

NIH Public Access

Author Manuscript

Patient Educ Couns. Author manuscript; available in PMC 2014 October 24.

Published in final edited form as:

Patient Educ Couns. 2013 August ; 92(2): 253–259. doi:10.1016/j.pec.2013.03.016.

Belief In Numbers: When and why women disbelieve tailored breast cancer risk statistics

Laura D. Scherer^{1,2}, Peter A. Ubel³, Jennifer McClure⁴, Sarah M. Green⁴, Sharon Hensley Alford⁵, Lisa Holtzman², Nicole Exe², and Angela Fagerlin^{1,2,6}

¹VA Ann Arbor Center for Clinical Management Research, Ann Arbor, MI, USA

²Center for Bioethics and Social Sciences in Medicine, University of Michigan, Ann Arbor, MI, USA

³Fuqua School of Business, Duke University, Durham, NC, USA

⁴Group Health Research Institute, Seattle, WA, USA

⁵Henry Ford Health System, Detroit, MI, USA

⁶Departments of Internal Medicine and Psychology, University of Michigan, Ann Arbor, MI, USA

Abstract

Objective—To examine when and why women disbelieve tailored information about their risk of developing breast cancer.

Methods—690 women participated in an online program to learn about medications that can reduce the risk of breast cancer. The program presented tailored information about each woman's personal breast cancer risk. Half of women were told how their risk numbers were calculated, whereas the rest were not. Later, they were asked whether they believed that the program was personalized, and whether they believed their risk numbers. If a woman did not believe her risk numbers, she was asked to explain why.

Results—Beliefs that the program was personalized were enhanced by explaining the risk calculation methods in more detail. Nonetheless, nearly 20% of women did not believe their personalized risk numbers. The most common reason for rejecting the risk estimate was a belief that it did not fully account for personal and family history.

Conclusions—The benefits of tailored risk statistics may be attenuated by a tendency for people to be skeptical that these risk estimates apply to them personally.

Practice Implications—Decision aids may provide risk information that is not accepted by patients, but addressing the patients' personal circumstances may lead to greater acceptance.

^{© 2013} Elsevier Ireland Ltd. All rights reserved.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

1. Introduction

One of the greatest challenges faced by health communication experts is communicating risks and benefits to patients in an accurate and effective way.¹ For example, communicating the risk of developing cancer, or having a heart attack, requires translating relatively complex numerical information into a format that can be understood by those with both high and low numeracy and literacy skills.^{2–5} Making matters even more complex is the fact that the risks and benefits are often not the same across people. Thus, effective health communication often involves using tailored risk statistics that reflect a particular person's personal health history, lifestyle, family history etc.

Tailoring is a health communication technique that uses "any combination of strategies and information intended to reach one specific person, based on characteristics that are unique to that person, related to the outcome of interest, and derived from an individual assessment".⁶ Tailoring can refer to any number of strategies that are meant to make information more appealing or relevant to a particular person. Indeed, there is evidence that tailored health communication can lead to more active, informed decision making than untailored information.⁷

However, tailoring is not limited to enhancing the personal appeal of a message frame. More pertinent to the present article, tailoring may also mean that a person is provided with risk statistics that are the best estimate for that person as an individual. For example, a woman's personal and family health history (e.g. age at first menses, family history of breast cancer) can be used to calculate an estimate of her personal absolute risk of developing breast cancer in the next five years.⁸ This personalized risk information should presumably help a woman make informed decisions related to that risk, such as whether to take a chemoprevention drug (i.e. tamoxifen or raloxifene) that can reduce her risk of developing a primary breast cancer. Currently, the most common way that a person might encounter personalized risk information is with a "risk calculator". Risk calculators are now available to assess an individual's risk of diseases such as heart disease, diabetes and periodontal disease.^{9–11} Many risk calculators are used by physicians, but a wide array of them are available online and can be used by anyone.¹²

Although risk calculators can provide potentially beneficial tailored information to individuals, this does not mean that people will always passively accept their risk numbers. In fact, recent evidence suggests that people often outright reject their personal risk numbers. In the context of colon cancer, one study found that of the participants who correctly remembered their personalized risk of getting colon cancer, only half actually accepted it as valid.¹³ However, this study remained ambiguous as to *why* these participants thought their risk numbers were wrong. Other studies have provided additional suggestive evidence that people often disbelieve tailored risk numbers. For example, one study of an online diabetes risk calculator showed that higher diabetes risk was associated with a greater number of risk recalculations.¹⁴ One possible interpretation of this effect is that high-risk participants were looking for a better number, or were trying to determine whether the factors that led to their risk estimate felt legitimate. In another study, many participants reported the same perceived diabetes risk before and after receiving their personalized risk

estimate, even when the risk calculator provided an estimate that was different from their own estimate.¹⁵ Although it is possible that these participants simply thought that the tailored numbers and their own estimates were "close enough", it is also possible that they rejected the tailored numbers in favor of their own perceptions. Together, these studies suggest that risk communication could be impeded not only because people often fail to understand risk information, but also because they fail to accept that information as valid.

