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Review Article

# The communication of uncertainty in health: A scoping review

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ABSTRACT

*Objective:* To conduct a scoping review of existing studies that examine communication strategies that address uncertainty in health and categorize them using the taxonomy of uncertainty.

*Methods:* Relevant articles retrieved from ten databases were categorized according to the dimensions of the taxonomy of uncertainty, and study characteristics were extracted from each article.

*Results:* All articles ($n$ = 63) explored uncertainty in the context of probabilistic risk and related to scientific issues ($n$ = 63; 100%). The majority focused on complexity ($n$ = 24; 38.1%) and uncertainty experienced by patients ($n$ = 52; 82.5%). Most utilized quantitative methods ($n$ = 46; 73.0%), hypothetical scenarios ($n$ = 49; 77.8%), and focused on cancer ($n$ = 20; 31.7%). Theory guided messages and study design in fewer than half ($n$ = 27; 42.9%).

*Conclusions:* Heterogeneity in terminology used to refer to different types of uncertainties preclude a unified research agenda on uncertainty communication. Research predominately focuses on probability as the source of uncertainty, uncertainties related to scientific issues, and uncertainty experienced by patients.

*Practice implications:* Additional efforts are needed to understand providers' experience of uncertainty, and to identify strategies to address ambiguity. Future studies should use consistent terminology to allow for coherence and advancement of uncertainty communication scholarship. Continued efforts to refine the existing taxonomy should be undertaken.



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## 1. Introduction

Uncertainty is pervasive in healthcare, and its role in decision-making across the medical care continuum is well established. Uncertainty can trigger aversive cognitive and affective reactions in individuals, such as increased anxiety and increased risk perception, which can lead to sub-optimal decision-making and avoidance behaviors [1,2]. In some instances, uncertainty may serve as a self-protective or motivational force, resulting in increased information-seeking or uptake of preventive, diagnostic, and treatment measures [1,2]. The various psychological and behavioral responses to uncertainty have led to an increased focus on the identification of appropriate strategies to address uncertainties as they occur in the health and medical domains. This is particularly important for shared decision-making and patient-centered care during which transparency and the open disclosure of uncertainty is an ethical and moral imperative [3].

Uncertainty is primarily managed through communicative practices, which emphasize communication in moderating the effect of uncertainty on health decision-making [4,5]. The need for effective strategies to communicate uncertainty has increased over the past years, as the complexities of uncertainties inherent in medical decision-making have grown in number and visibility. More specifically, technological innovations and scientific discoveries are rapidly emerging and often integrated into medical care without sufficient evidence as to their effectiveness and health impact [1]. Personalized healthcare and precision medicine require the translation of population-based evidence to the individual, which demands sophisticated understanding and skill to communicate limitations in risk estimates [3]. Diseases are constantly evolving, challenging healthcare providers and patients to make decisions based on limited or insufficient data. A notable example is the recent SARS-CoV-2 virus outbreak, which exposed the limits of human knowledge and revealed challenges of communicating uncertainties on an unprecedented scale.

The centrality of uncertainty in decision-making is recognized as a core competency in clinical care, requiring providers to address and communicate uncertainties inherent in medical decision-making [3]. Yet, current scholarship provides little evidence on how to do so. This is mainly due to the complex nature of uncertainty, which creates challenges for a unified research agenda to systematically examine communication strategies and their effects [6,7]. In an effort to synthesize existing communication research about uncertainty, we conducted a scoping review of studies that explored strategies to communicate various forms of uncertainties, using the taxonomy of uncertainty developed by Han, Klein, and Arora (hereafter referred to as the “taxonomy of uncertainty”) as a classification framework [7]. The taxonomy of uncertainty draws heavily upon prior work in the communication of uncertainty and acknowledges the multifaceted nature of uncertainty and may therefore be useful to unite studies that explored distinct manifestations and forms of uncertainty.

At the most basic level, uncertainty has been defined as “the subjective perception of ignorance” [7, p. 830], describing a state in which individuals are aware that they are lacking knowledge needed to make a decision or to take action. However, decades of research across disciplines have illuminated the multifaceted nature of uncertainty and the breadth of its sources, types, and manifestations [7]. A notable example is Mishel’s [8] theory of uncertainty in illness, which posits that uncertainty stems from ambiguity, vagueness, unpredictability, and lack of information. Brashers [4] proposed that uncertainty exists when situations are “ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general” (p. 478). Babrow, Kasch, and Ford [9] distinguish between five dimensions of uncertainty, namely complexity, qualities of information, probability, structure of information, and lay epistemology. Various other theorists have worked towards classifying and systematizing uncertainty in health, enhancing our understanding of the various ways in which uncertainty manifests itself [10,11].

One issue that has arisen from these efforts is the interchangeable use of terms, which limits comparisons from being drawn and the ability to apply study findings across health contexts [6,7]. To address this challenge, Han, Klein, and Arora developed a conceptual taxonomy of uncertainty based on these past approaches which sought to capture the various nuances and variations of uncertainties in health in a more systematic and comprehensive manner [7]. The authors define uncertainty along three main dimensions: source, issue, and locus. Each dimension is comprised of theoretically distinct domains. *Source* refers to the underlying cause of uncertainty, which is further divided into probability, ambiguity, and complexity. Probability, often referred to as stochastic risk, describes the likelihood of a certain outcome. Ambiguity is defined as the absence of reliable, credible, or adequate information. Complexity refers to the multiplicity of risk factors, options, or outcomes that make certain health events more difficult to understand. The second dimension, *issue*, refers to the context in which uncertainty occurs, for example, scientific, practical, or personal. Scientific uncertainty includes those related to diagnoses, prognoses, causes of disease, and treatment options. Practical uncertainties are system-centered and encompass a lack of knowledge about healthcare structures and processes. Personal uncertainties refer to the impact of health decisions on future wellbeing, quality of life, or relationships. The last dimension in the taxonomy is *locus*, which describes where uncertainty resides – uncertainty can exist in patients or providers or can be a shared experience.

The conceptualization of uncertainty as a multidimensional phenomenon comprised of theoretically distinct constructs allows for a more comprehensive and precise study of uncertainty, which requires different approaches to measurement, analysis, and management. The taxonomy of uncertainty may therefore be helpful in guiding strategies to identify distinct experiences of uncertainty, develop measures, and evaluate their influence on health outcomes [7]. Furthermore, the taxonomy of uncertainty may inform the development of communicative practices and interventions that target specific domains of uncertainty, potentially increasing the efficacy of uncertainty communication strategies.

A predominant concern in existing research on communicating uncertainty is the narrow focus on probability [7,12–14]. Probabilistic risk has been most commonly examined as it pertains to evaluation of the likelihood and severity of adverse health outcomes. This focus is reflected in studies that explored uncertainty stemming from assumptions inherent in risk prediction models and risk calculations [15,16], the consideration of risk-benefit tradeoffs [17], and the translation of population-based evidence to individual care [18,19]. Using the taxonomy of uncertainty to classify and organize existing literature will identify specific areas of uncertainty that remain unaddressed.

Therefore, the purpose of this article is to categorize previous studies that examined strategies (e.g., format, framing, visuals used in written or verbal messages) to communicate uncertainties in the health context using the taxonomy of uncertainty developed by Han, Klein, and Arora [7]. By synthesizing existing studies that examine messaging strategies based on the three dimensions - source, issue, and locus - we identify gaps in the literature and highlight opportunities for interdisciplinary exchange. Doing so may therefore contribute to a more systematic examination of uncertainty communication, increasing visibility and comparability of studies examining strategies to communicate specific domains of uncertainty. This scoping review seeks to answer the following research questions:

RQ1: To what extent do previous studies examining the communication of uncertainty address source, issue, locus, and their respective domains?
RQ2. What are the main characteristics of studies analyzing communication of uncertainty based on the source – probability, ambiguity and/or complexity?

## 2. Methods

### 2.1. Search strategy

In February 2020, we conducted a comprehensive literature search in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [20]. The search results were managed using Zotero and Microsoft Excel. We searched the following ten electronic databases: Web of Science, Scopus, Communication Source, PubMed, Science Direct, Embase, Cochrane, CINAHL, MEDLINE, and PsycINFO. We performed the searches using controlled terminology of each database and additional key words. The following search string was customized for each database: ("health" OR "healthcare" OR "health care") AND "risk" AND "decision-making" AND "communication" AND ("uncertainty" OR "probability" OR "ambiguity" OR "complexity"). An academic reference librarian supported this scoping review and ensured that search strategies and databases were appropriate.

### 2.2. Inclusion and exclusion criteria

To be included in the review, studies had to meet the following criteria: (1) be published in peer-reviewed journals or conference proceedings, (2) follow an empirical study design, (3) be published during or after the year 2000, as the volume of studies examining uncertainty has grown exponentially since the early two-thousands [6], (4) be published in English, (5) address health-related uncertainties directly (as opposed to climate change, for example), and (6) be conducted in the United States. Studies were only included if they were conducted in the United States because previous studies suggest that culture impacts people's understanding and interpretation of risk information [17], and to narrow the scope of the review.

Excluded were poster abstracts, commentaries and opinion pieces, dissertations, systematic reviews, meta-analyses, and case studies. We also excluded studies that did not pertain to humans and those that asked participants to recall or reflect on previous messages of uncertainty due to the potential for recall bias [21]. Lastly, articles were excluded that did not test a specific message or examine a conversation, or measured only participant preference since few studies support an association between participant preference and comprehension [22].

