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Tailoring risk communication to improve comprehension: Do patient preferences help or hurt?

Abstract

Objective: Risk communication tools can facilitate patients' understanding of risk information. In this novel study, we examine the hypothesis that risk communication methods tailored to individuals' preferences can increase risk comprehension.

Methods: Preferences for breast cancer risk formats, and risk comprehension data were collected using an online survey from 361 women at high risk for breast cancer. Women's initial preferences were assessed by asking them which of the following risk formats would be the clearest: 1) percentage, 2) frequency, 3) bar graph, 4) pictogram, and 5) comparison to other women. Next, women were presented with five different formats for displaying cancer risks and asked to interpret the risk information presented. Finally, they were asked again which risk format they preferred.

Results: Initial preferences for risk formats were not associated with risk comprehension scores. However, women with lower risk comprehension scores were more likely to update their risk format preferences after they evaluated risks in different formats. Less numerate women were more likely to prefer graphical rather than numeric risk formats. Importantly, we found that women preferring graphical risk formats had lower risk comprehension in these formats compared to numeric formats. In contrast, women preferring numeric formats performed equally well across formats.

Conclusions: Our findings suggest that tailoring risk communication to patient preferences may not improve understanding of medical risks, particularly for less numerate women, and point to the potential perils of tailoring risk communication formats to patient preferences.

Introduction

In his 2015 State of the Union address, President Obama unveiled a precision medicine initiative (Obama, 2015). A key feature of this initiative is to alter the practice of "one-size-fits-all" treatment, to one that "takes into account individual differences in people's genes, environments, and lifestyles" (Office of the Press Secretary, the White House, 2015). The President's call has followed a growing acknowledgement about the promise of precision medicine to help treat various diseases, especially cancer (Mirnezami, Nicholson, & Darzi, 2012). The precision medicine literature, however, is yet to acknowledge "precision communication." That is, in the same manner that "one-size-fits-all" treatment might no longer be suitable, "one-size-fits-all" risk communication might not fit all patients. As the first paper, to our knowledge, to link precision medicine with precision communication, the present study examined how (and whether) we should tailor risk information to women at risk, and whether this tailoring should be preference-based.

Treatment-related prevention decisions are often preference-driven: patients typically must choose whether to initiate effective treatments that hold the possibility of side effects that can negatively impact quality of life. Because of this, patients are often forced to make difficult tradeoffs between life expectancy and quality of life, such as whether to decrease breast cancer risk by drugs (Tamoxifen) or undergo mastectomy (Grann et al., 1999). This situation demands that patients be well informed and have a full understanding of the risks and benefits associated with each treatment option. Yet many factors in the clinical setting impede informed decision making, such as competing demands on physicians' time, the complexity of medical information, and the challenging tradeoffs involved (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999). To facilitate informed medical decision making, efficient communication methods are required. This is particularly relevant to breast cancer, as women often overestimate their risk of breast cancer in relation to other health risks (Alexander, Ross, Sumner, Nease, & Littenberg, 1996; Bluman et al., 1999; Katapodi, Lee, Facione, & Dodd, 2004; Lerman et al., 1995; Lipkus, Biradavolu, Fenn, Keller, & Rimer, 2001). Population-based studies have found that women who are considering and those who have undergone prophylactic mastectomies significantly overestimate their lifetime risk of breast cancer up to a factor of 3.4 prior to and after surgery, raising serious questions about the level of informed consent and the consequent appropriateness of these decisions (Meiser et al., 2000; Metcalfe & Narod, 2002).

Many patients are eager to take a more active role in making decisions (Cohen, 2000), and research has demonstrated that patients involved in their decisions experience better outcomes (Wagner et al., 2001). Risk communication tools can facilitate patients' understanding of the risks involved in their medical situation. In general, the existing methods of risk communication (Benichou, Gail, & Mulvihill, 1996; Fortin, Hirota, Bond, O'Connor, & Col, 2001; Julian-Reynier et al., 2003; Lipkus, Klein, & Rimer, 2001), typically consist of numerical information (e.g., 10%; 10 out of 100), and pictorial information (icon array)—to assist decision makers in the interpretation of the risk information. These estimates often take the form of percentages, frequencies and graphical presentations such as bar graphs and pictograms. While a number of studies have examined the effectiveness of these formats, studies have not been performed to match these methods to individuals' interpretation abilities or preferences (Zipkin et al., 2014).

Evidence suggests that different presentation formats can be effective, but means to assess the appropriateness of each approach based on individual patient characteristics have not been developed. To date, no consensus has been reached as to the best method of risk communication. Current approaches to risk communication assume "one method fits all" and the majority of research in this area is conducted to identify the best method, one that would lead to improved patient risk comprehension, across the board. Despite considerable research endeavors, there is no evidence on how patient's preferences regarding risk presentation formats contribute to the effectiveness of these risk formats in improving comprehension. Given that patients often have difficulty interpreting risk information (Hanoch, Miron-Shatz, & Himmelstein, 2010; Miron-Shatz, Hanoch, Graef, & Sagi, 2009; Rolison, Hanoch, & Miron-Shatz, 2012), whether risk communication should be tailored—or personalized—to preferences or abilities (e.g. numeracy) remains an open question.

This question is particularly important given that different presentation formats are not equally helpful for all individuals. Earlier work by Galesic and Garcia-Retamero has shown that individuals with low numeracy—usually defined as the ability to process and understand basic probability and mathematical concepts (Lipkus, Samsa, Rimer, 2001)—are more likely to be helped by graphical display than high numeracy individuals (Galesic & Garcia-Retamero, 2010; Galesic, Garcia-Retamero, & Gigerenzer, 2009). Higher levels of numeracy, in fact, have been linked to better understanding of lifetime risk of developing breast cancer (Hanoch et al., 2010), improved comprehension of ambiguous genetic test results (Hanoch, Miron-Shatz, Rolison, & Ozanne, 2014), and greater desire for shared decision making (Galesic & Garcia-Retamero, 2011; Hanoch, Miron-Shatz, Rolison, Omer, & Ozanne, 2014). Systematic reviews of the literature have further highlighted the relationship between numeracy and undergoing mammography screening, comprehension of risk information, and making informed decisions (Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz, & Woloshin, 2007; Reyna, Nelson, Han, & Dieckmann, 2009). Whether high and low numeracy individuals prefer different presentation formats and whether they perform better or worse with preferred formats remains to be examined.

