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Genetic testing and risk interpretation: How do women understand lifetime risk results?

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Abstract

Genetic screening for BRCA1 and BRCA2 gives women the opportunity for early detection, surveillance, and intervention. One key feature of genetic testing and counseling is the provision of personal lifetime risk. However, little attention has been paid to how women interpret lifetime risk information, despite the fact that they base screening, treatment and family planning decisions on such information. To study this vital issue, we set out to test the ability of women to choose the most appropriate interpretation of National Cancer Institute's (NCI) message about lifetime risk of developing cancer for a woman with altered BRCA1 and BRCA2 genes. Participants included 277 women who had not undergone genetic testing or had cancer and 207 women who had undergone genetic testing or had cancer. Over 50% of the women who had not undergone genetic testing or had cancer and 40% of those who had undergone genetic testing or had cancer misunderstood NCI's information. Furthermore, in line with a growing body of research, we found that high numeracy level (objective or subjective) is positively associated with a woman's ability to correctly interpret NCI's message.

Keywords: Genetic counseling, lifetime risk, numeracy, risk perception.

1 Introduction

Genetic screening for BRCA1 and BRCA2 — gene mutations that are associated with higher risk of developing breast and ovarian cancers — gives women a shot at early detection, surveillance, and intervention (Heshka, Palleschi, Howley Wilson & Wells, 2008). One key feature of the genetic counseling process is the provision of personal lifetime risk — or the risk of developing a specific disease during one's lifetime (Armstrong, Eisen, & Weber, 2000). Indeed, both patients and genetic counselors rate communication of lifetime risk information as a pivotal part of the process (Lobb et al., 2003). This is not surprising, as women who test positive for BRCA1/2 often rely on lifetime risk estimates to make future family plans (e.g., having children; MacDonald, et al., 2002) and to decide whether to undergo mastectomy despite being cancer free (Harmon, 2008).

Given the importance of lifetime risk information, researchers have been interested in whether women overestimate or underestimate their lifetime risk of developing cancer (Fagerlin, Zikmund-Fisher & Ubel, 2005; Heshka, Palleschi, Howley Wilson & Wells, 2008; Katapodi, Lee, Faciona & Dodd, 2004). Others have investigated the relationship between risk perception and emotional reaction, as well as between risk perception and mammography screening, and whether leaflets, genetic testing, and risk counseling improve women's accuracy in estimating their lifetime risk of developing cancer (Hallowell, Statham & Murton, 1998; Hopwood, Howell, Lallo & Evans, 2003; Lipkus, Biradavolu, Fenn, Keller, & Rimer, 2001; Slaytor & Ward, 1998; Vernon, 1999).

Although earlier studies examined women's estimation of their lifetime risk, a more fundamental issue is how women interpret lifetime risk information. After all, if women misunderstand the meaning of lifetime risk, whether they overestimate or underestimate incorrectly interpreted risk would be less important. Indeed, research has shown that people interpret numerical probabilities in multiple, mutually contradictory ways. Researchers (Gigerenzer, Hertwig, Van den Broek, Fasolo & Katsikopoulos, 2005; Murphy, Lichtenstein, Fischhoff & Winkler, 1980) have demonstrated that individuals interpret the seemingly unambiguous statement "There is a 30% chance of rain tomorrow" in different ways: "It will

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rain tomorrow in 30% of the region", "for 30% of the time", or "on 30% of the days like tomorrow" (Gigerenzer et al., 2005 p. 625). Since people misconstrue common and mundane probabilistic information, interpreting probabilistic information like lifetime risk of developing cancer proves to be an even greater challenge, given the added emotional impact. To the authors' knowledge, however, no previous studies have examined how women interpret statements regarding their lifetime risk of developing cancer or what variables (e.g., numeracy) might affect women's ability to correctly interpret such information.

A growing corpus of research has shown that numeracy — the ability to understand basic mathematical concepts — is important to the quality of decisions (Peters et al., 2006). Accordingly, researchers have long argued that numeracy levels play a key role in a host of medical decision making and might influence the way people perceive and understand risk (Ancker & Kaufman, 2007; Lipkus, Samsa, & Rimer, 2001; Woloshin, Schwartz, Black & Welch, 1999). A recent review (Nelson, Reyna, Fagerlin, Lipkus & Peters, 2008; Reyna, 2001; Reyna & Brainerd, 2007) summarized this idea well: "Low numeracy is pervasive and constrains informed patient choice... *impairs risk communication*, and affects medical outcome" (Nelson et al., 2008: p. 261; emphasis added). While data strongly indicate the existence of a relationship between numeracy and medical decision making, whether numeracy levels affect women's ability to interpret lifetime risk data is still an unanswered question.