### 2.3. Data selection

The first and second authors screened the articles for inclusion in multiple steps and calculated intercoder reliability using Krippendorff's alpha at each step. The three steps included title review, abstract review, and full text review. The process occurred as follows. In each step, the two authors met to discuss a portion of the articles together to refine the application of the inclusion/exclusion criteria. Approximately 10% of the articles were screened independently. Once intercoder reliability was established, the authors continued to screen the remaining articles independently. Drift was assessed approximately halfway through screening at each step. Any discrepancies were discussed until consensus was reached.

The screening was conducted using Zotero and Excel spreadsheets. First, results from the database search were transferred into Zotero and checked for duplicates ($N$ = 1,941). Following removal of duplicates, all remaining data ($n$ = 1,441) were transferred to Excel spreadsheets. During the title review, acceptable interrater reliability was initially achieved ($\alpha$ = 0.82) [23] and sustained half-way through the titles ($\alpha$ = 0.88). Abstracts ($n$ = 1,189) were then screened and intercoder reliability was achieved ($\alpha$ = 0.76) and maintained ($\alpha$ = 0.77). Finally, the full texts ($n$ = 366) were screened for relevance, and intercoder reliability was achieved ($\alpha$ = 0.90). The full text screening resulted in a final sample of 63 articles.

### 2.4. Data extraction

Upon identification of the final sample, the first and second authors identified the source, issue, and locus dimensions of the taxonomy of uncertainty and extracted information pertaining to the study characteristics. The following sections provide information about the coding scheme.

#### 2.4.1. Taxonomy of uncertainty

Articles included in the final sample were first classified along the taxonomy of uncertainty's three dimensions and their domains using a consensus-based approach. As expected, few articles used the exact terms and conceptualizations as defined by the taxonomy of uncertainty. Thus, to facilitate the coding process, a codebook was developed which contained examples of each of the dimensions and their domains based on previous research by Han and colleagues [6,7,24] (see Appendix). The first and second authors coded 10% of the articles together and reached acceptable intercoder reliability ($\alpha$ = 0.83); the first author then continued coding the remaining articles. The following paragraphs describe how the different dimensions were conceptualized (see Appendix for more detailed information).

The source of uncertainty refers to the cause of the uncertainty and includes the three domains of *probability*, *ambiguity*, and *complexity*. *Probability* refers to the random or unknown pattern of future outcomes, such as a "20% chance of benefiting from treatment." *Ambiguity* occurs when information is unavailable, inadequate, or imprecise, for example, "there is a 10% to 20% chance of benefiting from treatment." Other examples of ambiguity include conflicting expert opinions or lack of knowledge about how to access care. *Complexity* refers to uncertainty due to multiple factors affecting risk, for example in cases where several treatment options were available, or when side effects had to be considered.

The issue of uncertainty refers to topics or substantive matters about which the individual is uncertain. The issues of uncertainty are *scientific*, *practical*, and *personal*. *Scientific* uncertainty is disease-centered and encompasses uncertainty about diagnoses, prognoses, causes, and treatment recommendations. *Practical* uncertainty is system-centered and involves the lack of knowledge about the structure and processes of health care. *Personal* uncertainty is patient-centered and pertains to psychosocial and existential uncertainty, such as the impact of illness on one's goals and the wellbeing of loved ones.

The locus of uncertainty refers to the person in whom uncertainty resides. For this review, we classified the locus as either *providers* or *patients*. For simplicity, patients included laypeople and caregivers because study participants were often asked to think like or for a patient.

*2.4.2. Study characteristics*

Study characteristics were extracted from each article and included study design, sample characteristics, health context, type of situation, type of message, theories or models used, independent variables, and outcome measures.

*2.4.2.1. Study design.* Study design refers to approach, including qualitative, quantitative, or mixed methods, and the exact method (s) used to collect data, such as surveys, interviews, or focus groups.

*2.4.2.2. Sample characteristics.* Sample characteristics included number, age, race, and gender of participants, where noted.

*2.4.2.3. Health context.* The health context referred to the specific health issue that the article addressed (e.g., cancer, rheumatoid arthritis, or heart disease). If a study examined multiple health contexts, it was coded as "general health," since the results were not specific to a particular health issue.

*2.4.2.4. Type of situation.* The type of situation referred to whether the study examined a hypothetical or a real situation. An example of a hypothetical situation was a study in which participants were asked to make judgements about a nonexistent treatment based on a hypothetical risk [e.g., 25]. A real situation referred to a study that involved the participant making assessments based on an existing personal risk [e.g., 26].

*2.4.2.5. Type of message.* Type of message referred to whether the message in the study was an audio-taped conversation that was analyzed, or a standardized message that was tested. For example, some studies analyzed audio-recorded patient-provider conversations, while other studies manipulated specific messages to measure effects on various outcomes.

*2.4.2.6. Theories.* Theories, or theoretical frameworks and models, that guided study or message design were noted.

*2.4.2.7. Independent variables.* Independent variables mainly referred to the format of the message that was tested, such as different representation formats used in experimental groups (i.e., text-only vs. visual; or percentage vs. frequencies).

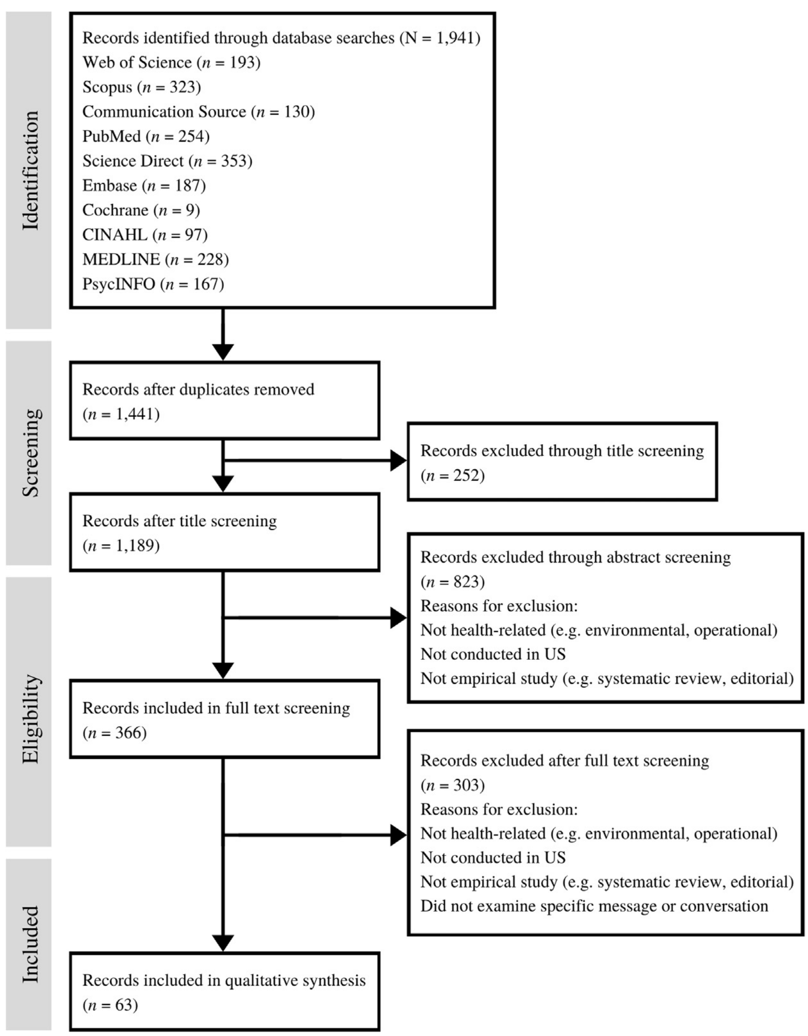


**Fig. 1.** PRISMA flow diagram illustrating the study selection procedure.

*2.4.2.8. Outcome measures.* Variables described as dependent variables were coded as outcome measures. We also coded variables that were examined as moderators or mediators of a relationship as outcome variables to decrease complexity in the coding scheme. For example, outcome variables included risk perception, recall and comprehension, or affective reactions.

## 3. Results

Through the database search, 1,941 articles were initially identified. After removal of duplicates ($n$ = 500), 1,441 articles were reviewed. Two hundred and fifty-two articles were removed based on title screening, 823 were excluded based on abstract reviews, and 303 articles were excluded during full text review, resulting in a final sample of 63 articles (see Fig. 1).

### 3.1. Classification of studies using the taxonomy of uncertainty

To answer the first research question, we classified each article by the source, issue, and locus dimension of the taxonomy of uncertainty (see Tables 1–5 for data extraction and classification results, and the Appendix for study examples pertaining to the various domains).

#### 3.1.1. Source

Of the 63 articles included in this review, twenty (31.8%) focused only on probability as the source of uncertainty (see Table 2). All articles addressing complexity ($n$ = 24; 38.1%; see Table 3) or ambiguity ($n$ = 9; 14.3%; see Table 4) also addressed probability. Ten articles (15.9%) mentioned all three source dimensions of uncertainty (see Table 5).