Our study applies a novel research design to assess whether risk communication methods tailored to individuals' preferences increase risk comprehension. We take a unique three-step approach: 1) participants are asked which of several graphical and numeric risk formats they prefer, 2) participants evaluate risk information in a variety of graphical and numeric formats (without providing feedback on their accuracy), and 3) participants are asked, again, about their risk format preferences to determine whether experience causes them to revise their preferences. Using this novel approach allows us to examine whether initial risk format preferences relate to risk comprehension; explore whether individuals' preferences for risk formats are static or whether they are informed by experience; and whether these informed format preferences are associated with improved risk comprehension. Throughout our study, the role of numeracy in the relationships among risk format preferences and risk comprehension is examined.

Method

Participants

One thousand and seven women were contacted via an email distributed by local branches of the Cancer Genetics Network (CGN) to complete an on-line survey. Four hundred and seventy-seven women (47% response rate) consented to participate in the study and completed the survey. Of these, breast cancer risk format preferences and risk comprehension data were collected from 361 participants.[1] The analytic sample consisted of 334 participants with complete data.

[1] Due a programming error, the risk format preference questions given to the first wave of respondents were incorrect. As a result, 116 of the 477 women agreeing to participate did not receive the correct risk format preference questions. We found no significant differences between those receiving and not receiving the correct risk format questions in numeracy, worry about BRCA testing, education, marital status, or age. However, women who did not receive the correct risk format questions were significantly more likely ($p<0.05$) to report prior *BRCA* testing experience.

Formed in 1999, CGN is a national network of centers specifically devised to help study the inherited predisposition to cancer. It maintains a registry of people (both females and males) "who have a personal or family history of cancer, and who are willing to be contacted regarding participation in studies about inherited susceptibility to cancer" (see http://www.cancergen.org/ retrieved August 11, 2015). Our CGN study participants were women who had no prior history of breast cancer, but were considered at increased risk of developing breast cancer due to having at least one of the following: 1) at least one relative diagnosed with breast cancer at age 45 years or younger, 2) two or more relatives diagnosed with breast cancer at age 50 years or younger, or 3) at least one relative diagnosed with ovarian cancer or male breast cancer. These high-risk criteria, as defined by CGN, have been shown to identify women at high risk for hereditary breast and/or ovarian cancer (McPherson, Steel, and Dixon, 2000). The CGN provided a de-identified database that included participants' demographic, family, and disease history data.

Participants received an e-mail from CGN and were asked to complete an on-line survey about *BRCA*1/2 testing, breast cancer risk format presentation preferences, objective numeracy, worry about BRCA testing, and BRCA testing history, among other questions. All participants were offered a $30 gift card and were not required to answer any questions that made them uncomfortable. The appropriate institutional review boards approved the study protocol, and all participants provided informed consented.

Risk format preferences

Women's initial risk format preferences were first assessed by asking them if a doctor were trying to inform them about their risk of breast cancer, which of the following risk formats would be the clearest: 1) percentage (e.g. 20% chance of developing cancer), 2) frequency (e.g. one in five women will develop cancer), 3) bar graph, 4) pictogram, or 5) comparison to other women (e.g. their risk is twice the average woman's risk). These five formats were selected for two main reasons. First, they are the most widely used in the clinical setting and research (see Gigerenzer et al., 2007). Second, researchers, have recommend using them to facilitate risk communication (e.g., Fagerlin, Zikmud-Fisher & Ubel, 2011). A categorical variable was created to indicate preferences for percentages, frequencies, bar graphs, pictograms, or comparisons to other women. Bar graphs and pictograms categories were combined due to few initial endorsements of these formats. After this initial preference was elicited, women were presented with different formats for displaying cancer risks (see below). Then, women were again asked which format would be clearest. A binary variable was created to indicate women who updated their preferences after viewing the risk format options.

Risk presentation formats

Five scenarios were given to participants in random order that varied in the manner that breast cancer and *BRCA1/2* risk information was presented. The risk information presented to the participants was adapted from the information provided on the NCI website (see http://www.cancer.gov/cancertopics/causes-prevention/genetics/brca-fact-sheet). The risk presentation formats were: 1) frequency (e.g. 12 out of 100 will develop breast cancer), 2) percentages (12% of women will develop breast cancer), 3) both frequencies and percentages, 4) frequencies and percentages with bar graphs, and 5) frequencies and percentages with pictograms (Figure 1).

Risk comprehension

After each of the five risk presentation scenarios, women were asked to correctly interpret the risk of breast cancer in the general population and for women with a *BRCA* genetic mutation by answering a multiple-choice question as follows:

Based on the information in the following paragraph (and accompanying graphic), please choose the correct option: 1) Breast cancer will develop in 12 percent of women (120 out of 1,000) who are found to have *BRCA1* or *BRCA2* mutations, 2) Breast cancer will develop in 60 percent of women (600 out of 1,000) who are found to have *BRCA1* or *BRCA2* mutations, 3) Breast cancer will develop in 120-600 out of 1,000 women who are found to have *BRCA1* or *BRCA2* mutations, 4) Women who are found to have mutations in the genes called *BRCA1* or *BRCA2* have 60 percent higher chance of developing breast cancer, and 5) Women who are found to have mutations in the genes called *BRCA1* or *BRCA2* are certain to develop breast cancer by the time they are 60.

From these questions, two objective measures of risk comprehension were constructed: 1) a sum of correct responses to the five scenarios, and 2) an indicator for whether all responses were correct.

Numeracy

Respondents completed one of the most widely used measures of numeric literacy (Lipkus, Samsa & Rimer, 2001). The numeracy scale examines individuals' ability to answer correctly three probability and related ratio problems (e.g., "Imagine that we flip a fair coin 1,000 times. What is your best guess about how many times the coin would come up heads in 1,000 flips?"). The measure been previously employed across a variety of populations and medical decision-making settings, and its psychometrics properties are well established. Correct answers were given a score of 1, while incorrect responses were coded as zero. A summary objective score was calculated and scaled to range from 0-3.