In light of the abovementioned research and the gap in the existing literature, we set out to examine two related hypotheses. We first predicted that a statement about lifetime risk of developing cancer would give rise to various interpretations, not all of which would be correct. Second, we predicted that participants with higher numeracy levels will have a better understanding of lifetime risk information than their peers with lower numeracy levels.

2 Experiment 1

The goal of this study was to provide initial evidence for our hypotheses regarding the ability of women to accurately interpret the NCI statement about lifetime risk of developing cancer, examine the relationship between numeracy levels and understanding of lifetime risk information, and evaluate whether higher numeracy levels lead to more accurate risk estimation.

2.1 Methods

Participants. Participants included 277 women, who completed an online survey through advertisements on social networking websites. Participants responded to advertisements for filling out a short survey on health decisions in return for entry into a raffle for a $50 gift certificate to Amazon.com; all advertisements specifically targeted women over 18 years of age. An introductory page appeared before the survey, which provided information on the study, the participant's right to withdraw without penalty, as well as information on the institution conducting the study. A small subsample ($n = 14$) of women had been previously tested for BRCA alterations or previously diagnosed with breast cancer. (See Study 2 below, however.) They were excluded from all analyses because of possible prior experience with BRCA screening (N after exclusion = 263). Participants were included in the analysis if they completed at least two questions in the survey; missing responses in the survey ranged from 0 to 24 (0–8.7% of sample). When the number of participants varies from the sample size ($N = 263$), n is indicated. The mean age of participants was 40.24 ($SD = 13.75$, $n = 246$). Additional demographic information can be found in Table 1.

Table 1: Genetic testing and lifetime risk

	Study 1 (n=246)		*Study 2 (n=191)*	
	n	*%*	*n*	*%*
Income				
10k or less	8	3.3	4	2.1
10,000–20k	12	4.9	0	0.0
20,001–30k	25	10.2	4	2.1
30,001–40k	23	9.3	7	3.7
40,001–50k	22	8.9	12	6.3
50,001–60k	20	8.1	15	7.9
60,001–70k	19	7.7	11	5.8
70,001–80k	18	7.3	18	9.4
80,001–90k	8	3.3	23	12.0
90,001–100k	19	7.7	17	8.9
Over 100k	72	29.3	80	41.9
Education				
Elementary school	1	.4	1	0.5
Middle school	1	.4	18	9.4
High school	46	18.7	97	50.8
College	409	44.3	75	39.3
Graduate school	89	36.2		

Procedure. Participants read the following information — taken directly from the official website of the National Cancer Institute (NCI, Unites States) — about lifetime risk of women with an altered BRCA1 or BRCA2 gene:

According to estimates of lifetime risk, about 13.2% (132 out of 1,000 individuals) of women in the general population will develop breast cancer, compared with estimates of 36 to 85% (360–850 out of 1000) of women with an altered BRCA1 or BRCA2 gene. In other words, women with an altered BRCA1 or BRCA2 gene are 3 to 7 times more likely to develop breast cancer than women with-out alterations in those genes (National Cancer Institute, 2002).

This statement was present on all pages that contained questions relating to risk interpretation, including most appropriate interpretation.

Most appropriate. After reading the above NCI statement, participants were asked to choose the most appropriate interpretation. Choices included (i) "Breast cancer will develop in 36 to 85% of women who are found to have BRCA1 and BRCA2 alterations" (the correct choice), (ii) "Breast cancer will develop in all women aged 36 to 85," (iii) "Women who have BRCA1 and BRCA2 alterations will exhibit 36 to 85% of the symptoms associated with breast cancer," and (iv) "Women who are found to have alterations in the genes called BRCA1 and BRCA2 have 36% to 85% higher chance of developing breast cancer." We created the variable, "Most appropriate correct," in which participants were coded as 1 (*correct*) for choosing the correct answer and 0 (*incorrect*) otherwise.

