Health literacy, numeracy, and interpretation of graphical breast cancer risk estimates

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Abstract

Objective—Health literacy and numeracy are necessary to understand health information and to make informed medical decisions. This study explored the relationships among health literacy, numeracy, and ability to accurately interpret graphical representations of breast cancer risk.

Methods—Participants ($N = 120$) were recruited from the Facing Our Risk of Cancer Empowered (FORCE) membership. Health literacy and numeracy were assessed. Participants interpreted graphs depicting breast cancer risk, made hypothetical treatment decisions, and rated preference of graphs.

Results—Most participants were Caucasian (98%) and had completed at least one year of college (93%). Fifty-two percent had breast cancer, 86% had a family history of breast cancer, and 57% had a deleterious BRCA gene mutation. Mean health literacy score was 65/66; mean numeracy score was 4/6; and mean graphicacy score was 9/12. Education and numeracy were significantly associated with accurate graph interpretation ($r = 0.42$, $p < 0.001$ and $r = 0.65$, $p < 0.001$, respectively). However, after adjusting for numeracy in multivariate linear regression, education added little to the prediction of graphicacy ($r^2 = 0.41$ versus 0.42, respectively).

Conclusion—In our highly health-literate population, numeracy was predictive of graphicacy.

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Practice implications—Effective risk communication strategies should consider the impact of numeracy on graphicacy and patient understanding.

Keywords

Health literacy; Numeracy; Graphicacy; Breast cancer; Risk communication

1. Introduction

1.1. Effectual health communication supports informed decision-making

Essential to informed patient decision-making is the ability to understand numerically and graphically presented health information. Previous studies have shown that health literacy [1,2], numeracy [2,3], and graph design [4,5] may influence patient understanding of health communications. Comprehension of prevention and risk information is important in decision-making for women who carry a *BRCA* mutation given the magnitude of the associated risks of breast and ovarian cancer. *BRCA* mutations confer an 85% lifetime of breast cancer [6,7] and a second primary breast cancer risk of approximately 50% [8] as well as a lifetime risk for ovarian cancer of about 15–50% [6,7,9]. Women who carry a *BRCA* mutation may consider bilateral mastectomy and/or bilateral salpingo-oophorectomy as risk-reduction strategies [10]. In order to make a fully informed decision regarding risk management, it is important that these women understand their cancer risks as well as the risk-reduction impact and quality of life outcomes of each surgical intervention. No studies to date have explored the ability of *BRCA+* women to interpret graphically presented risk information.

1.2. Health literacy and numeracy affect cancer prevention and treatment compliance

The United States Department of Health and Human Services has defined 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" [11]. As such, health literacy has been shown to be a critical component of meaningful cancer risk communication, treatment and screening compliance, informed consent, and overall patient health [1,12–16]. Individuals with low health literacy scores often do not understand basic cancer prevention, or diagnosis and treatment terminology such as screening, colon, tumor, lesion, and cure, which may contribute to a lack of adherence to potentially lifesaving screening recommendations [17].

Numeracy has been defined as, "the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" [18]. Until recently, numeracy was considered and often measured as a component of health literacy. However, several studies have shown that numeracy is a separate proficiency from literacy and that health numeracy is a significant and distinctive aspect of health knowledge and communication [2,18–21].

Patient numeracy and the presentation of probabilistic health outcome information impact health care in diverse areas from prevention to treatment [22–25]. Although patients report

higher trust and comfort with their health care provider when numerical data are included [26], they may not always understand the given data. In a study of 463 highly educated participants, about 40% could not solve a basic probability problem or convert a percentage to a proportion [27]. Therefore, health care providers cannot assume that well-educated patients are numerate when discussing treatment decisions and risk. In another study, less numerate women were less likely to accurately assess the reduction in breast cancer death from screening mammography [28]. Additionally, studies suggest that innumerate individuals are more likely than their numerate peers to inaccurately understand their health risks [3] and are more likely to have inaccurate perceptions of the health consequences of cancer screening, surveillance, and treatment choices [19,29].