In the present research, we attempted to address the question of why people reject tailored risk information in the context of a chemoprevention decision aid (DA). Tamoxifen and raloxifene are chemoprevention drugs that have been shown to reduce the relative risk of a primary breast cancer by 50% for women who are at above average risk.¹⁶ Our purpose was to determine both when and why women chose to disbelieve the personalized breast cancer risk numbers that were provided by the DA. In particular, the aims of the present study were threefold: (a) to determine the proportion of women who rejected their tailored risk information, (b) to examine whether providing specific information about tailoring methods influenced those beliefs, and (c) to document the reasons why women rejected their risk estimates.

It is worth mentioning at the outset that there are many reasons why women might disbelieve their personalized risk numbers. First, people are often skeptical of information that is inconsistent with their prior beliefs (i.e. a "motivated skepticism" account).^{17, 18} Thus, if the personalized risk number is higher or lower than expected, people may be motivated to question it, and thus debelive it.¹⁸ Second, research has shown that people are more likely to disbelieve health information that is personally relevant and threatening.¹⁹ For example, women who find their risk numbers to be threatening (e.g. because the numbers are unexpectedly high) might disbelieve their numbers as a result of a defensive coping strategy.¹⁹ Third, women might reject unexpectedly high risk numbers because they are unrealistically optimistic about their health prospects.^{20, 21} Such individuals might believe that although the risk estimate is accurate for most people, they are an "exception to the rule".²² Fourth, participants might believe the risk estimate is inaccurate because it does not take account of relevant information. For example, a woman might believe that her estimated risk of breast cancer does not adequately account for her extended personal or family health history. Fifth, it is possible that people are skeptical of tailored risk estimates when the methods used to arrive at the number are not sufficiently transparent, or the source of the number is not trustworthy. That is, if people do not know how the number is being generated, or don't trust the source by which that number is communicated, then they may be more prone to disbelieve it, especially if the number is inconsistent with their expectations.

2. Method

In the present report we analyzed responses from a large intervention study, the greater purpose of which was to test different risk communication techniques and their influence on the effectiveness of an online DA for breast cancer chemoprevention.²³ One component of this larger study was to experimentally test how the method of communicating tailored risk would impact women's perceptions of their personalized risk estimates.

2.1 Population

There were 1012 women recruited from The Henry Ford Health System in Detroit and Group Health in Seattle to participate in this study. These women were selected for participation because their medical records indicated that they might be at above average risk of developing breast cancer. Women were deemed eligible if an initial screening indicated that they were at or above average risk as estimated by the Breast Cancer Risk Assessment Tool (BCRAT; score range = 1.77-19.1, Mean = 2.69). Because our primary outcome measures involved perceptions of absolute risk information, for the present analyses we included only the 690 who received that risk information (i.e. we excluded women who were in the control groups). Women's ages ranged from 46 to 74 (Mean = 61.77), and 97.6% were White (see Fagerlin et al., 2011 for a more detailed description of the sample and methods).²³

2.2 Procedure

Potentially eligible women were contacted by letter and were provided with a link, username, and password to the study website. After screening eligible and enrolling in the study, they viewed the DA and completed all measures online, and were allowed to complete the study wherever they could access the Internet.

As part of the initial eligibility screen, women completed the BCRAT which calculates each woman's absolute risk of developing breast cancer within five years. The BCRAT score was calculated using the following factors: age, ethnicity, personal history of breast cancer, age at first menses, age at first live birth, number of first-degree relatives who have had breast cancer, and history of breast biopsies.

