**Opinion Paper**

Lekshmi Santhosh*, Calvin L. Chou and Denise M. Connor

# Diagnostic uncertainty: from education to communication

https://doi.org/10.1515/dx-2018-0088
Received September 5, 2018; accepted February 13, 2019; previously published online March 9, 2019

**Abstract:** Diagnostic uncertainty is common in clinical practice and affects both providers and patients on a daily basis. Yet, a unifying model describing uncertainty and identifying the best practices for how to teach about and discuss this issue with trainees and patients is lacking. In this paper, we explore the intersection of uncertainty and expertise. We propose a 2×2 model of diagnostic accuracy and certainty that can be used in discussions with trainees, outline an approach to communicating diagnostic uncertainty with patients, and advocate for teaching trainees how to hold such conversations with patients.

**Keywords:** communication; medical education; uncertainty.

## Introduction

The diagnostic process often occurs in the context of uncertainty. Physicians selectively identify and interpret data, the patient can only describe certain symptoms, and laboratory and imaging tests have limited sensitivity and specificity. In clinical practice, there is rarely a completely definitive understanding of a patient's "true" diagnosis; an educated and evolving hypothesis about the most likely diagnosis is far more typical.

Two main paradigms of clinical uncertainty have been proposed (Table 1) [1, 2]. In both, *diagnostic* uncertainty is considered a type of technical or scientific uncertainty [1] (i.e. inadequate scientific data to determine the "true" diagnosis). A recent literature review defined diagnostic uncertainty as "the subjective perception of an inability to provide an accurate explanation of the patient's health problem" [3]. Here, the clinician's subjective perception, rather than any objective measure, defines diagnostic uncertainty. A recent review found that most diagnostic uncertainty literature focused on the interaction of individual, cognitive, emotional, or ethical domains with uncertainty [4].

Diagnostic uncertainty has clinical consequences. It has been associated with a reluctance to withdraw intensive therapy [5] and a propensity to order more tests and refer to specialists more often, thus increasing health care costs [6, 7] and resulting in a bias toward overuse of high-technology medicine [8]. Moreover, stress related to managing uncertainty may be linked with lower resilience in trainees [9] and may contribute to burnout.

Most of the clinical reasoning literature focuses on issues related to diagnostic accuracy and considers cognitive strategies to reduce diagnostic error without addressing uncertainty [10]. While diagnostic uncertainty is an integral part of the reasoning process and a daily reality for practicing clinicians, there is scarce literature on how best to define, study, communicate, and teach about it [3].

In this paper, we explore the intersection of uncertainty and expertise. We propose a 2×2 model of diagnostic accuracy and certainty that can be used in discussion with trainees, outline an approach to communicating diagnostic uncertainty with patients, and advocate for teaching trainees how to have such conversations with patients.

## Clinical reasoning in the face of uncertainty

In the field of cognitive science, patient illnesses are "ill-structured problems" [11], leading to unique challenges in clinical reasoning. For instance, medical problem-solving is often described as a series of conditional probabilities, where pre-test probabilities are modified by Bayes' theorem, based on test characteristics, to yield post-test probabilities [12]. This mathematical framework is useful when interpreting diagnostic tests. However, pre-test

***Corresponding author: Lekshmi Santhosh,** MD, Assistant Professor of Clinical Medicine, Divisions of Pulmonary and Critical Care Medicine and Hospital Medicine, University of California, 505 Parnassus Avenue, San Francisco, CA 94143, USA, E-mail: Lekshmi.Santhosh@ucsf.edu. https://orcid.org/0000-0002-9897-3462
**Calvin L. Chou and Denise M. Connor:** Department of Medicine, University of California, San Francisco, CA, USA, E-mail: calvin.chou@ucsf.edu (C. L. Chou); denise.connor@ucsf.edu (D. M. Connor)

