

Issue Brief 12

Patient Experience as a Source for Understanding the Origins, Impact, and Remediation of Diagnostic Errors

Volume 2: Eliciting Patient Narratives



PATIENT SAFETY

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Executive Summary

Although the literature has established that patients can identify and reliably report on a range of adverse medical events, rigorous methods are needed to elicit patient experiences in ways that best enhance learning and provide constructive responses. Patient perspectives offer unique information about how diagnosis-related events alter patients' trajectories through the healthcare system and their expectations for clinicians.

This brief, the second of two volumes, considers:

1. How to most effectively elicit representative, in-depth narrative accounts of diagnosis-related events,
2. How patient feedback about the diagnostic process and its outcomes can most effectively be used to learn from patient and family experience, and
3. What questions about the elicitation of patients' diagnostic experience remain in need of additional research.

Key insights about learning from patient experience to address diagnostic problems include:

1. The extent of actionable feedback embedded in narrative accounts can be considerably enhanced by careful attention to elicitation techniques (e.g., question wording and sequencing).
2. To assess the full implications of diagnostic mishaps for patients and families, it is essential to elicit their experiences from both the mishap and its aftermath. Because substantial aftereffects can persist for many years, elicitation techniques must inquire about the impact of adverse events that occurred as much as 5 years in the past.
3. To ensure that a large number of patient experiences related to diagnosis are collected, it is important to assign responsibility for eliciting accounts in ways compatible with how patients and families respond after an adverse diagnostic event. Experiences that have short-term actionability are best elicited by incorporating questions about diagnostic experiences into existing patient experience surveys fielded by health plans, hospitals, long-term care facilities, and other clinicians. Identifying practices that affect the persistence of adverse effects long after a perceived diagnostic mishap or that cross organizational boundaries require population-based surveys designed for retrospective inquiry about past diagnostic events.
4. To encourage a healthcare system that can effectively learn from and respond to patient and family perspectives regarding diagnostic problems, a dual-channel approach is called for. Responsibility for eliciting patient experiences should be divided in a strategic manner between:
 - a. Healthcare providers responsible for rectifying diagnostic shortfalls related to clinician-patient interactions and
 - b. Agencies responsible for promoting structural reforms to promote safety for the healthcare system as a whole.

Introduction

Policymakers and clinician-leaders are increasingly looking to patient experience to improve health system performance.^{1,2} The first installment in this two-volume issue brief described the rationale for learning from patients and their families about the diagnostic process. It also discussed recognizing the persisting impact of diagnostic mishaps on patient health, healthcare utilization, trust in medical care, and general well-being. The first volume also documented gaps in existing methods for rigorously collecting and assessing these diagnostic experiences.^{3,4,5,6}

Foundational research on rigorous elicitation of patient experience began 50 years ago. It established two core principles that continue to guide the field:

1. Only some aspects of healthcare are observable from patients' perspectives, and
2. Observations will not necessarily be reported on surveys or other mechanisms for collecting experiential data.³

Rigor requires attending to these constraints. But it also calls for developing methods that can encourage patients (or their surrogates) to more thoughtfully recount their experiences and to help them report those experiences in the most complete, reliable, and representative way.⁷

The first generation of patient experience surveys, relying exclusively on closed-ended questions, did not ask about patient safety, because safety events were less reliably observed by patients than other aspects of healthcare, such as accessibility of care.³ But over the past decade, researchers have used open-ended questions to better understand patient experience.

It has become clear from the responses that patients and their families may not always understand every clinical detail, but they can still identify relatively nuanced events and processes that affect quality or threaten safety.^{3,8,9,10,11} For example, patients and families often have a more complete view than clinicians do about diagnostic experiences during transitions of care across settings, a well-known risk zone for safety.¹²

Attending to the second principle of rigorous elicitation calls for wording and sequencing survey questions in ways that encourage patients to convey full and complete accounts.^{13,14} Medical encounters are often complex and can involve a sequence of interactions with multiple clinicians. Thus, surveys must be structured to allow respondents to recount these interactions in an order that matches their experiences.

Survey questions should help patients reconstruct when and what they knew at different stages in the diagnostic process. Rigor also calls for using language that accords with the diverse ways patients (or their surrogates) think about and describe diagnostic encounters.

