Uncertainty Visualization in Cancer Prognoses: The Effect of Communicating Epistemic Uncertainty in Icon Arrays on Perceived Risk, Perceived Uncertainty, and Worry

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Abstract

Individualized prognostic tools, which use statistical models to provide individualized survival rates and predict the course of a disease, often contain epistemic uncertainty (i.e., the uncertainty that results from a lack of data or inaccurate probability estimates). While healthcare professionals (HPs) are aware of epistemic uncertainty, they often do not communicate it to patients. Many patients are not used to thinking in terms of probability, so it can be challenging for them to understand uncertainty in predictions. This study aimed to understand the impact of communicating epistemic uncertainty on ambiguity aversion (i.e., discomfort with uncertain situations), manifested by perceived risk, perceived uncertainty, and worry using two uncertainty visualization formats in icon arrays: the blurring vs. the stepwise color change visualization format. In addition, this study examined whether dispositional optimism and subjective numeracy moderated the effect of the visualization format on ambiguity aversion. A total of 162 people participated in an online experiment with a quasi-experimental design, manipulating the format and assessing the individual differences in subjective numeracy and dispositional optimism. The results showed that communicating epistemic uncertainty did not lead to ambiguity aversion; participants did not perceive more risk, uncertainty, or worry after one of the uncertainty visualizations was presented to them. Subjective numeracy and dispositional optimism did not moderate the effect of the visualization format on ambiguity aversion. Therefore, HPs could consider communicating epistemic uncertainty using the blurring or stepwise visualization format in icon arrays, as it does not lead to ambiguity aversion in the form of heightened perceived risk, uncertainty, and worry.

Keywords: epistemic uncertainty, individualized prognostic tools, ambiguity aversion, uncertainty visualization, perceived risk, perceived uncertainty, worry

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Uncertainty Visualization in Cancer Prognoses: The Effect of Communicating Epistemic Uncertainty in Icon Arrays on Perceived Risk, Perceived Uncertainty, and Worry

The use of individualized prognostic tools has increased rapidly in oncology in recent years (Harrison et al., 2019). Individualized prognostic tools are based on statistical models and are used to provide individualized survival rates and predict the course of the disease. These tools consider a wide range of factors, including the type and stage of cancer, the patient's age, overall health, and other personal characteristics (Rabin et al., 2013; Shariat et al., 2008). The goal of using individualized prognostic tools in oncology is to help doctors and patients make more informed decisions about treatment and care by providing an accurate and specific estimate of the likely outcome of the patient's condition (Cartwright et al., 2014; Enzinger et al., 2015). For example, patients can decide to start treatment because there might be a chance of recovery or decide to start with palliative treatments and have end-of-life conversations with relatives (Cartwright et al., 2014). However, communicating individualized prognostic information to patients can be challenging because, to make informed decisions, they also need to understand the underlying uncertainties of prognostic information (Harrison et al., 2019; Politi et al., 2007).

In the context of individualized prognostic tools, uncertainty arises when there is a lack of data (Harrison et al., 2019). For example, the lack of information about underlying factors that govern the progression of their condition (Shariat et al., 2008). Uncertainty can be distinguished into two types of uncertainty: aleatory uncertainty (i.e., the unpredictability of the future) and epistemic uncertainty (i.e., scientific uncertainty; Raphael et al., 2020; van der Bles et al., 2020). Epistemic uncertainty arises due to the lack of data and the lack of accurate probability estimates (e.g., “7% to 15% chance of survival”; Raphael et al., 2020; van der Bles et al., 2020). The communication of epistemic uncertainty can be difficult because patients generally seek clear and definitive answers about their disease and may not be accustomed to think in terms of epistemic uncertainty (Epstein, 2021; Meyer et al., 2021). Therefore, the focus of this study is specifically on epistemic uncertainty.

Often, healthcare professionals (HPs) refrain from communicating epistemic uncertainty to patients to prevent them from misinterpreting the information (Engelhardt et al., 2016; Gigerenzer et al., 2007; Rabin et al., 2013). When patients do not understand the epistemic uncertainty that is communicated, it can eventually lead them to regret their treatment decisions, to have false optimism about recovery, or to lose trust in their doctors because they perceive their doctors as incompetent (Sharia et al., 2008; The et al., 2000, van der Bles et al., 2019). In general, people tend to be aversive to ambiguous information (i.e., ambiguity aversion), which can be manifested by heightened perceived risk, perceived uncertainty, and worry (Ellsberg, 1961; Han et al., 2006; Han et al., 2009). The extent to which patients perceive risk, perceive uncertainty (i.e., the psychological experience of uncertainty and worry) can be affected by the communication of epistemic uncertainty because they might perceive epistemic uncertainty as ambiguous (Ellsberg, 1961; Han et al., 2006; Han et al., 2009; van der Bles et al., 2019).

However, to involve patients more and better in medical decisions, they need to understand and make sense of the communicated epistemic uncertainty (Politi et al., 2007). Therefore, it is essential to consider multiple formats (e.g., verbal, numerical, visual) in which it can be conveyed. For example, multiple studies show that icon arrays (i.e., pictographs) effectively help communicate epistemic uncertainty within healthcare because they allow for visualizing the part-to-whole relationship of the uncertainty group in relation to the risk group and non-risk group (Garcia-Retamero & Galesic, 2010; Recchia et al., 2022; Spiegelhalter, 2011; Tait et al., 2010). In addition, icon arrays have been shown to help people better recall information and decrease risk aversion, especially for people with low numeracy skills, because they provide a visual representation of the likelihood of different outcomes (Ancker et al., 2006; Peters et al., 2007; Recchia, 2022). However, little is known about the best ways to visualize epistemic uncertainty within icon arrays. Therefore, the effects of different visualization formats for visualizing epistemic uncertainty in icon arrays need to be examined.

This study explores two formats for visualizing epistemic uncertainty in icon arrays: the stepwise color change format from Raphael et al. (2020) and the blurring visualization format from MacEachren et al. (2012). The stepwise color change approach visualizes an uncertainty range by changing the color of the risk group step by step into the color of the non-risk group (Raphael et al., 2020). The stepwise uncertainty visualization was developed with patient advocates and HPs, but the effects of the stepwise uncertainty visualization have never been systematically tested. In addition, the blurring (i.e., fuzziness) visualization format presents the uncertainty by blurring the uncertainty range. The blurring format effectively conveys uncertainty because people intuitively interpret blurring as uncertainty (MacEachren et al., 2012). However, whether the stepwise color change approach and the blurring visualization formats effectively convey epistemic uncertainty in icon arrays and can be valuable for individualized prediction tools and what their effect is on perceived risk, uncertainty, and worry has yet to be empirically tested.

The effect of the uncertainty visualization format on perceived risk, uncertainty, and worry may be influenced by individual differences. People differ in their responses to uncertainty based on their characteristics, experiences, and cognitive abilities (Han et al., 2012; Peters et al., 2006; Peters et al., 2007; Scheier & Carver, 2018; van der Bles et al., 2019). For example, patients with low numeracy skills (i.e., lower ability to understand numbers) may be affected differently by the communication of epistemic uncertainty than patients with high numeracy skills. Patients with low numeracy have more difficulty understanding and interpreting quantitative information, such as probabilities or confidence intervals, and are, therefore, more likely to perceive risk inaccurately (Ancker et al., 2006;

Peters et al., 2006; van der Bles et al., 2019). In addition, dispositional optimism (i.e., a personality trait that refers to a person's tendency to expect positive outcomes) can also influence how people perceive communicated epistemic uncertainty. Individuals with low dispositional optimism have been shown to be more ambiguity averse (i.e., discomfort with uncertain or unclear situations; Han et al., 2006). Therefore, this study examines whether dispositional optimism and numeracy moderate the effect of communicating epistemic uncertainty within icon arrays on perceived risk, perceived uncertainty, and worry.

To conclude, more research needs to be conducted on visualizing epistemic uncertainty in icon arrays. In addition, no research has examined the effects of the blurring uncertainty visualization format and the stepwise uncertainty visualization format in icon arrays on perceived risk, perceived uncertainty, and worry and whether numeracy and dispositional optimism influence how people perceive the formats for visualizing epistemic uncertainty in icon arrays (Han et al., 2012; Peters et al., 2007; Recchia, 2022). Therefore, the following research question is formulated:

RQ: "*What are the effects of uncertainty visualization format (blurring vs. stepwise color change vs. no uncertainty) in icon arrays on perceived risk, perceived uncertainty, and worry and how do subjective numeracy and dispositional optimism moderate these effects?"*

Theoretical Framework

Definitions and sources of uncertainty

There are many definitions, types, sources, and expressions of uncertainty because uncertainty can occur in various contexts (van der Bles et al., 2019). According to the Cambridge dictionary, uncertainty can be referred to as "a situation in which something is not known, or something that is not known or certain" (Cambridge Dictionary, 2022b), and describes "uncertain", among other things, as "not knowing, not fixed, not certain, and unclear" (Cambridge Dictionary, 2022a). Wynne (1992) states that, within the more general scientific context, uncertainty about scientific knowledge that is consistent with a specific situation is called ‘indeterminacy’, and uncertainty that arises due to not knowing all the facts is called ‘ignorance’. When there is uncertainty about effects, Stirling (2007) refers to this as ‘ambiguity’, and when both probabilities and effects cannot be described with certainty, it is labeled ‘ignorance’. However, this study specifically focuses on epistemic uncertainty, and therefore, this is the type of uncertainty that will be discussed from now on.

According to Han (2012), there are three sources of uncertainty in health care: complexity, probability, and ambiguity. Complexity refers to aspects of risk information that reduce the understandability of the information or lead to information overloads, such as multiplicity in outcomes or conditional probabilities (Han, 2012). Probability can be referred to as the indeterminacy of future outcomes (Han, 2012). Ambiguity is a source of epistemic uncertainty, referred to as “the lack of reliability, credibility, or adequacy of information about probability” (Han, 2012, p. 4). Ambiguity occurs when risk information is unclear or uncertain and can be caused by information that contradicts itself or can be understood in multiple ways (Han et al., 2011).

Effect of communicating epistemic uncertainty

Research has shown that ambiguity can heighten risk perceptions and can lead to reluctance in decision-making because people tend to be uncomfortable in uncertain situations (Johnson & Slovic, 1995). People have the psychological need to have a sense of control and to be able to predict specific outcomes (Fiske, 2018). The discomfort with uncertain or unclear situations is referred to as ambiguity aversion. Ambiguity aversion occurs when people's ability and willingness to accept uncertainty and risk is low (Ellsberg, 1961). Individuals can be either ambiguity-seeking or ambiguity averse. Individuals that seek ambiguity revise risk estimations upwards, reflecting an optimistic bias (Han et al., 2006). On the contrary, ambiguity-averse people tend to avoid uncertain situations. They revise risk estimations downward, suggesting a pessimistic bias (Han et al., 2006). Thus, ambiguity-averse individuals perceive more risk and uncertainty when they find themselves in an uncertain situation (Han et al., 2012; van der Bles et al., 2020).

