

REVIEWS

Communicating Uncertainty: a Narrative Review and Framework for Future Research

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Discussing the uncertainty associated with a clinical decision is thought to be a critical element of shared decision-making. Yet, empirical evidence suggests that clinicians rarely communicate clinical uncertainty to patients, and indeed the culture within healthcare environments is often to equate uncertainty with ignorance or failure. Understanding the rationale for discussion of uncertainty along with the current evidence about approaches to communicating and managing uncertainty can advance shared decision-making as well as highlight gaps in evidence. With an increasing focus on personalized healthcare, and advances in genomics and new disease biomarkers, a more sophisticated understanding of how to communicate the limitations and errors that come from applying population-based, epidemiologic findings to predict individuals' futures is going to be essential. This article provides a narrative review of studies relating to the communication of uncertainty, highlighting current strategies together with challenges and barriers, and outlining a framework for future research.

KEY WORDS: communication; decision-making; doctor-patient relationships; patient-centered care; medical education.

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INTRODUCTION

Doubt is not a pleasant condition, but certainty is an absurd one. —Voltaire (1694 – 1778)

Disclosure and discussion of the uncertainty inherent in many medical decisions are essential for true shared decision-making and patient-centered care. Yet this is an ideal not easily mastered. Since the days of Hippocrates, humans have been striving to outsmart uncertainty, looking to deny its existence and eliminate its presence from most aspects of our lives, with the clinical environment being no exception. Indeed, we have a culture in healthcare that too often equates

uncertainty with ignorance or failure,¹ and an educational system that focuses on learning facts in a quest to reduce uncertainty. However, given that uncertainty is fundamental to healthcare, provider discomfort with uncertainty can impede open, honest, and respectful communication with patients and colleagues, undercutting the patient-provider relationship, and even decreasing trust.² Furthermore, the inability to communicate uncertainty may create a false sense of certainty among patients, which can lead to distrust when that certainty proves to be overstated.

What Is Uncertainty?

Despite decades of research into “uncertainty” in a multitude of disciplines, it has proven challenging to develop a unified definition of uncertainty that encompasses the numerous types, sources, and manifestations of uncertainty. Broadly, uncertainty can be thought of as the conscious awareness of being unsure, of having doubt, of not fully knowing.^{3,4} All medical decision-making occurs under conditions of varying levels of uncertainty about diagnoses, optimal treatments, and prognoses—it is ubiquitous in healthcare.⁵ Uncertainty has been recognized to have two major dimensions: (1) aleatoric uncertainty (from the Latin root for dice and gaming) relating to chance uncertainty, i.e., the inherent uncertainty due to random variability,⁶ and (2) epistemic uncertainty (from the Greek root *episteme*, meaning knowledge) relating to our incomplete knowledge that arises both from limitations in existing scientific knowledge about a medical question and limitations in the decision-makers ability to access and process effectively existing scientific knowledge. Any scenario has a combination of these two dimensions. As an example, there is inherent variability in whether a patient develops a certain disease (aleatoric uncertainty), and inherent limitations in the provider's ability to diagnose the disease—in part because scientific knowledge about the disease is imperfect and in part because of imperfections in the provider's access to, and use of, the existing knowledge (epistemic uncertainty). Table 1 outlines sources of uncertainty, categorized as aleatoric or epistemic uncertainty, in medical decision-making.

Why Is Communication of Uncertainty Important?

Uncertainty Is Commonplace in Healthcare, and Likely to Increase. Osler's maxim that “medicine is a science of

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Table 1 Sources of Uncertainty in Medical Decision-Making

| Nature of uncertainty | Source of uncertainty |
|---|--|
| Aleatoric, or chance, uncertainty (uncertainty due to random variability) | Variation in disease incidence or outcomes across patients Variation in personal significance of particular risks: tolerability, scope, timing, or temporal impact Potential for future developments that may affect risk of disease or outcomes |
| Epistemic uncertainty (uncertainty due to incomplete knowledge) | Inadequate scientific knowledge: <ul style="list-style-type: none"> • Uncertainty due to missing or inconsistent evidence • Uncertainty from translating population level findings to individuals Inadequate access to, and application of, existing scientific knowledge: <ul style="list-style-type: none"> • Uncertainty from ignorance of existing evidence • Uncertainty from complex or poorly understood evidence |

uncertainty and an art of probability”⁷ remains as true today as it has in centuries past. Decisions in healthcare continually have to be made on the basis of imperfect data and limited knowledge, coupled with unpredictable responses and healthcare outcomes that are far from binary.¹ The increasingly rapid emergence of new medical technologies that is outpacing the development of evidence regarding benefits, harms, and implications is resulting in uncertainty becoming a growing problem in healthcare.³ In addition, the exponential increase of knowledge in health sciences brings further levels of complexity that can, ironically, amplify uncertainty.

