

What Stumps Primary Care Clinicians? An Analysis of Diagnostic Uncertainty Cases Discussed in Practice Inquiry Meetings

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May 5, 2020

Abstract

INTRODUCTION Diagnostic difficulty is frequent in primary care, yet little is known about which clinical scenarios present uncertainty to primary care practitioners (PCPs) and how they respond. We describe types of clinical scenarios causing uncertainty that PCPs brought to regularly scheduled, confidential practice meetings. Information about these patients' characteristics and how clinicians responded could better define diagnostic uncertainty in primary care, explain and acknowledge the value of PCPs' uncertainty work, and promote deliberate attention to its management. **METHODS** We analyzed case log data from 459 case scenarios where PCPs presented patients involving uncertainty to peers in "Practice Inquiry (PI) Colleague Group" meetings held in 17 San Francisco-Bay Area primary care practices between 2002–2015. Case log data included: 1) uncertainty statement/question; 2) patient and clinician information provided by PCP during first 2-3 minutes of presentation (e.g., presenting symptoms), 3) colleagues' responses to presentation; and 4) patient follow-up offered by presenter at subsequent meetings. Using published criteria and ones designed to identify less-objectively presented diagnostic quandaries, diagnostic uncertainty cases were selected from the larger cohort and coded to describe patients' current status, already-known diagnoses/conditions; and diagnoses/conditions identified by presenter as possible uncertainty explanations. **RESULTS** Of 459 patients that PCPs presented in PI meetings, 258 (56%) involved diagnostic uncertainty. Patients' already-known diagnoses were discussed in 72%; 44% had at least two diseases/conditions. In 52%, clinicians discussed possible diagnoses that could explain uncertainty. For these, mental health/ behavioral/ neurodevelopmental conditions were discussed as potential uncertainty contributors for approximately 25% of patients. Both diagnostic and management dilemmas were presented in 30%; diagnostic adverse events were discussed in 14% including 6 deaths. **DISCUSSION** PI Colleague Groups are a useful forum where clinicians can admit to being 'stuck' and ask for help. Certain clinical scenarios, such as patients with mental health, behavioral/neurodevelopmental conditions, presenting with new complaints, pose special diagnostic challenges. This small-group process also facilitates discussions of diagnostic error and patient harm. Further qualitative analysis of the dataset should focus on case presenters' specific diagnostic questions, colleagues' responses to cases presented, and how patient follow-up reported at subsequent meetings contributes to uncertainty resolution.

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INTRODUCTION

Diagnostic difficulty is frequent in primary care yet little is known about what clinical scenarios present uncertainty to primary care practitioners (PCPs) and how they manage them.^{1,2} Uncertainty can arise from a patient presenting with worrisome symptoms that, over the course of the visit, form the substrate for an efficient investigation and reasonable path forward. Alternatively, uncertainty can arise from a patient presenting with the same symptoms that this time, given patient context, cause worry, frustration, cognitive overload, and hasty decisions. Such primary care scenarios, how they evolve and resolve, are rarely shared among clinicians since medical culture has undervalued acknowledgment and communication of uncertainty.^{3,4} Discomfort in confronting ‘not knowing’ engenders self-doubt, guilt and shame.⁵ Exacerbated by shortened patient visits and electronic health record (EHR) burden, inadequate management of diagnostic uncertainty is associated with medical error, clinician burnout and increased costs.⁶

We provide an initial description of patients causing diagnostic uncertainty that PCPs brought to regularly scheduled, facilitated, confidential practice meetings.⁷ Findings could advance understanding of how physicians talk about and manage patients with diagnostic uncertainty. Information about these patients’ characteristics and how their clinicians responded could better define diagnostic uncertainty in primary care, explain and acknowledge the value of ‘uncertainty work’ PCPs do, and promote deliberate attention to its management.

METHODS

We analyzed data from 459 patient scenarios where PCPs presented current, case-based instances of uncertainty *as defined by them* to peers in “Practice Inquiry (PI) Colleague Group” meetings. Meetings were conducted at 15 San Francisco-Bay Area primary care practices between 2002 - 2015 as part of a university-based continuing medical education program.² Practices were recruited incrementally as the first author contacted practices with graduates in Family Medicine and General Internal Medicine from the University of California, San Francisco. Most groups met on a monthly basis; the oldest group was 13 years old, the youngest group, 2 years old. Average number of cases provided by a group was 17. (Median: 9, Mode: 19)

The lead investigator (LS) facilitated 99.5% of meetings based on a structured group process (See Figure 1.) and recorded data for consecutive patients presented into a case log organized into four categories: 1) uncertainty statement/question; 2) patient and clinician information provided by case presenter during first 2-3 minutes of presentation, including symptoms, physical findings, lab/imaging findings, medical/social history, and patient-clinician relationship; 3) colleague group’s responses to presentation; and 4) patient follow-up offered by presenter at subsequent meetings. (See Figure 2.) At these meetings, colleagues reviewed log entries to edit and update.