An experiment that demonstrates ambiguity aversion is The Ellsberg paradox. In the experiment, people were asked to bet on one of two options with equal chances of winning (Ellsberg, 1961). Participants in the experiment had to draw a red or black ball from either an urn with 50 black and 50 red balls or from an urn with an unknown number of red and black balls. Although the probability of drawing a black or a red ball was equal, most people decided to bet on the option with a certain probability instead of an uncertain one (Ellsberg, 1961). The experiment shows that when people are faced with ambiguous information, they tend to assume that the likelihood of the ambiguous option is lower than it actually is and instead choose the unambiguous option (Ellsberg, 1961; Han et al., 2006). In other words, the experiment demonstrates that people perceive more uncertainty and risk when information is uncertain than when information is certain. In addition, Han et al. (2009) conducted a qualitative study in which a risk estimate containing a range (i.e., epistemic uncertainty) and a point estimate (i.e., no uncertainty) were presented to different focus groups. They found that most participants perceived more risk and reported more worry when the risk estimate with epistemic uncertainty (compared to without uncertainty) was presented to them (Han et al., 2009).

To conclude, people generally perceive ambiguity as unfavorable, and communicating epistemic uncertainty can lead to the occurrence of ambiguity aversion (Han et al., 2009). Ambiguity aversion can be reflected in increased perceived risk, worry, and perceived uncertainty (Ellsberg, 1961; Han et al., 2006; Han et al., 2009; van der Bles et al., 2019). Perceived uncertainty, or the psychological experience of uncertainty, can be referred to as the "subjective feeling of 'not knowing'" (van der Bles et al., 2019, p. 20). It can, therefore, be an indicator of ambiguity aversion (van der Bles et al., 2019). Thus, in this study, perceived uncertainty is different from epistemic uncertainty and is measured as an effect of the communication of epistemic uncertainty.

Visualizing epistemic uncertainty using icon arrays

The effect of communicating epistemic uncertainty may vary by the format in which it is presented (van der Bles et al., 2019). Epistemic uncertainty can be expressed extensively and in detail or by briefly naming it. Furthermore, it can be presented in a verbal, numerical, or visual format or by combining these three formats (van der Bles et al., 2019). Icon arrays are helpful when communicating uncertainty in risk estimates because they visualize the part-to-whole relationship (Spiegelhalter et al., 2011). Thus, through icon arrays, the relationship between the risk group, no-risk group, and uncertainty group is visible at once, which is especially helpful for individuals with low numeracy skills (Peters et al., 2007; Spiegelhalter et al., 2011; Garcia-Retamero & Galesic, 2010). Furthermore, also in particular for individuals with low numeracy skills, compared to bar charts, the information that is conveyed in icon arrays is easier to understand and recall (Peters et al., 2007; Spiegelhalter et al., 2011). Little is known about the effects of communicating epistemic uncertainty within icon arrays on ambiguity aversion, but given that communicating epistemic uncertainty in icon arrays may cause people to understand that there is uncertainty in their prognosis (Peters et al., 2007; Spiegelhalter et al., 2011), it is expected that they perceive more risk, uncertainty, and worry. Therefore, the following hypothesis was formulated:

H1: Communicating epistemic uncertainty (compared to not communicating epistemic uncertainty) in icon arrays leads to ambiguity aversion, manifested by (H1a) more perceived risk, (H1b) more perceived uncertainty, and (H1c) more worry.

Furthermore, little research has been done on visualizing the epistemic uncertainty in icon arrays. When looking at ways to visualize epistemic uncertainty, blurring (i.e., fuzziness) can be helpful (MacEachren et al., 2012). According to MacEachren et al. (2012), blurring is highly intuitive for uncertainty visualization (MacEachren et al., 2012; Padilla et al., 2021). The concept of 'natural mappings' explains that when the visualization of information (e.g., epistemic uncertainty) matches how the viewer thinks about the information naturally, it takes them fewer cognitive resources to process it (Padilla et al., 2021; Steuer, 1992). Thus, the blurring uncertainty visualization format can be beneficial for visualizing epistemic uncertainty within icon arrays because it matches individuals' natural thinking (MacEachren et al., 2012; Padilla et al., 2021).

Another way of visualizing epistemic uncertainty in icon arrays is by stepwise changing the color of the icons that fall within the uncertainty range (Raphael et al., 2020). The stepwise color change approach is based on using fading colors. However, Raphael et al. (2020) concluded that fading colors did not clearly visualize the contrast between groups. Therefore, instead of fading the colors from the risk group to the non-risk group, the icons in the uncertainty group were step-by-step colored from the risk group's color to the non-risk group's color (Raphael et al., 2020). Although the format for visualizing epistemic uncertainty was developed with HPs and patients, this format is not yet empirically tested (Raphael et al., 2020). In addition, it is not yet examined whether blurring and stepwise uncertainty visualization lead to more perceived risk, perceived uncertainty, and worry. However, since the blurring technique is highly intuitive for visualizing uncertainty (MacEachren et al., 2012), people might interpret the uncertainty range more naturally and interpret the communicated epistemic uncertainty more accurately than when uncertainty is visualized using the stepwise color change format. Therefore, the following hypothesis was formulated:

H2: Blurring the uncertainty range (compared to the stepwise color change approach) in icon arrays leads to greater ambiguity aversion, manifested by (H2a) more perceived risk, (H2b) more perceived uncertainty, and (H2c) more worry.

Individual differences

Individual differences can influence the effect of the uncertainty visualization format on ambiguity aversion. Individuals with low dispositional optimism (i.e., a personality trait that refers to an individual's tendency to expect positive outcomes) could perceive more risk, uncertainty, and worry than highly optimistic people (Han et al., 2010). Han et al. (2010) found that dispositional optimism moderated the effect of communicating uncertainty on ambiguity aversion. In the experiment, participants were presented with visual and textual formats for communicating risk estimates with either ambiguity (i.e., uncertainty) present or absent. They found that people with high (compared to low) dispositional optimism were less ambiguity averse when uncertainty was presented to them, which was manifested by higher perceived risk and worry (Han et al., 2010). Based on these results and on the theory that ambiguity-averse people tend to reflect a pessimistic bias (Han et al., 2006), the following hypothesis was formulated:

H3: The effect of uncertainty visualization format on perceived risk, perceived uncertainty, and worry is moderated by dispositional optimism such that low dispositional optimism (compared to high dispositional optimism) leads to greater ambiguity aversion, manifested by (H3a) higher perceived risk, (H3b) higher perceived uncertainty, and (H3c) more worry.

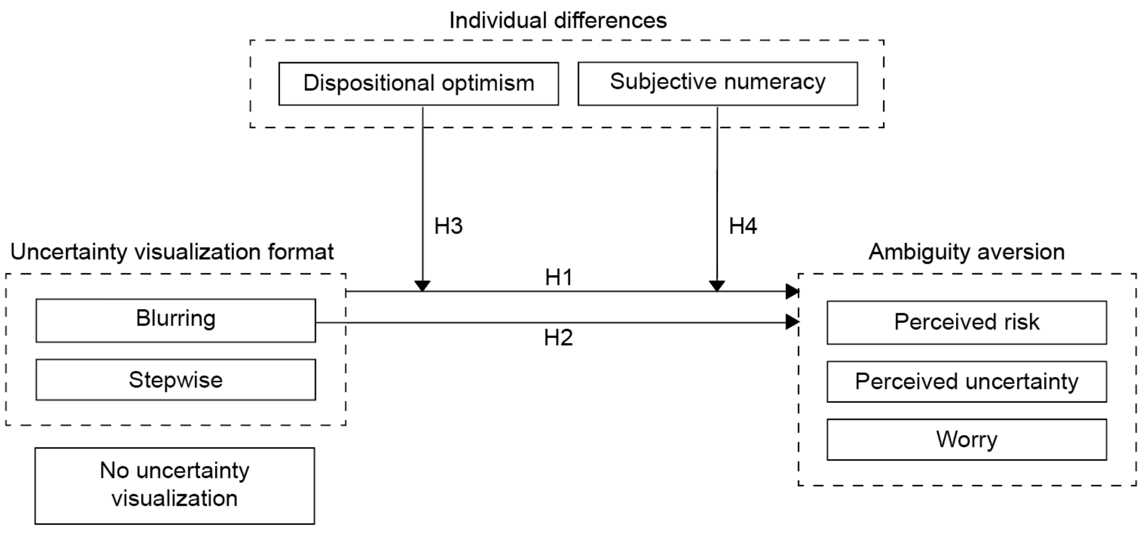
Moreover, the effect of the visualization of epistemic uncertainty on ambiguity aversion can be influenced by people’s numeracy level (Spiegelhalter, 2011). Numeracy can be referred to as the ability to understand and work with numbers (Peters et al., 2007; Yang, 2020). Lack of numeracy skills could hinder patients' comprehension of epistemic uncertainty in prognostic information and hinder their ability to make informed decisions about treatment or care (Peters et al., 2007). Thus, people with low numeracy can perceive epistemic uncertainty as more ambiguous than people with high numeracy (Peters et al., 2007; Schapira et al., 2001; Yang, 2020). Therefore, they could perceive more risk, uncertainty, and worry when epistemic uncertainty is communicated than when it is not communicated (Spiegelhalter, 2011; van der Bles et al., 2019). Therefore, the following hypothesis was formulated:

H4: The effect of uncertainty visualization format on perceived risk, perceived uncertainty, and worry is moderated by subjective numeracy such that low subjective numeracy (compared to high subjective numeracy) leads to greater ambiguity aversion, manifested by (H4a) higher perceived risk, (H4b) higher perceived uncertainty and (H4c) more worry.

An overview of the four hypotheses is shown in the conceptual model in Figure 1.

Figure 1

Conceptual model of the four hypotheses



Method

Design

An online experiment with a quasi-experimental design was performed to examine the effects of uncertainty visualization formats in icon arrays in the communication of epistemic uncertainty in cancer prognoses on perceived risk, perceived uncertainty, and worry. The study contained three experimental conditions: blurring uncertainty visualization vs. stepwise uncertainty visualization vs. no uncertainty visualization (control condition). Participants were randomly assigned to one of the three conditions. The dependent variables perceived risk, perceived uncertainty, and worry were measured within subjects. In addition, the moderating effects of dispositional optimism (high vs. low) and subjective numeracy (high vs. low) on the effect of visualization in icon arrays on perceived risk, perceived uncertainty, and worry were also measured within subjects.

Participants

A priori power analysis was performed using the G*Power program to determine the sample size for the experiment. With a medium-sized effect $d = 0.50$ and power of 0.80, the power analysis revealed a sample of 159 participants with three equal-sized groups ($N = 53$). Participants were required to have a minimum age of 45 because this study used a hypothetical scenario involving a colorectal cancer diagnosis, and 90% of all patients diagnosed with colorectal cancer are 50 years or older (*Darmkanker*, n.d.). In addition, participants were required to be Dutch because this was the language used in the experiment since the experiment was distributed in the Netherlands, and it contained a hypothetical scenario with which it was essential to empathize.

