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# Understanding the Harms and Benefits of Cancer Screening: A Model of Factors That Shape Informed Decision Making

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**Objective.** Decisions about cancer screenings often involve the consideration of complex and counterintuitive evidence. We investigated psychological factors that promote the comprehension of benefits and harms associated with common cancer screenings and their influence on shared decision making. **Methods.** In experiment 1, 256 men received information about PSA-based prostate cancer screening. In experiment 2, 355 women received information about mammography-based breast cancer screening. In both studies, information about potential screening outcomes was provided in 1 of 3 formats: text, a fact box, or a visual aid (e.g., mortality with and without screening and rate of overdiagnosis). We modeled the interplay of comprehension, perceived risks and benefits, intention to participate in screening, and desire for shared decision making. **Results.** Generally, visual aids were the most effective format, increasing comprehension by up to 18%. Improved

comprehension was associated with 1) superior decision making (e.g., fewer intentions to participate in screening when it offered no benefit) and 2) more desire to share in decision making. However, comprehension of the evidence had a limited effect on experienced emotions, risk perceptions, and decision making among those participants who felt that the consequences of cancer were extremely severe. **Conclusions.** Even when information is counterintuitive and requires the integration of complex harms and benefits, user-friendly risk communications can facilitate comprehension, improve high-stakes decisions, and promote shared decision making. However, previous beliefs about the effectiveness of screening or strong fears about specific cancers may interfere with comprehension and informed decision making. **Key words:** risk communication; cancer screening; shared decision making; emotions; risk literacy. (*Med Decis Making* 2015;35:847–858)

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Surveys show that the majority of American and European adults tend to be enthusiastic about cancer screening. Most people believe that cancer screenings are almost always beneficial and often grossly overestimate their benefits.<sup>1–6</sup> Many individuals are simply unaware that some screenings detect nonprogressive cancers and may lead to substantial harms such as unnecessary treatments.<sup>2–4</sup> When screenings show uncertain evidence of benefits, or when screenings are associated with substantial harms, experts recommend policies that promote informed and shared decision making.<sup>7,8</sup> Informed decision making requires that individuals understand the relevant benefits, risks, and limitations; consider their preferences; make a decision consistent with these preferences; and participate in decision making to the extent that they want.<sup>9</sup>

Several obstacles to informed decision making about screening have been documented. For instance, physicians often fail to discuss the potential harms of screening and fail to elicit their patients'

preferences.<sup>6,10,11</sup> The tension between benefits and harms can make decisions about screening cognitively taxing and psychologically difficult for all involved. Available evidence may be difficult to comprehend for some individuals,<sup>4,12</sup> and even when transparent “user-friendly” information is provided, some patients have difficulty integrating risks and benefits.<sup>13–16</sup> Compared to hard statistical evidence, anecdotes of the early detection of cancer obtained through everyday sources (e.g., social networks) can be powerful motivators and may increase the demand for screening, even when early detection is not life-saving.<sup>17,18</sup> Somewhat unique to this context, the idea that preventive behavior prescribed by experts can cause harm is surprising and counterintuitive for many individuals<sup>3,4</sup> and may conflict with persuasive campaigns encouraging cancer screening without specifying the benefit or potential harms.<sup>19</sup>

Given the increasing evidence of harms from screenings across a number of cancers (e.g., overdiagnosis in breast, prostate, lung, and thyroid cancer screenings<sup>8</sup>), patients and doctors should understand the benefits and harms that will be a major part of many screening decisions. Unfortunately, although there are good general theoretical frameworks, there is not a substantial body of scientific literature investigating how people make evidence- and preference-based decisions in this context. How can we help people comprehend the controversial and sometimes counterintuitive evidence about benefits and harms from some screenings? How does this evidence influence their desire to participate in screening and decision making about screening? To address these questions in an efficient manner, we conducted 2 risk communication experiments using representative and ecologically valid materials. In particular, we presented accurate information about common cancer screenings (e.g., prostate and breast cancer) to a diverse sample of individuals.

### What Factors Influence Comprehension?

Research suggests that physicians and patients have difficulty understanding screening statistics.<sup>20–22</sup> In part, this difficulty may result from differences in skills and familiarity with numerical and probabilistic information (e.g., low numeracy and poor risk literacy)<sup>13,21,23–26</sup> (see [www.RiskLiteracy.org](http://www.RiskLiteracy.org)). One factor that should influence the comprehension of screening statistics is the format used to communicate benefits and harms.<sup>27</sup> Consider, for example, fact boxes that depict the most relevant information in a tabular format and have been effective in

communicating benefits and harms in other contexts.<sup>12,28–30</sup> Similarly, visual aids in the form of pictographs depict the number of affected and unaffected individuals using a matrix of icons (e.g., circles and faces) and facilitate comprehension in various contexts and populations, particularly among less numerate and more vulnerable populations.<sup>31–37</sup>

Although user-friendly formats may facilitate comprehension, the perceived severity of cancer (i.e., the degree to which people deem the consequences of a particular disease to be serious<sup>38</sup>) can reduce understanding. When the consequences of a decision are perceived to be serious or are affect intensive (e.g., fear inducing), decision makers tend to pay less attention to numerical, probabilistic information and rely more on heuristic-like processes that neglect the likelihood of specific events.<sup>39,40</sup> This suggests that individuals who perceive cancer as an extremely severe diagnosis may pay less attention to the evidence of screening effectiveness or else may give less weight to potential harms from screening.