These results are largely based on studies' examination of complexity or ambiguity in the context of probabilistic risk. Most commonly, studies tested risk messages involving probability by manipulating the message to either increase its complexity (e.g., providing risk estimates for side effects), or ambiguity (e.g., including ranges or confidence intervals). Other studies focused more on the subjective experience of ambiguity and complexity, but even these explorations occurred in the broader context of being at risk, classified as probability.

The classification process further emphasized variation in terms used in previous studies (see Table 6). Authors used the word "probability" in most studies that explored only probabilistic communication ($n$ = 17; 85.0%). Studies that examined probability and ambiguity explicitly used the word "ambiguity" in only two of nine studies (22.2%), or denoted one source dimension explicitly, in other words, either "probability" or "ambiguity" ($n$ = 5; 55.6%). Ten

**Table 1**
Results of classification and data extraction of studies included in final sample ($n$ = 63).

| | Probability Only | Ambiguity + Probability | Complexity + Probability | Probability + Ambiguity + Complexity | Total |
|---|---|---|---|---|---|
| Total | 20 | 9 | 24 | 10 | 63 |
| Source | | | | | |
| Scientific Only | 17 | 7 | 21 | 2 | 47 |
| Scientific + Practical | 2 | 2 | 1 | 4 | 9 |
| Scientific + Personal | 1 | 0 | 2 | 1 | 4 |
| Scientific + Practical + Personal | 0 | 0 | 0 | 3 | 3 |
| Locus | | | | | |
| Patient | 16 | 8 | 23 | 5 | 52 |
| Patient + Clinician | 2 | 1 | 1 | 5 | 9 |
| Clinician | 2 | 0 | 0 | 0 | 2 |
| Study Design | | | | | |
| Quantitative | 17 | 7 | 21 | 1 | 46 |
| Qualitative | 1 | 2 | 1 | 8 | 12 |
| Mixed-Methods | 2 | 0 | 2 | 1 | 5 |
| Methods | | | | | |
| Surveys | 16 | 7 | 21 | 0 | 44 |
| Interviews | 0 | 0 | 0 | 6 | 6 |
| Focus groups | 0 | 2 | 1 | 1 | 4 |
| Observations | 1 | 0 | 0 | 2 | 3 |
| Combined methods | 3 | 0 | 2 | 1 | 6 |
| Situation | | | | | |
| Hypothetical | 14 | 6 | 23 | 6 | 49 |
| Real | 6 | 3 | 1 | 4 | 14 |
| Message | | | | | |
| Standardized message | 18 | 6 | 23 | 7 | 54 |
| Organic conversation | 2 | 3 | 1 | 3 | 9 |
| Health Context | | | | | |
| Cancer | 9 | 3 | 5 | 3 | 20 |
| General health | 7 | 3 | 7 | 0 | 17 |
| Genetic testing | 1 | 2 | 1 | 3 | 7 |
| Heart disease | 0 | 0 | 3 | 2 | 5 |
| Rheumatoid Arthritis | 0 | 0 | 4 | 0 | 4 |
| Down Syndrome | 1 | 0 | 1 | 0 | 2 |
| Violence | 2 | 0 | 0 | 0 | 2 |
| Consent | 0 | 0 | 0 | 1 | 1 |
| Diabetes | 0 | 0 | 1 | 0 | 1 |
| Mental illness | 0 | 0 | 0 | 1 | 1 |
| Physical activity | 0 | 0 | 1 | 0 | 1 |
| Vaccination | 0 | 0 | 1 | 0 | 1 |
| Vaping | 0 | 1 | 0 | 0 | 1 |

**Table 2**
Data extraction and classification results of studies ($n$ = 20) exploring the probability dimension of uncertainty (source = probability only).

| Author Year | Study Design | Health Context | Sample | Situation | Message | Independent Variables | Outcome measures | Issue | Locus |
|---|---|---|---|---|---|---|---|---|---|
| Bartels et al., 2010 [41] | Quant (Surv) | General | Experiment 1 $n$ = 70; 60% female; students<br><br>Experiment 2 $n$ = 163 70.6% female; students | Hyp | Standard | Experiment 1: four conditions: 2 (vaccine efficacy: Effective for 60% of the population, effective for 90% of the population) x 2 (message frame: gain, loss)<br>Experiment 2: four conditions: 2 (enzyme function: health benefit, health problem) x 2 (message frame: gain, loss) | 1. Effectiveness manipulation check<br>2. Evaluation of the article<br>3. Attitude towards vaccine<br>4. Interest in vaccine<br>5. Risk perceptions<br>6. Willingness to schedule appointment<br>7. Future willingness to test<br>8. Concern | Sci | Pa |
| Bergenstrom et al., 2003 [42] | Quant (Surv) | General | $N$ = 87; medical students | Hyp | Standard | 1. Scenario (real vs. not real); 2. Random order for verbal probabilities vs. non-random order | 1. Numerical risk estimates | Sci | Pa |
| Brewer et al., 2009 [43] | Quant (Surv) | Gen | $N$ = 163; mean age: 59; all female; 86% white; diagnosed with breast cancer and completed surgery | Hyp | Standard | 1. Health literacy<br>2. Format of information | 1. Estimating recurrence risk<br>2. Interpreting own recurrence risk<br>3. Interpreting others' recurrence risk (vignettes)<br>4. Impact of recurrence risk results (treatment)<br>5. Understanding of risk communication formats | Sci | Pa |
| Clayton et al., 2009 [36] | Quant (Obs) | Cancer | $n$ = 6 providers; 66.6% female; 83.7% white; $n$ = 60 breast cancer survivors; mean age: 61.67; 71.7% white | Real | Standard | N/A | Patient-centered communication categories and timing | Sci & Pers | Pa & Pr |
| Gurmankin et al., 2004 [44] | Quant (Surv) | Cancer | $N$ = 217 mean age: 39; 81% female; laypeople | Hyp | Standard | Risk information format: 4 scenarios x 3 risk (% vs. fraction vs. verbal) | 1. Personal cancer experience<br>2. Numeracy<br>3. Health status<br>4. Health behaviors<br>5. Individual differences<br>6. Risk perception | Sci | Pa |
| Gurmankin et al., 2005 [45] | Quant (Surv) | General | Group 1: $n$ = 109 laypeople; median age: 34; 82% female; Group 2: $n$ = 59; physicians; mean age: 26; 53% female; Group 3: $n$ = 80 physicians (mailing list); median age: 43; 73% male | Hyp | Standard | 1. Medical condition<br>2. Probability level | 1. Perceived risk severity | Sci | Pa & Pr |
| Han et al., 2012 [18] | Quant (Surv) | General | $N$ = 225 mean age: 53; 54% male; 92% white; laypeople | Hyp | Standard | 1. Representation format (text-only nonrandom control, enhanced text-only, visual non-random, visual static random, and visual dynamic-random) | 1. Perceived cancer risk<br>2. Cancer worry<br>3. Subjective uncertainty about cancer risk<br>4. Dispositional optimism | Sci | Pa |
| Heilbrun et al., 2004 [46] | Quant (Surv) | Viol | $N$ = 256; 64% male; psychologists | Hyp | Standard | 1. Risk level (high or low)<br>2. Risk factors (dynamic or static)<br>3. Risk model (prediction/ management) | Preference of communication style | Sci | Pr |
| Housten et al., 2020 [47] | Quant (Surv) | Cancer | $N$ = 187 median age: 58; 63% female; 70.1% African American; laypeople | Hyp | Standard | 1. Presentation format: (1) audiobooklet; (2) static video; (3) animated video | 1. Total, verbatim, and gist knowledge<br>2. Health literacy<br>3. Health numeracy<br>4. Program evaluation | Sci | Pa |
| Janssen et al., 2018 [48] | Quant (Surv) | General | $N$ = 835 mean age: 48; 57 % female; 53 % white; laypeople | Hyp | Standard | 3 (social comparison information: absent vs. above average vs. much above average) x 2 (risk reduction information: present vs. absent) x 2 (numerical format: words vs. words plus numbers) factorial design | 1. Absolute and comparative cognitive perceived likelihood<br>2. Absolute and comparative affective perceived likelihood<br>3. Cognitive risk uncertainty<br>4. Affective risk uncertainty<br>5. Numeracy<br>6. Family history | Sci | Pa |
| Klein et al., 2016 [26] | Mixed (Surv & Interv) | Cancer | Survey: $n$ = 69 mean age: 45; all female; 97.1% white<br><br>Interviews: $n$ = 21 mean age: 44.3; all female; 95.2% white | Real | Standard | Patient decision aid: risk information | 1. Positive predicted value estimate<br>2. Numeracy<br>3. Recall of risk information | Sci | Pa |