Materials

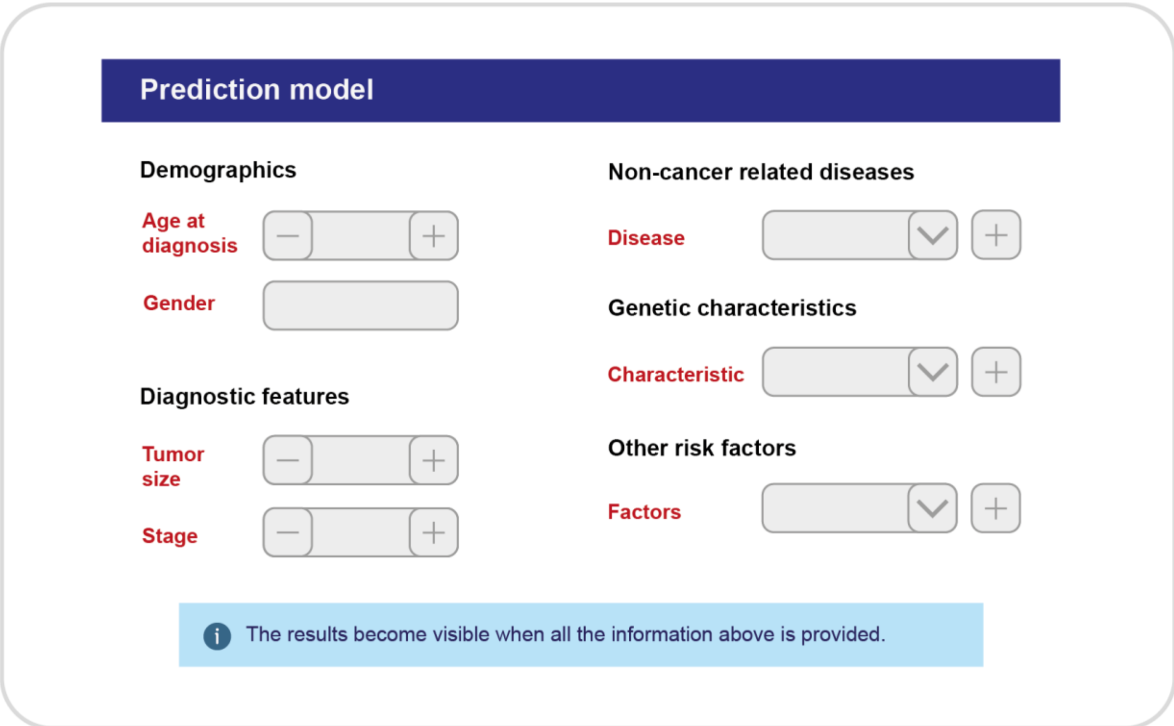
First, the stimuli for the hypothetical scenario were created. The scenario was based on theories described in the theoretical framework and started with a short description:

"Imagine you have been diagnosed with colorectal cancer. The examination revealed that you are dealing with stage 2 colon cancer, meaning that the tumor has grown through the muscle layer of the bowel wall but has not yet metastasized to other parts of the body. The doctor uses a prediction model to make the best possible estimate of your life expectancy five years from now. The doctor uses a mathematical model in which she enters various data about you. She also fills in risk factors, such as whether you smoke."

In addition to the description of the hypothetical scenario, a prediction model was displayed in the experiment in which it became clear which patient characteristics would be put in (Figure 2).

Figure 2

Prediction model displayed in the experiment

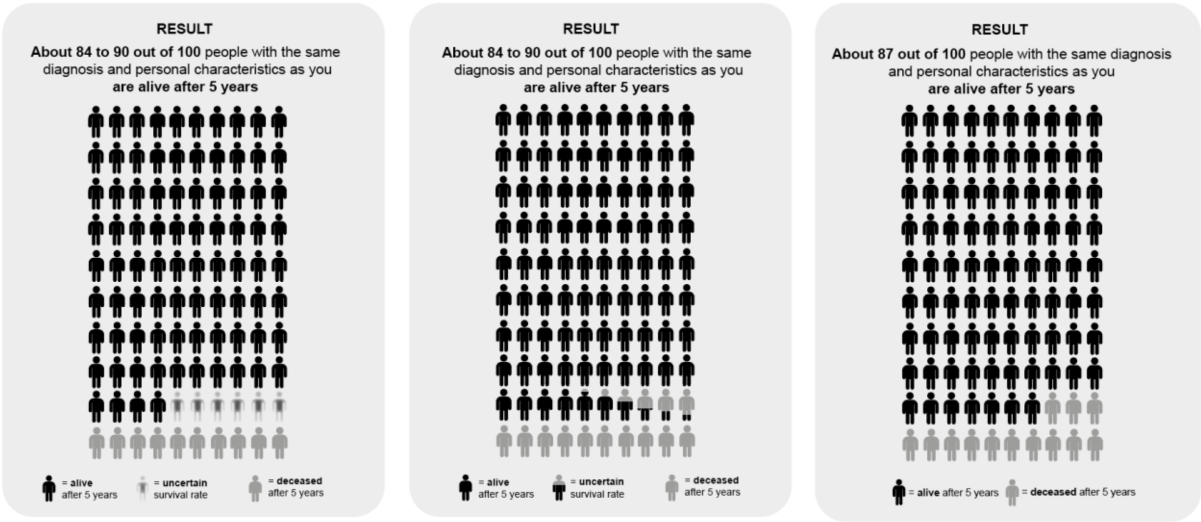


Stimuli materials were developed for the three conditions. All icon arrays contained 100 icons, of which ten grey icons (13 in the no-uncertainty visualization) represented the group of deceased patients after five years of their first diagnosis. The black icons represented people still alive five years after their first diagnosis. It was chosen to exclude colors within the visualization to control for a potential effect of color use. All visualizations were accompanied by a descriptive text and a legend in which it became clear that the black icons showed the group that was predicted to still be alive after five years. The grey icons showed the group that was deceased after five years. The number of people still alive after five years was based on the Dutch website for information about cancer prognoses (*Overlevingscijfers Van Darmkanker*, 2022). However, since there was no information about a specific uncertainty range, the uncertainty range was not based on actual numbers. The materials were icon arrays (pictographs) in which the epistemic uncertainty range was either visualized by blurring the uncertainty range, which is based on the study of MacEachren et al. (2012) or visualized by using Raphael et al.'s (2020) stepwise color change approach. Both uncertainty visualization formats (blurring and stepwise color change) can be seen in Figure 3. In the stimulus for the control group, there was no visualization of uncertainty, meaning only a point estimate was shown, which can also be seen in Figure 3.

All visualization contained a text in which the frequency was described as "about 84 to 90 out of 100", because, according to Gigerenzer's (1996), frequency-framing hypothesis, people naturally understand frequencies or ratios (e.g., 20 out of 100) better than the communication of probabilities as percentiles (e.g., 20% chance), and when presenting ratios, constant denominators and powers of 10 (e.g., 1 in 100) are easier to comprehend (Spiegelhalter et al., 2011). No explanation was given to participants in the experiment about the visualization of epistemic uncertainty because that might have influenced the potential effects of the visualization.

Figure 3

Blurring, stepwise, and no-uncertainty visualization formats



Note. From left to right: blurring uncertainty visualization, stepwise color change uncertainty visualization, no-uncertainty visualization

Pretest

A pretest was conducted among 11 adults (Mage = 49) to measure (within subjects) whether people (nine women, two men) could empathize with the hypothetical scenario and whether they recognized if uncertainty was communicated in the stepwise, blurring, and no-uncertainty visualization format. A complete overview of the pretest questionnaire can be found in Appendix A. The pretest revealed that uncertainty was perceived in the blurring uncertainty visualization (M = 4.22, SD = .62, *minimum* = 1, *maximum* = 5), as well as in the stepwise uncertainty visualization (M = 4.27, SD = .56, *minimum* = 1, *maximum* = 5). In addition, participants also accurately interpreted that the no-uncertainty visualization (M = 1.60, SD = .84, *minimum* = 1, *maximum* = 5) did not contain uncertainty. An overview of all the pretest results can be found in Appendix C.

Measures

Dependent variables

Perceived risk was measured using two adapted items (Han et al., 2012). The first item was: "Based on the prognosis you just received, how likely do you think it is that you will still be alive in five years?" adapted from the Health Information National Trends Survey (n.d.). This item was also presented in an opposing question statement. The second item was adapted from Han et al. (2012): "If I received these results, I would feel that I am still alive in five years" (Han et al., 2012). All items were rated on a 7-point Likert scale (1 = *totally agree*, 7 = *totally disagree*). After recoding the reversed item, scores were averaged. Cronbach's alpha revealed an acceptable reliability (α = .70) for this scale.

Perceived uncertainty was measured using two items adapted from van der Bles et al. (2020) and one from Lipkus et al. (2001). The three items were averaged. Example items were: "To what extent do you think that the prognosis in the visualization is certain or uncertain?" and "How much uncertainty do you think there is about the 5-year life expectancy estimate?". Participants could indicate their answers on a 7-point Likert scale (1 = *very certain*, 7 = *very uncertain*). The scale had acceptable reliability (α = .76).

Worry about dying was measured using the combination of two items from two studies. The first one was adjusted from Han et al. (2012): "If you received these results, to what extent would you feel worried about dying from colorectal cancer?". The second item, adapted from Rodenbach et al. (2021), was: "If you received these results, to what extent would you feel scared about your future?". Participants were asked to indicate their answers on a 5-point Likert scale (1 = *not at all worried*, 5 = *extremely worried*). Items were averaged and had good reliability (α = .84).

Moderators

Dispositional optimism was assessed using the optimism scale of the Life Orientation Test (Scheier et al., 1994). On a 5-point Likert scale, participants could indicate their answers to six statements. For example: "I am always optimistic about my future" and "I hardly ever expect things to go my way” (Scheier et al., 1994). After reverse coding some of the items, scores were averaged. Overall, the scale had good reliability (α = .80).

Subjective Numeracy was assessed using the Subjective Numeracy Scale, adapted from Fagerlin et al. (2007). Eight subjective numeracy items were presented to participants, of which four were about their mathematical skills. Answers were indicated on a 6-point Likert scale. An example item was: “How good are you at working with fractions?” (1 = *not at all good*, 6 = *extremely good*). The last four subjective numeracy items measured participants’ preferences for presenting numerical information (Fragerlin et al., 2007). For example, “Imagine you are listening to a weather forecast. Do you prefer predictions using percentages (e.g., ‘‘there will be a 20% chance of rain today’’) or predictions using only words (e.g., ‘‘there is a small chance of rain today’’)?” (1 = *always prefer percentages*, 6 = *always prefer words*). After reverse coding the seventh item, scores were averaged (Fragerlin et al., 2007). The scale showed good reliability (α = .85).

Control variables

To measure whether participants perceived the hypothetical scenario as relevant, *perceived relevance* of the scenario was measured using two items: “If I received these results, I would feel that the life expectancy prognosis would be personalized for me” and “If I received these results, I would find the way the life expectancy prognosis was given relevant to me” (1 = *totally disagree*, 5 = *totally agree*; Lustria et al., 2016; Vromans et al., 2020). In addition, to measure the extent to which participants could empathize with the hypothetical scenario, ‘*empathize* with the scenario’ was measured by two statements. For example, “It was easy to empathize with the scenario (1 = *totally disagree*, 5 = *totally agree*)”.

