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Laypersons' Responses to the Communication of Uncertainty Regarding Cancer Risk Estimates

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Abstract

Objective—To explore laypersons' responses to the communication of uncertainty associated with individualized cancer risk estimates and to identify reasons for individual differences in these responses.

Design—A qualitative study was conducted using focus groups. Participants were informed about a new colorectal cancer risk prediction model, and presented with hypothetical individualized risk estimates using presentation formats varying in expressed uncertainty (range v. point estimate). Semistructured interviews explored participants' responses to this information.

Participants and Setting—Eight focus groups were conducted with 48 adults aged 50 to 74 residing in 2 major US metropolitan areas, Chicago, IL and Washington, DC. Purposive sampling was used to recruit participants with a high school or greater education, some familiarity with information technology, and no personal or immediate family history of cancer.

Results—Participants identified several sources of uncertainty regarding cancer risk estimates, including missing data, limitations in accuracy and source credibility, and conflicting information. In comparing presentation formats, most participants reported greater worry and perceived risk with the range than with the point estimate, consistent with the phenomenon of "ambiguity aversion." However, others reported the opposite effect or else indifference between formats. Reasons suggested by participants' responses included individual differences in optimism and motivations to reduce feelings of vulnerability and personal lack of control. Perceptions of source credibility and risk mutability emerged as potential mediating factors.

Conclusions—Laypersons' responses to the communication of uncertainty regarding cancer risk estimates differ, and include both heightened and diminished risk perceptions. These differences may be attributable to personality, cognitive, and motivational factors.

Keywords

uncertainty; risk; ambiguity; cancer; risk prediction models

Statistical models to predict an individual's risk of disease have grown in number, visibility, and importance in the 3 decades following the development of the Framingham model of cardiovascular risk.[1,2] Since then, risk prediction models have been created for several other

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chronic diseases, most notably breast cancer and other malignancies,[3–5] and their application has expanded beyond research settings to the domain of clinical practice. In recent years, risk prediction models have been used to educate laypersons about their disease risks,[6–9] to identify individuals who might benefit from preventive interventions,[8–13] and to counsel and assist patients in clinical decision making.[12,14]

Despite broadening use of risk prediction models, much remains unknown about how best to communicate risk estimates produced by these models. One critical issue in this regard is the communication of the uncertainty associated with all risk estimates. This uncertainty has several sources, including model misspecification and limitations in external validity,[14,15] and is manifest by imprecision (e.g., wide confidence intervals) and variability in estimates produced by different models. To what extent and by what means this type of uncertainty should be communicated to model users is not clear. On one hand, a strong ethical justification exists to disclose this uncertainty, insofar as knowledge of the limitations of available evidence is an essential element of informed decision making.[16–23] On the other hand, communicating uncertainty is problematic, given that the optimal methods have not been defined, and the endeavor may have a variety of effects.[24]

For example, a large body of past research suggests that communicating the uncertainty surrounding estimates of risk influences people in several important ways. Decision theorists since Ellsberg[25] have used the term *ambiguity* to define uncertainty pertaining to the "reliability, credibility, or adequacy" of risk information. Ambiguity is thought to determine people's degree of confidence in the risk information at hand and thereby influence the impact of this information on judgments and decisions.[25–29] Numerous studies have shown that ambiguity has predictable psychological and behavioral effects, leading people to judge risks and potential choice outcomes pessimistically and to avoid decision making.[25,26,28]

This response, known as "ambiguity aversion," has been demonstrated in a variety of decision-making settings, including those involving health risks. For example, several studies have shown that presenting disease risks in terms of a numeric range rather than a point estimate leads to heightened perceptions of these risks[30–33] and lower trust in information.[34,35] Experimental studies have shown that ambiguity regarding the outcomes of preventive and therapeutic interventions lowers people's interest in these interventions,[36–38] and these findings have been corroborated in nonexperimental studies.[39–44]

Yet past research has also shown that ambiguity aversion is not a universal phenomenon. For example, Lipkus and others[45] provided actual Gail model[3] breast cancer risk estimates to women using either a point estimate or an ambiguous numeric risk range, and found that the format did not influence perceptions of risk or of the estimates' credibility or accuracy. This study did not control for the size of the risk range—and thus the amount of ambiguity—communicated to participants, potentially obscuring its true effects. Nevertheless, these and other data suggest substantial variability in people's responses to ambiguity.[24,26,29,32,46]

Elucidating the causes of this variability—and of the phenomenon of ambiguity aversion itself—is a critical next step for determining the optimal methods and outcomes of communicating uncertainty regarding disease risk estimates. Ambiguity aversion has been hypothesized to result from various factors, including people's beliefs that decision outcomes are unfairly biased against them, concerns about how decisions will be evaluated by others,[47] and feelings of incompetence[48] or vulnerability to future blame or regret.[27,47,48] Individual differences in these or other beliefs and motivations might account for individual variation in responses to ambiguity. However, these hypotheses remain unproven and do not account for why people perceive ambiguous options as riskier in the first place.[49–51]

We undertook the present study to explore these questions further. Our objective was to apply ambiguity theory as a framework for examining laypersons' responses to the communication of uncertainty regarding cancer risk estimates, and the reasons for differences in these responses. We focused on the uncertainty communicated through statistical confidence intervals and specifically related to the lack of precision and reliability of risk estimates. We used qualitative methods to elicit people's own accounts of their thought processes, with the goal of generating insights and testable hypotheses regarding the determinants of ambiguity aversion.