1.3. Graphicacy is a complex skill utilized to understand personal cancer risk

Graphicacy has been defined as "the ability to understand and present information in the form of sketches, photographs, diagrams, maps, plans, charts, graphs, and other non-textual, two-dimensional formats" [30]. Graphical representations of risk have been shown to improve patient understanding, informed consent, and decision-making accuracy [5,31], particularly for those individuals with low levels of numeracy [28,32].

Several studies have tested the effectiveness of various graphical formats. The presentation of health care data in simple forms, such as single line graphs [33], bar graphs [34] or frequency graphs showing highlighted human figures [4], has been shown to improve patient understanding and influence treatment decisions. A bar graph tailored to women's breast cancer risk improved accuracy of self-described risk among women with a family history of breast cancer [34]. Another study found that using a frequency diagram plus a bar graph improved risk perception accuracy more than by using a bar graph alone [35]. A focus group study concluded that frequency graphs are contextual, easy to understand, and meaningful; however, when compared to participants with more formal education, participants with less education more often perceived their risk of breast cancer to be erroneously high when using human figure frequency graphs rather than bar graphs [4]. In addition, some participants found that bar graphs were a more helpful format for the comparison of multiple risks [4]. Another study showed that utilizing two complimentary graphs, a frequency graph along with a bar graph, improved risk perception accuracy more than by using a single graph [35]. In studies considering patient understanding and treatment choice by comparing risk communication formats, researchers identified that graphical format alone influenced risk perception and treatment decisions [36,37].

Thus, graphicacy is considered a key patient skill utilized for breast cancer risk communication [38], yet, little is known about the relationship of graphicacy to health literacy and numeracy. Therefore, the aim of this study was to examine the relationship between literacy, numeracy, and graphicacy, in the context of breast cancer risk communication and decision-making about risk-reducing surgery for high risk patients.

2. Participants and methods

2.1. Study population and recruitment

This study was approved by the University of California Irvine's Institutional Review Board. Participants were recruited between December 2006 and January 2007 by placing a link on the FORCE breast cancer advocacy website at www.facingourrisk.org, and sending an email blast to approximately 4500 registered users. The email blast yielded 205 respondents within 24 h, and the total number of respondents was 219. Eligibility included women with a personal and/or family history of breast cancer. Consecutive respondents ($N = 120$) who provided adequate contact information were mailed the study information sheet and a sealed envelope containing the survey instruments. Participants were called by the lead investigator (SB) to review the study, obtain informed consent and complete the health literacy, numeracy and graphicacy assessments (described below). Demographic questions were asked including age, education, employment, income, breast cancer history, the type of clinician who provided risk education, BRCA testing history, and mutation status. All personally identifiable health information was anonymized.

2.2. Health literacy measure

Health literacy was assessed by administering the 66-word version of the Rapid Estimate of Adult Literacy in Medicine (REALM) [39]. REALM has been widely accepted and incorporated into medical research assessing health literacy. Participant ability to correctly read the 66-word list of medical/health terms was determined by subtracting one point for every word missed or mispronounced. The scale was scored as follows: 61–66 = high school, 45–60 = 7th to 8th grade, 19–44 = 4th to 6th grade, 0–16 = 3rd grade and below.

2.3. Health numeracy measure

Numeracy was assessed with a 6-question numeracy scale (Fig. 1) by combining two previously validated 3-question numeracy scales developed by Woloshin and Schapira to quickly analyze participant numerical ability [29,40]. Cronbach's alpha were 0.57–0.63 and 0.63, respectively [40,41]. Both scales included a simple coin toss question (Q1). Due to concerns that Internet recruitment would yield a highly educated population [42,43], a more difficult question (Q2) was added to allow for a greater range of numeracy scores.

One of the validated 3-question numeracy scales had been designed and used to produce a continuous numeracy variable [29], while the other produced a categorical variable [40] that resulted in the dichotomous categorization of individuals as numerate or innumerate. Because another study suggested the potential utility of further stratifying results to produce a moderately numerate category [44] and for ease of presentation, we chose to analyze numeracy as a continuous variable coded 1–6, with 1 point for each correct answer, and also to examine numeracy as a categorical variable (low: 1–2 points, moderate: 3–4 points, or high: 5–6 points).