**Table 2** (*Continued*)

| Author Year | Study Design | Health Context | Sample | Situation | Message | Independent Variables | Outcome measures | Issue | Locus |
|---|---|---|---|---|---|---|---|---|---|
| Krieger, 2014 [49] | Mixed (Interv & FG) | Cancer | Interviews: *n* = 11 mean age: 68.5; all white; cancer survivors<br>Focus groups: *n* = 30; female; mean age: 67.2; diagnosed with cancer or caregiver | Real | Conv | N/A | N/A | Sci & Prac | Pa |
| Miron-Shatz et al., 2009 [50] | Quant (Surv) | Down Synd | *N* = 241; students; mean age: 21.1; 61% female | Hyp | Standard | Risk format: (1) 1-in-N format, (2) frequency, (3) visual | 1. Comprehension<br>2. Risk assessment<br>3. Clarity<br>4. Numeracy<br>5. Recall | Sci | Pa |
| Robinson et al., 2008 [51] | Mixed (Obs, Surv) | Cancer | *n* = 51 oncologists mean age: 44.9; 78% male; 82% white<br><br>*n* = 147; patients; mean age: 60.0; 53% female; 84% white | Real | Conv | 1. Test results discussion<br>2. Treatment discussion<br>3. Prognosis discussion<br>4. Statement of optimism about past or present<br>5. Statement of optimism about the future<br>6. Statement of pessimism about the past or present<br>6. Statement of pessimism about the future<br>7. Statement of uncertainty | 1. Patient–physician concordance about chance of cure | Sci | Pa |
| Schapira et al., 2006 [52] | Quant (Surv) | Cancer | *N* = 254; mean age: 57.6; all female; 68% white; patients | Hyp | Standard | 6 graphic formats Pictorial displays: (1) background number of symbols, (2) shape of the symbol (human figures compared with a geometric form), and (3) pattern of foreground highlighted (consecutive versus random). | 1. Breast cancer risk factors<br>2. Numeracy<br>3. Perceptions and preferences regarding graphic formats<br>4. Five-year breast cancer risk<br>5. Perceived risk magnitude<br>2. Perceived truth of the data | Sci & Prac | Pa |
| Slovic et al., 2000 [37] | Quant (Surv) | Viol | Experiment 1 *n* = 409; psychiatrists; median age: 50; 84% male<br><br>Experiment 2 *n* = 470; psychiatrists; 72% male<br>Experiment 3 *n* = 479; psychiatrists; mean age: 50; 72% male | Real | Standard | Experiment 1: large percentage vs. small percentage vs. large frequencies vs small frequencies vs. small frequencies (1000); Experiment 2: large percentage vs. small percentage vs. large frequencies vs small; + tutorial; Experiment 3: probability vs. relative frequencies; high vs low risk | 1. Judgments of likelihood of violence<br>2. Perception of risk<br><br>3. Likelihood to recommend monitoring 4. Likelihood of reconsidering hospitalization | Sci | Pr |
| Stone et al., 2015 [53] | Quant (Surv) | General | Experiment 1 *n* = 314; 54.1% female; students<br>Experiment 2 *n* = 295; 60.7% female; students | Hyp | Standard | 2 (display type: graphical vs. numerical) x 2 (denominator type: common vs. noncommon) | 1. Recall memory<br>2. Recognition memory<br>3. Rankings of diseases<br>3. Comparing to known risks<br>4. Perceived understanding<br>5. Numeracy<br>6. Perceived likelihood<br>7. Negative emotions<br>8. Worry<br>9. Risk aversion | Sci | Pa |
| Weinfurt et al., 2005 [54] | Quant (Surv) | Cancer | *N* = 328; 56.1% male; mean age: 57.4; 85.1% white; patients | Real | Standard | Frequency type statement | 1. Numeracy<br>2. Previous experience<br>3. Expectations of therapy | Sci | Pa |
| Wong et al., 2012 [55] | Quant (Surv) | Cancer | *N* = 1,160; all female; 30.4% Chinese | Hyp | Standard | 3 content areas (breast, colorectal, cervical cancer); 2 risk formats: (1) icon array, (2) magnifying glass | 1. Correct indication of risk<br>2. Numeracy | Sci | Pa |
| Young et al., 2009 [56] | Quant (Surv) | General | Study 1a *n* = 59; laypeople; Study 1b *n* = 29; undergraduate students Study 1c *n* = 125; laypeople | Hyp | Standard | Study 1a: Risk format: 7 health outcomes x 6 semantic descriptors<br><br>Study 1b: Risk format: percentage vs. frequency x 7 health outcomes x 6 semantic descriptors<br>Study 1c: semantic vs. percentage risk information | 1. Percentage risk<br>2. Likelihood of taking the drug<br>3. Risk perception<br>4. Intended adherence rates<br>5. Likelihood of changing behavior<br><br>6. Fear of contracting the disease | Sci | Pa |

*Note*: The following abbreviations were used (in order of occurrence across columns): *Qual*=Qualitative methods; *Quant*=Quantitative methods; *Mixed*=Mixed methods; *FG*=Focus groups; *Surv*=survey; *Interv*=interview; *General*=General health; *Gen*=Genetics/genetic testing; *Down Synd*=Down Syndrome; *Viol*=violence; *Hyp*=Hypothetical scenario; *Real*=Real situation; *Standard*=Standardized message; *Conv*=Conversation; *Sci*=Scientifc; *Pers*=Personal; *Prac*=Practical; *Pa*=Patient; *Pr*=Provider.

**Table 3**
Data extraction and classification results of studies ($n = 24$) exploring the complexity dimension of uncertainty in addition to the probability dimension (source = probability and complexity).

| Author Year | Study Design | Sample | Health Context | Situation | Message | Independ. Variables | Outcome measures | Issue | Locus |
|---|---|---|---|---|---|---|---|---|---|
| Ancker et al., 2009 [57] | Qual (FG) | $N = 16$; 81.3 % female; 43.8 % African American; laypeople | Heart | Hyp | Standard | N/A | N/A | Sci & Prac | Pa |
| Armstrong et al., 2001 [58] | Quant (Surv) | $n = 246$; Group 1: mean age: 39.7; 68 % female; 55 % white; Group 2: mean age: 39.9; 66 % female; 47 % white; laypeople | General | Hyp | Standard | Message format: survival curves only, mortality curves only, and survival and mortality curves | 1. Comprehension | Sci | Pa |
| Armstrong et al., 2002 [59] | Quant (Surv) | $n = 451$; Group 1: 70 % female; mean age: 42.9; 52% white; Group 2: 65% female; mean age: 42.6; 55% white; Group 3: 72% female; mean age: 41.2; 46% white | General | Hyp | Standard | Message format: 1. Survival curves only; 2. Mortality curves only; 3. Survival and mortality curves | 1. Comprehension<br>2. Treatment preference | Sci | Pa |
| Blalock et al., 2015 [34] | Mixed (Obs & Surv) | $n = 450$; patients: 76.2% female; mean age: 61.8; 87.2%; white<br>Providers: 55.8% male; mean age: 48.1; 80.2% white | RA | Real | Conv | NA | 1. Medication risk<br>2. Attributes<br>3. Risk dimensions<br>4. Probability discussed | Sci | Pa & Pr |
| Cuite et al., 2008 [60] | Quant (Surv) | Overall sample: 67% female; mean age: 46; 82% white; $n = 4{,}159$ (wave 1), $n = 4{,}100$ (wave 2), $n = 7{,}514$ (wave 3); laypeople | Cancer | Hyp | Standard | 1. Format of information (1 in n; frequencies, percentages)<br>2. Mathematical operation<br>3. Risk level | 1. Accuracy | Sci | Pa |
| Eyler et al., 2017 [61] | Quant (Surv) | $N = 151$; 56.4% female; mean age: 41.7; patients | General | Hyp | Standard | 1. Risk presentation format (numeric only, numeric with icon arrays, number with spinners) | 1. Comparative risk knowledge<br>2. Numeracy | Sci | Pa |
| Fraenkel et al., 2003 [62] | Mixed (Surv & Interv) | $N = 100$; female 73%; mean age: 68; 84%; white; patients | RA | Hyp | Standard | Likelihood of adverse effect | 1. Willingness to accept risk<br>2. Levels of risk | Sci | Pa |
| Fraenkel et al., 2016 [63] | Quant (Surv) | $N = 254$; 54.2% female; mean age: 60.9; patients | Cancer | Hyp | Standard | Message format: (1) numbers only, (2) numbers and corresponding icon arrays, (3) numbers and illustrations | 1. Objective knowledge<br>2. Beliefs about lunger cancer screenings<br>3. Types of preferences 3. Perceived chance of developing lung cancer<br>4. Worry 5. Health status | Sci | Pa |
| Fraenkel et al., 2018 [64] | Quant (Surv) | $N = 655$; 78.7% female; mean age: 59.2; 84% white; patients | RA | Hyp | Standard | 2 (probability of infection: 2 % or 0.2 %) x 4 (numbers only, numbers + graphic, numbers + conceptual illustrations, or numbers + graphic, + conceptual illustrations) | 1. Risk perceptions<br>2. Likelihood of starting the medication<br>3. Risk-benefit expectation<br>4. Global impact | Sci | Pa |
| Grant Harrington et al., 2017 [65] | Quant (Surv) | Experiment 1: $n = 768$ 51% male; mean age: 19.6; 78.1% white undergraduates<br><br>Experiment 2: $n = 532$; 59% female; mean age: 19.8; 76.1% white; undergraduates | General | Hyp | Standard | 1. Deadly/ Gain-frame,<br>2. Deadly/Lossframe,<br>3. Easily Curable/ Gain-frame,<br>4. Easily Curable/Loss-frame<br>5. Degree of uncertainty 6. Severe/less severe health context | Choice of program | Sci | Pa |
| Hawley et al., 2008 [66] | Quant (Surv) | $N = 2412$; 52% female; mean age: 49; 82% white; laypeople | General | Hyp | Standard | 6 risk-benefit formats:<br>(1) bar graph; (2) pictograph; (3) modified pictograph ('sparkplug'); (4) pie chart; or (5) modified pie graph ('clock graph'); and (6) table | 1. Verbatim knowledge<br>2. Gist knowledge<br>3. Preception of graphs<br>4. Treatment choice | Sci | Pa |
| Janssen et al., 2018 [67] | Quant (Surv) | $N = 835$ 57.4% female; mean age: 48.34; 53.3% white; laypeople | Physical | Hyp | Standard | 2 (risk reduction information: present/absent) x 2 (numerical format: words/words and numbers) x 3 (social comparison information: none/somewhat higher than average/ much higher than average) | 1. Message comprehension<br>2. Message acceptance<br>3. Absolute and comparative cognitive perceived risk<br>4. Absolute and comparative feelings of risk<br>5. Response-efficacy<br>6. Worry<br>7. Anticipated regret<br>8. Intentions | Sci | Pa |
| LaVallie et al., 2012 [68] | Quant (Surv) | $N = 91$; mean age: 64; female 71%; all American Indian and Alaska Natives; laypeople | General | Hyp | Standard | Farming: (1) relative risk reduction, (2) absolute risk reduction, (3) number needed to treat | 1. Effectiveness of treatment<br>2. Risk comprehension<br>3. Numeracy | Sci | Pa |
| | | | Vaccine | Hyp | Standard | | | Sci | Pa |