Worry about BRCA testing

As Portnoy, Ferrer, Bergman and Klein (2014) established, affective responses to risk, including worry, are empirically distinguishable from commonly used perceived risk measures. Indeed, the evidence suggests that cancer worry facilitates adherence to mammography regimens among women with a family history of breast cancer (Diefenbach, Miller, & Daly, 1999). Thus, in this study, we also examined worry about BRCA testing of CGN women using the breast cancer worry scale (Miron-Shatz and Diefenbach, unpublished manuscript).

Participants rated how much they would worry about several items related to *BRCA1* and *BRCA2* screening test. The amount of worry was rated on a Likert scale ranging from 1 (*not worried at all*) to 5 (*very worried*). Items consisted of (i) the test might fail to detect that I am going to develop breast cancer, (ii) the test might be wrong in saying that I will develop breast cancer, (iii) the test might find something else wrong with me, and (iv) the test might find I am sick.

Other covariates

We also added controls for participant characteristics including whether they have been tested for a *BRCA* gene mutation, education (college graduate (referent), some college, high school or less), marital status (married (referent), unmarried), race (White (referent), non-White), and age.

Statistical analyses

Unadjusted associations between initial risk format preferences and numeracy measures, and initial format preferences and worry about BRCA testing were estimated using one-way ANOVAs. Adjusted associations between risk comprehension and initial presentation format preferences were estimated using Poisson (number of correct responses) and logistic (all correct) regression models. Adjusted associations between updating format preferences, risk comprehension, and initial format preferences were estimated using logistic regressions.

Differences in format-specific risk comprehension between initial and informed risk format preferences and the sample average were assessed using a two-sample probability test. Differences in format-specific risk comprehension when viewing preferred and non-preferred formats were tested using a multivariate test of means. All analyses were conducted in Stata 12.

Results

Sample characteristics

Among our 334 participants, most were white, married and a college graduate. The mean age was 50.4 years (standard deviation (SD) 7.8, Table 1). On average, participants correctly answered 3.7 out of 5 breast cancer risk comprehension questions (SD 1.7) and 55.4% answered all five questions correctly. Initially, most women stated they preferred breast cancer risk presented to them as a percentage (54.8%). After experiencing other risk presentation formats, however, the majority of women (59.6%) updated their preferred presentation modality. In regard to numeracy, participants scored 2.0 out of 3 (SD 0.9) on the objective numeracy scale.

Numeracy and initial risk format preferences

Numeracy scores varied significantly across initial risk format preferences (F-test = 3.6, $p<0.05$, Table 2). In post-hoc, pairwise comparisons of means we found the average numeracy score of participants initially preferring bar graphs or pictograms was significantly lower than those preferring percentages initially ($p<0.01$). Numeracy was not associated with updating preferences for risk format presentation before and after the risk comprehension questions were asked (t-test=1.1, p=0.28, Table 2).

Risk comprehension and initial format preferences

Initial risk format preferences were not significantly associated with either the number of correct responses or answering all questions correctly after adjustment for numeracy, worry about BRCA testing, *BRCA* testing history and demographic characteristics (Table 3). However, numeracy was positively correlated with risk comprehension. A one-point increase in objective numeracy scores was associated with a 16% (95% CI 1.09, 1.24) increase in the number of questions answered correctly and 2.03 times the odds (95% CI 1.53, 2.68) of answering all five questions correctly. Worry about BRCA testing was inversely associated with the odds of answering all comprehension questions correctly while level of education was positively associated with both the number of correct responses and whether all responses were correct.

Updating format preferences and risk comprehension

We next examined whether participants updated their risk format preference after experiencing them and whether risk comprehension and initial format preferences were associated with the tendency to change format preferences. We found women with higher risk comprehension scores were less likely to update their format preference. Answering one more response to the risk comprehension assessment correctly was associated with 0.84 times the odds (95% CI 0.72, 0.98) of updating preferences for risk presentation, after controlling for numeracy, worry about BRCA testing, *BRCA* testing history and demographic characteristics (Table 4). Women who answered all five questions correct had 0.60 times the odds (95% CI 0.36, 0.99) of updating their risk format preferences after adjustment compared to women who did not.

Initial preferences for risk presentation were significantly associated with the likelihood of updating preferences after experiencing all of the five risk formats presented. In particular, women who initially preferred risk presented as frequencies had about twice the odds of updating their preferences compared to women initially preferring percentages ($p<0.05$). Similarly, women initially preferring risk presented as a comparison to other women had twice the odds of updating their preferences ($p<0.05$). As in unadjusted analyses, numeracy was not associated with updating preferences for breast cancer risk formats.

Format-specific risk comprehension

Next, we examined whether women have improved risk comprehension when experiencing a risk format they prefer in several ways. To do so, we compared for each format whether the probability of answering correctly in a woman's preferred format differed from the sample average as well as whether the probability of answering correctly differed across initial and informed format preferences (Table 5). The results suggest that women preferring numeric risk formats (i.e. percentage, frequency) were as likely to answer the risk comprehension questions correctly when the risk was presented numerically compared to the average respondent. Further, there were no differences in the likelihood of answering correctly when the risk was presented numerically between women preferring these formats initially to those preferring them after experiencing all formats. Similarly, there were no differences in risk comprehension across initial vs. informed preferences for graphical formats. However, women preferring graphical risk formats (i.e. bar graph, pictogram) were less likely to correctly answer when risk were presented in graphical forms than the sample average ($p<0.05$ bar graph, $p<0.10$ bar graph or pictogram).

We also tested whether the probability of answering the risk comprehension question correctly in one's preferred format differed from that of one's non-preferred formats. We found those preferring numeric risk formats initially performed better when asked to interpret numeric risk compared to graphical risk ($p=0.05$, Table 6). Conversely, women who indicated bar graphs were their informed risk format preference were less likely to answer the risk comprehension question correctly when risk was presented as a bar graph than when it was presented in other formats ($p<0.10$). No other differences in performance across formats within individuals were found.