### How Does Comprehension Relate to Screening Decisions?

Comprehension can increase patients’ self-efficacy and perceived competence.<sup>41</sup> Comprehension can also help people realize the importance of their own preferences when careful, personal decision making is required.<sup>3,4</sup> Comprehension can promote understanding of the role of value judgments in addition to medical expertise,<sup>42</sup> while a lack of understanding can encourage patients to delegate decision making to others.<sup>43</sup>

Understanding that screening can cause serious harms, sometimes with minimal benefits, can dampen people’s generally high enthusiasm for screening.<sup>1</sup> When screening offers no benefits, on average (e.g., prostate cancer screening<sup>44</sup>), greater comprehension should be associated with intentions to avoid screening, in accord with expert recommendations.<sup>45</sup> Past research shows that men who reported being fully informed about the advantages and disadvantages of prostate cancer screening tended to be less likely to undergo high-intensity screening.<sup>11</sup> Similarly, recent simulation modeling suggests that if patients learn the true likelihood that the detection of early-stage breast cancer is lifesaving, screening rates may be reduced.<sup>17</sup> However, very weak relationships between comprehension and intentions to screen might suggest that other factors often have strong influences on screening decisions. These factors might include following a health professional’s

recommendation,<sup>46</sup> strong fear of the disease, or discounting the presented information as a result of strong prior beliefs.<sup>47–50</sup>

## OVERVIEW OF EXPERIMENTS

We conducted 2 related experiments using a paid web panel group of diverse computer-literate US residents (i.e., Amazon.com's Mechanical Turk).<sup>a</sup> We studied the effects of the information format and perceived severity on the comprehension of benefits and harms from cancer screening. We modeled the influence of risk comprehension on participants' intentions to participate in screening and their desire to share decision making with one's physician. Given that age recommendations vary depending on the type of cancer screening, we invited adults of various ages to participate in the experiments. To be able to generalize the effects of comprehension beyond specific age groups, we controlled for age in our analyses. In experiment 1, we communicated statistics about prostate cancer screening with PSA tests to men. According to many experts who recommend against early screening in the US, PSA screening does not reduce mortality and incurs a high risk of overdiagnosis.<sup>44,45</sup> In experiment 2, we tested the generalizability of our model and communicated statistics about breast cancer screening with mammography. According to experts, screening for breast cancer 1) offers modest but potentially lifesaving benefits,<sup>51</sup> 2) results in a smaller rate of overdiagnosis compared to prostate cancer screening,<sup>44,51</sup> and 3) may be better known to the public due to extensive media exposure and campaigns.<sup>52,53</sup>

## METHODS

### Participants

*Experiment 1: prostate cancer screening.* Participants were 256 men (mean [ $\pm$ SD] age,  $36 \pm 13$  years [range, 18–70 years]). Participants were white (81%), African American (7%), Hispanic (7%), Asian (4%), and other (1%). Participants had completed high school or less (12%), had at least some college education (27%), had a 2-year college degree (13%), had a 4-year college degree (35%), or had a master's degree or higher (13%). Participants had various occupations including

management (22%), unemployed (16%), working in service (11%), or sales/office (11%). Eighteen percent had been screened for prostate cancer at least once, and 25% had talked to a health professional about prostate cancer screening. Three percent had been diagnosed with prostate cancer, and 27% had a friend or a relative diagnosed with prostate cancer. Forty-six percent of participants reported not having heard of overdiagnosis before participating in the study, 40% knew that it existed but not much more, and 14% reported having extensive knowledge.<sup>b</sup>

*Experiment 2: breast cancer screening.* Participants were 355 women (mean age,  $38 \pm 14$  years [range, 18–85 years]) who were demographically similar to participants in experiment 1. Thirty-six percent had been screened for breast cancer at least once, and 44% had talked to a health professional about screening. Three percent had been diagnosed with breast cancer, and 48% had a friend or a relative diagnosed with breast cancer. Thirty-one percent of participants reported never having heard of overdiagnosis before participating in the study, 49% knew that it existed but not much more, and 20% reported having extensive knowledge.

### Design

Experiments 1 and 2 used the same design, measures, and procedure and only differed in 1) gender of the sample of participants and 2) type of cancer and screening information presented. Participants were provided with background information about prostate or breast cancer, respectively, adapted from the website of the US Centers for Disease Control and Prevention (available in online Appendix A), and statistical information about the benefits and harms from mammography or PSA test screening.<sup>44,51,c</sup> Participants in both experiments were randomly assigned to view the statistical information in 1 of 3 formats: text, fact box, or visual aid. Figure 1 shows the statistical information presented in the experiments and examples of the fact box and the

<sup>b</sup>The demographic and screening history questions for both experiments are available in online Appendix C.

<sup>c</sup>The statistics presented can vary depending on age group and other risk factors, and the exact estimates are still under discussion.<sup>66</sup> However, our purpose was to convey the possible extent of benefit and harm, so we presented averaged information. At the end of the study, participants were debriefed and advised to consult a medical professional or a government website if they wanted to obtain more personalized risk estimates.