METHODS

Study Design, Participants, and Data Collection

The study employed semistructured focus group interviews to elicit the range of laypersons' own understandings of risk and to explore these understandings in greater depth. The open-ended interactive nature of this methodology[52–55] made it well suited for the current study, given its exploratory aim and abstract subject matter.

In June 2007, 8 focus groups were conducted with 48 adults in 2 US metropolitan areas—Washington, DC and Chicago, IL. Participants were recruited over the telephone by a professional recruitment service, using eligibility criteria listed in Table 1. A purposive recruiting strategy was employed to obtain a sample age eligible for most cancer screening interventions and with average levels of education, familiarity with information technology, and exposure to health information, yet no extraordinary level of concern or expertise regarding cancer risk.

To achieve sufficient within-group homogeneity to encourage open discussion,[55] we stratified the groups by a 2 × 2 × 2 design according to 3 factors potentially relevant to people's understanding of risk information: sex, perceived cancer risk, and subjective health numeracy (self-rated ability to understand health-related numerical information; Table 2).[56–58] Perceived cancer risk was measured using an item from the Health Information National Trends Survey[59]: "Compared to the average {man/woman} your age, would you say that you are more likely to get colon cancer, less likely, or about as likely?" Perceived risk was categorized as low if participants reported being "about as likely" or "less likely" or high if they responded "more likely." Subjective health numeracy was measured using an item developed by Woloshin and others[60]: "In general, how easy or hard do you find it to understand medical statistics?" Subjective numeracy was categorized as low if participants responded "hard" or "very hard" or high if they responded "easy" or "very easy."

The groups were held at focus group facilities in Rockville, MD, and downtown Chicago, IL. Participants received $50 compensation. Each session lasted 2 hours and was audiotaped and transcribed verbatim by a professional transcription service. Investigators observed all sessions behind a 1-way mirror; participants gave consent for audiotaping and observation beforehand.

Interview Content

Each group was led by the same experienced professional focus group moderator who was not one of the research investigators and was naive to the subject matter. The moderator used an interview guide consisting of questions based on review of the decision science literature. During the course of the study, minor revisions were made in the interview guide to clarify emergent themes.

The interview began with open-ended questions regarding the meaning of risk. Participants were then informed about a new risk prediction model, developed at the National Cancer Institute[61] and based on a computer program that could calculate a person's lifetime risk of colon cancer, using information about 9 risk factors listed on a chart. They were then asked their general impressions regarding the program and their perceptions of its accuracy or reliability.

Next, participants were told to imagine that a friend, "Mr. or Mrs. Jones," had used the computer program and received a risk estimate of "9%." They were asked to write down how they would explain this estimate, and the moderator led a group discussion of responses. Participants were then asked their interpretations of 2 expressions: a numeric point estimate ("9%") and a numeric range ("5%–13%"). This magnitude of risk was chosen to approximate the 6% average lifetime colon cancer risk for US adults aged 50 and older[62] and to allow comparability of findings to a prior qualitative study.[34] To facilitate discussion, we showed visual displays (Figure 1) adapted from this prior study[34] to participants, who then recorded written responses to a series of questions asking which of these formats 1) was easier to understand, 2) seemed more accurate, and 3) would make them worry more. Participants in groups 3 to 8 were also asked which format would make them feel at greater risk, whereas participants in groups 2 to 8 were further informed that the population average lifetime colon cancer risk was 6%. The moderator then led a group discussion of participants' answers.

Finally, participants were presented with a third nonnumeric expression comparing the person's colon cancer risk relative to the population average ("your risk is higher than average"). A visual display of this expression (Figure 1), adapted from a publicly accessible cancer risk prediction model,[6,7] was provided to facilitate discussion. Participants were asked to compare all 3 formats, using the previous 4 questions as prompts.

Data Analysis

Data analyzed in this article related to participants' perceptions of uncertainty regarding the risk prediction program and their responses to the communication of ambiguity expressed through confidence intervals. Findings regarding the meaning of individualized cancer risk estimates are reported separately.