**Table 3** (*Continued*)

| Author Year | Study Design | Sample | Health Context | Situation | Message | Independ. Variables | Outcome measures | Issue | Locus |
|---|---|---|---|---|---|---|---|---|---|
| Leonhardt et al., 2018 [69] | Quant (Surv) | *N* = 282 mean age: 34.4; 54.6% female; 79.8% white; parents | | | | 2 (pictograph: present vs. absent) x 2 (risk option: single-risk vs multiple-risk) design | 1. Probability comprehension 2. Risk perception | | |
| Lin et al., 2013 [70] | Quant (Surv) | *N* = 2025 mean age: 56.5; 53.4% female; laypeople | Cancer | Hyp | Standard | 1. Survival framing (median vs landmark survival) 2. Baseline survival 3. Relative survival improvement | 1. Willingness to pay for treatment | Sci & Pers | Pa |
| Poirier et al., 2019 [71] | Quant (Surv) | *N* = 45; elderly people; Group 1: mean age: 72.8; 80% female<br>Group 2: mean age: 71.4; 66.6% female<br>Group 3: mean age: 72.3; 73.3% female | Heart | Hyp | Standard | Decision aid | 1. Numeracy<br>2. Graphicacy<br>3. Decisional Conflict<br>4.Comprehension/Recall | Sci | Pa |
| Rolison et al., 2012 [72] | Quant (Surv) | Experiment 1: *n* = 174 mean age: 59.5; 100% male; 89.5% white; laypeople<br>Experiment 2: *n* = 156 mean age: 58.4; 100% male;90.5 % white; laypeople | Gen | Hyp | Standard | 2 risk statements presented in random order; 2 lifetime risk statements | 1. Risk interpretation 2. Numeracy | Sci | Pa |
| Schoenborn et al., 2019 [73] | Quant (Surv) | *N* = 818 mean age: 74; 53.7% male; 67.7% white; patients with type 2 diabetes | Diabetes | Hyp | Standard | Decision aid | 1. Adding medicine or stopping medicine 2. Perceived importance of 7 factors in the decision to add or remove a diabetes medication | Sci & Pers | Pa |
| Sinayev et al., 2015 [74] | Quant (Surv) | *N* = 370; mean age: 51; 69%; female; 88.9% white | Heart | Hyp | Standard | 2 (numeric format: frequencies vs. percentages) × 2 (risk labels: present vs. absent) | 1. Willingness to use the drug<br>2. Risk comprehension<br>3. Numeracy | Sci | Pa |
| Waters et al., 2007 [25] | Quant (Surv) | *N* = 4,248 mean age: 42.5; 68.8% female; 82.6 white; laypeople | Cancer | Hyp | Standard | 2 (side effect: present, absent) x 2 (target cancer probability: 22 %, 42 %) x 3 (graphic display: none, bar graph, array) x 2 (target cancer: stomach, colon) | 1. Interest in undergoing preventive treatment<br>2. Willingness to undergo preventive treatment<br>3. Accuracy in evaluating the treatment | Sci | Pa |
| Waters et al., 2009 [75] | Quant (Surv) | *N* = 5,379 mean age: 45.9; 62.8% female; 82.5% white; laypeople | Cancer | Hyp | Standard | 1. Treatment scenario (no side effect control, mixed gain, multiple loss, multiple gain, mixed gain with summary statement, multiple loss with summary statement, multiple gain with summary statement)<br>2. Target cancer (stomach, colon kidney) 3. Target cancer probability (25 % vs 44 %) | 1. Willingness to accept treatment 2. Accuracy in evaluating the treatment | Sci | Pa |
| Wegier et al., 2017 [76] | Quant (Surv) | Experiment 1 *n* = 31, mean age: 19.4; 51.6% male (condition1); *n* = 33, 63.6% male (condition 2); undergraduate students<br>Experiment 2: *n* = 92, mean age: 36.4; 51.1% male (condition 1), *n* = 88, mean age: 34.3; 55.7% male (condition 2) | Down Synd | Hyp | Standard | Experiment 1: 2 (learning format: description vs simulated experience) x 2 (format of elicitation: probabilities vs. natural frequencies) Experiment 2: 2 (learning format: description vs simulated experience) | 1. Estimates of positive predictive value<br>2. Likelihood of undergoing screening<br>3. Concern regarding a positive test result<br>4. Likelihood of recommending screening | Sci | Pa |
| Wilhelms et al., 2018 [77] | Quant (Surv) | Experiment 1 *n* = 415 mean age: 19.8; 72.5% female; 61.3% white; students<br>Experiment 2 *n* = 292 mean age: 20.1; 65.5% female; 55.3% white; students | RA | Hyp | Standard | Scenarios: health status quo (acceptable or not), adverse event (pneumonia and cancer) | 1. Risk perception<br>2. Worry<br>3. Gist knowledge<br>4. Willingness to start medication<br>5. Numeracy | Sci | Pa |
| Zikmund-Fisher et al., 2008 [78] | Quant (Surv) | Study 1 *n* = 2,012; mean age: 42; 100% female; laypeople<br>Study 2 *n* = 1,393 mean age: 49; 50% African American; laypeople | General | Hyp | Standard | 1. Presentation type (total risk vs incremental risk)<br>2. Presentation mode (text only vs text and pictograph)<br>3. Risk denominator (out of 100 vs out of 1000)<br>4. Side effect order (increase vs decreasing probability)<br>5. Subjective Numeracy Scale (control)<br>6. Prior knowledge about tamoxifen (control) | 1. Risk worry<br>2. Numeracy<br>3. Knowledge | Sci | Pa |

*Note*: The following abbreviations were used (in order of occurrence across columns): *Qual*= Qualitative methods; *Quant*=Quantitative methods; *Mixed*=Mixed methods; *FG*=Focus groups; *Surv*=survey; *Interv*=interview; *Obs*=observation*; General*=General health; *Heart*=Heart disease; *RA*=Rheumatoid arthritis; *Gen*=Genetics/genetic testing; *Down Synd*=Down Syndrome; *Physical*=Physical activity; *Vaccine*=Vaccination; *Hyp*=Hypothetical scenario; *Real*=Real situation; *Standard*=Standardized message; *Conv*=Conversation; *Sci*=Scientifc; *Pers*=Personal; *Prac*=Practical; *Pa*=Patient; *Pr*=Provider.

**Table 4**
Data extraction and classification results of studies ($n = 9$) exploring the ambiguity dimension of uncertainty in addition to the probability dimension (source = probability and ambiguity).