**Table 1:** Models of uncertainty.

| Model 1 | | Model 2 | |
|---|---|---|---|
| **Type of uncertainty** | **Definition** | **Type of uncertainty** | **Definition** |
| Technical uncertainty | Inadequate scientific data (e.g. not knowing whether the new synthetic drug a patient may have ingested is detected on the laboratory's toxicology screen) | Scientific uncertainty | Data-centered uncertainty (e.g. not knowing how a mildly elevated ANA antibody impacts a diagnosis of new interstitial lung disease) |
| Personal uncertainty | Unawareness of a patient's wishes (e.g. being unsure how much diagnostic testing should be pursued when working up unintentional weight loss in a patient with unclear goals of care) | Personal uncertainty | Patient-centered uncertainty (e.g. being unsure of a patient's desires to pursue more diagnostic testing when treating metastatic breast cancer) |
| Conceptual uncertainty | Difficulty applying abstract criteria to concrete situations (e.g. strictly using diagnostic criteria for multiple sclerosis in a patient with an unclear or atypical presentation) | Practical uncertainty | System-centered uncertainty (e.g. not knowing the most efficient way to diagnose a malignancy in the outpatient setting) |

ANA, antinuclear antibody.

probability and the selection of appropriate tests are themselves often uncertain. Kassirer [13] noted the challenges of managing clinical data in the face of uncertainty: "…because nonquantitative terms do not have standardized meanings, the clinician's ability to combine clinical data characterized by such nonquantitative measures of uncertainty is compromised". Because of the reality of uncertainty, trainees learn that when diagnoses are unclear, an intuitive "clinical gestalt" [14] as to whether patients are "sick or not sick" often guides management, even when the diagnosis remains hidden. Ultimately, both analytic, semi-quantitative reasoning and less analytic, gestalt-based intuitive decision-making strategies are used in the setting of uncertainty [15].

The judgment and decision-making literature in psychology and behavioral economics provides insight into the mental operations used when making decisions under uncertainty. Individuals use three common heuristics in the face of uncertainty, which are economical and effective, but can lead to errors [16]. Under uncertainty, individuals often:

(a) assess the representativeness or similarity of one object/event to another (*e.g. in a patient with migraines and fibromyalgia, one may erroneously attribute abdominal pain to irritable bowel syndrome, reasoning that similar patients have a constellation of these three ailments*);
(b) assess the likelihood of a condition based on prior experience when estimating frequency/probability [*e.g. overestimating the probability of pulmonary embolism (PE) because the last time the clinician was on-service, there were six cases of PE*];
(c) form an inappropriate starting point in numerical prediction (*i.e. when individuals are given a "base-rate" for the prevalence of a disease like Zika virus, they will work from that starting point to estimate the probability that a patient has been exposed to Zika virus, even when the prevalence varies widely in different regions*).

## Expertise and diagnostic uncertainty

Expert clinicians may be able to more accurately recognize and accommodate diagnostic uncertainty compared to novices who are more prone to concrete problem-solving. However, expertise does not protect against the challenges of uncertainty. A study about experts (physicians on a selection committee) and novices (undergraduates) evaluating applications to medical residency programs demonstrated that despite superior encoding and recall skills, experts tended to emphasize some data in the application inappropriately and neglect other, more important information [17]. Another study explored the alignment between clinicians' diagnostic certainty and accuracy by asking medical students, residents, and faculty to generate differential diagnoses and confidence levels for challenging cases. Residents were overconfident in 41% of cases where accuracy and certainty were not aligned, faculty were overconfident in 36% of these cases, and students in 25% [18].