Procedure

Qualtrics was used for establishing and conducting the online experiment. Participants were recruited through convenience sampling. When participants started the experiment, they were shown the information letter in which the study was explained, and participants were informed that the study could evoke unpleasant emotions because it contained a hypothetical scenario in which they had to imagine they were diagnosed with cancer. Second, participants were asked to permit to the informed consent. Third, they were asked about their age, gender, level of education, and whether they had personal experiences with cancer (e.g., whether they or a family member was ever diagnosed with cancer). Then, participants were shown the hypothetical scenario and instructed to imagine they were diagnosed with stage two colorectal cancer. Stage two colorectal cancer was chosen because this has a relatively high 5-year survival rate when found early (*Colorectal Cancer - Statistics*, 2022), making it ethically justifiable to let participants imagine the hypothetical scenario. In addition, cancer occurs in both men and women, allowing the experiment to be conducted among men and women.

Next, participants were shown information about the use of prognostic tools in oncology and were told that they would receive a prognosis about their 5-year life expectancy using a prognostic tool. Participants were randomly assigned to one of the three conditions: they either saw an uncertainty visualization using ‘blurring’ or a visualization of uncertainty using stepwise color change or no visualized uncertainty (control group). Participants were asked to take the time to observe the visualization of their hypothetical prognosis. When they continued the survey, items were presented regarding perceived risk, perceived uncertainty, worry, subjective numeracy, and dispositional optimism. Finally, the experiment ended with a debriefing, thanking participants for their participation, explaining the purpose of the study, and directing them to a cancer support website in case the experiment had evoked unpleasant feelings. The entire experiment can be found in Appendix B.

Data analysis

First data was downloaded from Qualtrics, and SPSS version 29 was used to clean up and structure the data, recode variables, and to compute variables. First, reliability analysis using Chronbach's alpha was performed to measure the internal consistency of the scale items. Second, normality tests and tests for homogeneity were performed. Then separate Factorial ANOVAs were performed for each dependent variable (perceived risk, perceived uncertainty, and worry). Finally, the variables 'conditions', 'subjective numeracy', and 'dispositional optimism' were put in as fixed factors in all three ANOVAs.

To test the first hypothesis, it was analyzed whether there was a direct effect of the condition participants were in. Next, a Helmert contrast analysis was performed to analyze whether there was a difference between the uncertainty and the no-uncertainty conditions. To test the second hypothesis, the same Helmert contrast analysis results were used to determine if there was a difference in effect between the stepwise color change and the blurring uncertainty visualization conditions. Next, interaction effects were analyzed to examine the moderation effects as proposed in the third and fourth hypotheses. Then to analyze the influence of the control measures, Pearson's correlation tests were performed to measure whether there was a relationship between participants' personal experience with cancer and perceived risk, perceived uncertainty, and worry. Furthermore, a one-way ANOVA was performed to analyze whether the extent to which participants could empathize with the scenario differed per condition. Lastly, another one-way ANOVA was performed to analyze the extent to which participants perceived the hypothetical prognosis as relevant.

Results

Sample characteristics

In total, 191 Dutch adults clicked the link to start the survey. Of these adults, 188 (98%) gave permission to the consent form. One of those adults was excluded from the study since he did not have the minimum age required. Of all participants who were allegeable to participate in the study, 162 (87%) participants finished the experiment (Figure 4). The sample consisted of 74 men and 88 women. The ages ranged from 45 to 81 years (M = 55.50, *SD* = 7.45). Most participants followed higher or scientific education (69%). In addition, 83% of the participants indicated having personal experience with cancer. In total, 45% of the participants were in the low subjective numeracy group, and 48% were in the low dispositional optimism group. A complete overview of the participant characteristics is shown in Table 1.

Control measures

Pearson's correlation tests revealed no significant relationship between whether participants had *personal experiences with cancer* and perceived risk (r = .10, p = .227), perceived uncertainty (r = -.02, p = .805), and worry (r = .10, p = .210). F(1, 150) = .04, p =.851, η^2 = .00. The one-way ANOVA for *empathizing* with the scenario was not significant (F (2, 161) = .81, p = .446, η^2 = .01), indicating that the extent to which participants could empathize with the scenario did not depend on the condition they were in. The one-way ANOVA for *personal relevance* was also not significant (F (2, 161) = 2.70, p = .071, η^2 = .03), indicating that the condition participants were in did not affect whether they perceived the hypothetical prognosis as relevant.

Figure 4

Data collection process

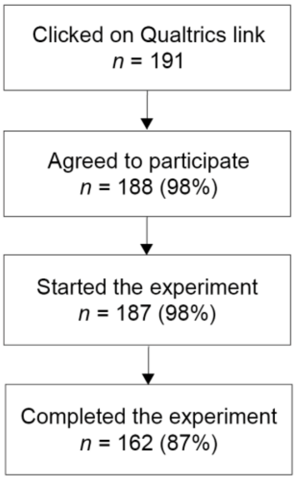


Table 1

Participant characteristics

Characteristics	*n* = 162	%
Gender		
Female	88	54
Male	74	46
Age, mean (SD)	55.5 (7.45)	
45-55	94	58
55-65	53	33
65>	15	9
Education		
Low[a]	13	8
Medium[b]	36	58
High[c]	113	70
Personal cancer experience		
Yes	134	83
No	25	25
Prefer not to say	3	3
Dispositional optimism, mean (SD)	3.78 (.67)	
Low	78	48
High	84	52
Subjective numeracy, mean (SD)	4.7 (.89)	
Low	73	45
High	89	55

Note. [a] = lower vocational education or lower secondary education, [b] = higher secondary education or vocational education, [c] = scientific education or higher professional education.

Perceived risk

Perceived risk was not normally distributed for all visualization conditions (Z*skewness* No uncertainty = 2.93; Blurring = - 2.13; Stepwise = 2.45; Z*kurtosis* No uncertainty = 1.37; Blurring = 0.47; Stepwise = 0.85). Therefore, the p-value may not be reliable, and more weight should be placed on the bootstrapped 95% confidence interval that will be provided.

Homogeneity can be assumed (VR = 1.77). The Factorial ANOVA showed a significant main effect of uncertainty visualization, $F(2, 150) = 5.69$, $p = .004$, $\eta^2 = .07$ (Figure 5). Perceived risk was highest for the no-uncertainty condition ($M = 2.52$, $SD = .99$, 95% CI [2.29, 2.82]), then for the stepwise condition ($M = 2.49$, $SD = .92$, 95% CI [2.33, 2.8]), and lowest for the blurring condition ($M = 2.04$, $SD = .74$, 95% CI [1.82, 2.62]). Helmert contrast analysis revealed no significant difference between the no-uncertainty and the uncertainty conditions ($p = .093$). Therefore, hypothesis 1a, stating that the communication of uncertainty in icon arrays leads to ambiguity aversion, manifested by higher perceived risk, is not supported. Helmert contrast analysis did reveal that perceived risk was significantly higher for the stepwise condition than for the blurring condition ($Mdif = .51$, $p = .004$, 95% CI [.19, .85]). However, since the contrary was predicted, hypothesis 2a, stating that communicating uncertainty by blurring the uncertainty range (compared to the stepwise format) in icon arrays would lead to more ambiguity aversion, manifested by higher perceived risk, is not supported.

Furthermore, perceived risk was not normally distributed for all subjective numeracy conditions (Z*skewness* Low numeracy = 2.37; High numeracy = 4.06; Z*kurtosis* Low numeracy = 0.28; High numeracy = 2.62) and not for all *dispositional optimism* conditions (Z*skewness* Low optimism = 3.39; High optimism = 3.38; Z*kurtosis* Low optimism = 2.43; High optimism = 0.71). However, homogeneity can be assumed for both (VR numeracy = 1.98; VR optimism = 1.15). The ANOVA showed no significant main effect of dispositional optimism on perceived risk $F(1, 150) = 3.30$, $p = .071$, $\eta^2 = .02$, and no significant main effect of subjective numeracy on perceived risk $F(1, 150) = 1.67$, $p = .20$, $\eta^2 = .01$. Furthermore, no interaction between visualization format and subjective numeracy ($F(2, 150) = 1.52$, $p = .222$, $\eta^2 = .02$), and no interaction between visualization format and dispositional optimism ($F(2, 150) = 1.06$, $p = .347$, $\eta^2 = .01$) has been found. Therefore, hypotheses 3a and 4a are not supported; subjective numeracy and dispositional optimism did not moderate the effect of the visualization format on ambiguity aversion, manifested by more perceived risk. Table 2 provides an overview of means and standard deviations for all conditions and moderators.

Figure 5

Mean perceived risk per condition (Error bars: 95% CI)