Discussion

President Obama's precision medicine initiative promises to make important changes to how medicine is practiced. Our novel extension of this line of reasoning to risk communication could also influence how medical-related information is conveyed to patients. Risk communication tools can facilitate patient understanding of the risks and probabilities associated with a genetic tendency to develop a condition, and patient ability to evaluate and compare prevention and treatment options. Although the extant evidence suggests risk communication formats vary in their effectiveness, it is not clear whether matching risk formats to patient preferences improves risk comprehension and, ultimately, patient decision making and health outcomes.

In our examination of whether risk communication methods tailored to individuals increased risk comprehension, we found that initial preferences for risk formats were not associated with risk comprehension scores. Women with lower risk comprehension scores were more likely to update their risk format preferences after they were asked to evaluate risks using a number of graphical and numeric risk formats. Interestingly, women preferring graphical risk formats, many of whom tended to be less numerate, had lower risk comprehension in these formats compared to numeric formats. Diverging from earlier findings (Garcia-Retamero & Galesic, 2010), it is possible that the reduced risk comprehension in the graphical format stemmed from the fact that participants did not view graphical presentation alone, but in conjunction with other information in multiple formats. As such, it is possible that performance was reduced due to the complexity or magnitude of information presented. Alternatively, women preferring numeric formats performed equally well across formats. In line with earlier studies (Gigerenzer & Hoffrage, 1995; Miron-Shatz et al., 2009), our results showed that the frequency format had slightly higher risk comprehension than other formats, but was not preferred by many women. In contrast, bar graphs were the most commonly preferred informed format, but had risk comprehension that was significantly lower than the average comprehension.

Recent systematic reviews have found that certain methods of risk communication may improve risk comprehension, while others appear to be less effective (Zipkin et al., 2014). However, no single method for risk communication was found to be superior to others. This is likely due in part to the heterogeneity across the studies. It is also possible that abilities with different formats vary across individuals, implying there is no best method of risk communication for a population. Our results found that some individuals did better with their preferred format of risk comprehension, but this result was likely mediated by numeracy. Those who were most numerate were more likely to prefer numerical formats and had higher risk comprehension. In contrast, those who preferred graphical formats did worse with these formats.

Several limitations and design considerations should be noted when evaluating our findings. First, our sample consisted of almost exclusively white women with at least some college education choosing to participate in the Cancer Genetics Network who responded to the online survey sent to them via email. Therefore, to the extent that gender, previous experience with genetic and other health risk information, valence associated with specific medical risk (e.g. cancer vs. diabetes), cultural experiences, and socioeconomic status are important determinants of how risk format preferences relate to risk comprehension, it is unclear how our findings generalize to other patient populations and the evaluation of other medical risks. Second, risk comprehension was assessed using responses to objective questions about risk when risks were presented in various graphical or numeric formats. However, graphical literacy, defined as understanding basic graphical representations, was not assessed. Prior work has found that graphical risk formats are associated with more accurate risk comprehension among lower numeracy individuals with high graphical literacy (Garcia-Retamero & Galesic, 2010), and that risk comprehension from graphical versus numeric formats depends on individual levels of graphical versus numeric literacy (Gaissmaier et al., 2012). Our work, furthermore, focused only on risk comprehension, which represents a single criterion for evaluating successful communication. We did not measure participants' recollection of the information, satisfaction, and ability to communicate the findings to others, for example. These are key factors that play important role in communicating with patients.

Importantly, an additional limitation is that the risk formats presented did not entirely comport with the risk preferences elicited. Most notably, multiple risk formats were presented simultaneously. For example, participants received information as a comparison to other women in tandem with one or more of the following formats: percent, frequency, graph, and pictogram (e.g., 12% of women in the general population will develop breast cancer compared to 60% with a mutation). Thus, our experimental design may not have been able to fully identify how participants' risk format preferences relate to their format-specific risk comprehension. However, the risk formats presented in the study were selected to balance fidelity to the NCI website and site's attendant risk estimates with preferences for specific formats by low and high numeracy women previously identified in the literature, as well as those identified by participants in our sample. The NCI website presents genetic testing information that includes risk information about both those who carry the genes and those from the general population. We felt it was important to preserve the messages endorsed by the NCI as the participants were considered at increased risk for breast cancer compared to the general population. Furthermore, studies and genetic counseling protocols (e.g., REVEAL study (Roberts, Christensen, & Green, 2011)) have shown that genetic counseling often presents patients with their own risk as well as the risk to the general population. It is therefore possible that by presenting each risk format along a comparison to other people reduces our ability to make firm conclusions about how participants' preferences may relate to their risk comprehension.

Furthermore, we presented graphical presentation of risk in tandem with frequencies, percentages and comparison to other women. In a graphical presentation of risk, a number generally has to be stated or spelled out in some format, and that this format is often percentages and or frequencies. Hence, percentages or frequencies will inevitably appear in many graphical risk formats. These numeric representations (e.g., 12%) are a basic information layer than can be supplemented with other representations. Importantly, recommendations to improve risk communication strategies between patients and clinicians highlight presenting graphical representations of risk in tandem with numeric information (Paling, 2003). This concept of layered information in risk formats should be considered when interpreting the findings presented. Thus, the most directly interpretable comparisons among the risk formats assessed were: 1) percent vs. frequency, 2) percent and frequency with and without a bar graph, 3) percent and frequency with and without a pictogram, and 4) percent and frequency with a graph vs. a pictogram. Further research is needed to provide more detailed contrast between risk presentation formats, format preferences, and risk comprehension.

When considering these results in the context of precision medicine, it questions efforts to foster “precision communication.” Our results do not necessarily support the concept that efforts to personalize formats of risk communication to individual preferences will be more effective than a more general population-based approach. This is similar to previous work finding that preference for and familiarity with a specific graphical format did not necessarily relate to patients’ understanding of the risk information (Hamstra et al., 2015). Instead, our results indicate that there may be subgroups for which informed preferences can predict higher risk comprehension, but it may not provide additional information once numeracy is taken into account. Further, it appears there may be subgroups of individuals whose risk comprehension is worse when presented with their informed preferred format for risk comprehension. This raises the question of how to best provide effective risk communication in the context of shared decision making. Ongoing efforts to democratize the decision-making process (Church et al., 2002) and ensure patients “share” in the decision-making process assumes that they have a basic level of understanding of the medical situation. If this democratization (Rychetnik et al., 2013) is taken further to methods of communication, it could lead to poorly informed patients making decisions. Perhaps clinicians wishing to personalize risk formats for individual patients should focus on what type of risk information is needed to make a specific medical decision (Zikmund-Fisher, 2013), rather than what formats seem palatable to each patient.