After completing the BCRAT questions and other baseline measures, women viewed a decision aid about breast cancer and chemoprevention. Within that DA, women were presented with tailored estimates of their absolute risk of breast cancer (i.e. their BCRAT score), as well as how much that risk would be reduced if they chose to take either tamoxifen or raloxifene. The latter risk estimate was derived using their 5-year risk, and adding the amount of risk reduction they would expect based on tamoxifen and raloxifene randomized controlled trials. Both of these tailored risk numbers (risk with and without taking the drugs) were presented several times throughout the DA.

2.3 Intervention

Women were randomly assigned to receive their personalized risk estimate in one of two different ways: Approximately half of the participants were given a detailed explanation of the factors that were used to calculate their tailored risk numbers. In particular, they were told exactly which of their personal characteristics were used to determine their risk number (see Table 1). In this condition, the personalization of the program was further reinforced by the use of pronouns and trait characteristics (e.g. "Among women who, like you, are 70 years old and White..."). The other half of participants were assigned to the "standard tailoring" condition. In this condition, participants were given no information about how their risk number was generated, and the risk calculation was reportedly based on simply "women like you". We hypothesized that women who received the more detailed

explanation would be more likely to feel that the DA was personalized, and would be more likely to believe their risk numbers.

2.4 Outcome Measures

After reading the DA, women answered a number of questions. These included four questions assessing their belief that the program was personalized (*I felt that the risk/benefit numbers I received were "my numbers"; I found the decision guide to be written personally for me; I felt that the information in this decision guide was relevant to me; I felt that the information guide was designed specifically for me)*. These questions were answered on a 1 (completely disagree) to 7 (completely agree) scale. The items were highly intercorrelated with a reliability alpha of .89, and so a composite measure was created by averaging participants' responses to the four questions.

Women were also asked to recall their risk of getting breast cancer in the next 5 years, both with and without taking tamoxifen or raloxifene. Answers were coded as correct if women reported that their risks with and without chemoprevention were within +/-.21 points of their BCRAT risk numbers. This cutoff was predetermined and was based on a previous study of tamoxifen decisions.²⁴ If either or both risk numbers (i.e. with and without chemoprevention) were incorrect, women were asked why the numbers they reported were different. Women were asked to respond categorically by indicating whether they (a) forgot, (b) made a rounding error, or (c) disagreed with the number. If a woman indicated that she disagreed with the numbers, she was then asked to explain why she disagreed. These openended answers allowed us to examine why women believed that their risk numbers were invalid.

Most demographic measures were assessed as a part of the BCRAT questions (e.g. race, age). In addition, we assessed numeracy using the subjective numeracy scale.²⁵

2.5 Analysis Strategy

First, ANOVA was used to determine whether the randomized intervention influenced women's responses to questions concerning their belief that the program was personalized. Second, a chi-squared analysis was used to determine whether the intervention made women less likely to disbelieve their risk numbers. Third, ANOVA was used to explore factors (e.g. BCRAT score, age, numeracy) that might predict why women disbelieved their risk numbers. Finally, women's explanations of why they rejected their risk numbers were coded for content. One author (LH), in collaboration with the first author (LDS), created categories into which the majority of answers fell. This author (LH) and a second author (NE) used these resultant categories to independently code participant responses. Resultant inter-rater reliability was very good (kappa = .88), and disagreements were resolved by consensus between the coders. The resultant response categories allowed us to identify which types of explanations were most commonly used for rejecting one's risk numbers.

3. Results

3.1 Influence of intervention on beliefs that the program was personalized

Half of the women received a detailed explanation of how their risk numbers were calculated, whereas the other women were given no specific information. Table 2 shows that women who received the detailed explanation were more likely to feel that the program was personalized, and this effect was significant when analyzing the composite measure of all four responses, p=.05. Table 2 also reveals that this effect was driven primarily by two of the four questions (*I found the decision guide to be written personally for me; I felt that the information in this decision guide was designed specifically for me*).

3.2 Belief in risk numbers

Women were also asked to report their risk numbers, both with and without chemoprevention. Four percent of the participants misreported only their risk without the drugs, and 20% misreported only their risk after taking the drugs. An additional 48% of participants misreported both of these questions. We tested whether the tailoring intervention, BCRAT score, age, education, and numeracy were related to whether participants misreported their risk either one or both risk numbers). Accuracy was not influenced by the experimental intervention (p>.80), nor was it related to age (p>.05). However, women who misreported their numbers had higher BCRAT scores (M=2.76) than those who answered correctly (M=2.40), F(1,688)=13.32, p<.001. Women who misreported their scores also had lower numeracy (M=1.47 vs. 1.64; F(1,688)=16.92, p<.001) and less education (M=6.46 vs 7.17, F(1,688)=28.02, p<.001) than those who answered correctly.