<sup>a</sup>Mechanical Turk is a web panel of paid individuals that provides relatively diverse samples and relatively high-quality data roughly comparable to those provided by convenience and community or quota sampling.<sup>65</sup>

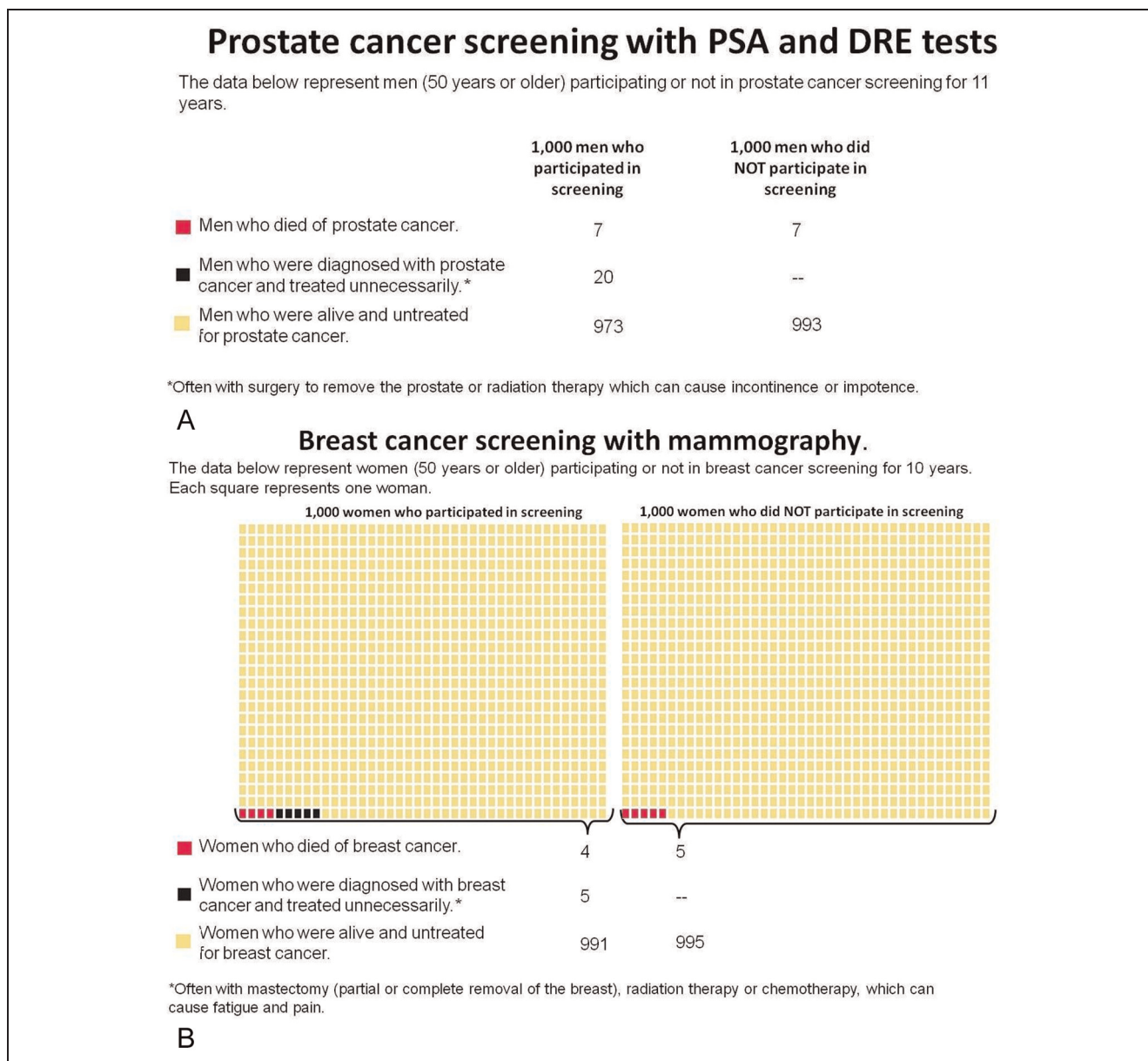


Figure 1 Statistical information about the benefits and harms from screening communicated to participants. (A) An example of the fact box used in experiment 1 (based on Ilic and others<sup>44</sup>). DRE = digital rectal examination. (B) An example of the visual aid used in experiment 2 (based on Gøtzsche and Jørgensen<sup>51</sup>). The fact box and the visual aid were designed after those provided by the Harding Center for Risk Literacy (<http://www.harding-center.de>).

visual aid. The full set of materials is available in online Appendix B.

### Dependent Measures

Internal consistency coefficients and descriptive statistics for all measures used in experiments 1 and

2 are presented in Table 1. Unless otherwise indicated, the items were developed specifically for this research.