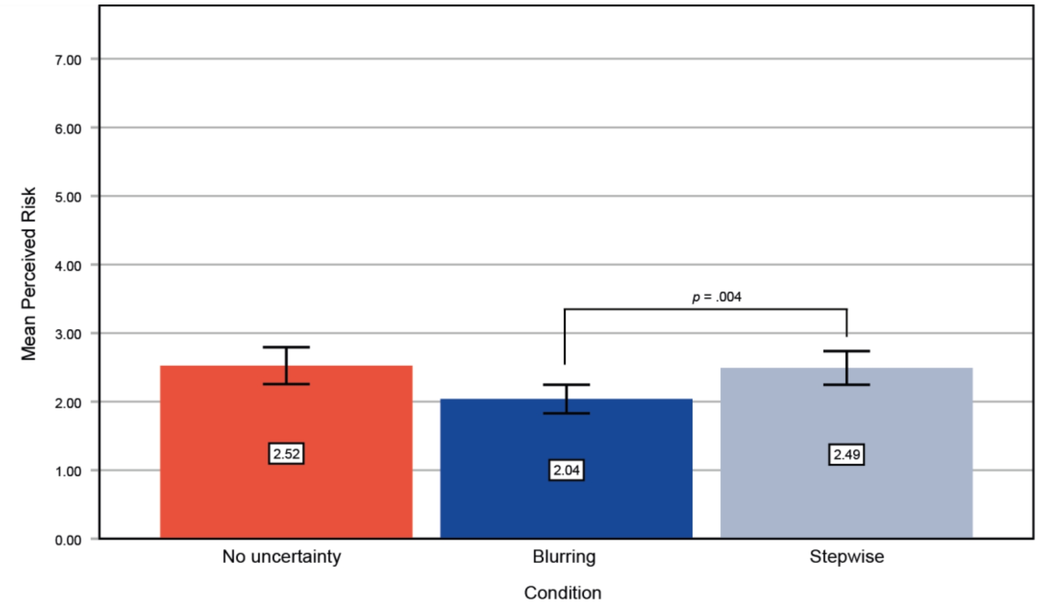


Table 2

Mean (SD) per condition and individual differences

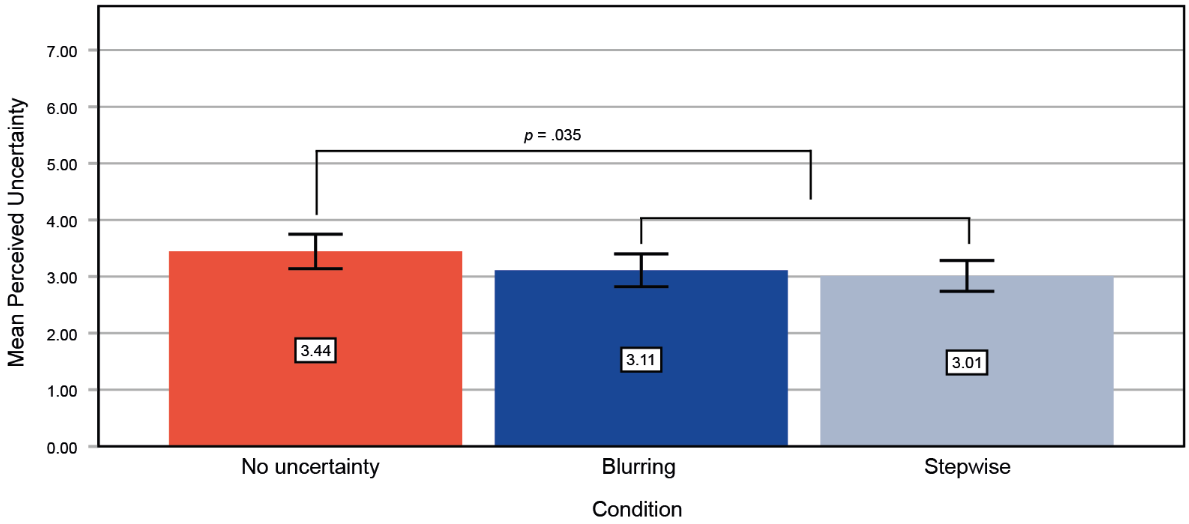
	Visualization format			Numeracy		Optimism	
	Blurring (N = 153)	Stepwise (N = 171)	No-uncertainty (N = 162)	Low (N = 73)	High (N = 89)	Low (N = 78)	High (N = 84)
	M (SD)	*M* (SD)	*M* (SD)	*M* (SD)	*M* (SD)	*M* (SD)	*M* (SD)
Perceived risk	2.04 (.74)	2.49 (.92)	2.52 (.99)	2.48 (1.07)	2.26 (.76)	2.48 (.94)	2.25 (.89)
Perceived uncertainty	3.11 (1.03)	3.01 (1.02)	3.44 (1.11)	3.38 (1.07)	3.03 (1.04)	3.4 (1.04)	2.99 (1.06)
Worry	2.87 (.84)	3 (1)	3.16 (.98)	3.07 (0.94)	2.97 (.96)	3.22 (.93)	2.82 (.92)

Perceived uncertainty

Perceived uncertainty was normally distributed for all visualization conditions, and homogeneity can be assumed (VR = 1.18). The Factorial ANOVA showed no significant main effect of uncertainty visualization, $F(2, 150) = 2.29$, p =.105, $\eta^2 = .03$ (Figure 6). However, Helmert contrast analysis revealed a significant difference between the no-uncertainty condition and the uncertainty conditions ($p = .035$). The visualization format without uncertainty ($M = 3.44$, $SD = 1.11$) led to more perceived uncertainty than the two visualization formats with uncertainty together. Furthermore, Helmert contrast analysis showed no significant difference between the stepwise and the blurring conditions (*Mdif* = .03, $p = .879$). Thus, hypotheses 1b and 2b are not supported; not communicating uncertainty in icon arrays led to more (instead of less) ambiguity aversion, manifested by perceived uncertainty than communicating uncertainty. There were no differences between the stepwise and the blurring visualization formats.

Figure 6

Mean perceived uncertainty per condition (Error bars: 95% CI)



In addition, perceived uncertainty was not normally distributed for the high subjective numeracy condition (Z-score skewness = 2.40; Z-score kurtosis = -0.23). For dispositional optimism, perceived uncertainty was normally distributed. Homogeneity can be assumed for both (VR numeracy = 1.05; VR optimism = 1.04). The ANOVA showed no significant main effect of subjective numeracy, $F(1, 150) = 2.61$, $p = .108$, $\eta^2 = .02$) on perceived uncertainty, but did show a significant main effect of dispositional optimism on perceived uncertainty $F(1, 150) = 5.63$, $p = .019$, $\eta^2 = .01$. Perceived uncertainty was highest for the low optimism group ($M = 3.40$, $SD = 1.05$) and lowest for the high optimism group ($M = 2.30$, $SD = 1.06$). However, no interaction between visualization format and subjective numeracy ($F(2, 150) = .09$, $p = .919$, $\eta^2 = .00$), and no interaction between visualization format and dispositional optimism ($F(2, 150) = .30$, $p = .740$, $\eta^2 = .00$) has been found.

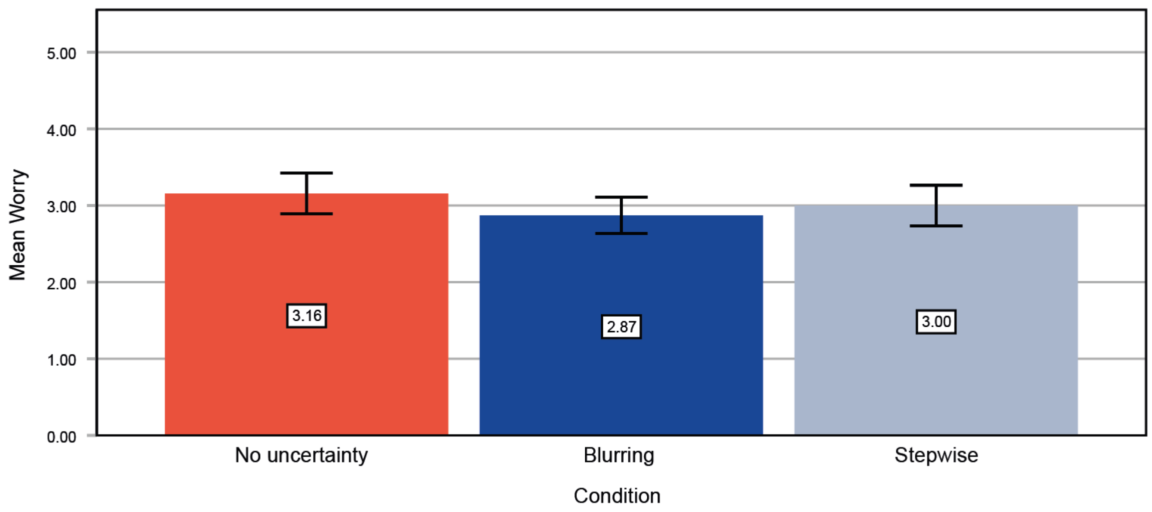
Worry

Worry was normally distributed for all visualization conditions, and homogeneity can be assumed (VR = 1.41). The Factorial ANOVA showed no significant main effect of uncertainty visualization, $F(2, 150) = 2.01$, $p = .138$, $\eta^2 = .03$ (Figure 7). In addition, Helmert contrast analysis also showed no significant difference between the no-uncertainty and the uncertainty conditions ($p = .075$) and no significant difference between the stepwise condition and the blurring condition (*Mdif* = .171, $p = .351$). Therefore, hypothesis 1c, stating that communicating uncertainty leads to more worry, is not supported, and hypothesis 2c, stating that the blurring visualization leads to more worry than the stepwise visualization is also not supported.

Worry was normally distributed for all dispositional optimism and subjective numeracy conditions and homogeneity can be assumed for both (VR numeracy = 1.04; VR optimism = 1.02). The ANOVA showed no significant main effect of subjective numeracy, $F(1, 150) = .04$, $p = .851$, $\eta^2 = .00$) on worry, but did show a significant main effect of dispositional optimism on worry $F(1, 150) = 7.91$, $p = .006$, $\eta^2 = .05$. Worry was highest for the low optimism group ($M = 3.22$, $SD = .93$) and lowest for the high optimism group ($M = 2.82$, $SD = .92$). Furthermore, no interaction between visualization format and subjective numeracy ($F(2, 150) = .02$, $p = .978$, $\eta^2 = .00$), and no interaction between visualization format and dispositional optimism ($F(2, 150) = .14$, $p = .871$, $\eta^2 = .00$) has been found. Therefore, hypothesis 3c is not supported; subjective numeracy and dispositional optimism did not moderate the effect of the visualization format on worry.

Figure 7

Mean worry per condition (Error bars: 95% CI)



Discussion

This study examined the effects of different formats (blurring vs. stepwise vs. no uncertainty) for visualizing uncertainty on people's perceived risk, perceived uncertainty, and worry. Furthermore, it is studied whether dispositional optimism and subjective numeracy moderate the effect of visualization format on the three outcome variables.

The data did not support the first hypothesis that communicating uncertainty in icon arrays leads to ambiguity aversion, manifested by more perceived risk, more perceived uncertainty, and more worry than not communicating uncertainty. Thus, this study shows that when epistemic uncertainty is communicated to people aged 45 or older using the blurring or stepwise visualization format in icon arrays, ambiguity aversion does appear through increased risk, uncertainty, and worry. However, contrary to what was predicted in hypothesis 1b, communicating uncertainty led to less perceived uncertainty than not communicating uncertainty (stepwise and blurring vs. no uncertainty). A possible explanation for this effect is that participants in the no-uncertainty condition perceived more uncertainty because they were aware of the existence of uncertainty. However, because uncertainty was not communicated, they might have felt they had not received all the information which may have caused them to perceive more uncertainty (Johnson & Slovic, 1995).

Data analysis only revealed a significant difference in the effect between the uncertainty visualization formats on perceived risk; participants significantly perceived more risk in the stepwise color change uncertainty visualization than in the blurring uncertainty visualization. This outcome was the opposite of what was predicted in hypothesis 2a. An explanation for this effect on risk perception can be that the uncertainty visualizations might be processed differently by the participants but not as expected. Given the intuitive nature of the blurring uncertainty visualization (McEachren et al., 2012), it was expected that it would be naturally understood better than the stepwise visualization. A possible explanation for this opposite effect might be that the stepwise color change visualization of epistemic uncertainty might have been processed more slowly. The dual-process theory explains two types of mental processes: system one processing includes fast and intuitive thinking, and system two processing includes slow and reflective thinking (Tversky & Kahneman, 1974). The stepwise color change uncertainty visualization may have been processed more in system two and the blurring visualization format more in system one. Thus, participants in the stepwise condition might have reflected more on the visualized uncertainty than participants in the blurring condition and perceived more risk.

This study showed that the effect of the uncertainty visualization format on ambiguity aversion, manifested by perceived risk, perceived uncertainty, and worry, was not moderated by individual differences. Dispositional optimism did not interact with the visualization format. Therefore, the effect of the visualization format on ambiguity aversion is not affected by people's level of optimism when uncertainty is visualized using the blurring or stepwise method. Participants with low dispositional optimism did not perceive more risk, uncertainty, or worry after they were shown the visualization format than participants with high dispositional optimism. In addition, no moderation effect of subjective numeracy was found. A possible explanation can be that this study contained a hypothetical scenario instead of a real scenario, as it is often harder to comprehend numerical information in real healthcare scenarios than in hypothetical ones (Peters et al., 2007). Another explanation can be that the communicated uncertainty was likely equally understandable for the entire sample regardless of their numeracy level. Communicating epistemic uncertainty using the blurring and stepwise visualization formats in icon arrays might have eliminated the difference between people with high and low numeracy skills. However, in this study, the level of understanding of the communicated epistemic uncertainty was not measured. Thus, that has not been proven in this study and will need further investigation.