Women who misreported their risk were then asked why they gave the wrong answer. Table 3 reveals that 27% of the sample reported that they forgot the numbers, 24% reported a rounding error, and 22% disagreed with one or both of the numbers. The most common reason for misreporting both of the risk numbers was a disagreement with the numbers (19% of the sample, N = 131).

We further examined five potential factors that could be related to a tendency to disbelieve the risk numbers: the tailoring intervention, BCRAT score, age, education and subjective numeracy. Women who received the detailed tailoring intervention had the same rates of disagreement with their numbers, forgetting their numbers, and rounding, as women who received the standard explanation (p = .20). BCRAT scores, age, and education level were also not related to participants' reason for misreporting their numbers (all p>.16). However, women who forgot their numbers had lower numeracy (M=4.08) than women who reported a rounding error or who disagreed with their numbers (M = 4.58 and 4.44, respectively; F(1,332) = 5.93, p < .01). This latter finding is important because it refutes the possibility that women who are low in numeracy are more likely to disbelieve their number than women who are high in numeracy.

3.3 Reasons for disagreement with tailored risk

Next, we examined the qualitative answers provided by the 131 participants who disagreed with both risk numbers. We did not explore the responses of women who disagreed with

only one of their numbers, because (a) those women represented only 3% of the total sample, and (b) we were particularly interested in participants who seemed to categorically disagree with all of the tailored risk information. Restrictions imposed by coders meant that a given response could be assigned up to two (but no more than two) categories. A number of the categories also contained subcategories that were used to further clarify the nature of the response. Results from this analysis are displayed in Table 4.

Most strikingly, over a third (37%) of the women who disagreed with their numbers indicated that their family history made them either more or less likely to develop breast cancer than their tailored risk numbers suggested. The majority of these women (N=28) believed that their risk should be higher, writing reasons such as "*I have aunts that have had cancer, my dad died of cancer.*" There were also women who believed that their *lack* of family history should make their risk smaller (N = 12). For example one woman wrote that her risk numbers were wrong "because there is no cancer in my family."

The second most common reason for reporting disagreement with the tailored risk information was that the risk number seemed too high or too low (N = 33; e.g. "*It just seemed low*", "*2.1% risk sounds too good to be true*", "*The percentage was low compared to my concern*"). This may be due to the fact that the BCRAT score indicates a woman's 5-year risk of breast cancer, which is low compared to the potentially more familiar statistic that cites "1 in 8" lifetime risk. Yet of the women who said that their number was too high or too low, 11 seemed to believe that their chance of getting breast cancer was at or close to either 0% or 100% (e.g. "*I do not think I will get breast cancer in my lifetime*", "*It seems that every woman is destined to get breast cancer at some point*"). Furthermore, about half (N = 17) of women in this category stated additional reasons for feeling that the number was too high or low, and this reason was captured by a secondary category. Of these 17 women, seven cited family history, three cited being an exception to the rule, and the rest were spread evenly between the other categories.

Health habits and lifestyle were also a common reason for disbelieving the risk numbers (e.g. "*I am in excellent health and I live an active healthy lifestyle. I do not believe that I will have breast cancer*" or "*I am overweight and do not eat the best*"). The majority of responses suggested that the women's health habits reduced their risk rather than increased it. A related category of responses was personal health history, which was cited by 15% of women. These women indicated that a preexisting or past health condition would make breast cancer more likely. For example, one woman had recently been diagnosed with endometrial cancer, and believed that this fact increased her risk of breast cancer. Another woman said "*I have many cysts…seems like good places for cancer to grow.*"

It is notable that across all 131 women who disbelieved their numbers, the vast majority (N = 112, or 85%) disagreed with their risk numbers because they thought that the calculation failed to account for relevant personal information, including family history (N=49), medical history (N=20), lifestyle (N=27), hormone replacement therapy (N=7), or unspecified (N=9). Furthermore, we did not find strong evidence that people think they are an exception to the rule, as only seven participants stated this view explicitly. One person wrote "*The risk numbers are for the average person. I may be different from the average person.*" Another

said "*Not everything goes by percentages!*" Moreover, no one stated that their disagreement stemmed from having too little information about where their number came from. Instead, these participants generally indicated that they disagreed with their risk numbers out of a belief that those numbers do not fully account for their personal circumstances.