2.4. Health graphicacy measure

Four hypothetical graphical representations of breast cancer risk were developed by the investigators to measure graph interpretation: vertical bar, horizontal bar, line, and iconic

(Fig. 2). Each graph illustrated the chance of a second primary breast cancer for a supposed patient given four surgical options: no surgery, bilateral mastectomy, bilateral oophorectomy, and bilateral mastectomy plus oophorectomy. The graphs were not individualized for each participant and the actual absolute risks were chosen for convenience and were not exactly what would have been expected after the proposed intervention. Participants were asked to review each graph and respond to question A, which required basic interpretation of the risk remaining after a surgical option, and to two related questions B and C, which required surgical decision-making based on the hypothetical patient and an interpretation of the resulting risk, respectively. The decision-making questions (B and C) for graphs 1 and 3 involved identifying two surgical options and comparing the difference in risk, and for graphs 2 and 4, involved identifying a single surgical option and the remaining risk. Correctly answering question C was dependent on correctly answering question B, therefore the percent who answered question C correctly is based on a smaller sample size. One point was given for each correct answer. Graphicacy was measured as the total number of correct answers from all four graphs and resulted in a total graph interpretation score of between 0 and 12 possible points. For ease of presentation, graphicacy was also analyzed as a categorical variable with four categories of 0–3, 4–6, 7–9, and 10–12.

2.5. Graph preference measure

Participants were asked to rate their preference for each graph based on a 6-point Likert scale, where 1 equaled a poor graph and 6 equaled a good graph.

2.6. Statistical analysis

Psychometric characteristics of the combined validated numeracy scales were assessed. Frequency and percentage distributions were determined for all variables and were analyzed in relation to numeracy and graphicacy. Categorical variables were tested for association with numeracy and with graphicacy using the Pearson chi-square test. Associations between continuous variables were assessed using Pearson correlations. The univariate relationship between graphicacy and numeracy and other independent variables was investigated using analysis of variance (ANOVA) and linear regression methods. Multiple linear regression was used to investigate the relationship between graphicacy (dependent variable) and health literacy, numeracy, age, years of college, income, personal and family breast cancer history, and *BRCA* status (independent variables). Statistical analysis was performed with the SYSTAT 11 program. Significance was set at the 0.05 level.

3. Results

3.1. Demographics

Participant-reported demographic characteristics, cancer history, and *BRCA* status of the 120 participants are shown in Table 1. The mean age of participants was 45.6 years (SD = 8.7). Participants were primarily European American (98%) who had completed at least some college (92%), had a personal (52%) and/or family history (86%) of breast and/or ovarian cancer, and carried a *BRCA* mutation (58%). Their reported average total household income of $123,410 (SD = $82,500) is more than double the national average of $48,000. [45] Participant addresses were distributed over 30 continental U.S. states.

3.2. Health literacy scores

All REALM scores fell within the highest literacy range. The average REALM score out of 66 possible points was 65.06 (SD = 1.04, range 61–66). Each participant read and attempted to pronounce each word; however, very few words (impetigo, colitis, and anemia) were occasionally mispronounced.

3.3. Numeracy scores

Fig. 1 shows the six numeracy questions and the percentage of participants responding correctly to each question. Psychometric analyses indicated that the resulting two 3-question numeracy scores were significantly correlated with each other ($r = 0.34$) and highly correlated with the 6 question assessment ($r = 0.58$ and 0.82), supporting the validity of the 6-question numeracy scale. Out of 6 questions, the mean number of correct answers was 4.11 (SD = 1.17, range 1–6). When categorized, 8% of the participants were low numerate (1–2 points), 53% were moderately numerate (3–4 points), and 40% were highly numerate (5–6 points). Completed years of college showed significant and strong association with numeracy ($r = 0.44$, $p < 0.001$). Participants who had not attended college never scored within the high numeracy range and none of those with a medical and/or doctorate degree scored within the low numeracy range. Health literacy was moderately associated with numeracy ($r = 0.27$, $p < 0.01$).