Limitations

This study contains several limitations. First, the way the survival probability was framed in the hypothetical prognosis may have affected perceived risk, perceived uncertainty, and amount of worry because the prognosis focused on whether patients would still be alive after five years. Results might differ when the estimates were focused on whether patients would be deceased in five years since this is a more negative framing. Furthermore, the chances of survival in the hypothetical prognoses were relatively high (i.e., “84 to 90 out of 100 people”). Therefore, it is recommended to further examine whether ambiguity aversion remains absent when visualizing epistemic uncertainty using the blurring and stepwise color change approach in different contexts, such as when a different type of message is conveyed in the prognosis (e.g., uncertainty in the probability of getting a disease or uncertainty in risks of treatments). It is also suggested to further examine the effect of the blurring and stepwise uncertainty visualizations when the prognosis is more negatively framed (e.g., focusing on how many people would be deceased after five years) and when the chances of survival are low.

Another limitation of this study is that subjective numeracy (i.e., instead of objective numeracy) was measured, meaning it was based on participants’ self-reported numeracy (Fagerlin et al., 2007). Although the subjective numeracy scale strongly correlates with the objective numeracy scale (Fagerlin et al., 2007), it can be of added value to also identify the objective numerical skills of participants to examine whether the moderation effect will appear. Furthermore, the study’s sample mainly consisted of highly educated people, and data analysis revealed a moderate positive correlation between education level and subjective numeracy in this study. In addition, the low numeracy group scored relatively high on subjective numeracy since their mean subjective numeracy score was 3.98 (minimum = 1, maximum = 6). Therefore, it is recommended to further examine whether the results of this study replicate when a lower educated sample, with a lower overall subjective numeracy, is involved.

In addition, the level of understanding of the visualized epistemic uncertainty was not examined. Therefore, it is suggested to further examine whether there are differences in understanding between the low and high subjective numeracy groups. Thus, since this study found no effect of communicating uncertainty on perceived risk, perceived uncertainty, and worry, it is recommended to further examine whether not finding an effect is the result of participants not understanding what was communicated or because they indeed equally understood the communicated uncertainty.

Lastly, this study did not explicitly consist of actual cancer patients, and people were asked to imagine a hypothetical scenario and only consisted of people with a minimum age of 45. Thus, the participants possibly perceived less risk, uncertainty, and worry during the experiment of this study than they would if the prognosis was based on their actual personal characteristics. In addition, people younger than 45 might react differently to the uncertainty visualizations than the participants in this sample. Therefore, it is suggested to examine whether this study's results replicate when the two uncertainty visualization formats are presented to people aged 45 and lower and when the visualization formats are used in actual prognoses because it can make a difference if people feel more personal relevance to the prognosis rather than having to empathize with a hypothetical scenario.

Implications

Regardless of the limitations, this study provides insight into the effect of communicating epistemic uncertainty in icon arrays on ambiguity aversion, manifested by perceived risk, perceived uncertainty, and worry in the context of five-year survival prognoses to Dutch adults with a minimum age of 45. This study is the first that empirically tested whether ambiguity aversion occurs as heightened perceived risk, perceived uncertainty, and worry when epistemic uncertainty in icon arrays is visualized using the stepwise color change and the blurring uncertainty visualization. Participants did not perceive more risk and uncertainty and did not worry more after the uncertainty visualization formats were presented to them. Therefore, communicating epistemic uncertainty using both visualization formats does not lead to ambiguity aversion manifested by more perceived risk, uncertainty, and worry.

The non-occurrence of ambiguity aversion in this study in the form of heightened perceived risk, perceived uncertainty, and worry can mean that the study participants did not perceive the presented uncertainty as uncomfortable or unclear (Ellsberg, 1961). In this study, the presentation of uncertainty led to less perceived uncertainty than when uncertainty was not communicated. This outcome may indicate that participants perceived the visualization of uncertainty using the blurring and the stepwise color change format, not as ambiguous information. Instead, they might have perceived the uncertain information as clarifying because they felt they had received all the prognostic information available (Johnson & Slovic, 1995). Thus, when epistemic uncertainty was communicated using the blurring or stepwise color change uncertainty visualizations, people did not experience the discomfort of uncertainty. Therefore, this study shows that the visualization of epistemic uncertainty in icon arrays makes it possible to communicate epistemic uncertainty without leading to ambiguity aversion in the form of heightened perceived risk, perceived uncertainty, and worry.

Practical implications

This study did not find an effect of communicating epistemic uncertainty on ambiguity aversion, manifested by more perceived risk, uncertainty, and worry. Therefore, HPs should reconsider their decisions or thoughts about not communicating epistemic uncertainty. Instead, it is recommended that HPs communicate epistemic uncertainty more often to help themselves and patients make more informed and shared decisions about treatment and care. When HPs communicate epistemic uncertainty, this can best be done using the blurring visualization format because participants that were shown the blurring visualization format perceived less uncertainty than participants that were shown the stepwise uncertainty visualization. Furthermore, this study shows that numerical skills and optimism do not need to be considered when uncertainty is communicated because low subjective numeracy and low dispositional optimism did not influence the effect of visualization format on perceived risk, perceived uncertainty, and worry. However, when deciding to communicate epistemic uncertainty using one of this study's visualization formats, it is essential to consider the limitations of this study.

Conclusion

To conclude, this study aimed to examine the effects of epistemic uncertainty visualization format (blurring and stepwise) in cancer prognoses on perceived risk, perceived uncertainty, and worry and whether subjective numeracy and dispositional optimism moderate these effects. Contrary to what was expected, this study showed that the communication of epistemic uncertainty did not lead to ambiguity aversion, manifested by more perceived risk, perceived uncertainty, and worry, and was not influenced by dispositional optimism and subjective numeracy. The findings of this study can provide valuable information for HPs who consider communicating epistemic uncertainty to patients and want to learn about helpful formats for conveying epistemic uncertainty and their effects on people's perceptions. In addition, scientists within the healthcare domain who want to obtain more knowledge about the effect of visualizing epistemic uncertainty in icon arrays on people's perceptions can provide from this study by using it as a starting point for future research on the visualization of epistemic uncertainty in icon arrays.

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Appendix A

Pretest

Information letter

Dear participant,

Thank you for your participation in this pre-test.

This research is being conducted by me, Emma Vreeswijk, as part of a master's thesis from the Communication & Information Sciences program at Tilburg University. The purpose of this pre-test is to test the materials for the study.

The study is intended for people 45 years and older and works with a hypothetical scenario. This means that during the study, participants are asked to imagine that they have been diagnosed with colorectal cancer. They then receive prognostic information surrounding the five-year survival rate. During this pre-test of the study, you will receive a hypothetical prognosis and three visualizations of a prognosis. This can be perceived as intense and may evoke (unpleasant) emotions. Based on the prognosis and visualizations, you will be asked to answer a number of questions. This pre-test will take a maximum of 10 minutes.

All data collected will be processed in strict confidentiality. This data will be processed and stored anonymously. This means that your data will be linked to an anonymous ID, which cannot be associated with your identity. The data will be stored for 10 years in accordance with Tilburg University regulations. Participation in the study is entirely voluntary and you can stop, without consequences, at any time.

If you have any questions or comments regarding this study, please contact Emma Vreeswijk at e.vreeswijk@uvt.nl.

Thank you in advance for your participation!

Kind regards,

Emma Vreeswijk

Informed consent

Informed consent

When I give consent, I certify that:

- I have read the information and understand what it says;
- I am aware of the purpose of this research;
- I am aware that my participation in this study is voluntary;
- I am aware that I may withdraw from the study at any time during my participation;
- I consent to the storage of my anonymized data as described in the information letter;
- I do not discuss the content of this study with other potential participants;
- I am at least 45 years old.

0 Yes, I consent.

0 No, I do not consent.

Demographics

- What is your age?
- What is your gender?

- o Male
- o Female
- o I’d rather not say
- o Other, namely…

Scenario

Suppose you have been diagnosed with colon cancer. The examination revealed that you are dealing with stage 2 colon cancer. That means the tumor has grown through the muscle layer of the bowel wall, but there are no metastases to other parts of the body yet. To make the best possible estimate of your life expectancy five years from now, the doctor uses a prediction model. That is, the doctor uses a mathematical model in which he enters several of your personal characteristics.

- Among other factors, the doctor enters the following:
- Demographic data, such as your age and gender
- Features of your diagnosis, such as the size of the tumor and that it is stage 2 colon cancer
- Non-cancer-related conditions to assess overall health status
- The impact of treatments you have had
- Genetic characteristics
- Other risk factors, such as whether you smoke

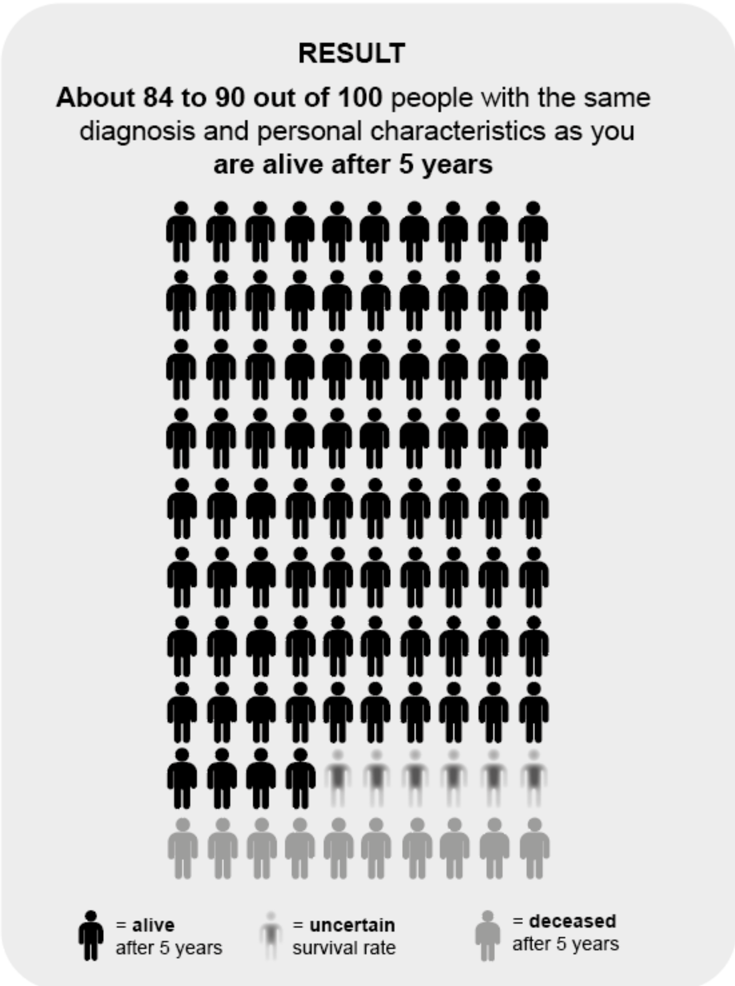
The calculation model uses your personal information to estimate your life expectancy five years from now. In other words, the prognosis that came out of the calculation module gives you insight into the question, "How likely is it that I will still be alive in five years?

Empathize scenario

The following statements are about the scenario you just read. Please indicate the extent to which you agree with the following statements (1 = totally disagree, 5 = totally agree).