Finally, included in Table 4 are the numbers of participants in the detailed versus standard tailoring conditions, by the type of reason provided. Although there were not enough participants to determine whether this randomized factor made a significant difference in women's reasoning, we included these data to provide a full report of the present results.

4. Discussion and Conclusion

4.1 Discussion

In the context of a breast cancer chemoprevention DA, approximately 20% of women did not believe that their tailored risk number was accurate. Although a more detailed explanation of the tailoring method increased beliefs that the program was personalized, this did not translate into an increased belief in the risk numbers themselves. In total, 19% of the sample explicitly indicated that they disbelieved both of their risk numbers, and the most common reason was a belief that the number did not adequately account for family history (despite the fact that the calculation did, in fact, account for the aspects of family history that are known to be relevant for breast cancer risk). More generally, most women rejected their risk numbers because they felt that the numbers did not adequately account for their personal background and circumstances.

Earlier, we proposed that women might reject their risk number as the result of a defensive coping strategy or unrealistic optimism.¹⁹²⁰ However, women with high BCRAT scores were not more likely to disbelieve there risk numbers than women at lower risk (although they were more likely to misreport their risk). Moreover, the majority of disbelievers thought their risk estimate was too low. This is inconsistent with the notion that rejecting health information serves to alleviate feelings of anxiety and threat. If anything, these women seemed to believe that their numbers should be *more* concerning and threatening. The minority of disbelievers indicated that their risk should have been lower, and defensive coping and unrealistic optimism could indeed explain this subset of responses.

A motivated skepticism provides a useful framework for understanding the present results. Considerable research has shown that the source of our feelings are often not identifiable, and as a result, the reasons that we provide for our feelings often appear logical, but are not correct.²⁶ For example, some women might have felt that their BCRAT risk estimate was too low, because this 5-year risk estimate is small compared to the potentially more familiar lifetime risk. When people have a preexisting belief or feeling about how high or low their risk ought to be, they may be motivated to reject their numbers if the numbers do not match that belief. The reason for rejection could be created post hoc, and include any number of reasonable-sounding explanations, such as family history, lifestyle, personal health, etc. However, as compelling of an explanation as this might be, one limitation of the present study is that we cannot know whether the participations' explanations represent post hoc

reasoning, or if we should instead take these reasons at face value. This is certainly an issue worthy of future research.

Another factor worth consideration is that at least one factor that women cited actually *is* related to greater breast cancer risk, but was not accounted for by the BCRAT. Specifically, in recent years there has been good evidence that hormone replacement therapy (HRT) increases the risk of breast cancer, and the BCRAT score does not include this as a risk factor.²⁷ Women who took HRT may have disbelieved their BCRAT number, regardless of what that number was and whether it conformed to their expectations, simply because they knew that their risk number did not account for this relevant factor.

Finally, the present data refuted some of the possible reasons that we proposed for why people might reject their numbers. For example, these data demonstrated that most women did not explicitly think of themselves as an exception to the statistical rule. Instead, they seemed to think that the numbers *might* apply to them if the numbers accounted for all of the relevant predictors. Women also did not explicitly articulate a desire for more information about how the number was calculated, and more information about the calculation did not affect their willingness to believe.

4.2 Limitations

The present study has several limitations that are worth mention. First, the sample was homogenous in terms of ethnicity, and it is possible that the rates of disagreement and reasons provided for disagreement were particular to this specific group. We also note that the sample was primarily composed of White women. This homogeneity is a weakness of the study, but it does add to the strength of our findings, because the BCRAT is more accurate for White women than of women of other races.²⁸ Therefore, it is likely that women of other races might be even more likely to disagree with the numbers (given that we told them of the limitations of the BCRAT for non-White women).

A second limitation is that in other health contexts, disagreement with tailored risk information might occur at different rates, and for different reasons. The present study suggests that if people think that the calculation method accounts for all predictors that are perceived as relevant, then they will be more likely to believe their numbers. We anticipate, however, that when risk numbers defy expectations, people will persist in their disbelief and simply come up with other reasons (besides faulty calculations) for that disbelief.