Our growing focus on personalized healthcare and precision medicine mandates a more sophisticated understanding of limitations and errors in applying and communicating population-based, epidemiologic findings to the individual. How to use risk estimates and risk prediction tools to improve and inform individual treatment decisions, while acknowledging and communicating their limited power to predict individual futures, is a critical challenge that will become even more important as new disease biomarkers are discovered and new tools for tailoring treatment are introduced.⁸ The importance of managing uncertainty is increasingly recognized as critical for medical education by accrediting bodies, including the ACGME defining “the capacity to accept that ambiguity is part of clinical medicine and to recognize the need for and to utilize appropriate resources in dealing with uncertainty” as a critical professional competency for trainees.

Effective Communication Is Fundamental to the Duty of a Provider. Communicating information about illness, treatment, and prognosis is a frequent and fundamental role of the provider, as part of the primacy of the ethical principle of autonomy, particularly as embodied in the doctrine of informed consent. One essential component of this dialogue is knowledge and discussion of the uncertainties that pervade medical decision-making.⁹

Patient-Centered Care and Shared Decision-making Demands Transparency and Disclosure of Uncertainty. Understanding the aleatoric and epistemic uncertainties that arise in clinical practice enables appropriate goals and strategies for managing uncertainty to be established, particularly with regard to the extent to which uncertainty is reducible. For example, uncertainty arising primarily from unclear information (epistemic uncertainty) is theoretically reducible and an appropriate goal could be to improve the comprehensibility and coherence of information, correcting misconceptions⁵—minimize “unnecessary uncertainty” (the knowable unknowns). This helps patients to make an informed decision or participate effectively in the shared decision-making process.¹⁰ In addition, a transparent dialogue between provider and patient that includes uncertainty is morally and ethically obligated. The importance of communicating uncertainty in the decision-making process is now evident in many guidelines and consensus statements including a recent National Academy of Medicine report “Improving Diagnosis in Health Care” that recommends that providers share their working diagnosis with patients including the degree of uncertainty associated with each diagnosis.¹¹ Although many providers are uncomfortable sharing uncertainty with their patients¹² and may feel that communicating the complexity of uncertainty will overwhelm and confuse patients, at least one study suggests that direct expressions of uncertainty, such as “I don’t know” or “It’s not clear”, result in higher levels of positive talk, patient engagement, and patient satisfaction, strengthening the provider-patient relationship.¹³ Several studies have shown that patients, family members, and healthcare providers all report communicating prognostic uncertainty to be a desirable trait of person-centered care.^{14–17} One study found that communication of scientific uncertainty led to decision dissatisfaction among women facing cancer treatment decisions, but not women facing prevention decisions, although there is debate as to whether decision satisfaction is an appropriate outcome measure of a good decision-making process and it is recognized that without an explicit discussion of the scientific uncertainty that complicates many decisions, informed decision-making likely falls short of its goals.¹⁸

Impact on Diagnostic Errors and Patient Outcomes. A provider’s ability to deal with uncertainty at a cognitive, emotional, and ethical level has been shown to influence the diagnostic process with potential for diagnostic error and impact on patient outcomes.¹⁹ Suppression of uncertainty and lack of consideration of alternative diagnoses can result in premature closure, the single most common phenomenon in misdiagnosis.²⁰

Why Is Training to Communicate Uncertainty Important?