*Comprehension.* Participants answered 8 questions designed specifically for this research (see Table S1 in the online supplement). Participants assessed the comprehension of potential harms

**Table 1** Descriptive Statistics of the Dependent Measures, Cronbach  $\alpha$  for Measures from Combined Items in Experiments 1 and 2, and Statistical Comparisons between the 2 Experiments

	Experiment 1: Prostate Cancer Screening				Experiment 2: Breast Cancer Screening				t Test Results	
	Min	Max	Mean $\pm$ SD	Cronbach $\alpha$	Min	Max	Mean $\pm$ SD	Cronbach $\alpha$	t Value	P Value
Perceived severity of cancer	1	7	5.55 $\pm$ 1.46	—	1	7	6.27 $\pm$ 1.18	—	-6.47	<0.0001
Comprehension	0	8	5.23 $\pm$ 2.04	.70	0	8	4.81 $\pm$ 1.76	.57	2.71	0.007
Positive affect	7	49	23.21 $\pm$ 9.57	.88	4	45	21.94 $\pm$ 8.99	.86	1.68	0.094
Negative affect	6	49	22.42 $\pm$ 10.23	.92	7	49	22.76 $\pm$ 10.86	.92	-0.39	0.695
Perceived risk of cancer	2	14	5.54 $\pm$ 2.94	.79	2	14	6.95 $\pm$ 3.15	.82	-5.61	<0.0001
Perceived benefit of screening	3	21	11.24 $\pm$ 5.69	.95	3	21	14.21 $\pm$ 5.00	.93	-6.70	<0.0001
Intention to participate in screening	1	7	4.21 $\pm$ 2.00	—	1	7	5.12 $\pm$ 1.94	—	-5.62	<0.0001
Intention to look for more information	1	7	4.48 $\pm$ 1.93	—	1	7	4.63 $\pm$ 2.00	—	-0.95	0.340
Shared decision making	2	10	6.47 $\pm$ 1.81	.84	2	10	6.81 $\pm$ 1.53	.82	-2.55	0.011
Numeracy	1	7	4.48 $\pm$ 1.71	—	1	7	3.26 $\pm$ 1.25	—	9.72	<0.0001

Note: min = minimum; max = maximum; SD = standard deviation.

from screening (Q1–3) and of statistical information presented about the degree of benefit and harm (Q4–8). The number of questions answered correctly showed good psychometric properties and was used as a measure of comprehension.

*Emotional reactions.* We assessed emotional responses to the communications of benefit and harm information with the Berlin Emotional Responses to Risk Scale, which is an instrument currently in the final stages of validation for cross-cultural risk communication applications. It consists of items developed for health behavior research and has been used in published risk communication research since 2011.<sup>54–56</sup> The scale asks participants to indicate how they felt when reading the information about the benefits and harms from screening. Specifically, on scales from 1 (not at all) to 7 (extremely), they indicated how assured, calm, cheerful, happy, hopeful, relaxed, relieved, anxious, afraid, discouraged, disturbed, sad, troubled, and worried they felt. The order of the adjectives was randomized. We averaged the scores across all negative adjectives as a measure of negative affect and across all positive adjectives as a measure of positive affect.

*Perceived severity of prostate/breast cancer.* Participants also rated the seriousness of the consequences of having prostate/breast cancer on scales ranging from 1 (not at all serious) to 7 (extremely serious).

*Perceived risk of prostate/breast cancer.* Participants indicated on scales from 1 (not at all) to 7 (extremely) 1) how likely it was that they developed prostate/breast cancer in the next 11 years and 2) how worried they were that they would

develop prostate/breast cancer in the following 11 years.

*Perceived benefit of prostate/breast cancer screening.* Participants indicated on scales from 1 (not at all) to 7 (extremely) 1) how effective prostate/breast cancer screening is in reducing the risk of dying from prostate/breast cancer, 2) how important it is to participate in prostate/breast cancer screening, and 3) how beneficial it is to participate in prostate/breast cancer screening.

*Intentions.* On scales from 1 (absolutely disagree) to 7 (absolutely agree), participants indicated to what extent they agreed with the following statements: 1) I intend to participate in prostate/breast cancer screening, and 2) I intend to look for information about prostate/breast cancer screening.

*Shared decision making.* We assessed participants' estimated willingness to participate in decision making about prostate/breast cancer screening with an adjusted version of the decision making subscale of the Problem-Solving Decision-Making Scale.<sup>57</sup> Participants indicated who should decide 1) how acceptable the risks and benefits of participating in prostate/breast cancer screening were and 2) whether they should get screened or not. The answer options were a) my doctor alone, b) mostly my doctor, c) my doctor and I equally, d) mostly I, and e) I alone. We computed a sum of the scores on both items and considered a score of 5 to 7 to indicate a preference for shared, <5 for delegated, and >7 for autonomous decision making.

*Numeracy.* We measured participants' numeracy with 3 items from Schwartz and others<sup>21</sup> and the

adaptive version of the Berlin Numeracy Test,<sup>25</sup> which is a test that is among the strongest predictors of one's ability to understand and make good decisions about risks (i.e., risk literacy; see RiskLiteracy.org for examples). Following Cokely and others,<sup>25</sup> we used the sum of the participants' scores on both tests as our estimate of overall numeracy.

### Procedure

The study was advertised as an investigation about "making decisions about health." Participants were eligible to take part if they were US residents who were male (experiment 1) or female (experiment 2) and 18 years of age or older. Participants received \$0.50 for their participation. They first read information about prostate/breast cancer and screening. Afterwards, they viewed statistical information about the benefits and harms in 1 of 3 formats: text, fact box, or visual aid. Then, they answered the questions described above. The Ethics Committee of the University of Granada approved the methodology, and all participants consented to participation at the beginning of the study. There were no time constraints, but the entire survey took about 15 minutes to complete on average.