We used data from categories 1 and 2 (excluding colleague responses and follow-up information) to select diagnostic uncertainty cases from the larger case cohort. To select cases, we used previously developed criteria from published work for PCPs’ direct and indirect expressions of certainty (e.g., question marks, absence of diagnosis at visit end) in electronic medical record notes. We refer to these in the paper as the “Bhise criteria.”⁸ Data for our study came directly from PCP case descriptions of what confused or puzzled them and verbalized within the first 2-3 minutes of their presentations. Different and rudimentary experiences of not knowing would occasionally be presented revealing diagnostic uncertainty indirectly as more general statements (e.g., “Am I doing everything I should do for this patient? What should I do next?” (See Figure 1, Case 1.) Such cases, lacking the key words/phrases/punctuation used in the Bhise criteria, nonetheless, dealt with the same topics as those coded by the Bhise criteria. Cases identified using the Bhise criteria and those characterized by more general statements were selected by two authors (LS and V); a third (HS) adjudicated differences. For each case selected, data were extracted from the case log in categories 1 and 2 above: the uncertainty statement and patient information provided in first 2-3 minutes. Two authors (LS and V) coded these data to describe patients’ presenting symptoms, abnormal physical exam findings, abnormal lab/ imaging; patients’ known diagnoses/conditions; and diagnoses/conditions identified by presenter as possible uncertainty explanations. We used a consensus approach to reconcile differences. Diseases/conditions were categorized using ICD-11 codes.

RESULTS

Of 459 cases PCPs presented to colleagues, 258 (56%) involved diagnostic uncertainty. Of these, 85% (220) were identified by the Bhise criteria and the remaining 15% (38) using clinicians’ more general expressions of not knowing. The latter cases dealt with 19 patients (14%) presented as reflected-upon, suspected, adverse diagnostic events. (See Case 5, Figure 1.) These included 6 deaths. The remaining cases comprised patients where clinicians were uncertain about how to diagnose cognitive deficits (e.g., “I don’t know what’s going on with this patient...”), adult or child abuse (e.g., “I fear that something bad is going to happen.”), substance abuse (e.g., “This patient may be addicted to what I’ve been prescribing.”), and preventable risk (“Never seen a vitamin D level this low!”).

Sixty-one percent of the 258 cases involved women, the median age decade was 50-59 years. Forty-four percent presented with two or more prior diseases/conditions. Fifty-three percent of patients had one or more non-pain, symptoms; 7% had only pain symptoms in the absence of abnormal physician exam or lab/imaging findings. A third of cases were both diagnostic and management dilemmas (See Case 3, Figure 2.)

Characteristics describing patients’ current status, past known diagnoses, and possible diagnoses explaining uncertainty are displayed in Table 1. Presenters discussed patients’ past known diagnoses in 186 (72%) cases; of these, the most prevalent, previously known diagnoses were mental health/ behavioral/ neurodevelopmental conditions (17%). Presenters speculated about possible diagnoses that could explain uncertainty in 133 cases (52%); of these, the most prevalent, possible diagnoses were mental health/behavioral/neurodevelopmental conditions (27%).

DISCUSSION

In this report, we describe an initial analysis of real-time, diagnostic uncertainty case discussions among PCPs at regularly scheduled, Practice Inquiry Colleague Group meetings. The 259-case dataset is unique: it was created over 13 years as PCPs came to meetings and, with no criteria defining ‘clinical uncertainty,’ presented patients that perplexed them for any reason. We uncovered new and different experiences of uncertainty not covered by the Bhise criteria and requiring further analysis and validation. For this initial study, we used limited criteria for identifying uncertainty in primary care. Future work with this dataset should consider how uncertainty has been conceptualized by several clinical uncertainty researchers and theorists such as Fox (uncertainty “forms”⁹ and later, “themes”¹⁰), Beresford (“dimensions”¹¹), Cassell (“roots”¹²), Djulbegovic (“knowledge deficiency” types¹³), and Han (“sources,” “issues,” “locus”¹⁴). The cases we found that did not meet the Bhise criteria often identified uncertainty experiences that were

presented as broader in scope than a single symptom or finding (e.g., diagnosing abuse, assessing disease risk); reflections on a untoward diagnostic outcome; treating a patient while the diagnostic process progresses; and dealing with one's emotions while coping with not knowing. An analysis that starts with PCPs' actual questions and statements of not knowing, coupled with appreciation of prior work to conceptualize clinical uncertainty, could result in a theoretical framework for defining and managing diagnostic uncertainty that could better support PCPs in daily practice.