Although providers are rationally aware when uncertainty exists, the culture of healthcare is often reluctant to

acknowledge this reality. Much of medical teaching, including case-based curricula, is driven by the goal of bringing together a constellation of signs, symptoms, and test results into a unifying solution rather than learning how to manage and communicate uncertainty.¹ This reluctance may be particularly great for physicians who do not hold a graduate degree other than an MD.^{9, 21} Communicating uncertainty is challenging and requires skill and training. Patients are known to have complex cognitive, emotional, and behavioral responses to uncertainty^{9, 22} and their comprehension of uncertainty varies by the way it is communicated. Studies have reported undesirable effects of communication, including heightened perceptions and feelings of vulnerability and avoidance of decision-making^{5, 22–26} and negative patient perceptions (lack of confidence, low visit satisfaction, worry, or concern)^{18, 27–32}, highlighting the need for skills in this domain. Patients may also not desire or have sufficient psychological capacity to tolerate information about uncertainty.³³ Furthermore, these challenges of uncertainty communication exist in among widespread challenges with provider-patient communication overall. Communication issues are a primary reason for malpractice action in over 80% of cases.³⁴

An inability to effectively communicate uncertainty may contribute to the relatively low levels of such communication in clinical encounters. In an analysis of 1057 clinical encounters by PCPs and surgeons, discussion of uncertainty about risks and benefits of treatment was done only 1% of the time for basic decisions; 6% for intermediate decisions; and 16.6% for complex decisions.³⁵ This discomfort with accepting and communicating uncertainty may also contribute to the evidence that anxiety due to uncertainty has a negative impact on physician wellbeing³⁶ and workplace satisfaction.³⁷

Strategies to Communicate Uncertainty

Although the empirical evidence about the optimal approaches for communicating uncertainty to patients is limited, current recommendations can be grouped under four primary domains: assessing patient preferences for communication, risk and ambiguity communication strategies, providing emotional support, and clarification of contingency plans.^{9, 22, 28, 38} Recommendations in these domains are highlighted in Table 2.

Potential Challenges and Barriers. Several challenges and barriers to successful communication of uncertainty have been highlighted, which need to be considered as strategies are developed:

- Patient education level: deficits in numeracy and health literacy reduce patients' capacity to understand information and to participate effectively in decision-making.^{44, 56, 57}
- Cultural challenges: in striving for certainty, the health-care field often creates a gap between expectation and reality, with a false sense that uncertainty equates to ignorance or failure¹; a shift in culture is required to role-

Table 2 Current Strategies to Communicate Uncertainty

| Broad domain | Individual strategies |
|--|--|
| Explicitly assess patients' desire for information and method of delivery for that information | Assess individual's informational preferences and capacity for understanding uncertainty. ³⁹ Tailor conversation for individual, altering specific type/amount of information according to various characteristics (gender, culture, education, psychological factors, behaviors of interest) that relate to patients' capacity to use/respond to such information. ^{40–42} |
| Strategies to communicate risk and ambiguity | Bracket estimates with ranges to convey realistic uncertainty, being sure to allow for exceptions in both optimistic and pessimistic directions. ⁴³ Round off numbers to avoid false illusions of precision. ⁴⁴ Use qualitative descriptions, but beware that many have no generally accepted anchoring at specific quantitative levels of frequency ^{44,45} ; may work to relate medical risks to nonmedical risks so they can be placed in larger perspective of persons' life. Visual aids to communicate probabilistic information improve cognitive outcomes. ^{9,46} Be aware of framing effects in conveying information on uncertainty which may impact uncertainty aversion: for example, gains versus losses; qualitative versus quantitative. ^{44,46,47} Consider presenting risk information in several formats (qualitative, graphical displays, positive frame, negative frame, frequency, proportions, absolute, relative) to avoid framing biases in perception of message. ⁴⁵ |
| Ensure support is fostered | Education/communication approach: CBT to improve patients' resilience and ability to cope with uncertainty. ^{48,49} Clarify the type of uncertainty that is most distressing to patient and explain complexities of each ⁵⁰ : uncertainty about probabilities; uncertainty about sources of information; uncertainty about evidence. See uncertainty as opportunity rather than danger. ⁵¹ Provide emotional support: "With you on the journey"; "I do not know, but I will be there no matter what happens" takes humility and a commitment to a meaningful engagement—that commitment is often what patients want most. ⁵² Assure will answer all questions, provide resources, inform of own biases and values, inform of alternative treatments. ^{53,54} |
| Clarify plan | Safety-netting is often used especially if diagnosis is uncertain and differential includes serious illness: say precisely what to look for; say precisely how to seek further care; be precise about time course. ⁵⁵ |

model to trainees the safe, and indeed desired, expression of uncertainty.