- It was easy to empathize with the scenario
- It was difficult to empathize with the scenario

Blurring visualization



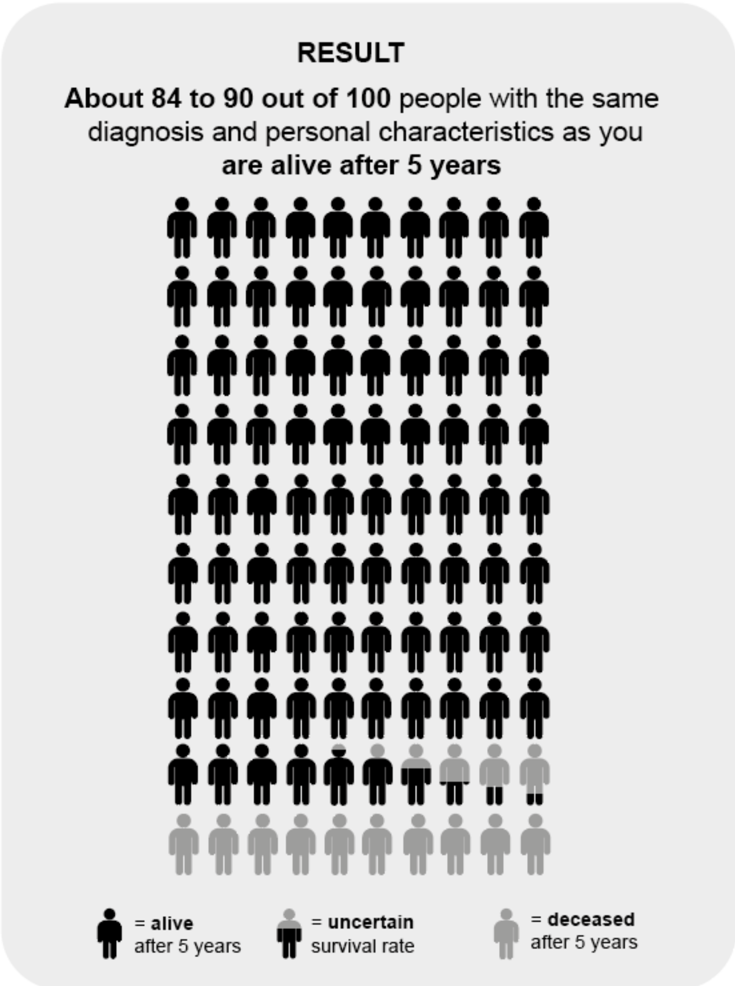
Please indicate the extent to which you agree with the following statements (1 = totally agree, 5 = totally disagree).

- The visualization represents a group with an uncertain probability of survival.

- The group with an uncertain survival probability is colored black and not faded/blurred.
- The group with an uncertain survival probability is blurred/blurred.
- The group with uncertain survival probability is grayed out and not faded/blurred.

How many of the 100 people in the visualization are in the group with an uncertain probability of survival?

Stepwise visualization

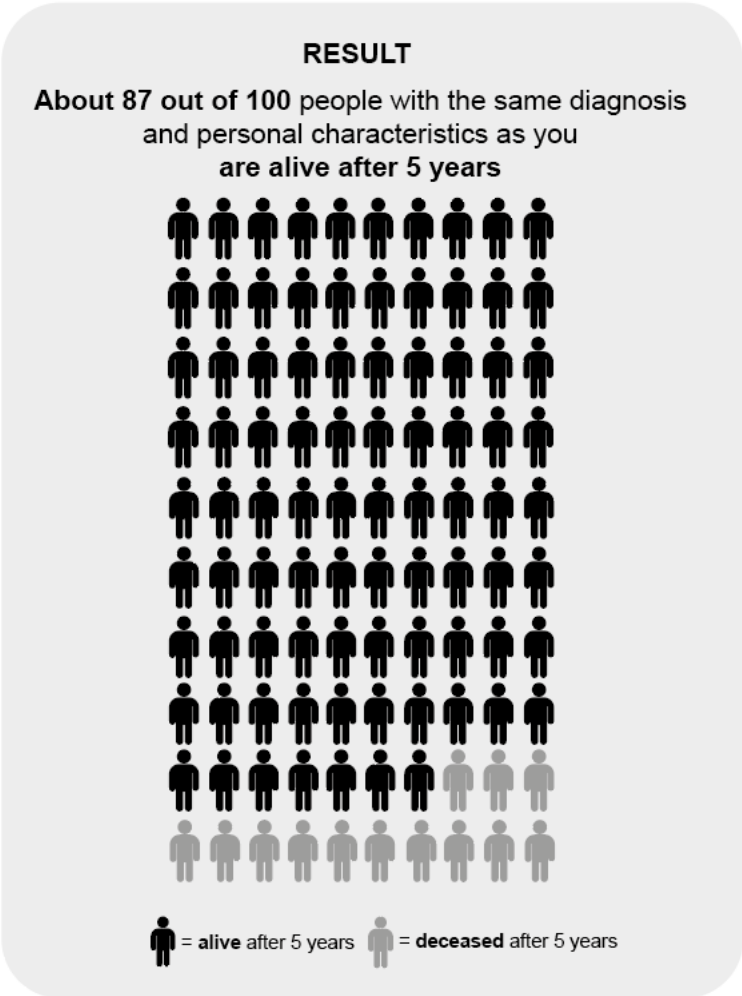


Please indicate the extent to which you agree with the following statements (1 = totally agree, 5 = totally disagree).

- The visualization represents a group with an uncertain probability of survival.
- The group with an uncertain survival probability is colored completely black.
- The group with uncertain survival probability is colored partly gray and partly black.
- The group with uncertain survival probability is colored completely gray.

How many of the 100 people in the visualization are in the group with an uncertain probability of survival?

No-uncertainty visualization



Please indicate the extent to which you agree with the following statements (1 = totally agree, 5 = totally disagree).

- The visualization represents a group with an uncertain probability of survival.
- The group with an uncertain survival probability is colored completely black.
- The group with uncertain survival probability is colored completely gray.

How many of the 100 people in the visualization are in the group with an uncertain probability of survival?

Debriefing

Thank you for your participation.

This is the end of the experiment. All your answers have been automatically saved.

Please be reminded again that your participation is voluntary. If you wish to withdraw your participation in this study, please let me, Emma Vreeswijk, know within 48 hours. You may also contact me with any questions or comments at: e.vreeswijk@uvt.nl.

Appendix B

Experiment

Information letter

Dear participant,

Thank you for your willingness to participate in this study. Please read the following information carefully before proceeding.

Purpose of the study

This research is conducted as part of my master's thesis from the Communication & Information Sciences program at Tilburg University. The purpose of the research is to gain more insight into how prognosis information can best be communicated to cancer patients. Using prediction models, it is possible to accurately estimate the course of the disease and the chance of survival. This is of great importance because patients can use these prognoses to make informed decisions about cancer treatment and/or end-of-life care.

Course of the study

This survey is intended for anyone with a minimum age of 45 years and lasts a maximum of 10 minutes. The study uses a hypothetical scenario. This means that during the study you will be asked to imagine that you have been diagnosed with colon cancer. Then you will receive prognostic information around the five-year survival rate and questions about this prognosis will follow. The last part of this questionnaire consists of a number of questions about how you interact with numbers and graphs and a number of other statements. Imagining the hypothetical scenario can be perceived as intense and may evoke (unpleasant) emotions. Therefore, it is important to note that participation in this study is completely voluntary and you can stop your participation at any time during the study. There will be no consequences.

Data

All data collected will be processed in strict confidence. This data will be processed and stored anonymously. This means that your data will be linked to an anonymous ID, which cannot be associated with your identity. The data will be stored for 10 years in accordance with Tilburg University regulations.

If you have any questions about the study, you can reach the researcher, Emma Vreeswijk, at e.vreeswijk@uvt.nl.

Thank you in advance and good luck with completing the questionnaire.

Kind regards,

Emma Vreeswijk

Informed consent

When I give consent, I certify that:

- I have read the information and understand what it says;
- I am aware of the purpose of this research;
- I am aware that my participation in this study is voluntary;
- I am aware that I may withdraw from the study at any time during my participation;
- I consent to the storage of my anonymized data as described in the information letter;
- I do not discuss the content of this study with other potential participants;
- I am at least 45 years old.

0 Yes, I consent.

0 No, I do not consent.

Demographics

- What is your age?
- What is your gender?
    - Male
    - Female
    - I'd rather not say
    - Other, namely…
- What is your highest level of education? If you are currently pursuing an education, select that one.
    - Lower vocational education
    - Lower secondary education
    - Higher secondary education
    - Vocational education
    - Scientific education
    - Higher professional education
    - Other, namely…

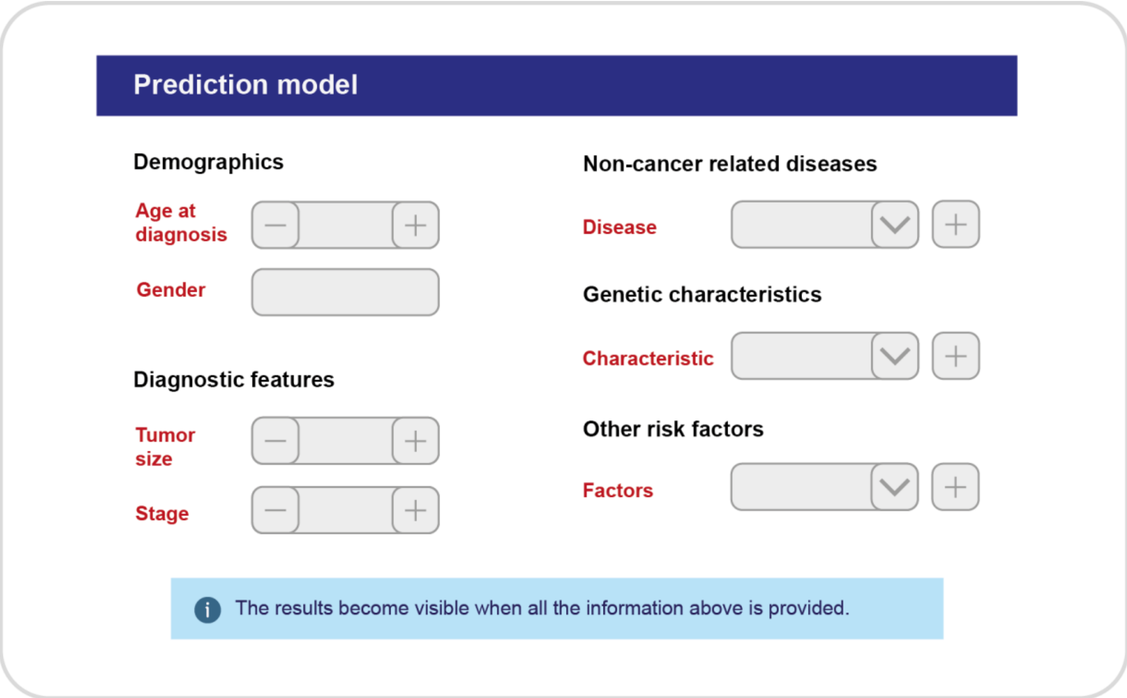
Hypothetical scenario

The following page describes a scenario in which you have been diagnosed with colon cancer. Please read this scenario carefully before proceeding.