Simple descriptive statistics were obtained to summarize responses to the written questions. Two of the investigators (PH and TL) performed in-depth analysis and line-by-line software-assisted coding of all interview transcripts using the program NVivo (Version 7, QSR International). Participants' verbatim statements were categorized according to thematic content, and emergent themes were organized within an overall conceptual schema according to logical relationships. The interpretive approach was both deductive and inductive. We began analysis with prior knowledge of specific conceptual problems identified in the literature, which sensitized us to deduce their presence in the interview text. At the same time, we remained open to new concepts and interpretations emerging from the data and explored how they might refine our theoretical preconceptions, consistent with an inductive "grounded theory" approach.[63–65]

One investigator (PH) generated a preliminary conceptual schema and codebook based on initial analysis of all 8 transcripts. The schema was reviewed and revised by the research team in an iterative fashion through subsequent discussions, and codes were added and reconstructed. Two investigators (PH and TL) then reapplied the revised codebook to the interview text. Coding decisions were compared, new themes were identified, and areas of disagreement were resolved through further team discussions.

RESULTS

A total of 48 respondents participated, and their characteristics are listed in Table 3.

Perceptions of Ambiguity Regarding the Risk Prediction Model

In response to questions about their attitudes toward the risk program, some participants thought the program seemed "great" and expressed no reservations about it; however, the majority raised several concerns regarding various sources of ambiguity. The most commonly expressed concern surrounded the potential for *missing data* in the risk prediction model, which was acknowledged in comments that the model was "not inclusive enough" in the risk factors ascertained: "There are things in the questionnaire that's not there, you know, circumstances that might increase your level or decrease it that's not being asked." Such missing data represent a principal cause of model misspecification,[14,15] a concern expressed by participants in other studies,[66,67] and a key source of ambiguity as conceptualized by decision theorists.[37,68]

Another significant concern pertained to the *reliability* or *accuracy* of the risk prediction model:

> *Participant*: Before I took the test, I'd like to know if they said you have an 80% chance of having it or a 50% chance or whatever percent chance, I'd want to know what's their percentage. . . how often are they correct?

This quote captures the fundamental meaning of ambiguity as a second-order uncertainty—the probability that the risk estimate itself is correct.[25] Concerns about reliability and accuracy had several evident sources, including the model's novel, untested nature and perceived limitations of statistics and technology generally: "it has glitches in it even more than people do." Other participants questioned the adequacy of the model's database, asking "how large the study was, and who was in it."

Concern about *source credibility* was another common concern: "The first thing I would look at is . . . Who put this out? How much weight would I put into it?" Several participants expressed concern about the "qualifications" and "experience and expertise" of the model developers. Source credibility concerns have also been prominent in other studies of responses to communicating uncertainty.[35]

A final concern pertained to *conflicting information*, a theoretically distinct source of ambiguity.[25,69,70] Several participants distrusted the risk model because they perceived the underlying science as plagued by expert disagreement and contradictory findings:

> *Participant:* "They [scientists] keep changing. . . on all the cancers. . . they keep changing what contributes to it. First they'll say this and then they negate it and now say it's that. So I think that the scientific community will just throw out these figures and statistics but you know they may change next week, so I don't really trust. . . I never really know what they mean by high risk or statistics.

Responses to Ambiguity Regarding the Risk Prediction Model

Some variation was evident, however, in participants' responses to ambiguity regarding the risk prediction model. Most participants did demonstrate ambiguity aversion, expressing disinterest in using it. One participant likened her disinterest to her conservative approach to other medical interventions: "it's like new drugs. . . I'm not the first to take the new drug. Put it out there for a while before I start taking it."

On the other hand, many participants showed ambiguity tolerance regarding the model: "I have a lot of faith in it even though they don't know everything." For some participants, this reflected faith in technology, in "what these computers can do today." For others, this tolerance appeared to be part of a more global acceptance of ambiguity in life:

> *Participant:* I'm not sure that it [ambiguity] matters. I think what's important is, they're doing the research. . . . And of course, there are a lot of unknowns. Many things that

> we do in life there are unknowns about, and you get yourself through it, whatever the end result is, you just accept.

Whether tolerant or averse to model ambiguity, however, nearly all participants felt that this ambiguity should be communicated to model users, that some “disclaimer” was needed to tell people “how much is it missing, what is that factor that's going to affect that percentage.” Only 2 participants in all groups disagreed, arguing that communicating ambiguity could cause inordinate worry. Most others agreed that communicating ambiguity was necessary to avoid conveying an illusory sense of certainty:

> *Participant:* Why should they [communicate ambiguity]? Because then they're giving people a false impression that the data that they have is the complete picture.. . . If they tell me that they don't know 40% and they say that I'm in the 95%. . . I'd say “What about the 40% that you don't know? What does that do to my risk?”

Responses to Ambiguity Regarding Cancer Risk Estimates

Participants’ written responses to structured questions about the different formats for communicating risk estimates are summarized in Table 4. Similar proportions of participants favored the point estimate and range formats in terms of understandability and accuracy. Regarding potential indicators of ambiguity aversion, 57.4% of participants reported greater worry with the range, 36.2% with the point estimate, and 6.4% reported indifference. Perceived risk showed a similar pattern, with 55.6% of participants reporting higher perceived risk with the range, 38.9% with the point estimate, and 5.6% reporting indifference. Although these between-group differences were relatively small, the overall trends are consistent with ambiguity aversion and approximate past findings.[25,26,30,31] To explore reasons for individual differences in ambiguity responses, we elicited participants’ explanations of their answers.