Finally, in this study we were not able to determine whether each participants' reasons for disbelief were valid or not. Disagreement with the numbers does not necessarily mean the women were wrong in their assessment. For some women, it may mean they actually had a better understanding of the limits of the BCRAT model. There are a handful of cases in the current study in which disbelief was well founded, including women who took hormone replacement therapy, which is known to increase the risk of breast cancer, and which is not accounted for by the BCRAT model. It is also possible that women who cited personal health factors (e.g. diet, exercise) may have had some merit behind their reasoning, because obesity can indeed raise the risk of breast cancer and the BCRAT model does not account for this factor either.^{29, 30}

4.3 Conclusion

Tailored risk and benefit statistics are likely to become more prevalent in patient decision tools and patient care. Hence, it is critical that we know (a) whether people actually believe these numbers, and (b) if not, why not. Previous research on risk calculators suggests that people do not always believe their personalized risks. The present study adds to this literature by demonstrating that a sizeable proportion of women rejected their breast cancer risk numbers, and by further elucidating why; namely, they did not think that the numbers accounted for personal information that was perceived to be relevant. Importantly, the majority of women believed that their risk should be higher, rather than lower, indicating that disbelief was not always the result of defensive coping strategies or unrealistic optimism. Although a motivated skepticism approach provides an adequate framework for understanding the present findings, this study could not determine whether women's reasoning was primarily the result of (a) post hoc rationalization of a feeling that the number was incorrect, or (b) specific and genuine concerns about the way that the risk was calculated. Hence, although this study shed light on the reasons that women provide for disbelieving their breast cancer risk, it also highlights numerous avenues for future research. We hope that the present study will guide future health interventions so that they can more effectively communicate tailored risks to patients.

4.3 Practice Implications

The present research has at least four important practice implications. First, health providers might be made aware that the risk information that they communicate to patients is not always taken at face value. Second, people may have preexisting beliefs about their risk (e.g. they might have familiarity with the typical lifetime risk statistic and less familiarity with their 5-year risk) and in these cases steps should be taken to explain, when possible, why their preexisting beliefs are different from the present estimate. Third, interventions that aim to increase belief in risk estimates should not assume that anxiety-fueled defensive mechanisms are the only potential reason for disbelief. Finally, it may be useful to explain to patients (a) how a given risk estimate accounts for a person's personal attributes, and (b) why other factors (like father's cancer history, or personal fitness) are not taken into account when calculating risk. By doing so, it may be possible to address an individual's concern that the number does not fully account for their personal circumstances.

References

- O'Connor AM, Légaré F, Stacey D. Risk communication in practice: the contribution of decision aids. Bmj. 2003; 327(7417):736. [PubMed: 14512487]
- Fagerlin A, Ubel PA, Smith DM, Zikmund-Fisher BJ. Making numbers matter: present and future research in risk communication. American Journal of Health Behavior. 2007; 31(Supplement 1):S47–S56. [PubMed: 17931136]
- 3. Edwards A, Elwyn G, Covey J, Matthews E, Pill R. Presenting risk information a review of the effects of framing and other manipulations on patient outcomes. Journal of health communication. 2001; 6(1):61–82. [PubMed: 11317424]
- Fagerlin A, Ubel PA, Smith DM, Zikmund-Fisher BJ. Making numbers matter: present and future research in risk communication. American Journal of Health Behavior. 2007; 31(Supplement 1):S47–S56. [PubMed: 17931136]