### RESULTS

We assessed the effects of the information format and perceived severity on comprehension in experiment 1. We then examined correlations between comprehension, emotional reactions, perceptions of risk and benefit, intentions to participate in screening, and shared decision making. Finally, in a multiple regression framework, we tested a series of mediation models to explain the relations between comprehension and decisions. We conducted similar analyses in experiment 2 to test the generalizability of the model derived in experiment 1. We controlled for demographic and other characteristics (e.g., age, education, numeracy) in the analyses. For the sake of brevity, we report the results of the 2 experiments together. Descriptive statistics are shown in Table 1. Table 1 also shows statistical comparisons between measures from the 2 experiments.<sup>d</sup>

<sup>d</sup>The information provided in the 2 experiments differed in more than one dimension (gender, evidence, etc.). Investigating the effect of these dimensions was not theoretically central in the current research. We comment on these results whenever they are relevant to the main analyses.

### Which Information Format Facilitates Comprehension?

On average, participants in both experiments correctly answered 62% (95% CI, 60%–64%) of the comprehension questions (65% [95% CI, 62%–69%] in experiment 1 and 60% [95% CI, 58%–62%] in experiment 2). Participants perceived the consequences of cancer as moderately to extremely severe. Breast cancer was perceived as more severe than prostate cancer ( $t = -6.47, P < 0.0001$ ) (Table 1). In both experiments, participants' perceptions showed a negative skew, with a median of 6 in experiment 1 and a median of 7 in experiment 2. We divided participants into 2 groups based on the median split, such that 62% of participants in experiment 1 and 60% in experiment 2 were classified into the "extremely severe" versus "moderately severe" group. We conducted analyses of variance (ANOVAs), with information format and perceived seriousness as independent variables and the number of correct comprehension questions as a dependent variable.<sup>e</sup>

*Experiment 1.* The information format had a significant effect on comprehension:  $F(2, 250) = 4.06, P = 0.018, \eta_p^2 = .03$ . Results show that visual aids increased comprehension (72% correct) compared to the textual message (64%,  $P = 0.050$ ) and the fact box (61%,  $P = 0.003$ ) (see Figure S1A in the online supplement). The fact box was not significantly different compared to the textual message ( $P = 0.314$ ). Perceived severity had no effect on the number of correct comprehension questions ( $P > 0.1$ ). Controlling for demographics did not influence the effect of format:  $P = 0.021, \eta_p^2 = .03$ .

*Experiment 2.* The information format had no significant main effect:  $F(2, 349) = 1.28, P = 0.281, \eta_p^2 = .01$ . There was a marginally significant effect of perceived severity. Women who perceived breast cancer as extremely severe tended to have lower comprehension (mean,  $4.67 \pm 1.73$ ) compared to women who perceived it as moderately severe (mean,  $5.01 \pm 1.80$ ):  $F(1, 249) = 3.09, P = 0.080, \eta_p^2 = .01$ . There was also a marginally significant interaction between format and perceived severity:  $F(2, 349) = 2.52, P = 0.082, \eta_p^2 = .01$  (see Figure S1B in the online supplement). Consistent with results in experiment 1, visual aids (67% correct) increased comprehension among people who

<sup>e</sup>Perceived severity was not a function of the information format:  $F(352) = .009, P = 0.99$ .

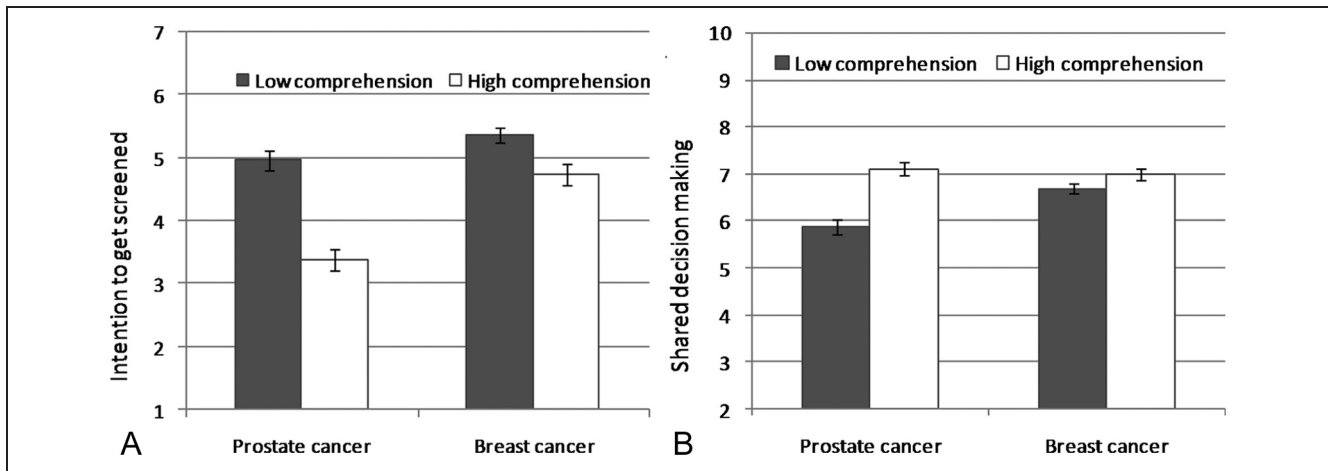


Figure 2 Intention to participate in screening (A) and desire for shared decision making (B) in experiment 1 (prostate cancer) and experiment 2 (breast cancer). For illustrative purposes, low comprehension was defined as  $\leq 5$  correct answers and high comprehension as  $> 5$  correct answers. (A) A score of 4 marks the midpoint of the scale (neither intends nor does not intend to participate). (B) A score between 5 and 7 marks a preference for shared decision making; a score  $> 7$  indicates a preference for active/autonomous decision making, and a score  $< 5$  indicates a preference for delegated decision making. Error bars are  $\pm 1$  SEM.