Numeracy. Participants completed a numeracy scale ($\alpha = 0.68$) composed of 11 items (Lipkus, Samsa & Rimer, 2001). Following the protocol of previous studies (Peters et al., 2006), we clustered participants into those with high numeracy levels versus those with low numeracy levels based on a median split on numeracy score. Participants who received a score of 9 or above were considered to possess high numeracy levels ($n = 128$); those with low numeracy levels received a score of 8 or less ($n = 111$). Participants in the high numeracy group were better educated than their low numeracy counterparts, $t(237) = -3.15$, $p < .002$. No difference existed between numeracy groups on age or income. This classification of high versus low numeracy level participants was only used in the context of one χ^2 test comparing group distribution on most appropriate correct. For regression, we used continuous numeracy, which yielded similar results as the dichotomous numeracy variable.

2.2 Results

Most appropriate. Less than half the participants, 48.7% ($n = 128$), chose the correct interpretation (option 1 above). A similar proportion (45.6%, $n = 120$) believed that "Women who are found to have alterations in the genes called BRCA1 and BRCA2 have a 36% to 85% higher chance of developing breast cancer" was the right answer. An additional 4.2% ($n = 11$) chose "Women who have BRCA1 and BRCA2 alterations will exhibit 36 to 85% of the symptoms associated with breast cancer," and 1.5% ($n = 4$) indicated that "Breast cancer will develop in all women ages 36 to 85" was the right answer. Thus, over 50% of our sample misrepresented the information provided by NCI.

A logistic regression on most appropriate correct by age, education, and continuous numeracy yielded several significant predictors. The chances of choosing the correct answer decreased as age increased (unstandardized B = –.02, $SE = .10$, $p < .03$). The likelihood of choosing the correct interpretation increased as education increased (B = .40 $SE = .20$, $p < .04$) and numeracy level increased (B = .22 $SE = .06$, $p < .0001$).

Numeracy. In line with earlier studies, we were interested in numeracy's relationship with women's ability to correctly interpret the NCI message, as well as with their risk perception. As predicted, numeracy level (continuous) significantly correlated positively with a ability to choose the correct interpretation of lifetime risk for breast cancer based on BRCA1/2 status, $r(239) = .28$, $p < .01$. The low numeracy group chose the correct interpretation about 35% of the time compared with the high numeracy participants, who chose the correct interpretation 64% of the time (Table 2).

2.3 Discussion

Do women accurately interpret the NCI message regarding life time risk of developing breast cancer? Are women with high numeracy levels better able to interpret the NCI message? Study 1 provided initial evidence that women misinterpret the NCI lifetime risk message. Indeed, only half of the participants provided the correct answer. Our results also supported our prediction that numeracy levels would be associated with more accurate interpretation of the NCI message. Women who were classified as high numeracy were significantly more likely to provide the correct interpretation compared to women with low numeracy levels.

Despite our promising results, Study 1 has a number of limitations. First, it is unclear whether our results can be generalized to other populations. More specifically, as our sample contained only a limited number of women who had experienced genetic testing or had can-

Table 2: Differences in comprehension, in terms of most appropriate correct. χ^2 tests are two tailed and uncorrected for continuity.

Study 1	Numeracy			
	Low (0–8)	High (9–11)	Total	χ^2
Correct	72	46	118	19.90
Incorrect	39	82	121	p < .0001
Total	111	128	239	
Study 2	Numeracy			
	Low (0–8)	High (9–11)	Total	χ^2
Correct	43	80	123	11.04
Incorrect	49	35	84	p < .001
Total	92	115	207	
Comparison between studies	Study			
	1	2	Total	χ^2
Incorrect	143	84	227	5.80
Correct	134	123	257	p = .016
Total	277	257	484	

cer, it is impossible for us to tell whether our results can be applied to women who have undergone or consider undergoing genetic testing or women who have had cancer. That is, women who are cancer-free and who have never considered genetic testing might be less likely to seek information about genetic testing and may have less motivation to fully engage in our study. Thus, it is important to examine how women who intend to undergo genetic testing, have already undergone genetic testing or have had cancer interpret the NCI message. It is feasible, after all, that this group of women would perform much better on our tasks as they have a clear interest in fully understanding their lifetime risk of developing cancer.

Finally, a number of authors (Fagerlin, Zikmund-Fisher, Ubel, Jankovic, Derry & Smith, 2007; Zikmund-Fisher, Smith, Ubel, & Fagerlin, 2007) have raised concerns over the usage of objective numeracy measures like the one used in Study 1. The authors argue that participants are not generally willing to undergo aptitude tests. More importantly, using objective measures of numeracy in internet-based studies is problematic, as researchers are unable to control participants' reliance on others or calculators in solving the numeracy problems. These issues serve as the underlying motivation to develop the Subjective Numeracy Scale (SNS) (Fagerlin, et al., 2007; Zikmund-Fisher, et al., 2007). The SNC has the advantage of being quicker, more accessible and less likely to cause participants to seek external help. At the same time, it is as useful in measuring numeracy abilities as more objective measures (Zikmund-Fisher et al., 2007).