In the sections that follow, we first synthesize what is known about effectively eliciting patient and family reported experiences related to healthcare generally. We then extend this information to learning from safety events and diagnostic errors specifically. We summarize the ways narrative elicitation about the diagnostic process can be enhanced, while noting the limits of reliable reporting on the part of patients and their families.¹ We conclude by identifying some promising opportunities for future research on rigorous narrative elicitation for diagnostic safety.

¹We will henceforth use the term “family” as a shorthand for these other actors. Our own (unpublished) data suggest that 79% of survey respondents who are not reporting on their own experiences as patients are describing experiences they identified as a family member of the patient.

Eliciting Patients' Diagnostic Experiences Using Rigorous Methods

To strengthen our future capacity to learn from patients' diagnostic experiences, we identify four challenging questions that have been posed in the existing literature but not yet adequately addressed. For each question, we offer some concrete, feasible responses to these challenges.

Who Should Report Their Diagnostic Experiences?

The Challenge: When eliciting accounts from patients and families, one cannot simply ask respondents if they have experienced a diagnostic error. Rather, the data collection method or instrument must define what is in scope to report. Although many Americans describe having heard about “medical errors” in the media,¹⁵ only about half report that they have any sense of what the term means, and a quarter have never heard the term at all.¹⁶

Conventional research practice has been to define “medical error” or “diagnostic error” within the survey. For example, in two large national surveys of Americans' experiences with patient safety, researchers at the Institute for Healthcare Improvement (IHI) used this definition:

Sometimes when people receive medical care, mistakes are made. These mistakes sometimes result in no harm, while other times they may result in additional or prolonged treatment, emotional distress, disability, or death. These types of mistakes are called medical errors.¹⁶

This definition is clearly worded and coherent. But clarity of language does not necessarily help respondents determine whether an adverse event experienced in a clinical setting was caused by a clinician's mistake or error. Respondents with limited education or from cultures that discourage challenging professional authority may be particularly reluctant to draw this conclusion.^{8,17} These barriers can induce or exacerbate disparities in “error” reporting.

Potential Response: Given the challenges with language, invitations for the public to report on diagnostic experiences should generally *avoid* asking respondents to determine whether their experiences fit some predefined criteria for medical or diagnostic errors. If a survey instead asks respondents about “feeling unsafe” during their experiences as patients, a much larger portion of the public will respond. In hospital settings, this shift in terminology from mistakes/errors to feeling safe roughly doubled the number of patient-reported safety events.¹⁸

Although it seems clear that elicitation methods should avoid labels such as “medical error” or “diagnostic error” when inviting reports about patient experiences, the preferred alternative is less apparent. Asking about “feeling unsafe” extrapolates imperfectly to diagnostic experiences and may be unduly influenced by respondents' prevailing level of trust in the healthcare system. If patients from certain backgrounds or with particular prior experiences are more likely to mistrust healthcare providers, they may never “feel safe,” regardless of their recent experiences.

One promising alternative would be to ask patients about “mistakes and problems” in obtaining a diagnosis, although this option has yet to be tested in any studies in the peer-reviewed literature. Framing experiences in terms of “mistakes” is more approachable than framing as “diagnostic errors,” since an error is seen by patients as implying culpability for the problem. Expanding the scope to also include “problems” encourages reporting of adverse events where patients and families do not necessarily blame clinicians for negative

outcomes.⁶ Whatever the specific wording, a sensible goal would be to broaden the scope of experiences being reported, in order to collect actionable feedback about as many diagnostic mishaps or concerns as possible.

Which Aspects of Diagnosis-Related Experiences Should Be Elicited and Reported?

The Challenge: Most studies eliciting patient experience with medical errors focus on the adverse event itself: the nature of the perceived medical mishap, the factors associated with its emergence, and the immediate harms it caused.¹⁹ To illustrate, the largest survey to collect narrative accounts from hospitalized patients about their safety concerns did so through a sequence of open-ended questions¹⁸:

1. Please tell us what happened with your concern or experience in as much detail as you can.
2. Why do you feel this was a safety concern for you?
3. What do you think could be done to stop this from happening again, to you or other patients in the future?