- Time challenges: providers now see more patients in shorter periods of time which places challenges on time that can be spent in complex, and difficult, conversations such as the communication of uncertainty.
- Reimbursement: financial mechanisms in place in hospitals and healthcare settings do not value or recognize discussion of uncertainty as reimbursable aspects of the consultation—an area which drives and dictates much provider behavior.
- Provider attributes: providers differ in their own capacity to acknowledge and embrace uncertainty.
- Team challenges: there is often disagreement within teams about level of disclosure of uncertainty.
- Fear of deleterious consequences in communicating uncertainty: while a significant component of earning patient and family member trust is the open acknowledgment of prognostic uncertainty,⁵⁸ acknowledgment can also be a source of mistrust and potential conflict.⁵⁹ There is often a fear that additional, complex information has the potential to overwhelm and confuse patients, impairing their ability to make truly informed decisions.⁶⁰ It has been shown that increasing people’s awareness of ambiguity about the safety of vaccines risks making them reluctant to receive them.^{61, 62} The same has been shown for certain cancer screenings, such as PSA testing⁶³ and breast cancer screening.⁶⁴
- Communication training: changing communication behavior is challenging and traditional didactic medical education does not address important factors in this domain, such as motivation, confidence, barriers, or skill.

Summary and Recommendations for Future Research

The practice of medicine involves innate uncertainty due to inherent variability in outcomes and unpredictability of patient response (aleatoric uncertainty) and due to the limitations and imperfection of our knowledge and complexity of risk information reliability, accuracy, and generalizability (epistemic uncertainty). Although the ideal of informed or shared decision-making implies a need for communicating this uncertainty to patients, there is currently wide variability in the degree to which providers actually engage in communicating conditions of scientific uncertainty, with few evidence-based recommendations for such communication.

The development of such recommendations will require empirical research in multiple domains including the neurobiology underpinning how people process, interpret, and respond to various types of uncertainty^{65, 66}; defining the circumstances and communication strategies to discuss uncertainty^{5, 9}; understanding how individuals vary in their reaction to uncertainty^{3, 36}; the impact of uncertainty discussions on health-related decisions and outcomes⁹; and in the

Table 3 Areas for Future Research Focus

| Broad domain | Research areas |
|--|---|
| Neuroscience | How do people process, interpret, and respond to various types of uncertainty inherent in clinical decisions? |
| Communication techniques | What are the mechanisms of framing effects in different patient populations that may affect how information is perceived and responded to, impacting uncertainty aversion? Is information about uncertainty best presented verbally, numerically, graphically, or using multiple formats? What is the effect of non-verbal communication to emphasize and embrace uncertainty (changes in tone, phonetics, and body language)? |
| Communication content | Under what circumstances is the communication of both aleatoric and epistemic uncertainty appropriate, and why? What degree of precision in communicating both types of uncertainty is necessary and optimal? |
| Assessing individual preference | How can an individual’s tolerance of uncertainty be assessed? Do patient factors, including cultural background, influence attitudes about uncertainty? Do physicians’ perceptions represent accurate assessments of their patients’ preferences about uncertainty? What are the most effective ways to reduce an individual’s intolerance of uncertainty? What patient characteristics influence effective communication of uncertainty? |
| Creating and assessing impact of communication | What are the trade-offs in different approaches to communicating uncertainty? What strategies enhance the likelihood that the discussion of uncertainty is viewed as a sign of honesty rather than incompetence and how does this impact vary by patient characteristics? In what ways, and under what circumstances, does communication of uncertainty improve outcomes for patients? What is the longer-term impact of protective uncertainty on patient outcomes? |
| Measurement tools | How do we accurately measure and quantify uncertainty? |

development and validation of measures of component and composite uncertainty³ (Table 3).

One of the biggest challenges facing the coming era is the authentic disclosure and communication of uncertainty in a meaningful way that enhances trust in the patient-provider relationship, and improves decision-making and healthcare outcomes. There is growing recognition of the importance of diagnostic error with regard to patient safety. Our quest for certainty may well be driving many of the cognitive errors contributing to this crisis. Learning to discuss and reflect on uncertainties—aleatoric and epistemic—is essential for true shared decision-making and patient-centered care. The time is ripe for focused research efforts in this field.

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