The findings have broad and important implications in this era, when individuals seek out – and readily find - information outside of the clinic. Those who prefer graphical formats will be more likely to seek them out online and in other media. However, if such formats do not improve comprehension yet patients report they are “informed,” providers may not inquire further about patients' comprehension of the treatment decisions they face. This dovetails with evidence on the discrepancy between measures of the patient's sense of readiness to choose a treatment, having thoroughly deliberated on the treatment choices (Elwyn and Miron-Shatz, 2010), and objective measures of knowledge. The disconnect suggests that attention must be given to objective knowledge as well, despite the fact that evidence suggests that, for many patients, such knowledge is of secondary importance (e.g., Grinshpun-Cohen, Miron-Shatz, Ries-Lavie, and Pras, 2014).

In summary, our findings suggest tailoring risk communication to patient preferences may not improve understanding of medical risks, particularly for less numerate women. Whether it is better to use numeric formats to communicate risks, even when patients prefer contextual-based formats, is unclear. This gap in knowledge points to the potential perils of focusing on shared decision-making processes in the era of precision medicine without attention to the potential promises and pitfalls of precision communication to improve patients' understanding of the risks and benefits involved in their medical situation.

References

Alexander, N. E., Ross, J., Sumner, W., Nease, R. F.,Jr, & Littenberg, B. (1996). The effect of an educational intervention on the perceived risk of breast cancer. *Journal of General Internal Medicine, 11*(2), 92-97.

Benichou, J., Gail, M. H., & Mulvihill, J. J. (1996). Graphs to estimate an individualized risk of breast cancer. *Journal of Clinical Oncology, 14*(1), 103-110.

Bluman, L. G., Rimer, B. K., Berry, D. A., Borstelmann, N., Iglehart, J. D., Regan, K., . . . Winer, E. P. (1999). Attitudes, knowledge, and risk perceptions of women with breast and/or ovarian cancer considering testing for BRCA1 and BRCA2. *Journal of Clinical Oncology, 17*(3), 1040-1046.

Braddock, C. H.,3rd, Edwards, K. A., Hasenberg, N. M., Laidley, T. L., & Levinson, W. (1999). Informed decision making in outpatient practice: Time to get back to basics. *Journal of the American Medical Association, 282*(24), 2313-2320. doi:joc91394 [pii]

Church, J., Saunders, D., Wanke, M., Pong, R., Spooner, C., & Dorgan, M. (2002). Citizen participation in health decision-making: Past experience and future prospects. *Journal of Public Health Policy, 23*(1), 12-32.

Cohen, J. (2000). Patient autonomy and social fairness. *Cambridge Quarterly of Healthcare Ethics: CQ: The International Journal of Healthcare Ethics Committees, 9*(3), 391-399.

Diefenbach, M. A., Miller, S. M., & Daly, M. B. (1999). Specific worry about breast cancer predicts mammography use in women at risk for breast and ovarian cancer. *Health psychology, 18*(5), 532.

Elwyn, G., & Miron-Shatz, T. (2010). Deliberation before determination: the definition and evaluation of good decision making. *Health Expectations, 13*(2), 139-147.

Fagerlin, A., Zikmud-Fisher, B.J., & Ubel, P.A. (2011). Helping patients decide: Ten stepds to better risk communication. Journal of the National Cancer Institute, 103(19), 1436-1443.

Fortin, J. M., Hirota, L. K., Bond, B. E., O'Connor, A. M., & Col, N. F. (2001). Identifying patient preferences for communicating risk estimates: A descriptive pilot study. *BMC Medical Informatics and Decision Making, 1*, 2.

Gaissmaier, W., Wegwarth, O., Skopec, D., Müller, A., Broschinski, S., & Politi, M. C. (2012). Numbers can be worth a thousand pictures: Individual differences in understanding graphical and numerical representations of health-related information. *Health Psychology, 31*(3), 286.

Galesic, M., & Garcia-Retamero, R. (2010). Statistical numeracy for health: A cross-cultural comparison with probabilistic national samples. *Archives of Internal Medicine, 170*(5), 462-468. doi:10.1001/archinternmed.2009.481

Galesic, M., & Garcia-Retamero, R. (2011). Do low-numeracy people avoid shared decision making? *Health Psychology, 30*(3), 336-341. doi:10.1037/a0022723 [doi]

Galesic, M., Garcia-Retamero, R., & Gigerenzer, G. (2009). Using icon arrays to communicate medical risks: Overcoming low numeracy. *Health Psychology, 28*(2), 210.

Garcia-Retamero, R., & Galesic, M. (2010). Who profits from visual aids: Overcoming challenges in people's understanding of risks. *Social Science & Medicine, 70*(7), 1019-1025. doi:http://dx.doi.org/10.1016/j.socscimed.2009.11.031

Gigerenzer, G., & Hoffrage, U. (1995). How to improve Bayesian reasoning without instruction: Frequency formats. *Psychological Review, 102*(4), 684.

Gigerenzer, G., Gaissmaier, W., Kurz-Milcke, E., Schwartz, L. M., & Woloshin, S. (2007). Helping doctors and patients make sense of health statistics. *Psychological Science in the Public Interest, 8*(2), 53-96. doi:10.1111/j.1539-6053.2008.00033.x

Grann, V., Jacobson, J.S., Sundararajan, V., Albert, S. et al. (1999). The quality of life associated with prophylactic treatments for women with BRCA1/2 mutations. *The Cancer Journal from Scientific American*, 5.5, 283.

Grinshpun-Cohen, Julia, Talya Miron-Shatz, Liat Ries-Levavi, and Elon Pras. "Factors that affect the decision to undergo amniocentesis in women with normal Down syndrome screening results: it is all about the age." *Health Expectations* (2014).