## Diagnostic accuracy and certainty: a 2×2 model

To facilitate discussions of uncertainty, we propose a 2×2 model (Figure 1) that considers diagnostic accuracy

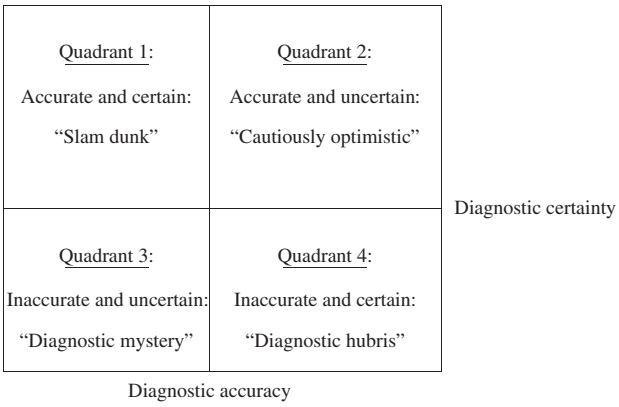


**Figure 1:** Proposed model considering diagnostic accuracy vs. certainty.

separately from diagnostic certainty. While the goal in most clinical encounters is to be both accurate and certain (quadrant 1, the "slam dunk" diagnoses), physicians are frequently in quadrant 2 (accurate but uncertain; "cautiously optimistic") or quadrant 3 (inaccurate and uncertain, "diagnostic mysteries"). The dangers of false confidence and diagnostic hubris lie in quadrant 4 (inaccurate and overconfident). Other 2×2 models surrounding concepts in diagnosis have focused on the harm of misdiagnosis vs. the costs of reducing misdiagnosis [19]. By sorting the types of certainty-accuracy dyads into these quadrants, educators may begin discussions with trainees about the potential relationships between uncertainty and accuracy in specific cases, beginning important conversations about issues that are often left unspoken.

For example, in a complex case involving diagnostic uncertainty about an elderly patient with leukemia who is being treated for shock [20], an attending physician who had previously introduced this 2×2 model to a team of learners might bring diagnostic uncertainty to the forefront of rounds by asking, "what quadrant of decision-making with respect to uncertainty and diagnostic accuracy are we in at this moment"? This question could trigger a discussion of whether any diagnostic tests might help to move the team from one quadrant to another. For example, would another set of negative blood culture improve the team's certainty, or would such results simply provide false reassurance? This kind of explicit discussion about uncertainty has the potential to not only develop shared mental models around uncertainty and to improve clinical decision-making, but also to contribute to a culture of high-value care, where clinicians explicitly discuss how further diagnostic tests might impact diagnostic certainty and management.

Encouraging learners to explicitly discuss diagnostic uncertainty on rounds using presentation models like SNAPPS (summarize relevant patient history, narrow the differential, analyze the differential, probe about uncertainty, plan management, and select case-related issues for self-study) [21] could not only combat learner overconfidence, but also could lead to a more nuanced discussion of the medical decision-making process [22].

## Communicating diagnostic uncertainty

The problem of communicating in the face of uncertainty affects the scientific community broadly. Experts in fields ranging from artificial intelligence to mathematical reasoning [23] to communication theory [24] have all wrestled with this problem differently.

The National Academy of Sciences recommends that communication about scientific uncertainty should include "identifying the facts relevant to recipients' decisions, characterizing the relevant uncertainties, assessing their magnitude, drafting possible messages, and evaluating their success" [25]. The principles of effective patient-provider communication described by the Agency for Healthcare Research and Quality also apply to communicating about diagnostic uncertainty (Box 1A) [26]. The psychology literature suggests that study participants do not inherently dislike uncertain advice. In fact, study participants tolerate advisors who frame uncertainty about predicting outcomes of stock prices or sports results by providing ranges of outcomes or numerical probabilities [27].

**Box 1A:** Agency for Health Care Research and Quality (AHRQ) "universal precautions" for health literacy communication, adapted from the AHRQ toolkit.