3.4. Graphicacy scores

The mean graphicacy score was 8.84 points (SD = 2.23, range 4–12). When categorized, 17% of the participants had a low graph score (4–6 points), 42% had a moderate score (7–9 points), and 42% had a high score (10–12 points).

Fig. 3 shows the graph assessment questions and the percentage of participants responding correctly to each question. Graph question A(1–4), which asked participants to interpret the breast cancer risk following a preventive surgery choice, was answered correctly the majority of the time for all four graphs. However, a higher percentage of participants answered correctly when viewing the horizontal (96%) or vertical (93%) bar graphs compared to the line (72%) or iconic (84%) graphs. In contrast, question B(1–4), which asked participants to use the graph to make a surgical decision was answered correctly less often for the vertical bar graph (45%) than for the horizontal bar graph (73%), line graph (96%), and iconic graph (93%). Questions C1 and C3 asked participants to compare the difference in remaining risks after two preventive surgical options. The percent correctly answering C1 and C3 was similar (65% and 63%, respectively). Questions C2 and C4 asked participants to state the remaining risk after a single preventive surgery. The percent correctly answering C2 and C4 was the same (87%).

Respondents found it more difficult to compare the risk-reduction values between two surgeries than to determine the risk after a single preventive surgery, independent of graph format. Overall, participants answered the questions correctly more often when using the iconic graph (88%) compared to the horizontal bar (85%), line (77%), or vertical bar (68%) graphs.

The mean preference score for each graph is shown in the legend of Fig. 3. Study participants reported the highest preference for the graph with the lowest percent answering correctly (vertical bar graph) and a lower preference for the graph with the highest percent answering correctly (iconic graph). On a scale of 1–6, the participants preferred the vertical bar graph (4.7), compared to the horizontal bar graph (4.3), the iconic graph (3.6), or the line graph (3.3).

3.5. Relating the independent variables to graph interpretation

Fig. 4 illustrates the mean graphicacy score for each numeracy level. The correlation between numeracy and graphicacy was positive and significant ($r = 0.64$, $p < 0.001$).

Both numeracy and education (completed years of college) were significantly associated with graphicacy score in univariate analyses ($r = 0.64$, $p < 0.001$ and $r = 0.37$, $p < 0.001$, respectively). However, after adjusting for numeracy in multiple linear regression, education added little to the prediction of graphicacy ($r^2 = 0.41$ versus 0.42, respectively) (Table 2). In stepwise linear regression, no other covariates studied were significant predictors of graphicacy after adjusting for numeracy.

4. Discussion and conclusion

4.1. Discussion

The reasons for using graphs to communicate health risks are compelling: patients may gain valuable understanding, develop the judgment needed to compare outcomes, and may achieve improved confidence in decision-making [32]. Decision aids may potentially be developed that incorporate numeracy and graphicacy assessment, tailor for patient preference and understanding, as well as provide individualized risk interpretation tutorials.

While it may seem reasonable for clinicians to presume that health-literate and educated patients will have proficient numerical ability and will correctly interpret graphical risk information, findings from this and other studies profiling subject numeracy indicate that education level does not predict numeracy [2,27,46]. An expert review of visual communication suggests that less numerate individuals may benefit from graphical representation of risk [32]. However, our study found that individuals who had lower numeracy had lower graphicacy levels, suggesting that less numerate individuals may have less ability to interpret the graphs.

Preference for a particular type of graph does not always relate to performance of the graph [41]. Our study found that the vertical bar graph was the most preferred format, while the iconic graph led to the highest graphicacy scores. One reason the iconic graph may have been preferred was because of the ease of understanding the shading in a figure with only ten icons. But it is not possible to express more precise figures (e.g., a 12% risk) in such a format; perhaps the iconic format would be less preferred if a reference group of 100 or 1000 figures were used. Hence, further investigation is needed to determine how to best recognize which individuals may benefit most from different graphical risk formats. Nelson et al. argue that there may be situations in which patients should be able to choose their

preferred format because patients may be more likely to use decision aids if graphical formats are customized to their personal preference for numerical presentation.