| Author Year | Study Design (Method) | Sample | Health Context | Situation | Message | Independ. Variables | Outcome measures | Issue | Locus |
|---|---|---|---|---|---|---|---|---|---|
| Allen et al., 2014 [79] | Quant (Surv) | *N* = 191; 50.79% female; median age: 21; students and laypeople | General | Hyp | Standard | 1. Format of graph (error bars, scatterplot, PDF, CDF, CCDF) 2. Cognitive load (number memorization task vs no number memorization task) | 1. Graph interpretation 2. Behavioral choice | Sci | Pa |
| Brewer et al., 2012 [80] | Quant (Surv) | *N* = 133; 100% female; median age: 59; breast cancer patients | Gen | Real | Standard | 1. Risk format (percentage, percentage and graphic, percentage and graphic and CI, percentage and recurrence score, graph, actual oncotype DX report, icon array) | 1. Gist 2. Attitudes toward test results 3. Preference | Sci | Pa |
| Han et al., 2011 [81] | Quant (Surv) | Experiment 1 *n* = 240; 50% female; mean age: 52; 90% white; laypeople<br>Experiment 2 *n* = 135; mean age: 54; 92% white; laypeople | Cancer | Hyp | Standard | 2 (ambiguity condition absent vs present) × 2 (uncertainty confidence intervals vs point estimate) × 2 (format text vs visual) Experiment 2: 3 conditions: 1) text only, 2) integrated text + solid bar graph range, and 3) integrated text + blurred bar graph range 6. Optimism 7. Numeracy | 1. Perceived cancer risk 2. Worry 3. Perceived credibility 4. Dispositional optimism, 5. Numeracy | Sci | Pa |
| Klein et al., 2015 [82] | Quant (Surv) | *N* = 247; 100% female; undergraduates | General | Hyp | Standard | 1. Self affirmation or no-affirmation 2. Alcohol consumption | 1. Perceived ambiguity 2. Perceived vulnerability 3. Message acceptance 4. Anxiety/ worry | Sci | Pa |
| Lawal et al., 2018 [83] | Quant (Surv) | *N* = 81; 48.1% female; 80.3 % white; patients | Gen | Real | Standard | 1. VUS sub classification (VUS high vs VUS low) | 1. Perceived risk (absolute and comparative) 2. Perceived severity 3. Perceived value of information 4. Self-efficacy 5. Decision regret 6. Behavioral intentions to share results and change behaviors | Sci | Pa |
| Pepper et al., 2019 [35] | Quant (Surv) | *N* = 2,508; 52.7% female; 67.2% white; laypeople | Vaping | Hyp | Standard | 1. Message (control vs uncertainty) | 1. Risk perceptions 2. Behavioral intentions 3. Health literacy | Sci | Pa |
| Politi et al., 2011 [84] | Quant (Surv) | *N* = 75; 100% female; mean age: 51; 76% white; patients | Cancer | Real | Conv | 1. Quality of physician communication 2. Reactions to uncertainty 3. Numeracy | 1. Patient surgical choice 2. More vs. less aggressive choice 3. Decision satisfaction | Sci | Pa & Pr |
| Schapira et al., 2001 [85] | Qual (FG) | *N* = 41; 83100% white; 100% female; laypeople | Cancer | Hyp | Conv | N/A | N/A | Sci & Prac | Pa |
| Schapira et al., 2008 [86] | Qual (FG) | *N* = 59; 47% female; patients | General | Hyp | Conv | N/A | N/A | Sci & Prac | Pa |

*Note*: The following abbreviations were used (in order of occurrence across columns): *Qual*=Qualitative methods; *Quant*=Quantitative methods; *FG*=Focus groups; *Surv*=survey; General = General health; *Gen*=Genetics/genetic testing; *Hyp*=Hypothetical scenario; *Real*=Real situation; *Standard*=Standardized message; *Conv*=Conversation; *Sci*=Scientifc; *Pers*= Personal; *Prac*=Practical; *Pa*=Patient; *Pr*=Provider.

studies (41.7%) used the word "complex" or "complexity" to denote the complexity dimension of uncertainty (as opposed to the broader usage of the adjective and noun), while 12 studies (50.0%) used terms consistent with the taxonomy for one of the two dimensions ("probability," "complexity," "complex"). Of the ten articles that explored all three dimensions of uncertainty, one (10.0%) used the exact wording to describe the three dimensions as proposed by the taxonomy and six (60.0%) used the specific terminology for one or two of the dimensions. Some studies used the words "uncertainty," "risk," and "probability" interchangeably, and often as an overarching term for any of the three dimensions described in the taxonomy. Two studies used the phrase "evidentiary uncertainty" but with different conceptualizations: one article conceptualized the phrase as ambiguity, while the other used it to describe complexity.

### 3.1.2. Issue

All 63 studies assessed uncertainty pertaining to prognoses, diagnoses, causes, and treatment for disease (i.e., scientific uncertainty). Few explored practical uncertainty, referring to system-centered uncertainty ($n = 9$; 14.3%), such as uncertainty about how to access care, or patient-centered uncertainty ($n = 4$; 6.3%), which describes uncertainty about future wellbeing, goal achievement, or relationships. Three studies (4.8%) addressed all three issue domains.

**Table 5**
Data extraction and classification results of studies ($n$ = 10) exploring all three source dimensions of uncertainty (source = probability, complexity, and ambiguity).

| Author Year | Study Design (Method) | Sample | Health Context | Situation | Message | Independ. Variables | Outcome measures | Issue | Locus |
|---|---|---|---|---|---|---|---|---|---|
| Bylund et al., 2012 [39] | Qual (Obs) | *N*= 16; mean age: 48; 100 % female; 81.3 % white; mothers | Gen | Real | Conv | NA | NA | Sci, Prac, & Pers | Pa & Pr |
| Clayton et al., 2008 [87] | Quant (Obs) | *n* = 6 providers; 66.7 % female; *n* = 60 breast cancer survivors; mean age: 61.7; 71.7 % white | Cancer | Real | Conv | NA | NA | Sci, Prac, & Pers | Pa & Pr |
| Donovan-Kicken et al., 2013 [88] | Qual (Interv) | *N*= 254; median age: 35.07; 65 % female; 53 % white; laypeople | Consent | Hyp | Standard | NA | NA | Sci & Prac | Pa |
| Goldman et al., 2006 [89] | Qual (FG) | *N*= 50; age range: 27–84 years; laypeople | Heart | Hyp | Standard | NA | NA | Sci | Pa |
| Kukafka et al., 2015 [90] | Mixed (FG, Surv) | *N*= 34; mean age: 53.4; 100 % female; 61.8 % Hispanic; laypeople | Gen | Hyp | Standard | NA | 1. Numeracy<br>2. Internet access<br>3. Sources of information<br>4. Breast cancer risk factors<br>5. Perceived breast cancer risk<br>6. Evaluation of tool | Sci, Prac, & Pers | Pa |
| Narayan et al., 2017 [91] | Qual (Interv) | *N*= 24 mean age: 55.5; 66 % female; 71 % white; patients | Heart | Real | Standard | NA | NA | Sci & Prac | Pa |
| Roberts et al., 2016 [92] | Qual (Interv) | *N*= 15; 53 % male; oncologists | Gen | Hyp | Standard | NA | NA | Sci & Prac | Pa & Pr |
| Schapira et al., 2016 [40] | Qual (Interv) | *N*= 22; 68.2 % male; 72.3 % African American; laypeople | Cancer | Real | Standard | N/A | N/A | Sci | Pa |
| Wackerbarth et al., 2007 [38] | Qual (Interv) | *N*= 65 median age: 41; 67.7 % male; 93.9 % white; primary care physicians | Cancer | Hyp | Conv | N/A | N/A | Sci & Prac | Pa & Pr |
| Zisman-Ilani et al., 2018 [93] | Qual (Interv) | *N*= 24; 58.3 % female; episodes of psychosis; clinicians; family members of patients; experts; patients | Mental Illness | Hyp | Standard | NA | NA | Sci & Pers | Pa & Pr |

*Note*: The following abbreviations were used (in order of occurrence across columns): *Qual*=Qualitative methods; *Quant*=Quantitative methods; *Mixed*=Mixed methods; *FG*=Focus groups; *Surv*=survey; *Obs*=observation; *Interv*=Interview; *Gen*=Genetics/genetic testing; *Heart*=Heart disease; *Hyp*=Hypothetical scenario; *Real*=Real situation; *Standard*=Standardized message; *Conv*=Conversation; *Sci*=Scientifc; *Pers*= Personal; *Prac*=Practical; *Pa*=Patient; *Pr*=Provider.

**Table 6**
Terminology used in articles by source dimension.

| Source Dimension | Probability Only ($n$ = 20) | Ambiguity & Probability ($n$ = 9) | Complexity & Probability ($n$ = 24) | Probability & Ambiguity & Complexity ($n$ = 10) |
|---|---|---|---|---|
| Terms coded as consistent with taxonomy source dimension terms | "probability" | "probability," "ambiguous,"* "ambiguity"* | "probability," "complex,"* "complexity"* | probability," "ambiguous," "ambiguity," "complex," "complexity" |
| Authors used taxonomy wording | 17 | 2 | 10 | 1 |
| Authors used taxonomy wording for at least one dimension | 0 | 5 | 12 | 6 |
| Authors did not use taxonomy wording | 3 | 2 | 2 | 3 |
| Examples of terms used in studies for each source dimension | risk, uncertainty; probabilistic uncertainty; stochastic (or random) uncertainty | risk, uncertainty, evidentiary uncertainty; scientific uncertainty; statistical uncertainty | risk, uncertainty; evidentiary uncertainty | |

*Note*: *Studies that used the words "complex," "complexity," "ambiguous," or "ambiguity" were only coded as consistent with taxonomy wording if it was clear that the term used referred to complexity or ambiguity inherent in uncertainty (as opposed to the broader use of the adjective or noun).

### 3.1.3. Locus

The majority of studies examined uncertainty experienced by the patient ($n$ = 52; 82.5%). Two explored uncertainty as experienced by providers (3.2%), and nine focused on both patients and providers (14.3%).

## 3.2. Study characteristics

To answer the second research question and further characterize the 63 articles, we extracted information about each article (see Tables 2–5). A discussion of notable findings is presented below.

Since 2000, there was a growth in articles about uncertainty communication, with major spikes after 2007 and 2012. Articles that focused solely on probability largely dominated the literature between 2003–2006. The focus on ambiguity and complexity was more common after 2007. Studies examining complexity increased considerably after 2015 (see Fig. 2).