perceived breast cancer as moderately severe compared to the other formats:  $t(143) = -1.62$ ,  $P_{(1-tailed)} = 0.053$  (fact box: 60% correct; text: 61% correct). However, for women who perceived breast cancer to be extremely severe, the textual message was the best format, with 63% correct, as compared to lower scores on both the fact box, with 55% correct, and the visual aid, with 57% correct:  $t(208) = -2.34$ ,  $P = 0.020$ . Controlling for demographics rendered the interaction between format and perceived severity significant:  $P = 0.046$ ,  $\eta_p^2 = .02$ .

Finally, we checked whether having a relative or a friend diagnosed with prostate/breast cancer had an effect on comprehension or moderated any of the above mentioned effects. However, in both experiments, there were no significant effects of this variable ( $P$  values  $> 0.05$ ).

### How Is Comprehension Related to Decisions?

Table 1 shows that, on average, participants in both experiments intended to participate in screening and preferred to share decision making with their physician. It is noteworthy that even when the screening statistics showed no benefits but showed substantial harm (experiment 1), 44% of participants intended to participate in screening (indicated by a score  $> 4$ ), while 37% intended not to participate (score  $< 4$ ). When screening had both benefits and harms (experiment 2), 66% intended to participate (score  $> 4$ ), while only 21% intended not to

participate (score  $< 4$ ). Results also showed that greater comprehension was related to less strong intentions to participate in screening and more desire to participate in decision making about screening (see Table S2 in the online supplement). Figure 2 shows that compared to participants who failed to understand the majority of the information, those who had good overall comprehension, on average, intended to forego screening in experiment 1. In experiment 2, high comprehension was also associated with less intention to get screened, although, on average, more participants intended to get screened. Figure 2 shows that despite the fact that comprehension was associated with an increase in the desire to participate in decision making, on average, even participants with the highest comprehension still preferred to share decision making rather than be absolutely autonomous decision makers: People who understood the information the best still wanted to discuss options and consider the opinion of their physicians.

Greater comprehension was also related to lower positive affect, lower perceived risk of prostate/breast cancer, and lower perceived benefit of screening (see Table S2 in the online supplement). These variables were in turn related to the outcome variables (intentions to get screened and shared decision making), suggesting that they can be potential mediators of the relationship between comprehension and decisions.

It is also noteworthy that correlations between comprehension and outcome variables were consistently stronger in experiment 1 than in experiment



2, showing that empirical evidence had a smaller impact on decisions in experiment 2. In contrast, perceived severity was more strongly related to perceived benefit and intentions in experiment 2 than in experiment 1, showing that the perceived seriousness of cancer had a larger effect on decisions in experiment 2.

### Multifactorial Process Modeling

We used process modeling to assess how comprehension was related to decision making. Process modeling is an extension of mediation analysis that estimates direct and indirect effects in a multiple regression framework.<sup>58</sup> We tested for indirect effects with a bias-corrected bootstrap procedure using SPSS PROCESS Macro.<sup>58</sup> Each model was based on 5000 bootstrap samples. We first analyzed data from experiment 1, testing one model for each outcome (i.e., intention to get screened and shared decision making). Comprehension was included as a predictor, and positive affect, perceived risk of cancer, and perceived benefit of screening were included as potential mediators (in this order). The choice of the candidate mediators was based on the presence of a significant correlation between the candidate mediator and the independent and outcome variables (see Table S2 in the online supplement) and theoretical approaches emphasizing the influence of comprehension on decision making through emotions and perceived benefits and risks.<sup>13,26</sup> The order of mediators for the sequential effects was based on the sequence in which the measures were administered and the above-mentioned theoretical approaches. Each model tested for 3 simple indirect effects (i.e., through each single mediator) and 4 sequential indirect effects (i.e., through a sequence of 2 or all 3 mediators) operating simultaneously. In each model, we controlled for age, education level, numeracy, information format, negative affect, and perceived severity of cancer. We checked for mediation, indicated by a significant total indirect effect. An indirect effect was considered significant if the 95% CI excluded 0.

Next, we sought to replicate the results from experiment 1 with the data from experiment 2. Because the perceived severity of breast cancer was associated with important differences in the results in experiment 2, we estimated 2 separate models: one for the moderate and one for the extremely severe groups. The final results are displayed in Figure 3.

*Experiment 1.* In experiment 1, there were significant total indirect effects of comprehension on the

intention to get screened ( $-.33$  [95% CI,  $-.43$  to  $-.25$ ]) and shared decision making ( $.12$  [95% CI,  $.05$  to  $.21$ ]) (Figure 3I). Participants who understood a larger proportion of the information perceived a smaller risk of cancer, felt less relieved by the information about screening, and judged the benefits of screening to be smaller. Consequently, they reported being less likely to get screened and reported more interest in shared decision making.

*Experiment 2: moderately severe group.* Results for the group of women who judged breast cancer to be moderately severe were highly similar to the model results from experiment 1. There were significant total indirect effects of comprehension on the intention to get screened ( $-.24$  [95% CI,  $-.37$  to  $-.10$ ]) and shared decision making ( $.10$  [95% CI,  $.03$  to  $.19$ ]). The same paths as in experiment 1 emerged as significant (Figure 3IIA).