1. Greet patients warmly.
2. Make eye contact.
3. Listen carefully and try not to interrupt patients when they are talking; pay attention and be responsive.
4. Use plain, nonmedical language.
5. Use the patient's words.
6. Slow down; speak clearly and at a moderate pace.
7. Limit and repeat content; prioritize what needs to be discussed, limit information to three to five key points, and repeat them.
8. Be specific and concrete: do not use vague and subjective terms that can be interpreted in different ways.
9. Show simple graphics and use demonstrations.
10. Invite patient participation; encourage patients to ask questions and be involved.
11. Encourage questions.
12. Apply teach-back.

The impact of communicating about uncertainty on the doctor-patient relationship is complex, and studies have reached conflicting conclusions. Parents of pediatric patients who participated in a vignette-based study felt that physicians who explicitly expressed uncertainty were less competent and less trustworthy, resulting in lower confidence in the providers and lower adherence to provider recommendations [28]. Conversely, patient satisfaction and engagement were higher in encounters where primary care physicians directly expressed uncertainty using phrases such as "it's not clear" [29]. Krawczyk and Gallagher found that explicit discussions of prognostic uncertainty were associated with higher ratings of providers in overall communication and satisfaction with care (allowed family members to plan more appropriately for end-of-life care) [30]. However, in the same study, communicating poorly about uncertainty led to negative impressions, with families feeling providers were unhelpful at best and malicious at worst. For example, providers who avoided communicating the real possibility of a patient's death, used confusing euphemisms, or gave false hope, were perceived poorly. Providers communicating effectively about prognostic uncertainty used an iterative process where they preliminarily mentioned the possibility of death early in the conversation and gave more details as the clinical situation evolved. Given this complexity, it is not surprising that physicians often hesitate to admit diagnostic uncertainty [31].

## A four-step model for communicating diagnostic uncertainty

Because patients may have negative reactions to uncertainty, we propose a four-step model (Box 1B) for communicating diagnostic uncertainty that draws on a "breaking bad news" approach [32]. The steps include explicitly acknowledging uncertainty, eliciting the patient's reaction, deepening the therapeutic alliance with empathy, and clearly conveying next best steps.

The therapeutic nature of attending to patients' reactions to bad news and the role of empathy are well documented [32]. Upon revealing the "bad news" of diagnostic uncertainty, we favor the "Ask-Respond-Tell" approach to hearing patients' concerns and validating them before moving on to discussing next steps (Box 1B) [33].

Providing some closure in conversations involving uncertainty with the goal of moving toward certainty is important. This part of the conversation can include sharing possible diagnoses, proposing next steps in the diagnostic work-up, explaining that further testing may not reveal an exact diagnosis ("prior warning") [34], or simply focusing on safety, comfort, and follow-up planning. Communication about the diagnostic possibilities including absolute risks and balanced framing (i.e. presenting both risks and benefits with concrete numbers when possible) decreases the possibility of misinterpretation. A caveat to generalizing this practice is that clinicians rarely know the absolute risks and benefits for most medical scenarios with such quantitative precision. Furthermore, conveying these principles can sometimes be challenging given the prevalence of low health "numeracy" (i.e. when patients have difficulty interpreting percentages and relative risks).

Given the complex nature of these discussions, opportunities to practice and receive feedback on uncertainty conversations are important. Feedback on "goals of care" conversations is becoming common practice in graduate medical education [35]. Conversations focused on communicating uncertainty will likely also benefit from focused practice. A simulation-based method was effective in