3 Experiment 2

To overcome two of the limitations in the first study, we amended our research in two important ways. Our second study involved women who had either undergone genetic testing or had cancer previously. With a more ecologically valid sample, we ensured that our participants possessed knowledge about and experience with genetic testing, thus eliminating the possibility that our initial results were due to ignorance about genetic testing. Our sample was likely more engaged as well, increasing the likelihood that any misconceptions stemmed from the nature of the NCI message rather than from participants' lack of motivation. Furthermore, to address the concerns over usage of an objective numeracy scale (Lipkus et al., 2001) in an internet-based study, we decided to employ the newly developed subjective numeracy scale (Fagerlin et al., 2007; Zikmund-Fisher et al., 2007). By using the SNS, we were able to overcome concerns over participants' reluctance to engage in problem-solving and reduced the likelihood that participants were seeking external aid (e.g., calculator or another person). Our aims, however, remained the same as in Study 1. We first predicted that a statement about lifetime risk of developing cancer would give rise to various interpretations, not all of which would be correct. Second, we predicted that participants with higher numeracy levels would have a better understanding of lifetime risk information than their peers with lower numeracy levels.

3.1 Method

Participants. Participants included 207 women who completed an online survey through advertisements on a breast cancer mailing list of approximately 5,000 subscribers. Participants responded to an email sent by the manager of the online mailing list for filling out a short survey on health decisions, in return for entry into a raffle for a $50 gift certificate to Amazon.com. An introductory page appeared before the survey, which provided information on the study, the participant's right to withdraw without penalty, as well as information on the institution conducting the study. Most participants ($n = 175$, 84.5%) had either been screened for BRCA1 and BRCA 2 or had previously been diagnosed with breast cancer. Partici-

pants were included in the analysis if they completed at least two questions in the survey; missing responses in the survey ranged from 0 to 18 (0–8.7% of sample). When the number of participants varies from the sample size ($n = 207$), n is indicated. The mean age of participants was 43.13 ($SD = 9.69$, $n = 189$). Additional demographic information can be found in Table 1.

Procedure. The procedure was nearly identical to that found in the first study. The only notable difference involved numeracy, described below.

Numeracy. Participants completed the subjective numeracy scale: $\alpha = 0.89$ (Fagerlin et al., 2007; Zikmund-Fisher et al., 2007), which consisted of 8 items. The scale is more user-friendly and roughly equivalent ($r = 0.7$) to the standard numeracy scale used in the study above (Zikmund-Fisher et al., 2007; Fagerlin et al., 2007). Participants rated their subjective ability with fractions, percentages, calculating tips, calculating discounts, and reading newspaper tables and graphs on a scale of 1 (*not at all good*) to 6 (*extremely good*). Two questions assessed preference for numeric or lexical presentation of mathematical data, rated on a scale of 1 (*always prefer words*) to 6 (*always prefer numbers*). The final question indicated how useful the participant find numeric information, on a scale of 1 (*never useful*) to 6 (*always useful*). The scale score represented the mean response to all 8 questions.

As in the previous study, we performed a median split to determine participants high in numeracy (mean subjective numeracy score greater than or equal to 4.625) versus those low in numeracy (mean subjective numeracy score less than 4.625). The low subjective numeracy group consisted of 92 participants who scored, on average, 3.61 on subjective numeracy ($SD = 0.71$). The high subjective numeracy group consisted of 115 participants who scored, on average, 5.27 ($SD = 0.42$). Participants who scored high in subjective numeracy ($M = 9.18$, $SD = 2.43$, $n = 106$) were in a higher income bracket than participants low in subjective numeracy ($M = 8.22$, $SD = 2.73$, $n = 85$): $t(189) = -2.56$, $p < .01$. No differences existed between numeracy groups on age or education.