Hamstra, D. A., Johnson, S. B., Daignault, S., Zikmund-Fisher, B. J., Taylor, J. M., Larkin, K., . . . Fagerlin, A. (2015). The impact of numeracy on verbatim knowledge of the longitudinal risk for prostate cancer recurrence following radiation therapy. *Medical Decision Making, 35*(1), 27-36. doi:10.1177/0272989X14551639 [doi]

Hanoch, Y., Miron-Shatz, T., Rolison, J. J., Omer, Z., & Ozanne, E. (2014). Shared decision making in patients at risk of cancer: The role of domain and numeracy. *Health Expectations,* doi:10.1111/hex.12257 [doi]

Hanoch, Y., Miron-Shatz, T., & Himmelstein, M. (2010). Genetic testing and risk interpretation: How do women understand lifetime risk results. *Judgment and Decision Making, 5*(2), 116-123.

Hanoch, Y., Miron-Shatz, T., Rolison, J. J., & Ozanne, E. (2014). Understanding of BRCA1/2 genetic tests results: The importance of objective and subjective numeracy. *Psycho-Oncology,* , n/a-n/a. doi:10.1002/pon.3537

Julian-Reynier, C., Welkenhuysen, M., Hagoel, L., Decruyenaere, M., Hopwood, P., & CRISCOM Working Group. (2003). Risk communication strategies: State of the art and effectiveness in the context of cancer genetic services. *European Journal of Human Genetics*, *11*(10), 725-736. doi:10.1038/sj.ejhg.5201037 [doi]

Katapodi, M. C., Lee, K. A., Facione, N. C., & Dodd, M. J. (2004). Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: A meta-analytic review. *Preventive Medicine, 38*(4), 388-402. doi:10.1016/j.ypmed.2003.11.012 [doi]

Lerman, C., Lustbader, E., Rimer, B., Daly, M., Miller, S., Sands, C., & Balshem, A. (1995). Effects of individualized breast cancer risk counseling: A randomized trial. *Journal of the National Cancer Institute*, *87*(4), 286-292.

Lipkus, I. M., Biradavolu, M., Fenn, K., Keller, P., & Rimer, B. K. (2001). Informing women about their breast cancer risks: Truth and consequences. *Health Communication, 13*(2), 205-226. doi:10.1207/S15327027HC1302_5 [doi]

Lipkus, I. M., Klein, W. M., & Rimer, B. K. (2001). Communicating breast cancer risks to women using different formats. *Cancer Epidemiology, Biomarkers & Prevention, 10*(8), 895-898.

Lipkus, I. M., & Peters, E. (2009). Understanding the role of numeracy in health: Proposed theoretical framework and practical insights. *Health Education & Behavior, 36*(6), 1065-1081. doi:10.1177/1090198109341533

McPherson, K., Steel, C., & Dixon, J. M. (2000). ABC of breast diseases: breast cancer—epidemiology, risk factors, and genetics. *BMJ: British Medical Journal, 321*(7261), 624.

Meiser, B., Butow, P., Friedlander, M., Schnieden, V., Gattas, M., Kirk, J., . . . Tucker, K. (2000). Intention to undergo prophylactic bilateral mastectomy in women at increased risk of developing hereditary breast cancer. *Journal of Clinical Oncology*, *18*(11), 2250-2257.

Metcalfe, K. A., & Narod, S. A. (2002). Breast cancer risk perception among women who have undergone prophylactic bilateral mastectomy. *Journal of the National Cancer Institute, 94*(20), 1564-1569. doi:10.1093/jnci/94.20.1564

Mirnezami, R., Nicholson, J., & Darzi, A. (2012). Preparing for precision medicine. *The New England Journal of Medicine, 366*(6), 489-491. doi:10.1056/NEJMp1114866 [doi]

Miron-Shatz, T., Hanoch, Y., Graef, D., & Sagi, M. (2009). Presentation format affects comprehension and risk assessment: The case of prenatal screening. *Journal of Health Communication, 14*(5), 439-450. doi:- 10.1080/10810730903032986

Obama, B. H. (2015). *Remarks by the president in State of the Union Address - January 20, 2015*. Washington, DC. Retrieved from https://www.whitehouse.gov/the-press-office/2015/01/20/remarks-president-state-union-address-january-20-2015

Office of the Press Secretary, the White House. (2015). Fact sheet: President Obama's precision medicine initiative. Retrieved from https://www.whitehouse.gov/the-press-office/2015/01/30/fact-sheet-president-obama-s-precision-medicine-initiative

Paling ,J. (2003). Strategies to help patients understand risk. BMJ, 327, 745-748.

Portnoy, D. B., Ferrer, R. A., Bergman, H. E., & Klein, W. M. (2014). Changing deliberative and affective responses to health risk: a meta-analysis. Health psychology review, 8(3), 296-318.

Reyna, V. F. (2008). A theory of medical decision making and health: Fuzzy trace theory. *Medical Decision Making, 28*(6), 850-865. doi:10.1177/0272989X08327066 [doi]

Reyna, V. F., Nelson, W. L., Han, P. K., & Dieckmann, N. F. (2009). How numeracy influences risk comprehension and medical decision making. *Psychological Bulletin, 135*(6), 943-973. doi:10.1037/a0017327

Reyna, V. F., Nelson, W. L., Han, P. K., & Pignone, M. P. (2015). Decision making and cancer. *The American Psychologist, 70*(2), 105-118. doi:10.1037/a0036834 [doi]

Roberts, J. S., Christensen, K. D., & Green, R. C. (2011). Using Alzheimer's disease as a model for genetic risk disclosure: implications for personal genomics. *Clinical genetics, 80*(5), 407-414

Rolison, J. J., Hanoch, Y., & Miron-Shatz, T. (2012). What do men understand about lifetime risk following genetic testing? the effect of context and numeracy. *Health Psychology, 31*(4), 530-533. doi:10.1037/a0026562 [doi]

Rychetnik, L., Carter, S. M., Abelson, J., Thornton, H., Barratt, A., Entwistle, V. A., . . . Glasziou, P. (2013). Enhancing citizen engagement in cancer screening through deliberative democracy. *Journal of the National Cancer Institute,* doi:10.1093/jnci/djs649

Wagner, E. H., Grothaus, L. C., Sandhu, N., Galvin, M. S., McGregor, M., Artz, K., & Coleman, E. A. (2001). Chronic care clinics for diabetes in primary care: A system-wide randomized trial. *Diabetes Care, 24*(4), 695-700.