Several aspects intrinsic to the study design limit generalization of the findings. Participants were female, highly educated, and mostly Caucasian. Conducting this study with a less homogeneous sample and with other populations may clarify the global utility of our findings. In addition, the graphs were presented in the same order for every study participant, therefore, a trend in graph score could be associated with graph order as an artifact of subject learning. Also, the effect of graph format may be due to differences in the questions posed for each format.

4.2. Conclusion

To our knowledge, this report represents the first study to consider the relationship of patient numeracy to graphicacy, independent of health literacy and education. We found that although there was nearly a ceiling effect for health literacy, there was considerable variability in numeracy and graphicacy. In our study, numeracy accounted for 41% of the variation in graph interpretation scores, suggesting that numeracy and graphicacy are strongly linked.

Overall, graphicacy scores varied by graph format; participants scored highest when using the iconic graph. Interestingly, performance and preference did not match; participants answered the fewest questions correctly when using the vertical bar graph but ranked this graph highest in personal preference. Our findings confirm previous studies showing that participants preferred simple bar graphs [47] and that preference was not always associated with accuracy [48]. Consequently, the graphicacy assessment instrument may be an important tool in risk communications research. Further investigation is needed to determine the effect of graph format on risk perception and behavior and to develop formats that target specific communication goals.

4.3. Practice implications

As the direction of patient–clinician communication moves towards shared decision-making and increased patient autonomy, appropriately addressing patient numeracy and graphicacy becomes increasingly important. To improve patients' understanding, compliance, and health outcomes, clinicians should consider these proficiencies when counseling patients about risk, options and outcomes including preventive choices and treatment decisions.

Acknowledgments

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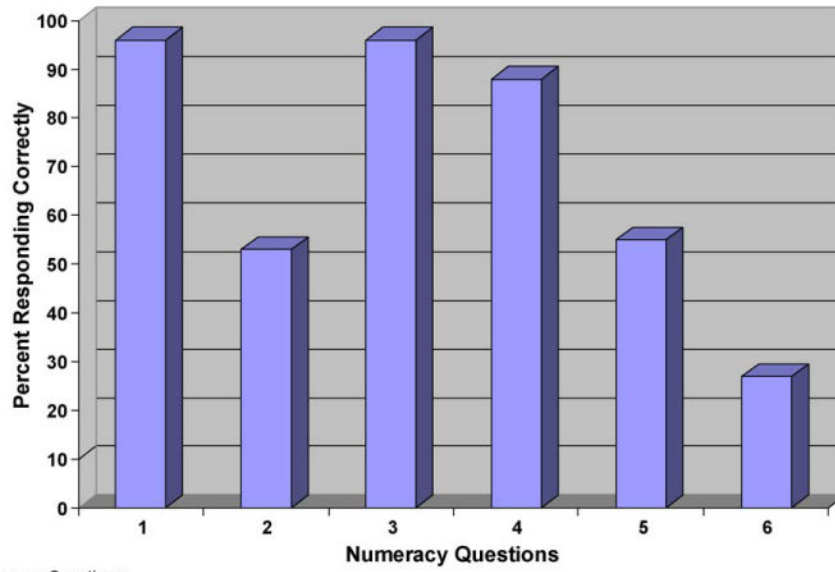
Numeracy Questions:
1. Imagine that you flip a coin 100 times. About how many times will the coin come up heads?
2. After flipping a coin 10 times you have counted 7 heads and 3 tails. What is the chance that your next flip will come up heads?
3. 100 people have entered the Spring City Run. Seventy percent of the runners will finish the race. Of the 100 people who enter the race, how many will finish?
4. In the Washington School raffle 5 people out of 100 who enter will win a prize. What percentage (%) of people who enter will win a prize?
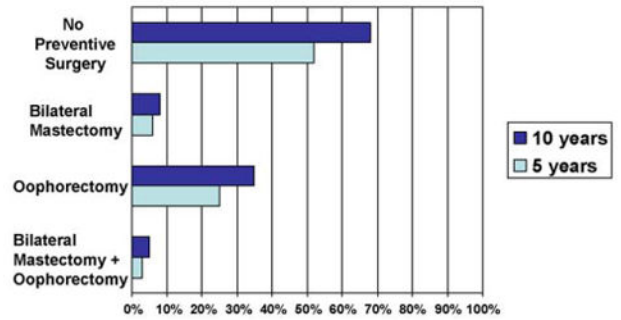5. How much is one percent of 1000?
6. One is what percent of 1000?