- 5. Zikmund-Fisher BJ, Fagerlin A, Roberts TR, Derry HA, Ubel PA. Alternate methods of framing information about medication side effects: Incremental risk versus total risk of occurrence. Journal of health communication. 2008; 13(2):107–124. [PubMed: 18300064]
- Kreuter MW, Skinner CS. Tailoring: what's in a name? Health education research. 2000; 15(1):1. [PubMed: 10788196]
- Noar SM, Benac CN, Harris MS. Does tailoring matter? Meta-analytic review of tailored print health behavior change interventions. Psychological bulletin. 2007; 133(4):673. [PubMed: 17592961]
- Gail MH, Mai PL. Comparing breast cancer risk assessment models. Journal of the National Cancer Institute. 2010; 102(10):665–668. [PubMed: 20427429]
- Heikes KE, Eddy DM, Arondekar B, Schlessinger L. Diabetes risk calculator. Diabetes Care. 2008; 31(5):1040. [PubMed: 18070993]
- Page RC, KRALL EA, MARTIN J, MANCL L, GARCIA RI. Validity and accuracy of a risk calculator in predicting periodontal disease. The Journal of the American Dental Association. 2002; 133(5):569–576. [PubMed: 12036161]
- Parekh DJ, Pauler Ankerst D, Higgins BA, et al. External validation of the Prostate Cancer Prevention Trial risk calculator in a screened population. Urology. 2006; 68(6):1152–1155. [PubMed: 17169636]
- Waters EA, Sullivan HW, Nelson W, Hesse BW. What is my cancer risk? how internet-based cancer risk assessment tools communicate individualized risk estimates to the public: content analysis. Journal of medical Internet research. 2009; 11(3)
- Weinstein ND, Atwood K, Puleo E, Fletcher R, Colditz G, KAREN ME. Colon cancer: risk perceptions and risk communication. Journal of health Communication. 2004; 9(1):53–65. [PubMed: 14761833]
- 14. Holmberg C, Harttig U, Schulze MB, Boeing H. The potential of the Internet for health communication: the use of an interactive on-line tool for diabetes risk prediction. Patient Education and Counseling. 2010
- Harle CA, Downs JS, Padman R. Effectiveness of Personalized and Interactive Health Risk Calculators: A Randomized Trial. Medical Decision Making. 2012
- Vogel VG, Costantino JP, Wickerham DL, et al. Effects of tamoxifen vs raloxifene on the risk of developing invasive breast cancer and other disease outcomes. JAMA: the journal of the American Medical Association. 2006; 295(23):2727.
- 17. Ditto PH, Lopez DF. Motivated skepticism: Use of differential decision criteria for preferred and nonpreferred conclusions. Journal of Personality and Social Psychology. 1992; 63(4):568.
- Ditto PH, Scepansky JA, Munro GD, Apanovitch AM, Lockhart LK. Motivated sensitivity to preference-inconsistent information. Journal of Personality and Social Psychology. 1998; 75(1):53.
- Liberman A, Chaiken S. Defensive Processing of Personally Relevant Health Messages. Pers Soc Psychol Bull. 1992; 18(6):669–679.
- Helweg-Larsen M, Shepperd JA. Do moderators of the optimistic bias affect personal or target risk estimates? A review of the literature. Personality and Social Psychology Review. 2001; 5(1):74– 95.
- 21. Klein CTF, Helweg-Larsen M. Perceived control and the optimistic bias: A meta-analytic review. Psychology and Health. 2002; 17(4):437–446.
- 22. Weinstein ND, Klein WM. Unrealistic optimism: Present and future. Journal of Social and Clinical Psychology. 1996; 15(1):1–8.
- Fagerlin A, Dillard AJ, Smith DM, et al. Women's interest in taking tamoxifen and raloxifene for breast cancer prevention: response to a tailored decision aid. Breast cancer research and treatment. 2011:1–8.
- Fagerlin A, Zikmund-Fisher BJ, Smith DM, et al. Women's decisions regarding tamoxifen for breast cancer prevention: responses to a tailored decision aid. Breast cancer research and treatment. 2010; 119(3):613–620. [PubMed: 19908143]
- Zikmund-Fisher BJ, Smith DM, Ubel PA, Fagerlin A. Validation of the Subjective Numeracy Scale: effects of low numeracy on comprehension of risk communications and utility elicitations. Medical Decision Making. 2007; 27(5):663–671. [PubMed: 17652180]

- 26. Nisbett RE, Wilson TD. Telling more than we can know: Verbal reports on mental processes. Psychological Review. Psychological Review. 1977; 84(3):231.
- 27. Chlebowski RT, Hendrix SL, Langer RD, et al. Influence of estrogen plus progestin on breast cancer and mammography in healthy postmenopausal women. JAMA: the journal of the American Medical Association. 2003; 289(24):3243.
- Gail MH, Costantino JP, Pee D, et al. Projecting individualized absolute invasive breast cancer risk in African American women. Journal of the National Cancer Institute. 2007; 99(23):1782–1792. [PubMed: 18042936]
- 29. Huang Z, Hankinson SE, Colditz GA, et al. Dual effects of weight and weight gain on breast cancer risk. JAMA: the journal of the American Medical Association. 1997; 278(17):1407–1411.
- Morimoto LM, White E, Chen Z, et al. Obesity, body size, and risk of postmenopausal breast cancer: the Women's Health Initiative (United States). Cancer Causes and Control. 2002; 13(8): 741–751. [PubMed: 12420953]
- 31. Euhus DM, Leitch AM, Huth JF, Peters GN. Limitations of the Gail model in the specialized breast cancer risk assessment clinic. The breast journal. 2002; 8(1):23–27. [PubMed: 11856157]

Table 1

Standard versus detailed tailoring conditions.