Scenario

Suppose you have been diagnosed with colorectal cancer. The examination revealed that you are dealing with stage 2 colon cancer, meaning that the tumor has grown through the muscle layer of the bowel wall but has not yet metastasized to other parts of the body. The doctor uses a prediction model to make the best possible estimate of your life expectancy five years *from now. The doctor uses a mathematical model in which she enters various data about you. She also fills in risk factors, such as whether you smoke.*

The physician uses the calculation model below. View the image to see what characteristics need to be entered.

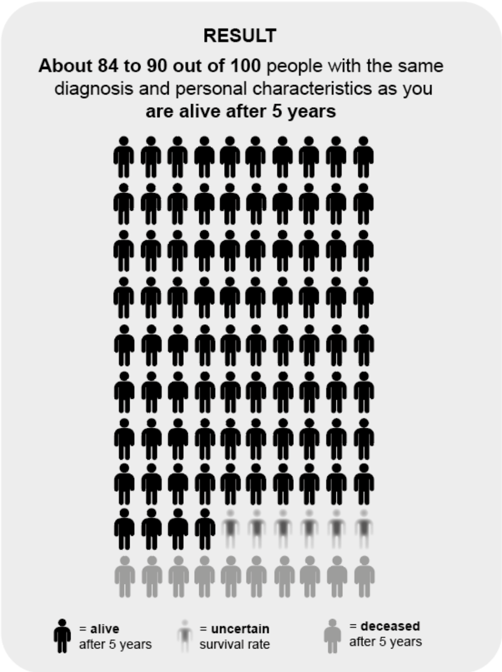


The mathematical model now uses your data to estimate your life expectancy five years from now. In other words, the result that comes out of the prediction model gives you insight into the question, "How likely is it that I will still be alive in five years?"

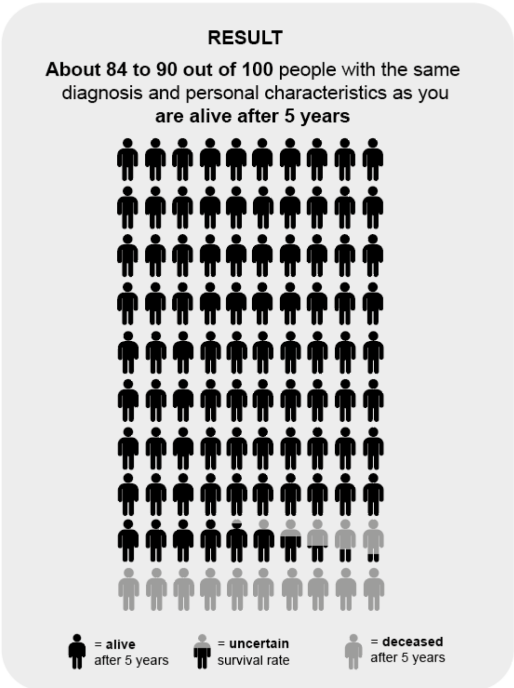
The doctor will show you the result on a computer screen. Click continue to view the result.

Participants are randomly assigned to one of the three conditions below

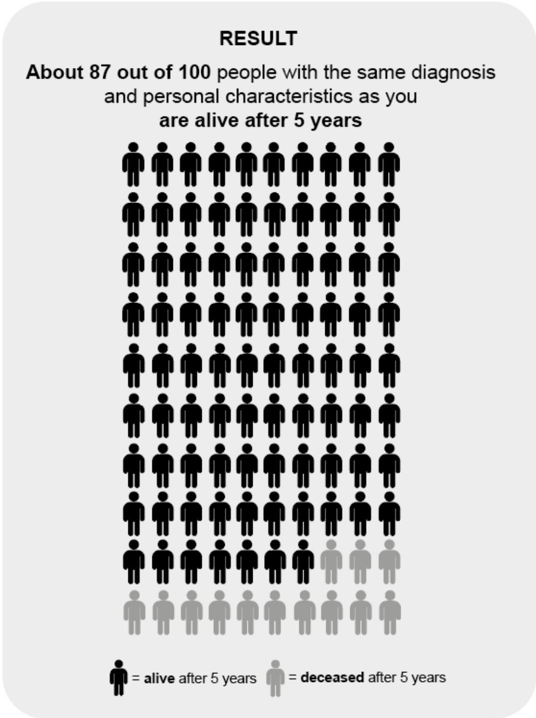
Condition 1: Blurring (uncertainty visualization)



Condition 2: Stepwise (uncertainty visualization)



Condition 3: Control condition (no-uncertainty visualization)



Now, there will follow some questions and statements related to the prognosis you just received.

Perceived risk

- Based on the prognosis just received, how likely do you think it is that you will still be alive in five years? (1 = very unlikely, 7 = very likely)
- If I received these results, I would feel that I would still be alive in five years. (1 = totally disagree, 7 = totally agree)
- Based on the prognosis just received, how likely do you think it is that you will not be alive in five years? (1 = very unlikely, 7 = very likely)

Perceived uncertainty

- To what extent do you think the prognosis in the visualization is certain or uncertain? (1 = very certain, 7 = very uncertain)

- To what extent do you think the prognosis in the visualization is accurate or inaccurate? (1 = very accurate, 7 = very inaccurate)
- How much uncertainty do you think there is around the prognosis in the visualization? (1 = no uncertainty at all, 7 = a lot of uncertainty)

Worry

- Based on the information you just received, to what extent would you be concerned about dying from colorectal cancer? (1 = not at all concerned, 5 = very concerned)
- Based on the information you just received, to what extent would you be afraid of the future? (1 = not afraid at all, 5 = very afraid)

Perceived relevance

- If I received these results, I would feel that the life expectancy information would be personalized for me. (1 = totally disagree, 5 = totally agree)
- If I received these results, I would find the way the life expectancy information was given relevant to me. (1 = totally disagree, 5 = totally agree)

Surprise

- To what extent would you be surprised if it eventually turns out that 70 out of 100 people will still be alive in five years? (1 = not surprised at all, 7 = very surprised)

Empathize scenario

- It was easy to empathize with the scenario (1 = totally disagree, 5 = totally agree).
- It was difficult to empathize with the scenario (1 = completely disagree, 5 = completely agree).

Personal experience cancer

- Do you have personal experiences with cancer? For example, have you or someone in your family had a form of cancer in the past?
    - Yes
    - No
    - I’d rather not say

Subjective Numeracy Scale

The questions that follow now are no longer about the prognosis you received earlier. Information about diseases and side effects often talks about odds, such as how likely it is that you will get a particular disease or side effect. The following are some statements about how you deal with probabilities and numbers. For each statement, indicate what applies to you. There are no right or wrong answers.

- How good are you at calculating with fractions? (1 = not at all good, 6 = very good)
- How good are you at calculating with percentages? (1 = not at all good, 6 = very good)
- How well can you calculate a 15% tip? (1 = not at all good, 6 = very good)
- How well can you calculate the price of a T-shirt if you get 25% off? (1 = not at all good, 6 = very good)
- When you read the newspaper, how much do you benefit from tables and graphs that accompany an article? (1 = not much at all, 6 = very much)
- Suppose people tell you something about the probability that something will happen. Do you want them to use words (e.g., "It rarely happens") or numbers (e.g., "The probability is 1%")? (1 = I always prefer words, 6 = I always prefer numbers)
- Suppose you listen to the weather report. Do you prefer to hear predictions in percentages (e.g., "Today there is a 20% chance of rain") or predictions in words (e.g., "Today there is a small chance of rain")? (1 = I always prefer percentages, 6 = I always prefer words).
- How often do you benefit from information in the form of numbers? (1 = never, 6 = very often)

Dispositional optimism

Please indicate the extent to which you agree or disagree with the statements below (1 = completely disagree, 5 = completely agree).

- In uncertain times, I usually expect the best.
- If something can go wrong for me, it will.
- I am always optimistic about my future.
- I almost never expect things to go my way.
- I rarely count on good things happening to me.
- In general, I expect more good things to happen to me than bad.

Debriefing

Thank you for your participation.

Please remember to click the button below to submit your responses.

The survival rates mentioned in relation to stage 2 colon cancer at the beginning of this questionnaire were devised for this study and are therefore incorrect. You may have your own experience with cancer. Perhaps this provides unpleasant memories. If you want help and support with the effects of cancer, please check this website: www.kanker.nl/hulp-en-ondersteuning.

The purpose of this study was to understand the effect of communicating uncertainty in cancer patients' prognoses. With the help of prognostic tools, it is possible to make a more accurate estimate of the course of the disease and the chance of survival. Even though these tools contribute to a more accurate disease picture, there is always (statistical) uncertainty involved. Failure to properly communicate this uncertainty or misinterpretation of the prognosis can lead to patient misunderstanding and potentially result in a different treatment decision.

Using the questionnaire you have just completed, we measured whether the communication of uncertainty in different visualization forms affects your perceived uncertainty and perceived risk and to what extent you would be concerned. In addition, whether individual differences such as numerical ability and optimism influence the effect was also examined.

Please be reminded again that your participation is voluntary. If you wish to withdraw your participation in this study, please let me, Emma Vreeswijk, know within 48 hours. You may also contact me with any questions or comments at: e.vreeswijk@uvt.nl.

Thank you very much again. Your participation is greatly appreciated.

Kind regards,

Emma Vreeswijk

Appendix C

Pretest results

First, a pretest was performed to examine whether all visualization conditions were manipulated accurately and whether participants could empathize with the hypothetical scenario. In total, 2 men, 9 women participated in the pretest. All participants were shown the hypothetical scenario and the three visualization formats (blurring, stepwise, control). First, to test the extent to which participants could empathize with the hypothetical scenario, they were asked to rate two statements (“It was easy for me to empathize with the scenario”, “It was hard for me to empathize with the scenario”) on a 5-point Likert scale (1 = totally disagree, 5 = totally agree). Next, participants were shown the two uncertainty visualizations (blurring and stepwise). After each visualization they were shown four statements. For example: “the visualization shows a group with uncertain survival chances”, and “the group with an uncertain survival chance is blurred”. Participants were asked to rate their answers on a 5-point Likert scale (1 = totally disagree, 5 = totally agree). Lastly, participants were shown the visualization without uncertainty (control), to measure whether they actually see the difference between the manipulation and the control condition. For this visualization format participants were asked to rate four statements on a 5-point Likert scale.

SPSS Statistics was used to analyze the pretest data. Descriptive statistics showed that the no-uncertainty condition was rated lower in perceiving uncertainty (M = 1.61, SD = .84), than the blurring condition (M = 4.23, SD = .62), and lower than the stepwise condition (M = 4.27, SD = .56). In addition, the no-uncertainty condition did significantly differ from the uncertainty conditions (M = 4.25, SD = 1.60) in the extent to which uncertainty was perceived in the visualization ($Mdif$ = 2.64, $t(10)$ = 6.90, $p < .001$). Therefore, it can be assumed that uncertainty and no-uncertainty are visualized in a clear manner. Furthermore, the overall score for empathizing with the hypothetical scenario was M = 3.41, SD = .70, indicating that people could empathize with the scenario on a medium level. Therefore, after conducting the pretest the scenario was adjusted.