Ambiguity aversion. Participants who endorsed greater worry and perceived risk in response to the range format offered several explanations. Several participants used decision theory terms to describe their aversion: “It's just vague,” “more ambiguity, more fudge factor.” Underlying many participants’ worry was a heightened mental salience of the 13% upper limit of the range; ambiguity-averse participants tended to focus on “the possibility that you are at the high end” compared with the point estimate:

> *Facilitator:* Which makes you feel at greater risk, D?
>
> *Participant:* 5% to 13%. The 13% is higher than 9, so it's from 5 to 13. It seems like I would feel at a greater risk in that category than just using a hard number and saying 9%. Thirteen is higher than 9.

This pessimistic focus on the upper-limit, “worst-case scenario”[35,71] overpowered what some participants recognized as an equal opportunity to focus optimistically on the lower limit:

> *Facilitator:* Now, some of you thought the blue one [range format] would worry you more. Why, P?
>
> *Participant:* I guess because of the higher percentage, the 13. It was a higher percentage than the 9. Yet, I liked the 5.

This propensity to devote disproportionate attention to one or the other limit of the range corroborates data from a study by Highhouse,[72] who examined ambiguity pertaining to the success of a hypothetical medical treatment and showed that individuals deciding against the ambiguous treatment tended to underweight optimistic probabilities while over-weighting pessimistic ones. However, that study also found that the presentation of an interval v. a point estimate led to more *optimistic* subjective probability judgments and *greater* choice of the ambiguous option overall. This contrastingly optimistic response to ambiguity could relate to

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the fact that the ambiguity in that study surrounded the success of disease treatment, rather than the risk of disease (as examined in our study).

The heightened salience of pessimistic probabilities for our participants appeared to be a perception that entailed little rational deliberation:

> *Participant:* All you have to do is just look at that. . . 5 and 13 and then you take the median; it's 9. And a lot of people aren't going to do that. . . first of all, I just think that 13 is going to set off an alarm on people.

The unresolved question is what primes this intuitive response bias; when confronting ambiguity, why do some people give preferential consideration to the worst-case scenario in the first place? To shed light on this question, we probed thought processes underlying ambiguity tolerance.

Ambiguity tolerance. Many participants endorsed lower risk perceptions and worry in response to the risk range than to the point estimate. This ambiguity tolerance reflected a selective attentiveness to optimistic rather than pessimistic probabilities:

> *Facilitator:* Did anybody say the green [point estimate] would worry you more?
>
> *Participant 1:* Yes, green would worry me more.. . . It's too finite, too specific, too something. I guess the other one [range] was more. . .
>
> *Participant 2:* It gives you hope.
>
> *Participant 1:*. . . more hopeful, yes. You can think you're 5, 6, 7, or 8. You don't want to think that you're 10, 11, 12, or 13.

The range afforded the opportunity to perceive oneself as being at lower risk, in contrast to the point estimate, which allowed no interpretive flexibility and caused some people to feel “caught in between the lines.”

Ambiguity tolerance also appeared to relate to the *perceived mutability* of one's risk. Several participants preferred the range because it connoted the opportunity to change their risk, in contrast to the point estimate, which represented an immutable “hard number”:

> *Participant:* It [risk range] makes it more preferable because the 9% is too definitive. It locks you into a number. . . 9% of the people in this room are going to get this. If you say 5 to 13, I got a chance. . . 9% says I'm not rolling the dice. I'm going to lose. Five to 13, okay, you can pass me. It's giving me that degree of confidence that I could beat this.

This finding supports Rode and colleagues' hypothesis[51] that ambiguity effects occur because people perceive ambiguous risk information as signifying high outcome variance. In this view, responses to ambiguity depend on the desirability of high outcome variance, which in turn is determined by individual motivations and needs. One such motivation for our participants was to reduce feelings of vulnerability to cancer. The range format made salient not only the variance of risk but also the potential of people's own actions or behaviors to alter this risk:

> *Participant:* The range seems to give you more leeway to think of what your lifestyle is about.. . . If you say you've got a 9% chance, that means no matter what you do, it's 9%, where this range of 5 to 13, it could be on the high end or the low end and you can make adjustments.

Preference for the ambiguous range, rather than the point estimate, also originated from its *perceived credibility*. For some participants, the precise point estimate seemed more risky because it was less trustworthy. Various participants expressed the notion that “science isn't perfect,” and thus “it's just not believable” that scientists could “hit it on the nose . . . there is stuff they don't know." In this view, reported in other studies as well,[35] the point estimate is paradoxically *more* ambiguous—and thereby more worrisome—because it raises the question of what factors have not been adequately accounted for. Preference for the ambiguous range may thus paradoxically manifest ambiguity aversion.