This type of wording is the norm for collecting patient narratives related to safety issues. The focus of questions is on the immediate antecedents and outcomes of the adverse event. By narrowing the scope of inquiry in this manner, researchers hope to have patients and families report on the aspects of their experience that are closest to the adverse event in question.^{10,18,20,21}

But this approach has notable shortcomings. First, it focuses only on the actions, attitudes, and circumstances associated with *preventable* events. Given the uncertainties inherent in diagnosis, a portion of adverse diagnostic events that are not always preventable would be missed. Those that are identified in research as not being preventable have been shown to affect patients' well-being as severely as preventable errors do.²²

A second limitation of focusing solely on the adverse event is that the ways patients and clinicians interact in the aftermath of that event go unreported. The literature on medical errors documents that the long-term harms associated with adverse events are often worsened by clinicians' actions after the event. Some cases involve actions they fail to take, while others involve actions clinicians or healthcare systems do take that make matters worse for patients and their families.^{23,24}

Conversely, the negative consequences that follow medical errors and adverse events can be partly mitigated by effective communication in the aftermath of the incident.^{25,26} Although these remedial benefits from communication have been amply documented for treatment errors, we know less about their benefits after diagnostic mishaps. More effective learning from patient and family accounts could help identify whether and when mitigation efforts were more or less effective for diagnostic-related experiences.^{27,28}

Potential Response: Because past studies of perceived diagnostic mishaps have not focused on interactions between patients and clinicians after the adverse event, the peer-reviewed literature has no evidence about their prevalence or impact on patient well-being. Nor do we have any evidence on how best to elicit experiences in the aftermath of a diagnostic mishap.

However, we can build on the small body of prior research that asked respondents about their experiences in the aftermath of other medical mishaps.^{23,24,25,26} Although these were largely focused on adverse treatment events, some also collected data related to perceived diagnostic problems.

In a prior study of experiences with medical errors in Massachusetts, we documented the lasting sequelae of medical errors by asking explicitly about the clinician actions that might have "improved the situation

following the medical error.” We also asked about clinician actions following the perceived medical error that “made things worse.” In studies published on these findings, we did not separate out the impact of perceived diagnostic errors.²⁵

If we now parse out cases involving perceived diagnostic failures, it becomes clear that diagnostic mishaps also have persisting consequences. Considering only respondents for whom the diagnostic problem happened 3 or more years in the past, 28 percent still report having felt abandoned by their clinicians after the adverse event. In addition, 22 percent report feeling anxious when they access medical care. Finally, 78 percent express a continued loss of trust in clinicians to protect against future diagnostic errors.²⁵ Illustrative accounts of these experiences, in patients’ own words, are shown in Exhibit 1 (examples are verbatim and have not been edited).

Exhibit 1. Illustrations of persisting sequelae of diagnostic mishaps reported in elicited patient narratives

Examples of Persisting Anxiety

In 2019 I fell and dislocated my shoulder and had 3 fractures in my pelvic area. After 3 days in a rehab facility I developed pneumonia which I had never had and then within 30 days of inpatient care I developed C. diff. I demanded to be transferred to an ER where I was diagnosed with a dangerously low potassium level. I nearly died. I am very concerned if not fearful that these rehab convalescent, skilled nursing places do not realize that some patients have their mind intact and should be listened to when they are sick and insist on a hospital and not a warehouse for the elderly.

I was having chronic stomach and intestinal pain. The doctor ran multiple tests but was not able to identify the source of pain or a treatment. I was in pain for many months. My diet and exercise was impacted and I was more distracted and worried in the workplace. Not having an answer increased my anxiety and feelings of hopelessness.

Examples of Persisting Perceived Abandonment by Clinicians

I’ve been bedridden 80% of the day for around 10 years. I’m considered a chronic pain patient, which is the “unsorted” bin where they toss those of us without a clear diagnosis. I’m on Medicaid (Title 19) and the program doesn’t pay enough to make them care. They have absolutely no incentive to put in the time or work to correctly diagnose. I wasn’t offered any after care [post back surgery]. My surgeon closed shop immediately afterward and probably jetted off to Maui. [The care team did] nothing. Not one damn thing [to make things better following the error].

I went to the emergency room in severe pain. Hospital staff noted that I was dozing off and possibly drug seeking. Which in fact was not the case at all. I was a victim of domestic abuse and had a fractured skull, fluid on the brain, multiple broken bones, and a ruptured eardrum. My abuser was right there so I could not tell them (hospital staff) but no one bothered to ask...[long-term response]... I tried to avoid healthcare professionals at all cost.

