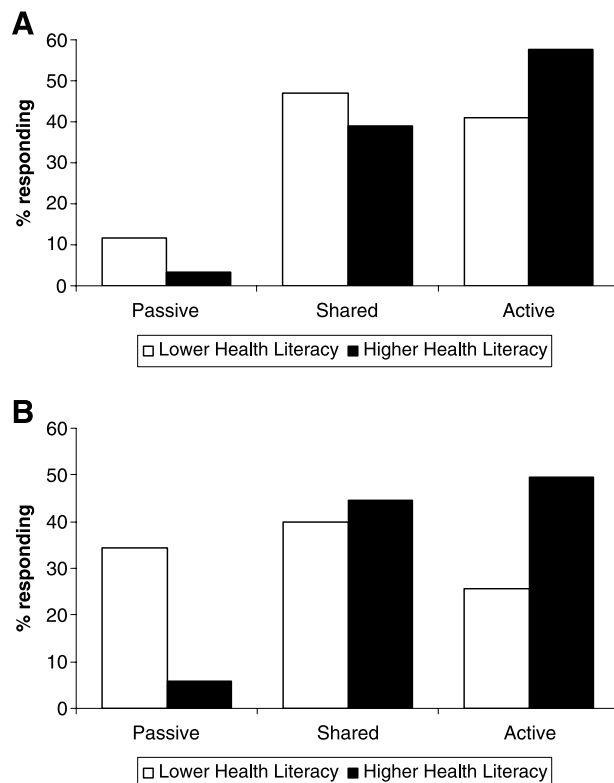


Figure 4. **A.** Reported decision-making preferences for getting the recurrence risk test done. Women with higher health literacy preferred more active involvement in the decision to be tested. **B.** Reported decision-making preferences for the use of the recurrence risk test results to inform treatment decisions. Women with higher health literacy preferred more active involvement in treatment decisions.

that women expressed the lowest interest in information about the scientific development of the recurrence risk test.

Women with higher health literacy were more likely to prefer an active role in the decision to have the recurrence risk test (before statistical adjustment) and more likely to prefer an active role in the decision to use the test results to inform treatment. Although women with lower health literacy were less interested in active participation in these decisions, they desired the same amount of information as women with higher health literacy. Previous studies have addressed an association between the desire for information and decision-making preference with varied results (45-48), suggesting that these constructs may only partially overlap. Although our results illustrate breast cancer patients' preferences related to decision making, actual roles in decision making often do not match desired roles (49). Such a match may lead to greater satisfaction with treatment choice and increased quality of life (50). Clinicians, then, may need to identify their patients' preferences for participation in decision making, being aware of the role of health literacy.

This study has several limitations. Because the assessment of the effects of health literacy on information retention employed a post-test only design, baseline differences in knowledge of the recurrence risk test between health literacy groups may have existed. However, the presence of a pretest could have confounded our results, and we are confident the post-test only design did not meaningfully affect our results, as information about the recurrence risk test was not widely available at the time the study was conducted. It is possible that women with lower health literacy underperformed on this assessment as a result of feeling threatened by the appearance

of a test or quiz; if true, this would lessen the generality of our findings related to information retention. Furthermore, we limited our sample to posttreatment patients because the extreme novelty of the recurrence risk test meant that the number of women having the test was too small to analyze the effects of health literacy when women are making decisions about their actual care. We did not use the most traditional scoring of the REALM. Because our sample had high REALM scores, the use of typical cutoff points would not have provided an adequate number of people in a lower health literacy group, which may be stretching the instrument's ability to discriminate at these relatively high health literacy levels. However, finding effects of health literacy among women with this restricted range of scores suggests that even larger effects of health literacy may be found among the general population. The materials we presented about the recurrence risk test included general, but not specific, information about the accuracy of the test, as the significance of that information was not fully understood at the time of the study. We did not examine whether women's understanding of and responses to genomic and conventional prognostic information differed. Future studies should address these issues.

A number of studies have looked at cancer patients' retention of information, their desire for more information, or their medical decision-making preferences (26-30, 32-34, 36, 42, 44-50). This report is, to our knowledge, the first to explore these questions in the context of genomic breast cancer recurrence risk testing and health literacy. Overall, our results indicate that health literacy is fundamental to understanding women's capacity to learn about the new breast cancer recurrence risk genomic tests as well as their desire for active participation in medical care. These findings have important implications for communicating with women newly diagnosed with breast cancer, as risk for breast cancer recurrence information will soon play a significant role in their treatment. It is vital, then, to understand women's responses to information provided about genomic tests and how those responses inform active involvement in medical decision making.

Appendix. Information about the recurrence risk test given to study participants

The new test is called the recurrence risk test.

Here is how a woman uses the test. She gets a test after she has undergone surgery to remove her cancer. The test tells the chances that her cancer will recur or come back. The woman and her doctor talk about her test results and her other medical information. Then, they decide if she needs more treatment.

Here is how the test works. The test looks at genes in the cancer that make it recur. These genes may be different from ones that control breast cancer being passed onto one's children. The test does not require extra surgery because it is done using some of the cancer that was already removed.

The test has a few benefits. First of all, the test results can help a woman choose the most effective treatment. For example, a woman with a high chance of recurrence might want chemotherapy to improve her chances of being cured. On the other hand, a woman with a low chance of her cancer recurring may not need chemotherapy. Hence, she could avoid unneeded treatment and side effects. A second benefit is that the test can give more accurate results than the medical tests we use today. Thus, a woman can choose her treatment with more confidence.

On the downside, tests do not always give the right answer. This means that some women will get the wrong information about their chances. Another problem is that the test may be expensive and may not be paid for by health insurance.

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