Certain clinical scenarios, such as patients with mental health, behavioral/neurodevelopmental conditions who present with a new symptom appear to have posed special diagnostic challenges. What are these patients' co-morbidities and how do they affect diagnostic thinking? Although pain alone appears to be less likely, what are their presenting complaints? Analysis of the third category of data collected - Discussion Points - could reveal colleagues' response patterns to these patients and how they suggest proceeding. For example, how did colleagues, using abductive reasoning in addition to intuitive and analytic thinking, generate new thinking about these patients?^{15,16} Did they comment about the new symptoms (in the context of already-known mental illness) as in need of immediate intervention or watchful waiting? How did they opine about shared decision-making for new symptom work-up and safety-netting? (See Case 4 in Figure 1.)

Further qualitative work should study how clinicians presented their experiences of diagnostic uncertainty. What were their specific concerns? (e.g., symptom cause, completeness of work-up, managing the diagnostic process while providing care, disclosing uncertainty, handling their own emotions) Additionally, understanding clinicians' responses to their colleagues' cases (e.g., advice given, literature suggested, support offered) could offer a useful window into potential value of PI Colleague groups and how they can be enhanced. For example, how should facilitators be trained to lead discussions of critical thinking, knowledge gaps, system deficits, and clinicians' emotional reactions to uncertainty? Lastly, approximately one third of the cases had patient follow-up presented at subsequent meetings. Analysis of these could contribute to understanding how clinicians experience uncertainty resolution.

Longevity of PI Colleague Groups, new group formation (20 since 2015) and high scores on annual satisfaction surveys¹ suggest they are useful forums for supporting PCPs and their organizations in improving care while revealing the challenging work that PCPs do. They merit continued evaluation and broader implementation to become safe, 'slowing down' places for colleagues to engage uncertainty through experiencing the paradox of expert practice: "to act with confidence while simultaneously remaining uncertain."¹⁶

CONFLICT OF INTEREST: Neither the first author nor the co-authors have any conflict of interest to report in regards to this manuscript.

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Figure I
PI Colleague Group Process

1. The Uncertainty & Story

Uncertainty Statement/Question:

"In one sentence, Jane, can you tell us the essence of your dilemma for your patient?"

Story:

"Now, while we all listen without interrupting, please tell us about who this patient is, your relationship with him/her, and about you when it comes to taking care of patients like this one."
(Facilitator encourages "more story" when the presenter pauses by saying, "What else?" at least once if not twice.)

2. Inquiry

Clarifying questions:

"Colleagues, there is time now for 3-5 clarifying questions. You are looking for essential, factual information you need to make sense out of what's going on; no 'hows' or whys, rather yes/no answers or simple responses, e.g., "Any foreign travel?"

Presenter's Starter Question:

"Jane, please start us off with a question that focuses on a key aspect of your uncertainty. Or, you can repeat your original uncertainty statement/question or modify it.

Colleagues (Gentle) Queries/Observations:

"You now know what's on Jane's mind. Your task: try to spark NEW INPUTS to her judgment about this patient or help new insights emerge by making GENTLE INQUIRIES as opposed to giving advice." Jane will sit back and listen until at least five questions are on the board. Then she can respond, ask for 5 more, or ask a totally different question."

3. Synthesis

Open-Ended Discussion:

"Jane, feel free to respond to any/all of what's on the board. It may trigger new insights as you revisit original assumptions. Feel free to think out loud; with this mix of new material, you might get a different take on the original uncertainty and identify the decision challenges. Ask you colleagues how they can help you."

Case Wrap-up:

"Since we're running out of time, can you tell us, Jane, how this has been for you?"

Case Implications (beyond the case):

"Any observations, anyone, about what we just did together and its implications for our other patients, our way of doing things at the office, or, on a more general level, how to care for patients when we're uncertain?"