*Experiment 2: extremely severe group.* The results for the group of women who judged the consequences of breast cancer to be extremely severe showed systematic deviations from previously estimated process models (Figure 3IIB). In this group, comprehension of the evidence had a small effect on decisions. There was a small total effect of comprehension on intentions to get screened ( $-.16$  [95% CI,  $-.28$  to  $-.06$ ]) and shared decision making ( $.04$  [95% CI,  $.004$  to  $.09$ ]).

Similar to the previous models, for the extremely severe group, higher comprehension was associated with a smaller perceived benefit of screening and less intention to get screened. However, comprehension was not related to positive affect or the perceived risk of cancer. Regardless of how well they understood the evidence, women who perceived breast cancer to be extremely severe reported being at a high risk for breast cancer and reported feeling more assured and relieved upon reading the information about screening. These high-risk perceptions and feelings of assurance were related to their increase in the perceived benefit of screening and their stronger intentions to screen.

## DISCUSSION

When benefits and harms were communicated following risk communication guidelines,<sup>27</sup> people understood a large proportion of the information correctly. Presenting the numerical information accompanied by a visual aid improved comprehension

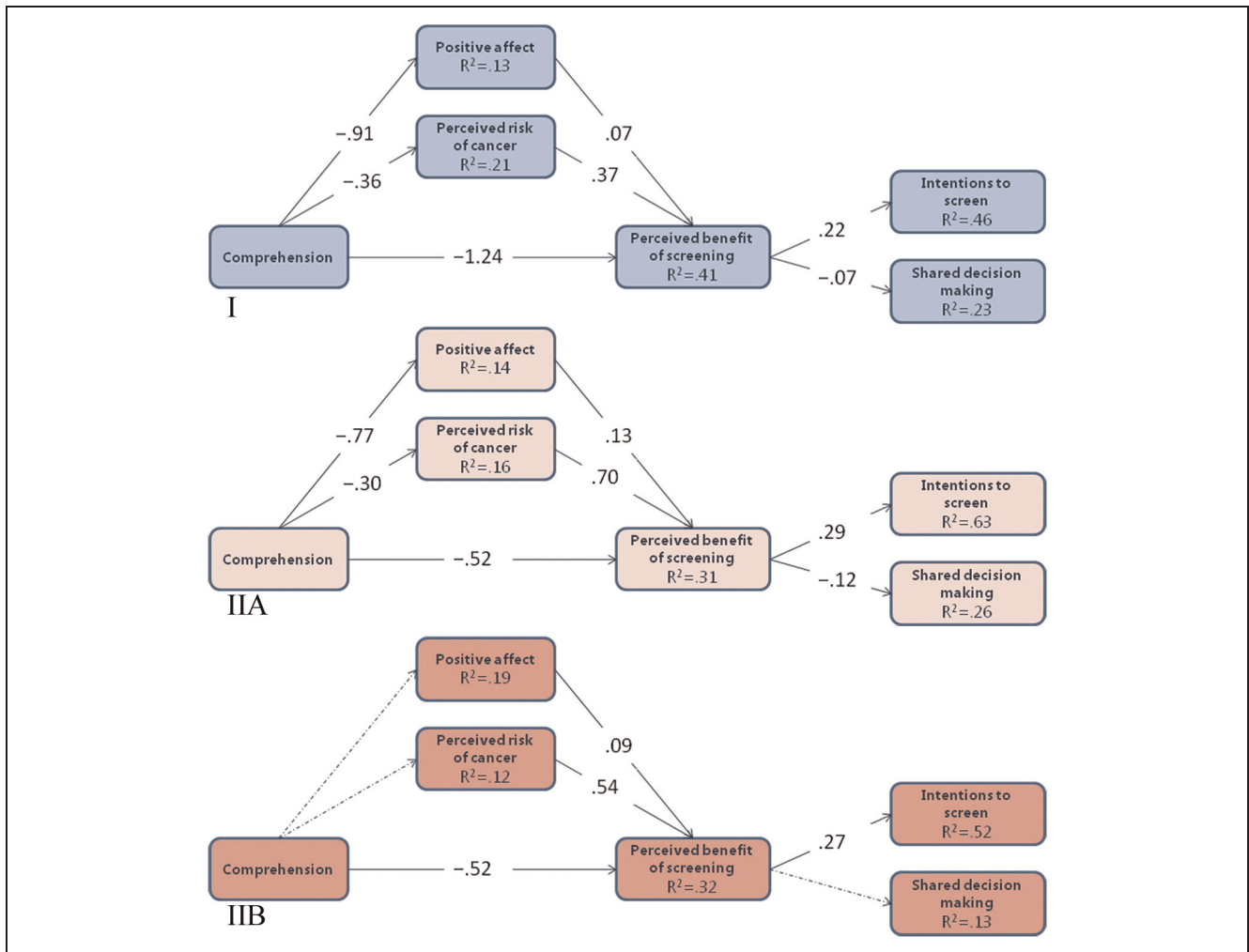


Figure 3 Mediation models. (I) Experiment 1: prostate cancer screening. (II) Experiment 2: breast cancer screening. (IIA) Moderately severe group and (IIB) extremely severe group. Coefficients are unstandardized B. The models control for age, education level, numeracy, information format, negative affect, and perceived severity of cancer (in experiment 1). Dashed lines indicate nonsignificant paths ( $P \geq 0.05$ ).

compared to alternative formats in participants who did not perceive the consequences of cancer as extremely severe (e.g., up to 18% relative improvement in experiment 1). This result is consistent with that in previous research<sup>31,33,35,59</sup> and suggests that simple visual aids can substantially improve risk comprehension even when risk communications involve complex, emotionally charged counterintuitive evidence.