Examples of Persisting Loss of Trust in Clinicians’ Diagnostic Acumen

My aunt was falsely diagnosed with COPD. A year later she switched doctors, was diagnosed with stage 4 lung cancer and lived a way too short 2.5 months after that. It’s definitely hard to trust doctors after that. You can’t drag me to a hospital or doctor for anything other than giving birth.

[First] doctor never mentioned an aortic aneurysm and he viewed the same MRI [as another doctor who found the aneurysm]. [I believe that] race and insurance [led up to the mistake]. I wish I was told of this medical issue that could have been fatal. We never spoke with the doctor again. He did not report it or anything. We just changed doctors. We no longer trust white doctors.

Virtually every respondent who reported a persisting harm identified at least one action they wished their clinicians had taken in the aftermath of the diagnostic problem. In addition, nearly half (46%) of those who reported persisting harms noted at least one clinician action after the diagnostic mishap that they felt made matters worse, including, most often, clinicians refusing to acknowledge that the diagnostic process had gone awry. Patients and families saw this stance as dismissing or denigrating their experiences.

Thus, it seems imperative to elicit patient experiences in ways that generate learning about the extended aftermath of adverse diagnostic events. For completeness, elicitation questions should inquire specifically about clinicians' postevent actions, practices, and policies that:

- Improved patients' well-being after a diagnostic shortfall,
- Exacerbated harms associated with the adverse event, and
- Might have reduced the harms if those actions had been made available to patients and families who had experienced the diagnostic shortfalls.

How Should Timeframes Be Handled for Eliciting Diagnostic Experiences?

The Challenge: To assess the longer term aftermath of perceived diagnostic mishaps, one must elicit patient experiences about events that occurred multiple years in the past. This need poses certain additional challenges related to potential reporting biases (e.g., recall, attrition) and the costs required to reduce these biases.

Research on treatment errors suggests that aftereffects can persist up to 5 to 10 years.^{25,26} How best can we assess such long-persisting sequelae? Two general approaches are possible.ⁱⁱ The first identifies a panel of respondents who report experiencing a diagnostic mishap in any one year, then follows them over time, repeatedly collecting information about their current well-being.

This approach is challenging and costly to implement. Substantial attrition is inevitable among panel participants over 5 to 10 years. Remaining participants may represent a biased subset of the original cohort, distorting the prevalence and distribution of long-term effects and how clinician practices and organizational factors shape them. These challenges are sufficiently daunting that, to our knowledge, no one has conducted longitudinal studies of diagnostic or medical mishaps.

The second approach involves collecting patient experiences at a single point in time, asking about diagnostic events that occurred several years in the past. Population-based surveys of medical errors typically have had "look-back" periods of up to 5 years.^{16,25,29} With this approach, about 23 percent of respondents report having experienced a medical error in their own care or that of a family member or friend over the past 5 years.¹⁶ Stratifying elicited experiences based on how many years earlier the adverse event occurred makes it possible to construct a profile of how the consequences of the events change over time.²⁵

Cross-sectional surveys that ask respondents to look back in this manner also have limitations. Chief among these is recall bias: the farther back into the past respondents are asked to recall events, even memorable ones such as medical mishaps, the more likely they are to forget some experiences.

ⁱⁱPresenting these as two options is a simplification. Many hybrids involve some combination of tracking experiences and asking retrospective questions. The simplified dichotomy illustrates the issues and is not intended to define all possible survey design responses.

For example, on the 2017 survey IHI fielded, 9 percent reported that they or someone they know experienced a medical error in the past year. But only 14 percent more reported such an event from 2 to 5 years before the survey (less than half of what one would expect if a 9% annual rate were replicated for each of the 4 previous years). Since mishaps with minor consequences are more likely forgotten than those with large impact, recall bias threatens to also distort understanding of the true prevalence of various effects and aftereffects.

Potential Response: Although longitudinal studies have the greatest potential for tracking the extent of and influences on aftereffects, their complexity and cost make them largely infeasible for monitoring populationwide effects of diagnostic problems.ⁱⁱⁱ This limitation leaves cross-sectional surveys that ask respondents to look into their past to identify diagnostic events as the most realistic approach for monitoring diagnostic experiences at large scale. To deploy cross-sectional surveys in this way, it is essential to address the problems created by recall bias.