**Box 1B:** Four-step model for communicating with patients about diagnostic uncertainty.

1. Explicitly **acknowledge** uncertainty of the clinical situation, but list a differential diagnosis, including the current 'most likely' diagnosis; avoid euphemisms
   *"I'm sorry to tell you that it's not clear what's causing your chest pain"*.
2. **Ask** for the emotional reaction of the patient/family in face of this uncertainty
   *"Hearing about uncertainty can bring up different feelings for many people. I'd like to hear about yours"*.
3. **Respond using empathy**, convey a therapeutic alliance; mirror shared goals with the patient
   *"I am hearing your frustration about the lack of clarity, and I share your desire to do what is necessary to figure things out"*.
4. **Tell next best steps** for how you may work together to continue to understand the patient's problem, using absolute risks and balanced framing (i.e. X out of a 100 patients like you… and 100-X will not) if they are available, and about a clear follow-up plan
   *"I will refer you for some additional testing. I can say that for every 100 patients that come in with symptoms like yours, only 15 of them turn out to have heart problems, while most, the other 85, turn out to have less serious problems, such as indigestion or muscular pain. We'll do our best to figure out if you are in the first group with heart problems, or the second group with something less certain. And, I would like to see you again in 2 weeks after your test to discuss the results and plan our next steps"*.

improving trainees' skills around communicating diagnostic uncertainty to patients and is a promising method [36]. Our four-step model, based on evidence in several different domains, may be a helpful starting point for simulation training and warrants further study.

## Conclusions

Teaching trainees how to acknowledge and communicate diagnostic uncertainty is challenging. We suggest embedding curricula that address communication about diagnostic uncertainty throughout the continuum of medical training, from undergraduate to graduate medical education and beyond. However, given the conflicting evidence base, the best ways to both teach and communicate diagnostic uncertainty are unknown. Although the uncertainty literature raises more questions than it answers, much can be learned about diagnostic uncertainty from other disciplines and traditions. While we await additional research in this field, we must continue to improve communication with patients, families, and trainees about our uncertain world.

**Author contributions:** All the authors have accepted responsibility for the entire content of this submitted manuscript and approved submission.
**Research funding:** None declared.
**Employment or leadership:** None declared.
**Honorarium:** None declared.
**Competing interests:** The funding organization(s) played no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the report for publication.