Results

Most appropriate. Slightly more than half, 59.4% ($n = 123$), chose the correct interpretation (option 1 above). A similar proportion (40.1%, $n = 83$) believed that "Women who are found to have alterations in the genes called BRCA1 and BRCA2 have a 36% to 85% higher chance of developing breast cancer" was the right answer. An additional 0.5% ($n = 1$) chose "Women who have BRCA1 and BRCA2 alterations will exhibit 36 to 85% of the symptoms associated with breast cancer." No one in the second sample believed all women with BRCA1 and BRCA2 would develop breast cancer. Still, over 40% of the sample misrepresented the information provided by the NCI.

A logistic regression on most appropriate correct by age, education, and subjective numeracy (continuous) yielded several significant predictors. The chances of choosing the correct answer decreased as age increased ($B = -.03$, $SE = .16$, $p < .04$). The likelihood of choosing the correct interpretation increased as education increased ($B = .51$ $SE = .25$, $p < .01$) and subjective numeracy increased ($B = .56$ $SE = .17$, $p < .02$).

Numeracy. In line with earlier studies, we were interested in numeracy's relationship with a woman's ability to correctly interpret the NCI message, as well as with her risk perception. As predicted, numeracy level (continuous) significantly correlated positively with a participant's ability to choose the correct interpretation of lifetime risk for breast cancer based on BRCA1/2 status, $r(207) = .29$, $p < .01$. The low numeracy group chose the correct interpretation about 47% of the time compared with the high numeracy participants, who chose the correct interpretation 70% of the time (see Table 2).

3.1.1 Between-study comparison

Participants in Study 2 were slightly older ($M = 43.13$, $SD = 40.68$) than participants in experiment 1 ($M = 40.68$, $SD = 13.63$): $t(447) = -2.11$, $p < .04$. Participants in Study 2 ($M = 8.75$, $SD = 2.61$) also had slightly higher income than participants in experiment 1 ($M = 7.19$, $SD = 3.30$): $t(449) = -5.42$, $p < .001$. Participants in Study 2 (123 of 207 versus 134 of 277) were generally more likely to choose the correct interpretation of breast cancer risk: $\chi^2 = 5.80$, $p < .02$.

3.2 Discussion

In the second study, we aimed to replicate our findings from Study 1 with two notable differences: Testing a more ecologically valid sample and using a subjective numeracy scale rather than an objective one. Our results followed a similar pattern to the one found in the first experiment. Despite the fact that the majority of the sample in Study 2 (close to 85%) had undergone genetic testing, over 40% were unable to correctly identify the most appropriate answer. This result is still more worrisome than what we obtained in our first study, as it indicates that confusion persists even among women who have undergone BRCA 1/2 genetic testing and genetic counseling. Participants in Study 2, however, did perform better than those who participated in Study 1, possibly due to great experience with genetic testing. Also in line with Study 1, we found that subjective numeracy perceptions correlated positively with women's ability to identify the cor-

rect interpretation of lifetime risk for breast cancer based on BRCA1/2 status. Thus, Study 2 complements and extends our findings from Study 1 in two important ways. First, it indicates that the ability to correctly interpret genetic testing results about lifetime risk of developing breast cancer is a challenging task regardless of whether one has relevant knowledge. Second, our data also provides support for the utility of using a subjective measure of numeracy.

4 General discussion

DNA technology has been developing rapidly, leading to an enhanced use of genetic testing in our understanding of disease diagnosis, treatment, and prevention. At the same time, there has been greater concern over people's ability to understand and use lifetime risk information. Previous research has demonstrated, for example, that women often overestimate or underestimate their probability of developing cancer (Lipkus, Samsa & Rimer, 2001). Yet, researchers have barely paid attention to exactly how women interpret lifetime risk information regarding cancer development.

Our results demonstrate that women — regardless of whether they have undergone BRCA1/2 genetic testing or not — translate lifetime risk information about the probability of developing breast cancer in multiple ways: examples include (a) the number of people of who will develop cancer, (b) the age range by which a woman will develop breast cancer, (c) the percentage of symptoms that a women is likely to experience, and (d) as a comparison to other women. The participants in our studies often chose the wrong interpretation.