The majority of the 63 articles utilized quantitative methods ($n$ = 46; 73.0%), followed by qualitative methods ($n$ = 12; 19.0%), and mixed-method designs ($n$ = 5; 7.9%). As could be expected given the preeminence of quantitative study designs, experiments and surveys were the most common approach to examine the effect of uncertainty communication strategies on various outcomes ($n$ = 44; 69.8%). Qualitative approaches were mainly used in studies that addressed all three dimensions of uncertainty – probability, ambiguity, and complexity ($n$ = 8; 12.7%). Overall, six studies (9.5%)

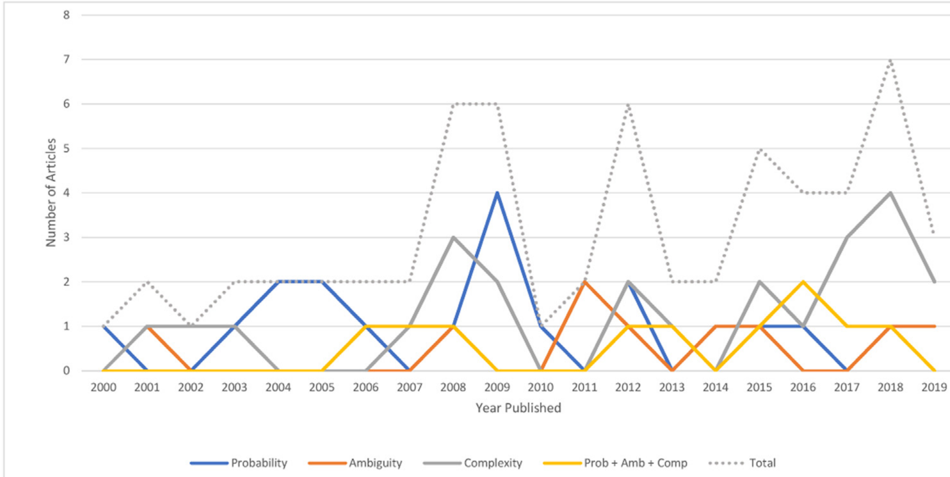


**Fig. 2.** Number of articles by source dimension between the years 2000 and 2019.
*Note*: The ambiguity and complexity dimensions both also include probability but were labeled “ambiguity” and “complexity” for simplification purposes.

utilized interviews and six studies (9.5%) used a combination of approaches, such as interviews and focus groups, or mixed methods like interviews and surveys.

Most articles investigated the communication of uncertainty by using a hypothetical scenario ($n$ = 49; 77.8%), and fewer a real situation ($n$ = 14; 22.2%). Furthermore, most studies ($n$ = 54; 85.7%) tested standardized messages – messages about uncertainty created by the authors and tested across all participants. A few based their analyses on actual conversations between patients and providers ($n$ = 9; 14.3%). The most common health contexts were cancer ($n$ = 20; 31.7%) and general health ($n$ = 17; 27.0%), followed by genetic testing ($n$ = 7; 11.1%), heart disease ($n$ = 5; 7.9%), and rheumatoid arthritis ($n$ = 4; 6.3%).

Theory guided the development of material and/or the design of studies in less than half of all articles ($n$ = 27; 42.9%). The most commonly used theories were Kahneman and Tversky’s [27] Prospect Theory ($n$ = 6; 9.5%) and framing effects ($n$ = 6; 9.5%), followed by the Uncertainty in Illness Theory ($n$ = 3; 4.8%) [8]. Less commonly used were Reyna and Brainerd’s [28] Fuzzy-Trace Theory ($n$ = 2; 3.2%), Mead and Bower’s [29] theoretical dimensions of patient-centered relationship ($n$ = 2; 3.2%), and the Health Belief Model ($n$ = 2; 3.2%) [30,31]. Other theories were used by only one article each, for example, the Communication and Uncertainty Management Theory ($n$ = 1; 1.6%) [5], the Health Action Process Approach ($n$ = 1; 1.6%) [32], or the General Evaluability Theory ($n$ = 1; 1.6%) [33].

Authors across all articles most commonly examined the impact of uncertainty communication strategies on comprehension ($n$ = 41; 65.1%), which included understanding of risk information, accuracy of risk estimates, knowledge, and recall. Other outcome measures were most often related to behavior ($n$ = 32; 50.8%), for example, behavioral choices between programs or treatment options or intentions to change behavior, and participants’ perception of risk ($n$ = 23; 36.5%). Articles further examined individuals’ preferences for message format and assessment of message quality ($n$ = 20; 31.7%), the role of emotions ($n$ = 15; 23.8%), and changes in attitudes and beliefs ($n$ = 5; 7.9%).

## 4. Discussion and conclusion

### *4.1. Discussion*

The purpose of this scoping review was to classify existing studies that examine the communication of uncertainty in health, using Han, Klein, and Arora’s [7] taxonomy of uncertainty as a framework. The value of the taxonomy lies in its consideration of the various nuances that uncertainty carries, the multitude of causes that lead to uncertainty, and the person that experiences uncertainty. Studies predominately focused on probability, used language to describe uncertainty heterogeneously, primarily focused on patients, and did not attend to practical uncertainty.

The examination of the volume and focus of studies on uncertainty over the past two decades was helpful to map the growth of the field and to ascertain whether studies have picked up on the various nuances of uncertainty in health. Our findings suggest that probability as the source of uncertainty remains the preeminent focus of uncertainty communication research. Despite the growth in studies exploring ambiguity and complexity as sources of uncertainty since 2007, most continue to focus on identifying, testing, and evaluating strategies to communicate probabilistic risk. This is concerning because of an increasing acknowledgement of limitations in scientific evidence and a multiplicity of equally beneficial medical options which make complexity and ambiguity more frequent causes of uncertainty in medical encounters. Our review therefore provides evidence that supports recent calls for research and intervention development to improve the management of uncertainty arising from ambiguous and complex information [6,34,35].

Of even greater concern is the variation in terminology use to describe uncertainty. In many studies, authors used the umbrella term *uncertainty* or *risk* when referring to complexity or ambiguity. Moreover, studies used terms interchangeably to describe the different experiences and formats of uncertainty. Authors who published prior to the development of the taxonomy of uncertainty were likely unaware of the nuances in terminology. However, the continued use of heterogenous language decreases the chance for comparative research and may lead to continued misunderstandings or confusion. As discussed previously, the same phrase, such as “evidentiary uncertainty,” may be used in different articles to describe different sources of uncertainty. A unified language, such as that proposed by Han, Klein, and Arora [7] may contribute to increased transparency and comparisons across studies.

Another important finding was the surprisingly low number of studies that examined uncertainty experienced by providers. While it is encouraging that studies test interventions to aid patients in interpretation and management of uncertainty, studies indicate providers also struggle with ambiguous evidence and complex decisions. For example, analyses of patient-provider interactions in clinical settings included in this review found that uncertainty affects providers' ability to maintain patient centeredness during patient-provider conversations [36], form risk judgements [37], and have risk- benefit discussions [38]. Providers' ability to effectively communicate uncertain information is a prerequisite to ensure patient understanding and informed decision-making. Additional research on providers' experience with uncertainty can elucidate opportunities for provider-facing interventions that may improve patient outcomes.

The *issue* dimension of the taxonomy revealed that most studies focused on scientific uncertainty about diagnoses, prognoses, causes, and treatment options, and measured outcomes such as screening intentions or medication adherence. Very few considered the experience of practical uncertainty – lack of knowledge about structure and access to healthcare, and personal uncertainty – the unknown impact on personal goals, future wellbeing, or relationships. To explore practical uncertainty, previous studies have assessed patient perspectives and confusion related to medical disclosure and consent documentation [88] as well as confusion related to the process for participating in clinical trials [49]. To explore personal uncertainty, researchers have investigated factors of importance to treatment, such as effort [73] and impact on usual activities [93]. However, few articles addressed these issues of uncertainty despite findings from qualitative studies included in this review that suggest patients' experience of personal uncertainty has negative impacts [38,39]. For example, Bylund found mothers' uncertainty about the psychosocial impact of genetic testing on their children impacted sharing and discussing test results with their daughters [39]. Additional research should explore personal and practical uncertainty to better understand how these two dimensions of uncertainty may impact health outcomes.

The taxonomy of uncertainty proved useful in identifying gaps in the current literature, yet its application to the classification process revealed several limitations. First, it was challenging to disentangle probability from ambiguity and complexity, as studies generally explored these two dimensions within the context of probabilistic risk. Therefore, studies about ambiguity and complexity included a probabilistic dimension as well. Similarly, boundaries between the issue domains- scientific, practical, personal- were blurry and often intertwined. For example, study participants often described uncertainty about health insurance coverage (a practical issue), which caused them to worry about the financial impact of treatment on their lives (a personal issue). A more detailed description of the relationship between the specific domains within the three dimensions and more refined distinctions may strengthen the discreteness of the various conceptualizations of uncertainty.

Few authors relied on theories or frameworks to guide study design or message development, and few used communication theories. Several theories were adapted from other disciplines such as Prospect Theory from economics [27], or the General Evaluability Theory from psychology [33]. Some utilized theory related to behavioral outcomes, such as the Health Action Process Approach [32]. As such, there are myriad opportunities for communication scholars to develop or extend theory, and ultimately, identify strategies and create interventions to improve the communication of uncertainty information.