Surprisingly, the fact boxes used in this research did not reliably increase comprehension. Because information processing varies as a function of task complexity,<sup>60,61</sup> there is reason to think that a structured tabular representation of information may

primarily facilitate comprehension when the amount of information is larger. For example, in the current research, we did not include other potentially relevant information, such as information about mortality from all causes or the proportion of false-positive screening test results.<sup>12</sup> In cases where this information is highly relevant and should be included, a fact box may be more beneficial.

In contrast to men's relatively moderate attitudes towards the severity of prostate cancer, a large proportion of women perceived breast cancer to be extremely severe. Our models indicated that the decisions of these women were less influenced by the available evidence. Women's feelings of assurance

were not dampened by the evidence of harms from screening. Ironically, these feelings and perceptions were associated with more perceived benefit and more readiness to screen. Theoretically, these women could have given more weight to the benefits of screening than to the harms. Alternatively, the decisions of these women may have been more influenced by pre-existing beliefs about the effectiveness of screening<sup>11</sup> along with decision strategies (i.e., heuristics) stemming from the fear of disease (e.g., “prevention is always better”). Research shows that strong affective reactions related to the decision outcome (e.g., a potentially deadly disease)<sup>39,40</sup> or existing preconceptions based on previous information<sup>48</sup> can profoundly influence information processing, comprehension, and decision making when new information is presented. To illustrate, people find the idea of harms from screening surprising and counterintuitive<sup>1,3,4</sup>; at the same time, many people report that screening is an obligation to one’s family and society.<sup>1,3,4</sup> The presence of such strong previous beliefs and emotions may also explain why the subgroup of women who perceived breast cancer as extremely severe did not benefit from visual aids and even showed worse comprehension. Under conditions of more extreme emotional reactions to cancer, participants might have been less motivated to carefully study the information in an unfamiliar format, instead relying on established beliefs about effectiveness. These women may have also been distrustful of the information about harms, processing it more shallowly or discounting it as inconsistent with their beliefs.<sup>48</sup>

In addition, people are likely to have little experience with serious harms resulting from preventive behaviors. This could explain why a large proportion of participants, and especially those who perceived breast cancer as extremely severe, were very enthusiastic about screening despite possible harms. To illustrate, people often know that drugs can cause side effects, and this may reduce their willingness to take a drug (e.g., many women would choose not to take tamoxifen to reduce a high breast cancer risk because of its side effects<sup>33</sup>). In contrast, personal accounts of people who were diagnosed with cancer after screening typically emphasize the idea that screening may have saved their life rather than that it may have caused them to undergo unnecessary surgery. Finally, the discrepant mammography recommendations issued by different official bodies in the US and the resulting controversy could have influenced some women’s attitudes towards mammography and the provided information.<sup>62</sup> Future research should estimate the influences and

processes by which non-evidence-based beliefs or anxieties create obstacles to informed decision making and the means of overcoming these obstacles.

Several factors limit the generalizability of these findings. It should be noted that screening for cancer is usually recommended after the age of 50 years. Although approximately one third of our participants were among the age group that was eligible for recommended screening, the participant samples also contained many younger participants for whom screening was not yet as relevant. In addition, white and highly educated individuals were overrepresented. Future research can replicate our study in probabilistic national samples and provide tailored information to participants consistent with their age and risk factors. Similarly, people who had some personal experience with prostate or breast cancer were overrepresented in our studies. While this might limit the generalizability of our findings, results showed that the benefits of comprehension were independent of age and education. Nevertheless, future research should verify to what extent the effects of comprehension are similar among the populations underrepresented in our studies. Another potential limitation of the current set of studies is that perceived severity was measured after exposure to the information, and so it may have been influenced by the way the information was presented. However, analyses showing a consistent lack of the effect of format on perceived severity speak against this possibility, as does the fact that participants in all conditions received the same information about factors related to perceived severity (e.g., risk factors, symptoms, and treatment of the disease).

## CONCLUSIONS

Previous research has shown that stable characteristics such as age, gender, type of disease, and type of decision play a role in patients’ preference for shared decision making.<sup>43,63,64</sup> The current findings add to this literature, showing that a modifiable factor, that is, comprehension (i.e., an essential component of informed decision making), can promote the willingness to participate in high-stakes value-sensitive decisions, independent of other influential factors (e.g., emotions and demographics). Broadly, the current research suggests that one’s previous beliefs about the effectiveness of screening, emotions instilled by persuasive campaigns, or strong fears about specific cancers may interfere with shared and informed decision making. Results also suggest

that user-friendly risk communications designed following expert guidelines<sup>27</sup> may help attenuate the influence of these factors and more generally can improve high-stakes decisions while simultaneously promoting shared decision making. Just as one's comprehension of the harms and benefits of cancer screenings helps people make better choices and plans, perhaps understanding the need for informed decision making in one context will naturally translate into more participatory, informed decision making in other high-stakes domains.

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