Fig. 1.
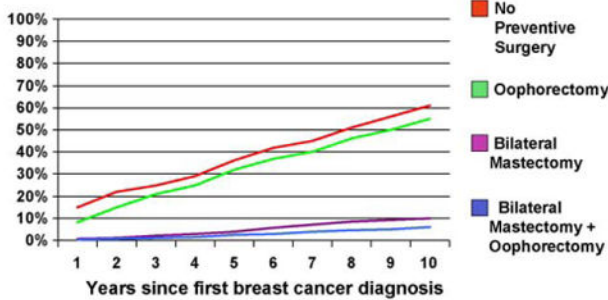Numeracy assessment: percent correct responses to numeracy questions ($N = 120$).
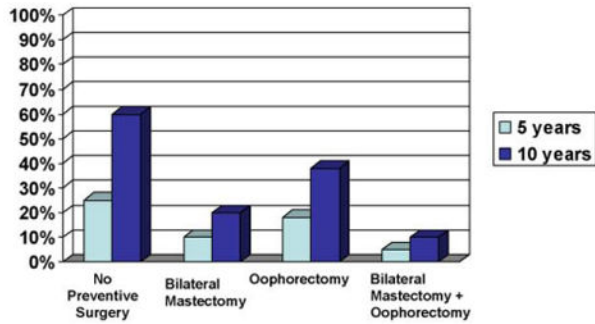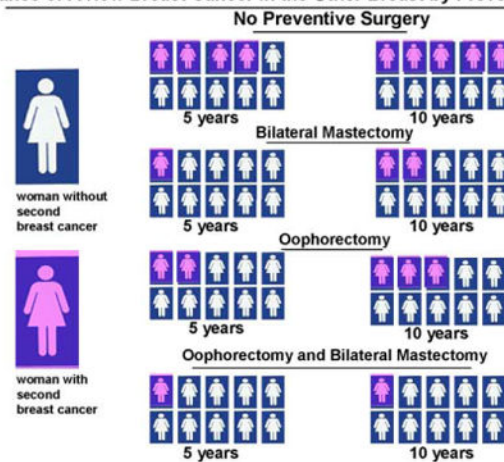
Fig. 2.
Survey instrument: graph formats showing breast cancer risk for hypothetical cases.

Graph Comparison and Questions
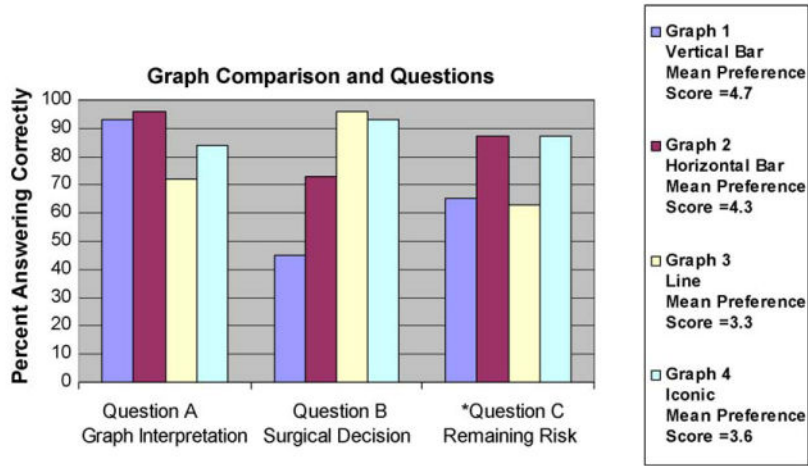
*Question C : Percent answering C correctly includes only participants who answered question B correctly.