Standard tailoring explanation:

BREAST CANCER: Our best estimate of your 5-year risk

We used the information you gave us at the beginning of this program to estimate the risk of breast cancer for people like you in the next 5 years.

Our estimate of this risk is: 10.3%. Among women like you, 10.3% would be diagnosed with breast cancer in the next five years.

This means that if there were a room of 100 women like you, 10.3 would get breast cancer in the next 5 years.

Detailed tailoring explanation:

BREAST CANCER: Our best estimate of your 5-year risk

You told us that you have the following characteristics:

- You are White
- You are 70
- Started your period before age 12
- Have had no live births
- Have 2 relatives with breast cancer
- Have had 1 biopsy

Based on these traits, our estimate of your personal risk of developing breast cancer in the next 5 years is: 10.3%. Among women who, like you, are 70 years old and White, 10.3% would be diagnosed with breast cancer in the next 5 years. This means that if there were a room of 100 seventy year old White women who were just like you in all the traits listed above, 10.3 would get breast cancer in the next 5 years.

Table 2

Perceptions of DA personalization

	Tai	Tailoring			
	Detailed M(SD)	Detailed M(SD) Standard M(SD) Difference F statistic	Difference	F statistic	p value
Written for me	4.50 (1.61)	4.25 (1.60)	0.25	4.04	.04*
Designed for me	4.36 (1.65)	4.10 (1.70)	0.26	4.41	.04*
My numbers	5.36 (1.59)	5.23 (1.67)	0.13	1.13	.29
Relevant to me	5.23 (1.53)	5.05 (1.50)	0.18	2.53	H.
Average of 4 questions	4.85 (1.39)	4.64 (1.41)	0.21	3.80	.05 *

Table 3

Participants who reported incorrect risk numbers by reason for error.

	Disagree with number	Forgot the number	Rounding error	Total
Misreported risk without drugs	1%	1%	2%	4%
Misreported risk with drugs	2%	11%	8%	21%
Misreported both risk numbers	19%	15%	14%	48%
Total	22%	27%	24%	

Table 4

Reasons generated by participants who disagreed with risk numbers

Reason	Count	Detailed v. standard Subcategory tailoring condition	Subcategories(if applicable)	Subcategor Count
Medical history: Family	49 (37.4%)	Detailed = 23	Family history of BC	20
		Standard = 26	Family history of any cancer	8
			Family has no history of BC	12
			BC runs in family but this does	
			not increase personal risk	6
			No other specific information	3
Number seems too high/low	33 (25.2%)	Detailed = 17	Believe risk number is too high	5
		Standard = 16	Believe risk number is too low	17
			Believe will never get BC	8
			Believe will definitely get BC	3
Lifestyle and health habits		Detailed = 9	Health habits reduce risk	16
(e.g. diet, exercise)	27 (20.6%)	Standard = 18	Health habits increase risk	5
			No other information	6
Medical history: Self	20 (15.3%)	Detailed = 10	Diagnosed with any cancer	2
		Standard = 10	Diagnosed with other health condition	10
			No other specific information	8
Believes other factors				
involved in risk, but no		Detailed = 5		
specific factors listed	9 (6.9%)	Standard = 4		
Explicitly stated that				
they are an exception	7 (5.3%)	Detailed = 2		
to the rule		Standard = 5		
Took or currently taking				
hormone replacement				
therapy (e.g. estrogen	7 (5.3%)	Detailed = 1		
or progesterone)		Standard = 6		
Do not want to take	7 (5.3%)	Detailed = 4		
Medication		Standard = 3		
Indicated prior knowledge	6 (4.6%)	Detailed = 3	Knowledge of BC because	
of risk		Standard = 3	friend had cancer	2
			Seen risk numbers previously	1
			No other specific information	3
Gave an inaccurate answer				
to one or more questions		Detailed = 4		
in the risk calculator	6 (4.6%)	Standard = 2		
Does not want to dwell				
or does not want to worry				
oneself with the possibility	6 (4.6%)	Detailed = 2		
of getting sick.		Standard = 4		

Reason	Count	Detailed v. standard Subcategory tailoring condition	Subcategories(if applicable)	Subcategory Count
Have a gut feeling	3 (2.3%)	Detailed = 2		
		Standard = 1		
Other / no answer	8 (6.1%)	Detailed = 3		
		Standard = 5		