Fortunately, a plausible approach exists for doing so.²⁵ Questions about perceived diagnostic shortfalls in the past can ask patients about the impact of diagnostic problems both in the immediate aftermath of the event and those currently experienced. One would predict from prior research on recall bias that events having more modest short-term impact are more readily forgotten in the long term. If this assumption is valid for diagnostic mishaps, the immediate impact reported for diagnostic problems experienced multiple years in the past would reflect a larger percentage of serious harms than were reported for events experienced within the past year.

One can assess the magnitude of recall bias in this manner. Moreover, these estimates can then be used to statistically adjust for the impact of recall bias on the prevalence of reported experiences. Using reported prevalence of harms from diagnostic events within the past year to “reweight” the frequency of minor and major diagnostic events from the more distant past makes it possible to offset some of the biases caused by uneven recall of more distant diagnostic mishaps. Although this method does not eliminate concerns about recall bias for retrospective questions, it can at least mitigate some concerns.

How Do We Encourage the Most Complete Reporting of Diagnostic Experiences?

The Challenge: Most studies of narrative reporting about safety experiences have drawn on accounts volunteered by patients and families.^{iv,3,23,26} That leaves open the questions of who might be reporting and how completely their reports convey all aspects of their experiences.

Patients and families may unevenly report experiences for many reasons. They may unevenly convey positive versus negative experiences, because they anticipate that one or the other will be more likely to induce a constructive response from clinicians.^{30,31} Some patients may fail to report their experiences at all, doubting that doing so would yield meaningful change. If patient narratives are less frequently or extensively reported by respondents who have limited trust in medical care, uneven reporting may exacerbate disparities in diagnostic shortfalls.

ⁱⁱⁱLongitudinal studies may still be feasible for addressing more limited objectives, if incorporated into existing longitudinal surveys or fielded for smaller, stable populations of respondents.

^{iv}The exception is collected narratives during the course of a stay in the hospital.^{8,18} These demonstrate that narratives of patient experience can be collected from a broader cross-section of the public but share the shortcomings discussed in the text. That is, they lack a way to validate whether the information being reported in the narratives reliably replicates the events respondents actually experienced.

One option is to add questions about diagnostic safety to existing patient experience surveys. However, this approach has several challenges. First, when patients experience adverse medical events, they frequently switch to alternative venues for their subsequent medical care.³² Studies suggest that up to half of all patients and families switch providers in the aftermath of an adverse medical event.^{v,25} Therefore, clinician-based surveys of *current* patients will understate the prevalence of diagnostic problems as well as their impact on patients and families, since many of those experiencing problems will have already switched to another clinician.

If switching is most pronounced when diagnostic problems have created the most serious harms for patients and families, the most impactful adverse events will also be the most undercounted by surveys fielded by the delivery systems within which the problem emerged.

The second challenge to collecting accounts about diagnostic mishaps through existing patient experience surveys relates to survey format and timing. Surveys that are distributed shortly after a discharge or a visit might be premature for assessing diagnostic issues, which often take some time to resolve and sometimes even longer for patients and families to sensibly interpret.³³

Surveys asking about experiences over a set timeframe, such as 6 to 12 months, allow more reflective, retrospective questions that aid in assessing the aftereffects of a perceived diagnostic mishap. However, even a 12-month look-back period is insufficient to track some of the more persisting sequelae that follow these mishaps.

The challenge of collecting detailed, representative narrative data is thus twofold. First, it is essential to identify a source for sampling experiences that will ensure a representative group of patients and families is appropriately motivated to participate. Second, elicitation methods must be structured to ensure the accounts are collected in ways that allow patients to reflect on their diagnostic experiences. For example, patients need enough time to assess when diagnoses were appropriate, timely, and effectively communicated.

Potential Response: To address the first of these challenges, it is essential to collect information about diagnostic experiences through multiple channels. To collect information that is most immediately actionable, incorporating questions about diagnosis into encounter-based patient experience surveys or those that rely on a relatively short look-back period holds promise. However, these forms of elicitation will miss the experiences and distributional patterns of patients who have switched clinicians in response to their diagnostic mishap. Such patients are too focused on short-term experiences to provide much understanding of the more persisting implications of diagnostic shortfalls or how those perceived mishaps are addressed.