But low perceived credibility appeared to cut both ways, at other times making a risk format feel *less*—rather than more—risky. Some participants, for example, viewed the *range* as being the less credible format; however, this lower credibility led participants to discount its significance and hence view it as less worrisome than the point estimate:

> *Participant:* I'm more worried about the 9%. Once again, I can dismiss a range. You know, I'm looking at. . . well, they don't have a clue here, do they? You know it's somewhere between this and this. . . well, forget the whole thing.

The critical factor may be the *level* of perceived credibility regarding a risk estimate, with sufficiently low levels leading people to disregard the estimate altogether.[35] Credibility perceptions may thus mediate ambiguity aversion, in this case counteracting the propensity toward heightened risk perceptions in response to the ambiguous risk range.

Numeric v. verbal risk estimates. In the final portion of the interview, we explored the ambiguity associated with numeric v. verbal risk estimates by comparing participants' responses to the numeric risk estimates and the verbal estimate of risk relative to the population average. Some participants perceived the numeric risk estimates as more precise and more informative than the verbal estimate, consistent with a common view among experts.[29] Many others, however, believed the verbal estimate was more precise because it specified "exactly where your risk category is," unlike numeric estimates, which "could be numbers on any end of the spectrum."

The important factor that made the verbal estimate more precise and less ambiguous appeared to be the comparison to the average; this provided an anchor allowing participants to extract a gist meaning of the risk, which made numbers superfluous:

> *Participant:* If you've got a high risk, average risk, low risk; that's what it's going to boil down to for me anyway. The numbers are just going to be kind of, oh yeah, the computer says. . . That's nice.

The comparison to the population average provided a gist interpretation for a number that otherwise lacked intrinsic meaning to participants and was subject to arbitrary interpretations:

> *Participant:* It would be easy for a person to say, "Ah, I'm 5%. Okay, I'm good," or "9%. . . that's not so bad." But when a person sees it's higher than average, they don't have to guess. They don't have to speculate. They know, "Hey, this is not good. I'm more at risk than the average person."

This passage further highlights how ambiguity has potential psychological utility, allowing the interpretation of risk estimates in self-serving ways (e.g., to lower feelings of vulnerability) and how verbal comparative risk estimates remove this opportunity by disambiguating the meaning of numbers. This may explain the well-described influence of comparative information on risk peceptions[73,74] and our participants' views that the verbal estimate was "scary" or "alarmist."

DISCUSSION

In this study, we used qualitative methods to explore how laypersons perceive and respond to uncertainty regarding cancer risk prediction models and the individualized risk estimates derived from them. We obtained several findings that shed light on the mechanisms of

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ambiguity aversion, suggest testable hypotheses for future studies, and have practical implications for risk communication efforts.

First, participants were able to perceive various sources of ambiguity as conceptualized by decision theorists (e.g., missing data, limitations in reliability and accuracy, questionable source credibility, conflicting information). Perceptions of ambiguity, furthermore, appeared to have different effects. For many participants, perceived ambiguity was tied to distrust and disinterest in using the model. Other participants, however, acknowledged the ambiguity and appeared to tolerate it. Yet regardless of their response, nearly all participants felt that ambiguity was necessary to communicate to model users.

This communication might take several forms and deal with various sources of ambiguity. We focused primarily on statistical imprecision as expressed by confidence intervals, the communication of which appeared to have varying effects. A slight majority of participants demonstrated ambiguity aversion, reporting heightened cancer risk perceptions and worry in response to the ambiguous risk range. However, many participants demonstrated ambiguity tolerance, reporting either no change or lowered perceived risk and worry. These findings corroborate growing evidence that the phenomenon of ambiguity aversion is highly variable, less robust, and more complex in decision-making domains of real life than in the tidy world of laboratory experiments involving games of chance.[28,48,75,76] Yet available evidence suggests that this is due not to a lack of influence of ambiguity—our participants' accounts illustrated this influence vividly—but to variability in the way ambiguity affects different people.

The critical question is what accounts for this variability,[75,77] and our data go beyond prior studies in identifying not only several potential determinants of ambiguity aversion—including personality, cognitive, and motivational factors—but also possible mechanisms for their influence. Several participants, for example, acknowledged a tension between optimistic and pessimistic interpretations of the risk range, raising the question of whether dispositional optimism might moderate ambiguity aversion—a possibility raised by experiments using hypothetical decision-making scenarios in health[77] and nonhealth domains.[78] Other participants' responses suggested a mediating role of perceptions of the credibility of risk information and of the mutability of one's cancer risk. In other words, presentation of the ambiguous risk range appeared to influence cancer risk perceptions and worry through its influence on perceptions of source credibility and risk mutability. These findings have not been reported previously and evince the power of qualitative methods to generate insights by eliciting people's own accounts of their reasoning processes.