Zikmund-Fisher, B. J. (2013). The right tool is what they need, not what we have: A taxonomy of appropriate levels of precision in patient risk communication. *Medical Care Research and Review : MCRR, 70*(1 Suppl), 37S-49S. doi:10.1177/1077558712458541 [doi]

Zipkin, D. A., Umscheid, C. A., Keating, N. L., Allen, E., Aung, K., Beyth, R., . . . Feldstein, D. A. (2014). Evidence-based risk communication: A systematic review. *Annals of Internal Medicine, 161*(4), 270-280. doi:10.7326/M14-0295 [doi]

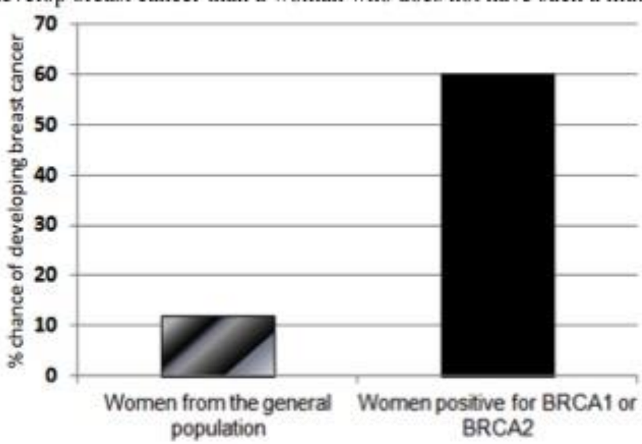
Figure 1. Breast Cancer Risk Presentation Formats

Scenario 1. According to estimates of lifetime risk, about 120 out of 1,000 women in the general population will develop breast cancer sometime during their lives compared with about 600 out of 1,000 women who have inherited a harmful mutation in *BRCA1* or*BRCA2*.
In other words, a woman who has inherited a harmful mutation in *BRCA1* or *BRCA2* is about five times more likely to develop breast cancer than a woman who does not have such a mutation.

Scenario 2. According to estimates of lifetime risk, about 12 percent of women in the general population will develop breast cancer sometime during their lives compared with about 60 percent of women who have inherited a harmful mutation in *BRCA1* or*BRCA2*. In other words, a woman who has inherited a harmful mutation in *BRCA1* or *BRCA2* is about five times more likely to develop breast cancer than a woman who does not have such a mutation.

Scenario 3. According to estimates of lifetime risk, about 12 percent of women (120 out of 1,000) in the general population will develop breast cancer sometime during their lives compared with about 60 percent of women (600 out of 1,000) who have inherited a harmful mutation in *BRCA1* or *BRCA2*. In other words, a woman who has inherited a harmful mutation in *BRCA1* or *BRCA2* is about five times more likely to develop breast cancer than a woman who does not have such a mutation.

Scenario 4. According to estimates of lifetime risk, about 12 percent of women (120 out of 1,000) in the general population will develop breast cancer sometime during their lives compared with about 60 percent of women (600 out of 1,000) who have inherited a harmful mutation in *BRCA1* or *BRCA2*. In other words, a woman who has inherited a harmful mutation in *BRCA1* or *BRCA2* is about five times more likely to develop breast cancer than a woman who does not have such a mutation.



Scenario 5. According to estimates of lifetime risk, about 12 percent of women (120 out of 1,000) in the general population will develop breast cancer sometime during their lives compared with about 60 percent of women (600 out of 1,000) who have inherited a harmful mutation in *BRCA1* or *BRCA2*. In other words, a woman who has inherited a harmful mutation in *BRCA1* or *BRCA2* is about five times more likely to develop breast cancer than a woman who does not have such a mutation.

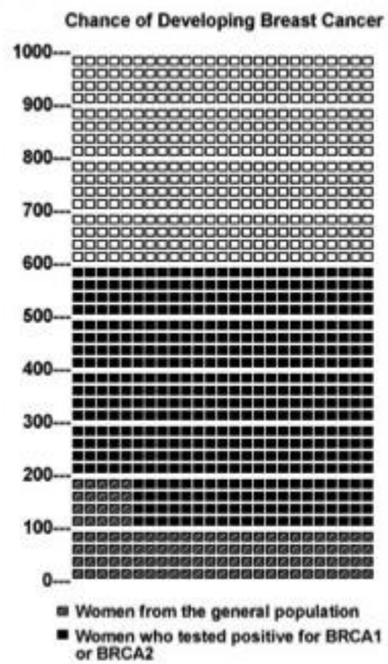


Table 1. Sample Characteristics (n=334)

Variable	Percent or Mean (SD)
Outcomes	
Number of correct answers (out of 5)	3.7 (1.7)
All answers correct	55.4%
Initial format preferences	
Percentage	54.8%
Frequency	18.0%
Bar graph	1.8%
Pictogram	0.3%
Comparison to other women	25.2%
Final format preferences	
Percentage	31.1%
Frequency	9.6%
Bar graph	41.6%
Pictogram	9.6%
Comparison to other women	8.1%
Updated preference	59.6%
Objective numeracy (out of 3)	2.0 (0.9)
Worry about BRCA testing (out of 5)	1.9 (0.8)
Ever tested for *BRCA*	24.9%
Education	
College graduate	68.8%
Some college	23.7%
High school or less	7.5%
Not married	19.5%
Nonwhite	4.5%
Age	50.4 (7.8)

Table 2. Numeracy and Risk Format Preferences (n=334)

	Objective Numeracy (0-3 scale)	p-value
Initial format preference[1]		$p<0.05$
Percentage	2.08	
Frequency	1.78	
Bar graph or pictogram	1.14[2]	
Compared to other women	2.00	
Updated preference[3]		$p=0.28$
No	2.05	
Yes	1.94	

[1]ANOVA F-test =3.6, [2] Significantly different from average numeracy of those preferring percentages ($p<0.01$) in post hoc analyses using a Bonferonni correction, [3]t-test=1.1.