Figure 2 Representative Diagnostic Uncertainty Cases			
Uncertainty	Clinical case Vignette	Group Discussion Points	Follow-up
1. Am I doing everything I should do for this patient? What should I do next?	11 yo male brought in by dad for STD testing; while living in Guam with mom and older cousin reports he mounted cousin when younger (6) and watched porno films (?how long) Pleasant, likeable, pre-pubescent; appearing to know behavior was wrong; now lives with dad but could go back to mom if dad deployed; called CPS for advice	<ul style="list-style-type: none"> What actually happened? Was cousin abusing him? Effects of pt retelling story? Definitions of abuse? Do anal exam Effect of watching porno over times in early years? 	<ul style="list-style-type: none"> CPS referral made Lost to follow-up
2. Who else should see this patient - Specialists, others?	Morbidly obese female with pain in multiple body parts was diagnosed with fibromyalgia, arthritis, hypothyroid. She had premenopausal sweats, anxiety and dark colored toes with possible Raynaud's syndrome; better on duloxetine for 6-8 months and now worse, now on acetaminophen and oxycodone and has pain while walking. Married with 8 year old daughter. Husband had recent AMI. Followed by pain clinic, neurology, rheumatology, GI clinics; given knee injections. Now complains of abdominal pain. Could this be POEMs?	<ul style="list-style-type: none"> Use ACE (Adverse Childhood Experience questionnaire) What does patient bring to table? How much harder must PCP work? Rethink role of psychosocial forces Chronic (sub-acute) dissecting abdominal aortic aneurysm? 	<ul style="list-style-type: none"> No follow-up

3. What is this patient's diagnosis? Should I start her on empirical therapy?	45-year-old female with hx of Raynaud's syndrome, hemoptysis mostly in the morning for one year; treated with radioactive iodine for hyperthyroidism in the Philippines in 2009. Appears sick with puffy hands, face, and feet, fatigue, hair loss, denies cough or weight loss, and has slow reflexes. Had positive TB test in 2005 and was treated with isoniazid for 6 months and then treatment was stopped. Unable to get into rheumatology clinic for 3 months.	<ul style="list-style-type: none"> • Check HIV, Hep C status • Explore reasons for not taking meds, taking supplements? • Explore more re family • Lit review for RAI rx complications; • Make case to take med • Further work-up for extra-pulmonary TB? chest CT? 	<ul style="list-style-type: none"> • No follow-up
3. I would like to limit further testing for this patient but continue responding to his concerns...not sure how.	32-year-old college-educated male seen by PCP one year ago for chest pain. After work-ups, diagnosed with suspected social anxiety disorder. Asked to return in 1 year unless problems. Had 15 ER visits and one psychiatric inpatient admission for threatening suicide after initial primary care visit. Returned to primary care clinic and accused PCP of giving him medication that made him worse. Now complains of abdominal pain and headaches.	<ul style="list-style-type: none"> • Difficult to engage through traditional motivational interviewing techniques • Issue of PCP being accused by pt of making him worse • How to help suspicious patient who keeps coming back to you? • Discussed general strategies for working with pts with MUS e.g., admitting there's nothing else to offer; Would you like to go elsewhere? • Suggesting that diagnosis has yet to announce itself 	<ul style="list-style-type: none"> • Didn't show up for last visit • One before that, seemed more willing to hear that there's no organic disease >> "We're at a détente." •

		<ul style="list-style-type: none"> Regardless of no dx, assuring that PCP will stick with patient and problems 	
4. In retrospect, I may not have appropriately judged urgency of complete work-up for this patient.	<p>3 ½- year-old female with hx of UTI. Pt's mother called by daycare for Pt's puffy eyes and overall lethargic appearance. Mother with Pt came same day to the clinic and seen by triage PCP. Urinalysis: positive for blood and protein. Negative urine culture; patient sent home. Mother called PCP later that day who sent them to ER. Pt had abnormal albumin and creatinine; admitted for possible nephrotic syndrome.</p>	<ul style="list-style-type: none"> Catharizing children in the Clinic Power of outcome bias Unusual presentation Dealing with acute care issues in Clinic – open access changes things Value of obtaining collegial input in real time 	<ul style="list-style-type: none"> Dx: post-strep glomerulonephritis; prognosis still unclear

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JECP-Table1.docx available at <https://authorea.com/users/301808/articles/431669-what-stumps-primary-care-clinicians-an-analysis-of-diagnostic-uncertainty-cases-discussed-in-practice-inquiry-meetings>

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