Our data are more striking than the ones reported in previous studies (Gigerenzer, Hertwig, Van den Broek, Fasolo & Katsikopoulos, 2005) for many reasons. First, the information provided by NCI and used in our experiment spelled out the reference class. That is, participants were clearly informed that 360–850 out of 1000 women with an altered BRCA1/2 gene are likely to develop breast cancer. Such presentation is associated with increased accuracy, in contrast with the traditional probabilistic presentation (Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz & Woloshin, 2008). Second, the NCI information states that women with altered BRCA1/2 genes have 3–7 times the risk of developing breast cancer, not 36–85% higher risk as almost half of our sample believed. This is not minor misinterpretation, as having a 36–85% higher risk of developing breast cancer is equal to a lifetime risk of only 18–24.4%, which is 2–3.5 times *lower* than a lifetime risk of 36–85%. Third, even though women who had undergone genetic testing for BRCA 1/2 exhibited better performance, over 40% failed to identify the correct answer. Earlier studies (Butow, Lobb, Meiser, Barratt, & Tucker, 2003; Meiser & Halliday, 2002) have shown that risk perception improves after genetic counseling, which could help explain the improved results. However, the effects of improved risk perception seem relatively short-term (see Sivell, Elwyn, Gaff, Clarke, Iredale et al., 2008). As we had no data regarding the time interval between undergoing genetic testing and participating in our research, it is possible that evaluating women directly after the genetic counseling session would yield better results. Finally, women's false intuition about the correct answer is similar to the findings reported by Kahneman and Federick (2002) in other domains. In addition, both of our samples were more educated and wealthier than the general population, which raises even more concern over how a less educated and less affluent group would fare on our task. On the somewhat positive side, only 6% (and practically none among those who had undergone genetic testing) of our sample from study 1 believed that the NCI information indicated that all women between 36–85 years of age will develop breast cancer or that women with BRCA1/2 will experience 36–85% of the symptoms.

These results raise important questions about earlier research that focused on how accurately women estimate their lifetime risk. If women misinterpret the meaning of predicted lifetime risk, it is unclear what information they are actually estimating. For example, if women understand NCI's information as indicating that all women between 36–85 years of age will develop breast cancer, do they over- or underestimate the age by which women would develop cancer? Do they attempt to estimate the percentage of symptoms that a woman will experience? Or do they estimate the likelihood that a woman with positive BRCA1/2 results will develop cancer? Unfortunately, we are unable to provide satisfactory answers.

Our data strongly demonstrate that objective numeracy levels play a crucial role in a woman's ability to correctly identify the NCI's intended message. Our results also reveal a similar pattern with regard to subjective numeracy levels, providing further support to using subjective numeracy measures rather than more objectives ones. Taken together, our data from the two studies are perfectly aligned with a growing body of evidence demonstrating the importance of numeracy in decision making in general, and medical decision making in particular (Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz & Woloshin, 2008; Peters et al., 2006). Our study thus provides further support for the connection between numeracy level and accurate risk perception.

Our studies have a number of limitations. First, in Study 1 we surveyed a non-representative online sample and also asked them to think about a hypothetical person rather than themselves. Study 2, on the other hand, suf-

fered from a low response rate. Thus, we are unable to tell whether those who participated in Study 2 are representative of the women who undergo genetic testing for BRCA 1/2. Since we have not evaluated general literacy levels and focused only on numeracy abilities, it is possible that general literacy levels are also associated with better ability to interpret the NCI message. A number of researchers (e.g., Brewer, Tzeng, Lillie, Edwards, Peppercorn, et al., 2009) have demonstrated that low health literacy is related to higher risk perception for developing breast cancer. Given the complexity of the NCI message and of the result from genetic testing, it is important that future studies evaluate both general literacy levels as well as numeracy abilities. Despite these limitations, our data are important for a number of reasons. In addition, despite earlier indications showing that including numeric risk information can increase trust and belief in the message (Gurmankin, Baron, & Armstrong, 2004), we did not pursue this important line of investigation. Our results, nonetheless, clearly demonstrate that women (regardless of whether they have undergone genetic testing) understand lifetime risk information in more than one way. We also highlight the importance of (objective and subjective) numeracy in understanding lifetime risk information.

This study focused on women and breast cancer, yet it is likely that similar results would emerge with males and with other medical conditions (e.g., coronary heart disease; e.g., Lloyd-Jones, Larson, Beiser, & Levy, 1999). Furthermore, we concentrated on lifetime risk information, given that academics, practitioners and national cancer organizations use this terminology. It is possible that using a one-year or a five-year risk estimate would yield similar results. Further research should examine whether the obstacle to correct interpretation lies with the concept of lifetime risk itself, or from the fact that lifetime risk is presented as a range. As genetic testing becomes more widespread and available options increase, it is important to ensure that patients correctly interpret the lifetime risk information yielded by these tests and do not act upon misconstrued lifetime risk assessments.

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