Our data also build on prior work suggesting the influence of motivational factors on ambiguity responses.[29,33,51,69,70,75,77] For example, participants articulated a self-enhancing desire to reduce feelings of vulnerability to cancer, as well as a related motivation to maintain personal control over one's cancer risk. These motivations may have contributed to participants' responses to ambiguity as well as their preferences for comparative risk information. The influence of motivations reflects the instrumental value of ambiguity; it provides the interpretive flexibility people need to form judgments that serve these motivations.[29,75] Participants' comments affirmed Kuhn's observation that "people can use uncertainty as justification for discounting the seriousness of any threat posed."[75]

These findings all represent testable hypotheses and a departure from most previous work in decision theory, which has focused on accounting for ambiguity aversion in terms of normative or descriptive models of decision making.[27,79] Little work has been done, in contrast, to elucidate underlying mechanisms and the causes of individual variation in ambiguity aversion; the current study provides specific insights to guide future work toward these explanatory aims.

For example, our study suggests the value of future quantitative studies to specifically test the moderating role of personality and motivational factors on ambiguity perceptions and responses or the mediating effect of perceptions of source credibility or risk mutability (Figure 2). Such work might help determine the mechanisms of ambiguity aversion and yield insights to inform risk communication efforts.

Further research is also needed to address limitations of the current study. The restricted sample and qualitative methodology limit the generalizability of our findings. The qualitative approach did have the advantage of allowing people's reasoning processes to be examined directly rather than indirectly (e.g., through closed-ended surveys or experiments). However, this approach also raises questions of causal direction, given that people's self-described thought processes might represent post hoc rationalizations for—rather than causes of—expressed preferences.[72] The validity of our findings may also have been limited by the study's hypothetical nature. We asked participants about an imaginary person's reactions to a hypothetical colorectal cancer risk estimate. People are known, however, to be poor at forecasting their own—let alone others'—future responses to bad news and stressful situations.[80] Notably, this limitation also applies to most past research on ambiguity, which has similarly used hypothetical scenarios.

Other limitations point to key questions for future research. We did not examine ambiguity regarding levels of risk higher or lower than 9%, nor did we vary the confidence interval, although the magnitude of both risk and uncertainty may moderate ambiguity aversion.[26,81] We also did not explore framing effects in the representation of risk and ambiguity, which may also influence ambiguity responses.[26,33,75] These could have included effects of the visual graphics used in our study, because graphical presentations of risk have been shown to influence responses to risk information, increasing risk avoidance in comparison to numerical information.[82,83] Finally, we focused only on the risk of colorectal cancer in otherwise healthy older adults and did not examine the influence of disease type, health status, and other individual or situational factors, which could have also influenced ambiguity responses.

Despite these limitations, our study provides convergent evidence that in the communication of health risk information, as in other domains of decision making, ambiguity matters to people. This has important practical implications for risk communication efforts. People want and deserve to know the degree of uncertainty surrounding information about risks,[84] and this knowledge influences judgments and decisions. It may lead to heightened vulnerability perceptions, distrust in health information and expert knowledge, and avoidance of decision making. Such outcomes may be undesirable and call for caution to avoid overstating the ambiguity at hand.

Yet substantial individual variation exists, and many people will be either indifferent to ambiguity or else respond with lowered risk perceptions and decision avoidance or greater trust of expert information. These outcomes may be warranted if based on people's true preferences but unwarranted if based on misunderstanding. This underscores the need to fully inform people about ambiguity and to identify and correct misconceptions that may underlie various responses to it. For example, in response to the ambiguity represented by statistical confidence intervals, respondents in our study formed judgments about source credibility and the mutability of colon cancer risk. Such judgments, however, have no logically necessary relationship to the existence of confidence intervals per se and would not justify ambiguity aversion from a normative standpoint. Misunderstandings of the meaning of confidence intervals would thus be important to identify and address in risk communication efforts.

At a more fundamental level, Winkler[76] has also observed incisively that ambiguity aversion may reflect an erroneous belief in the existence of a single "true" objective probability for individual events and a discomfort with not knowing this probability. The communication of ambiguity may therefore entail a broader need to ensure people's understanding that all risk estimates—whether accompanied by information about ambiguity or not—represent uncertain expressions of subjective belief rather than exact accounts of some objective reality.

Because this subjective interpretation of probability construes risk estimates solely as expressions of epistemic uncertainty,[85,86] one might argue that the concept of ambiguity (i.e., of uncertainty about probability) becomes unnecessary,[87,88] and that ambiguity aversion simply boils down to risk aversion. In theory, however, one can be more or less uncertain about even subjective probability beliefs, and the concept of ambiguity gives expression to this additional uncertainty.[27] Furthermore, ample empirical evidence suggests that in practice, people—both experts and laypersons alike—do distinguish between probability and uncertainty about probability, treating risk estimates as if they were objective and responding differently when they are accompanied by information about their adequacy, reliability, or credibility.[68,76,89]

The critical question, therefore, is not whether ambiguity matters to people but why, as well as how various cognitive biases and errors that underlie some responses to ambiguity might be overcome. This is an open question given the many known barriers to informed decision making, including low numeracy—in the context of which the provision of added information about ambiguity may simply end up confusing people. The communication of ambiguity—and of uncertainty more generally—therefore poses formidable challenges, which further pertain not only to the use of disease risk prediction models but also to risk communication efforts in other decision-making domains both in and outside of health care. Helping people to understand and respond optimally to uncertainty in these circumstances requires a clearer understanding of what ambiguity is, how it is perceived by people, why people respond to ambiguity in different ways, and what communication approaches are appropriate and feasible. The current study provides preliminary insights for further research to address these important questions.