Our findings should be considered in light of a few limitations. This review focused specifically on communication of uncertainty in healthcare settings. We excluded articles that only examined patients' and providers' *preferences* for managing uncertainty through communicative practices, as we wanted to limit the review to studies that tested or analyzed specific messages or conversations. Other exclusion criteria may have inadvertently eliminated relevant material, such as our parameters to only include articles published in English and in the United States. Furthermore, we did not describe the effect of communication strategies on uncertainty, as the primary focus of this review was to reduce fragmentation in the field of uncertainty communication research by synthesizing existing studies. A meta-analysis on this topic may be useful to explore the effects of communication strategies on outcomes. Future work could also take a closer look at the methodologies used to explore outcomes (e.g., experimental vs. correlational study designs). We used the taxonomy of uncertainty to guide our search strategy because the taxonomy was informed by uncertainty research in various disciplines, most notably, communication. Specifically, we used the terms "uncertainty," "probability," and "ambiguity," or "complexity" in our search. However, in choosing to use these terms, we may have excluded studies that might have fit within the definition of these terms but did not explicitly use these terms (e.g., knowledge studies). Finally, we acknowledge subjectivity in the classification process of studies based on the different source dimensions and their respective domains as a limitation.

### 4.2. Conclusion

As uncertainty becomes increasingly pervasive in the health and medical fields, it is important to acknowledge distinct formats and nuances to maximize the potential and effectiveness of communication strategies and interventions. Authors of future studies examining uncertainty should be considerate of nuances in uncertainty terminology. The Han, Klein, and Arora [7] taxonomy of uncertainty is useful as it differentiates between probability, ambiguity, and complexity. Many scholars use such linguistic distinctions but name them differently. In addition to source, specificity related to the issue and the locus of uncertainty is also recommended.

### 4.3. Practice implications

Our review revealed a significant amount of research about the communication of probabilistic risk that can inform practice. However, patient-provider interactions increasingly involve uncertainties stemming from ambiguous and/or complex information, yet research is lacking in these areas emphasizing the need for effective strategies to facilitate discussion and management of these dimensions of uncertainty. Furthermore, studies have predominately focused on scientific uncertainty, but neglected practical and patient-centered uncertainty. Practical and patient-centered uncertainty may decrease patient adherence to medical recommendations and decrease satisfaction with the patient-provider relationship. Therefore, more research is needed to identify messages that help patients manage uncertainty related to practical and patient-centered issues. Few studies focused on uncertainty experienced by providers. Additional research exploring how providers experience and manage distinct dimensions of uncertainty is vital, as providers' ability to manage uncertainty influences their ability to communicate uncertainty to their patients.

Most studies used hypothetical scenarios and standardized messages to test people's perception and comprehension of risk information. Yet, it is equally important to analyze current strategies used in interpersonal settings, particularly as they occur organically in patient-provider communication. We therefore recommend future studies explore how providers and patients experience and communicate uncertainty in clinical settings, when faced with making health decisions under conditions of uncertainty.

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## Declaration of Competing Interest

The authors declare that they have no conflicts of interest.

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## Appendix A

Codebook used to Classify Studies According to the Dimensions of the Taxonomy of Uncertainty

| **Source** | | | |
|---|---|---|---|
| (refers to the cause of a given uncertainty or the fundamental reason for a specific knowledge gap) | | | |
| | *Description* | *Conceptualization* | *Study Examples* |
| **Probability** | Likelihood of a future event, stochastic uncertainty<br>Probability (otherwise known as risk) refers to the fundamental indeterminacy or stochastic nature of future outcome<br>Risk, or uncertainty about future outcomes | • Individualized/personalized risk estimates<br>• Point estimate of risk (e.g., “20% probability of benefit from treatment”) | • Comprehension of lifetime risk for developing breast cancer [52]<br>• Ease of understanding breast cancer recurrence risk [43]<br>• Judgments about risk severity [45]<br>• Likelihood of being diagnosed with cancer at annual check-up [44]<br>• Personalized cancer risk estimate [18]<br>• Mortality/survival rate [51]<br>• Effectiveness of prevention/screening options [26] |
| **Ambiguity** | Relates to the quality or strength of scientific evidence/ information; lack of reliability, credibility, validity, or adequacy of risk estimates<br>Risk information is unavailable, inadequate, imprecise, vague, incomplete<br>Risk information is unreliable, conflicting; expert knowledge is contested<br>Statistical precision of a risk estimate | • Missing or inconsistent empirical data<br>• Conflicting expert opinions and recommendations<br>• Inadequacies in scientific evidence: study design (randomized controlled trial v. observational), blinding, duration of treatment and follow-up, appropriateness of the outcome measures used, controlling of confounders in design and analysis, sample size, and sample population<br>• Use of a confidence interval (CI) around a point estimate of risk | • Variants of uncertain significance results as scientific “grey zones” [82]<br>• Use of error bars to depict distribution of data [79]<br>• Use of confidence intervals to denote range of possible values for disease risk [80,81]<br>• Manipulation of strength in scientific evidence regarding link between alcohol consumption and breast cancer risk in cancer prevention message [82] |
| **Complexity** | Uncertainty arising from aspects of the phenomenon itself that make it difficult to comprehend<br>Uncertainty arising from the complexity of risk information | • Multiplicity<br>- multiple risks and benefits<br>- multiple causes, effects, or interpretive cues related to an event (example: the existence of varied risk factors, symptoms, or signs of a given disease)<br>- multiple possible states of an event or concept, such as the existence of numerous potential outcomes from a medical treatment<br>• Temporality<br>- processing and interpretation of multiple risks simultaneously<br>- making sense of risks that change over time and as a consequence of different actions<br>• Conditional probabilities | • Comparing both survival and mortality curves at the same time; understanding how risk changes over time [59]<br>• Comparing several probabilities (i.e., adding together probabilities of different side effects) [76]<br>• Evaluating tradeoffs (benefits and harms) [61]<br>• Understanding personalized risk estimates [57]<br>• Considering/discussing medication side effects and impact on medication adherence [34]<br>• Testing understanding of incremental risk [78] |

| **Issue** | | | |
|---|---|---|---|
| (refers to the substantive situation, outcome, or alternative to which a given uncertainty applies) | | | |
| | *Description* | *Conceptualization* | *Study Examples* |
| **Scientific** | Disease-centered<br>Scientific uncertainty encompasses uncertainties about diagnosis, prognosis, causal explanations, and treatment recommendations | Relates to concerns, methods, and activities of researchers—such as measurement, sampling, and modeling. | • Uncertainty about accuracy of cancer risk estimates [52,43]<br>• Understanding probability of cancer diagnosis at annual check-up [44]<br>• Uncertainty about the strength of scientific evidence related to diagnosis, prognosis, causes, and treatment [80,81,82] |
| **Practical** | System-centered<br>Lack of knowledge about both the structures of health care (i.e., the institutional facilities and resources of | • Uncertainty about the competence of one's physician, the quality of care one can expect to receive from a given clinician or institution | • Confusion or lack of knowledge about the importance of colorectal cancer screening for asymptomatic individuals, leading to screening hesitancy [38] |

(*Continued*)

| **Issue** | | | |
|---|---|---|---|
| (refers to the substantive situation, outcome, or alternative to which a given uncertainty applies) | | | |
| | *Description* | *Conceptualization* | *Study Examples* |
| | the health-care system) and the processes of health care | • Uncertainty about the responsibilities, procedures, and actions required to deliver, access, or utilize health-care services | • Unclear financial consequences of undergoing genetic testing for *BRCA* [39,90]<br>• Concerns about the usefulness of genetic testing results for health decisions [90] |
| **Personal** | Patient-centered<br>Personal uncertainty pertains to psychosocial and existential issues including the effects of one's illness or treatment on one's goals or outlook on life, one's personal relationships, the welfare of loved ones, future wellbeing, or one's sense of meaning in life.<br>Uncertainty about the personal significance of particular risks (e.g., their severity, timing) | • Personal identity<br>• Interpersonal relationships<br>• Ethical or moral concerns (e.g., whether and when results should be shared with others)<br>• Financial concerns<br>• Impact of procedures on emotional well-being | • Worry and anxiety about the emotional impact of positive *BRCA* genetic testing result on daughters [39]<br>• Consequences of positive *BRCA* genetic testing result on decisions related to career, marriage, and having children [39]<br>• Fear of cancer recurrence, which reduces quality of life [87] |

| **Locus** | | | |
|---|---|---|---|
| (the particular party or stakeholder in whose mind(s) a given uncertainty resides). | | | |
| | *Description* | *Conceptualization* | *Study Examples* |
| **Clinician** | Uncertainty resides in healthcare provider/health care professional | • Any health professional<br>• Extents to individuals working in the lab | • Oncologists [92]<br>• Physicians [38]<br>• Psychiatrists, mental health counselors, and administrators [93] |
| **Patient** | Uncertainty resides in patient | • Any individual facing health or medical decisions<br>• Extents to family members | • Multi-ethnic, low-numerate women [90]<br>• Breast cancer survivors [87]<br>• Mothers at risk for a *BRCA 1/2* mutation [39]<br>• Family members of patients with psychosis [93] |

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