Graph 1: A) "According to this graph, what is the percent risk for developing another breast cancer within 10 years after an oophorectomy and bilateral mastectomy?" B) "If this patient has decided to have her breasts removed, but is undecided about whether or not she should also have her ovaries removed, which two treatment options is she considering? C) How would you describe the numeric difference in risk between these two choices?" (N=54 for Question C)
Graph 2: A) "According to this graph, what is the percent risk for developing another breast cancer within 10 years after an oophorectomy?" B) "If this patient wants to limit her treatment choice to having only one of the surgery types, which surgical treatment should she chose? C) What will her 10 year risk be with this treatment choice?" (N=87 for Question C)
Graph 3: A) "According to this graph what is the percent risk for developing another breast cancer with 7 years after bilateral mastectomy?" B) "If this patient is deciding to have her ovaries removed but does not want to have her breasts removed, which treatment option is she considering? C) How does her risk after this preventive surgery compare to her having no preventive surgery?" (N=115 for Question C)
Graph 4: A) "According to this graph, what is the percent risk for developing another breast cancer within 5 years if there is no preventive surgery?" B) "If this patient wants to have the very lowest chance of another breast cancer, which preventive options should she choose?" C) What will her 5 year percent risk be after surgery?" (N=111 for Question C)

Fig. 3.
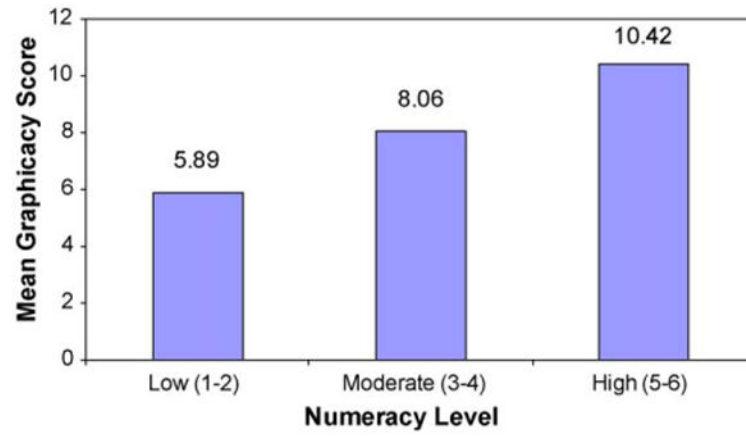Graphicacy assessment: percent correct responses to survey instrument ($N = 120$).

Fig. 4.
Relationship of numeracy to graphicacy ($N = 120$).

Table 1

Socio-demographic and breast cancer history/genetic characteristics of study participants ($N = 120$).

Characteristic	N (%)
Age in years (range 24–69)	
Less than or equal to 50 years	90 (75)
Greater than 50 years	30 (25)
Race/ethnicity	
Caucasian, Non-Hispanic	118 (98)
African American	1 (1)
Hispanic	1 (1)
Education	
High School	9 (8)
Some College	17 (14)
Bachelor degree	50 (42)
Master degree	37 (31)
MD and/or PhD	7 (6)
Occupation	
Home-maker, retired, student	30 (25)
Laborer	3 (3)
Administrator	15 (13)
Science/medicine	30 (25)
Other professional	42 (35)
Total household income ($N = 117$)[a]	
Less than $50,000	11 (9)
$50,000–99,999	35 (30)
$100,000–149,999	33 (28)
$150,000 or higher	38 (33)
Breast (or ovarian) cancer	
Family history	103 (86)
Personal history	62 (52)
BRCA testing	
Tested	94 (78)
Mutation positive	69 (58)

[a] Three participants declined to state their total household income.

Table 2

Prediction of graphicacy: multivariate regression.

Independent variables	Effect	Coefficient	SE	t	p (2 tail)	Multiple r^2
Numeracy	Constant	3.843	0.575	6.684	<0.0005	
	Numeracy	1.217	0.135	9.040	<0.0005	0.409
Numeracy + education	Constant	3.454	0.613	5.633	<0.0005	
	Numeracy	1.101	0.149	7.374	<0.0005	
	Education	0.402	0.233	1.725	0.087	0.424

In stepwise linear regression, after adjusting for numeracy, no covariates were significant predictors of graphicacy. Education added little to the prediction of graphicacy.