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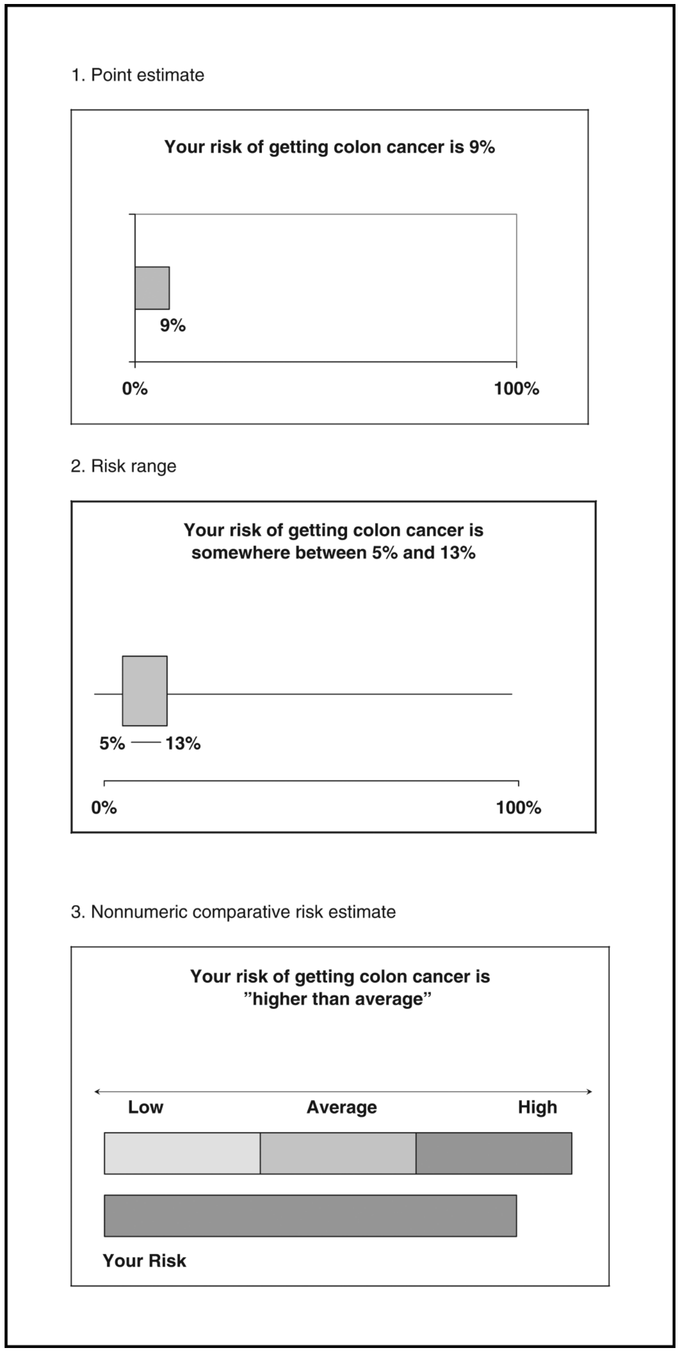

Figure 1.
Visual displays used in the study.