Table 3. Adjusted associations between risk comprehension and initial presentation format preferences (n=334)

Variable	Number correct[1] (IRR)	All correct[2] (OR)
Initial format preferences		
Percentage	Referent	Referent
Frequency	1.04 (0.89, 1.21)	1.18 (0.61, 2.26)
Bar graph or pictogram	0.97 (0.63, 1.49)	0.58 (0.09, 3.75)
Comparison to other women	0.99 (0.87, 1.13)	1.05 (0.59, 1.86)
Objective numeracy	**1.16***** (1.09, 1.24)	**2.03***** (1.53, 2.68)
Worry about BRCA testing	0.95 (0.89, 1.02)	**0.68***** (0.50, 0.91)
Ever tested for *BRCA*	0.99 (0.87, 1.13)	0.91 (0.52, 1.57)
Education		
High school or less	**0.65***** (0.50, 0.85)	**0.37**** (0.15, 0.95)
Some college	**0.88*** (0.77, 1.02)	**0.55**** (0.31, 0.98)
College or more	Referent	Referent
Not married	**1.14*** (0.99, 1.30)	1.80 (0.97, 3.36)
Nonwhite	1.13 (0.87, 1.47)	0.91 (0.29, 2.87)
Age	1.00 (0.99, 1.00)	1.00 (0.97, 1.03)
Constant	**3.51***** (2.29, 5.38)	0.69 (0.11, 4.13)

[1]Poisson model, [2]Logistic regression *p<0.10, **p<0.05, ***p<0.01

Table 4. Adjusted associations between updating format preferences and comprehension (n=334)

Variable	Updated format preference[1] (OR)	
	Model 1	Model 2
Risk comprehension		
Number correct	**0.84**** (0.72, 0.98)	--
All correct	--	**0.60**** (0.36, 0.99)
Initial format preferences		
Percentage	Ref	Ref
Frequency	**2.20**** (1.15, 4.20)	**2.18**** (1.14, 4.18)
Bar graph or pictogram	0.28 (0.05, 1.55)	0.27 (0.05, 1.49)
Comparison to other women	**2.22***** (1.26, 3.91)	**2.24***** (1.27, 3.96)
Objective numeracy	0.95 (0.72, 1.24)	0.94 (0.71, 1.23)
Worry about BRCA testing	1.00 (0.76, 1.33)	0.99 (0.75, 1.32)
Ever tested for *BRCA*	1.13 (0.66, 1.95)	1.12 (0.66, 1.92)
Education		
High school or less	1.96 (0.67, 5.70)	2.16 (0.75, 6.21)
Some college	0.63 (0.36, 1.11)	0.64 (0.36, 1.12)
College or more	Ref	Ref
Not married	**0.61*** (0.34, 1.08)	**0.59*** (0.33, 1.06)
Nonwhite	1.31 (0.42, 4.01)	1.22 (0.40, 3.78)
Age	1.00 (0.98, 1.03)	1.01 (0.98, 1.04)
Constant	2.12 (0.34, 13.34)	1.40 (0.24, 8.15)

[1]Logistic regression. *p<0.10, **p<0.05, ***p<0.01

Table 5. Format-specific risk comprehension across samples

	Percent of all participants answering correctly by format (n=334)	*Percent of participants answering correctly within their preferred format: percent, frequency, bar graph, pictogram, or comparison to other women (n)*	
		Question Matched Initial Format Preference[1]	*Question Matched Informed Format Preference*[1]
Risk format presented[1]			
Percent	73%	76% (183)	80% (104)
Frequency	77%	78% (60)	84% (32)
Bar graph, percent, frequency[2]	74%	50% (6)	**65%** (139)**
Pictogram, percent, frequency[3]	74%	0% (1)	63% (32)
Percentage or frequency[4]	83%	84% (253)	88% (136)
Bar graph or pictogram (w/percent & frequency)[4]	81%	57% (7)	**74%** (171)*

Notes: [1]Participants received information as a comparison to other women in tandem with other formats. [2]Bar graph treated as the preferred format. [3]Pictogram was treated as the preferred format. [4]Participants were scored as having a correct response if they responded correctly in either of the formats combined in these rows (e.g., correct in the percent or in the frequency format). Two-sample tests of proportions were used to determine differences in the probability of answering correctly across samples. *Significantly different from sample average at $p<0.10$. **Significantly different from sample average at $p<0.05$.

Table 6. Format-specific risk comprehension within individuals

	Percent answering correctly in each format[1]						
	Percentage	Frequency	Bar graph, percent, frequency	Pictogram, percent, frequency	Percentage or Frequency	Bar graph or Pictogram (w/percent & frequency)	p-value[2]
Initial format preference							
Percentage (n=183)	76%	79%	76%	74%	--	--	0.33
Frequency (n=60)	72%	78%	70%	75%	--	--	0.47
Bar graph (n=6)	83%	83%	50%	50%	--	--	0.31
Pictogram (n=1)	100%	0%	0%	0%	--	--	--[3]
Percentage or Frequency (n=243)	--	--	--	--	84%	80%	**0.05**
Bar graph or Pictogram (n=7)	--	--	--	--	57%	86%	0.43
Informed format preference							
Percentage (n=104)	80%	81%	82%	82%	--	--	0.95
Frequency (n=32)	78%	84%	84%	81%	--	--	0.83
Bar graph (n=139)	68%	75%	65%	69%	--	--	**0.06**
Pictogram (n=32)	69%	66%	66%	63%	--	--	0.96
Percentage or Frequency (n=136)	--	--	--	--	88%	88%	1.00
Bar graph or Pictogram (n=171)	--	--	--	--	80%	74%	0.24

[1]Participants received information as a comparison to other women in tandem with other formats.[2]p-value multivariate test of means. [3]There were an insufficient number of participants initially preferring pictograms to test for a difference in the likelihood of answering correctly.