## References

1. Beresford EB. Uncertainty and the shaping of medical decisions. Hastings Cent Rep 1991;21:6–11.
2. Han PK, Klein WM, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. Med Decis Making 2011;31:828–38.
3. Bhise V, Rajan SS, Sittig DF, Morgan RO, Chaudhary P, Singh H. Defining and measuring diagnostic uncertainty in medicine: a systematic review. J Gen Intern Med 2018;33:103–15.
4. Alam R, Cheraghi-Sohi S, Panagioti M, Esmail A, Campbell S, Panagopoulou E. Managing diagnostic uncertainty in primary care: a systematic critical review. BMC Fam Pract 2017;18:79.
5. Christakis NA, Asch DA. Biases in how physicians choose to withdraw life support. Lancet 1993;342:642–6.
6. Tai-Seale M, Stults C, Zhang W, Shumway M. Expressing uncertainty in clinical interactions between physicians and older patients: what matters? Patient Educ Couns 2012;86:322–8.
7. Wennberg JE, Barnes BA, Zubkoff M. Professional uncertainty and the problem of supplier-induced demand. Soc Sci Med 1982;16:811–24.
8. Kassirer JP. Our stubborn quest for diagnostic certainty: a cause of excessive testing. N Engl J Med 1989;320:1489–91.
9. Simpkin AL, Khan A, West DC, Garcia BM, Sectish TC, Spector ND, et al. Stress from uncertainty and resilience among depressed and burned out residents: a cross-sectional study. Acad Pediatr 2018;18:698–704.
10. Elstein AS, Schwarz A. Clinical problem solving and diagnostic decision making: selective review of the cognitive literature. Br Med J 2002;324:729–32.
11. Barrows HS, Feltovich PJ. The clinical reasoning process. Med Educ 1987;21:86–91.
12. Sox HC, Blatt MA, Higgins MC, Marton KI. Medical decision making. ACP Press, 2007.
13. Kassirer JP. Diagnostic reasoning. Ann Intern Med 1989;110:893–900.
14. Cervellin G, Borghi L, Lippi G. Do clinicians decide relying primarily on Bayesian principles or on gestalt perception? Some pearls and pitfalls of gestalt perception in medicine. Intern Emerg Med 2014;9:513–9.
15. Custers EJ. Medical education and cognitive continuum theory: an alternative perspective on medical problem solving and clinical reasoning. Acad Med 2013;88:1074–80.
16. Tversky A, Kahneman D. Judgment under uncertainty: heuristics and biases. Science 1974;185:1124–31.
17. Johnson EJ. Expertise and decision under uncertainty: performance and process. In: Chi MT, Glaser R, Farr MJ, editors. The nature of expertise. Hillsdale, NJ: Lawrence Erlbaum Associates, Inc., 1988:209–28.
18. Friedman CP, Gatti GG, Franz TM, Murphy GC, Wolf FM, Heckerling PS, et al. Do physicians know when their diagnoses are correct? J Gen Intern Med 2005;20:334–9.
19. Newman-Toker DE, McDonald KM, Meltzer DO. How much diagnostic safety can we afford, and how should we decide? A health economics perspective. BMJ Qual Saf 2013;22(Suppl 2):ii11–ii20.
20. Walter JM, Singer BD, Corbridge T. More than a touch of gray: embracing uncertainty in the intensive care unit. Am J Respir Crit Care Med 2016;194:932–3.
21. Wolpaw TM, Wolpaw DR, Papp KK. SNAPPS: a learner-centered model for outpatient education. Acad Med 2003; 78:893–8.
22. Wray CM, Cho HJ. Annals for hospitalists inpatient notes-medical uncertainty as a driver of resource use – examining the "gray zones" of clinical care. Ann Intern Med 2018;168:HO2–3.
23. Crupi V, Nelson JD, Meder B, Cevolani G, Tentori K. Generalized information theory meets human cognition: introducing a unified framework to model uncertainty and information search. Cognitive Sci 2016;42:1410–56.
24. Coiera E. Mediated agent interaction. In conference on artificial intelligence in medicine in Europe. Springer, Berlin, Heidelberg, 2001:1–15.
25. Fischhoff B, Davis AL. Communicating scientific uncertainty. Proc Natl Acad Sci 2014;111(Suppl 4):13664–71.
26. DeWalt DA, Callahan LF, Hawk VH, Broucksou KA, Hink A, Rudd R, et al. Health literacy universal precautions toolkit. Rockville, MD: Agency for Healthcare Research and Quality, 2010:1–227.

27. Gaertig C, Simmons JP. Do people inherently dislike uncertain advice? Psychol Sci 2018;29:504–20.
28. Bhise V, Meyer AN, Menon S, Singhal G, Street RL, Giardina TD, et al. Patient perspectives on how physicians communicate diagnostic uncertainty: an experimental vignette study. Int J Qual Health Care 2018;30:2–8.
29. Gordon GH, Joos SK, Byrne J. Physician expressions of uncertainty during patient encounters. Patient Educ Couns 2000;40:59–65.
30. Krawczyk M, Gallagher R. Communicating prognostic uncertainty in potential end-of-life contexts: experiences of family members. BMC Palliat Care 2016;15:59.
31. Katz J. Why doctors don't disclose uncertainty. Hastings Cent Rep 1984;14:35–44.
32. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES – a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist 2000;5:302–11.
33. Chou CL, Cooley L, editors. Communication Rx: transforming healthcare through relationship-centered communication. McGraw Hill Professional, 2017.
34. Than MP, Flaws DF. Communicating diagnostic uncertainties to patients: the problems of explaining unclear diagnosis and risk. BMJ Evid Based Med 2009;14:66–7.
35. des Ordons AR, Kassam A, Simon J. Goals of care conversation teaching in residency – a cross-sectional survey of postgraduate program directors. BMC Med Educ 2017;17:6.
36. Olson ME, Borman-Shoap E, Mathias K, Barnes TL, Olson AP. Case-based simulation empowering pediatric residents to communicate about diagnostic uncertainty. Diagnosis 2018;5:243–8.