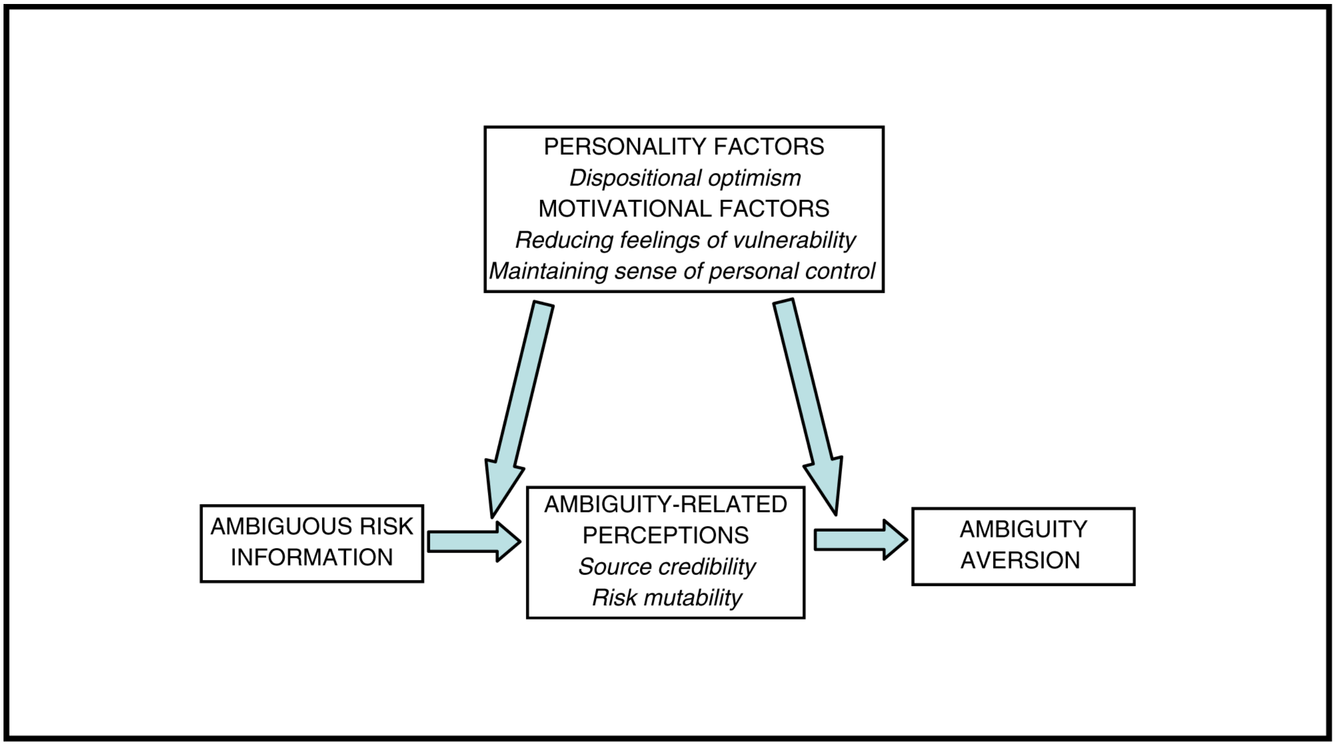

Figure 2.
Theoretical model of ambiguity aversion.

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Table 1

Eligibility Criteria

Age 50 to 74
Minimum education level of high school diploma, maximum level of master's degree
Personal computer use of at least once per month
Not employed in health, computer programming, mathematical, or statistical fields
Responsible for making one's own health decisions
No personal history of cancer
No history of cancer in household members

Table 2

Focus Group Composition

		Perceived Colon Cancer Risk	
		Low	**High**
Gender	Male	Low subjective numeracy (*n* = 6)	Low subjective numeracy (*n* = 3)
		High subjective numeracy (*n* = 8)	High subjective numeracy (*n* = 6)
	Female	Low subjective numeracy (*n* = 7)	Low subjective numeracy (*n* = 6)
		High subjective numeracy (*n* = 8)	High subjective numeracy (*n* = 4)

Table 3

Characteristics of Focus Group Participants

	Total: 8 Groups (*n* = 48)		Washington, DC Metropolitan Area 4 Groups (*n* = 22)				Chicago, IL Metropolitan Area 4 Groups (*n* = 26)			
			Women 2 Groups (*n* = 11)		Men 2 Groups (*n* = 11)		Women 2 Groups (*n* = 14)		Men 2 Groups (*n* = 12)	
Participant Characteristics	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Age										
50–59	29	60	6	55	6	55	10	71	7	58
60–69	16	33	3	27	4	36	4	29	5	42
70–74	3	6	2	18	1	9	0	0	0	0
Race/ethnicity										
White/Caucasian	27	56	7	64	5	45	9	64	6	50
African American	19	40	3	27	6	55	4	29	6	50
Hispanic	2	4	1	9	0	0	1	7	0	0
Other	0	0	0	0	0	0	0	0	0	0
Highest level of education										
High school graduate	1	2	0	0	1	9	0	0	0	0
Some college	22	46	2	18	6	55	7	50	7	58
College graduate	16	33	5	45	2	18	5	36	4	33
Postgraduate	9	19	4	36	2	18	2	14	1	8
Perceived colon cancer risk										
Low	29	60	7	64	8	73	8	57	6	50
High	19	40	4	36	3	27	6	43	6	50
Subjective numeracy										
Low	22	46	7	64	3	27	6	43	6	50
High	26	54	4	36	8	73	8	57	6	50

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Table 4

Frequencies of Written Responses to Structured Questions

	N (%)[a]	95% CI
Result that is more understandable		
Point estimate	22 (46.8)	33.1–60.9
Range	17 (36.2)	23.6–50.4
Both/neither	8 (17.0)	8.4–29.6
Result that seems more accurate		
Point estimate	21 (44.7)	31.1–58.9
Range	24 (51.1)	37.1–64.9
Both/neither	1 (2.1)	0.2–9.5
Result that would worry you more		
Point estimate	17 (36.2)	23.6–50.4
Range	27 (57.4)	43.2–70.8
Both/neither	3 (6.4)	1.8–16.1
Result that would make you feel at greater risk[b]		
Point estimate	14 (38.9)	24.3–55.2
Range	20 (55.6)	39.4–70.8
Both/neither	2 (5.6)	1.2–16.7

Note: CI = confidence interval.

[a] Total n = 47 for all 8 groups.

[b] Question asked only in groups 3 to 8 (n = 36).