Several principles for robust narrative elicitation emerged from various studies. First, many otherwise willing respondents find it difficult to convey a coherent account of their healthcare experiences. The questions they are asked need to be carefully sequenced to help patients reflect on their experiences, recount events in the order in which they occurred, and consider both positive and negative aspects of their experiences.¹³

^vTo provide a sense of how much switching occurs after a diagnostic mishap, we can again separate out the diagnostic problems from among the medical errors reported in our earlier study of Massachusetts residents.²⁵ Fifty-nine percent of respondents who reported diagnostic problems switched doctors after the event; a comparable percentage switched hospitals if they had a diagnostic problem at that facility.

Second, more complete narrative accounts were elicited when the questions about patient experience incorporated a form of “scaffolding,” question wording that helps respondents consider multiple ways to respond to the query.¹⁴ For example, rather than simply asking patients about their positive or negative experiences with clinicians, scaffolding questions asked about these encounters *and* encouraged respondents to “explain what happened, how it happened, and how it felt to you.”

The impact of this scaffolding approach on question design was most pronounced for respondents with less experience offering their accounts about healthcare. This group includes historically marginalized populations: those who are economically disadvantaged, those with stigmatized health conditions, or those who have previously experienced or perceived discrimination when interacting with clinicians and health systems.¹⁴ The impact of question design was particularly evident for the extent to which narratives conveyed “actionable” information for improving care in the future.³⁴

Elicitation questions designed in accord with these principles hold the promise of encouraging the most coherent and complete narrative responses. But that does not guarantee that these responses will reliably convey all aspects of patients’ healthcare encounters. To test this reliability, the content of elicited narratives needs to be compared with the more complete accounts about patient experiences that can be obtained from intensive interviews conducted by interviewers trained to actively encourage the most complete accounts.¹³

Synthesizing Insights About Rigor in Eliciting Patient Experiences With Diagnosis

We have identified above four key challenges to eliciting narratives about diagnostic experiences, along with ways to constructively address those challenges:

- Potential respondents should be encouraged to report diagnostic experiences that felt problematic or threatening to their safety, rather than those narrowly defined as medical error.
- Open-ended questions should be designed to provide information about both the emergence of the problem and its consequences in the aftermath of the event.
- Questions should be worded in ways that provide scaffolding that encourages more complete and balanced responses, especially from those with less experience recounting their medical experiences. Those sequences of questions need to be tested to assess which aspects of diagnostic experience can be reliably elicited and which cannot be.
- The sequences of elicitation questions, once carefully designed and tested, should be incorporated into surveys appropriate to the potential uses for that feedback. To identify and respond to diagnostic shortfalls that are most immediately actionable, elicitation questions might be most appropriately incorporated into existing patient experience surveys based on one-off encounters or with short look-back periods. However, to provide a more complete assessment of the prevalence, distribution by population subgroups, and impact of diagnostic shortfalls, it would be essential to include elicitation questions as part of population-based surveys, not just those fielded by specific organizations. These findings are summarized in Exhibit 2.

Exhibit 2. Recommendations regarding elicitation of patient experience with diagnosis

1. Defining Whose Experiences Are Being Elicited
 - Eligibility should NOT be based on clinical definitions of diagnostic errors.
 - Respondents should be encouraged to report on both mistakes and diagnostic problems.
2. Describing Which Experiences Are Relevant
 - It is essential to elicit experiences related to both the origins and aftereffects of perceived diagnostic mishaps.
 - It is essential to assess the sequelae of diagnostic shortfalls for as long as 5-10 years after the emergence of a perceived diagnostic problem.
3. Determining Which Entities Should Be Responsible for Eliciting Patient Experience
 - Patient experience with diagnostic shortfalls must be elicited through multiple channels.
 - Patient experiences that are immediately actionable and centered on single organizations are most effectively collected by incorporating elicitation questions into existing patient experience surveys.
 - Patient experiences that involve diagnostic problems crossing clinical settings and organizational boundaries, as well as assessing long-term sequelae of diagnostic shortfalls, need to draw on population-based surveys designed for this purpose.
4. Designing the Most Effective Elicitation Methods
 - To promote greatest participation in reporting of diagnostic problems, elicitations must be conducted by entities seen as both trustworthy and capable of inducing change.
 - To encourage the most complete and representative reports about diagnostic problems, elicitation question sequences must be designed to encourage coherent responses.
 - To establish which aspects of diagnostic experiences can be reliably reported, elicitation techniques need to be tested against intensive interviews as a gold standard. for learning from patients' narrative accounts.

Learning From Narratives About Diagnostic Experience

Questions for Future Research

Methods exist to elicit more reliable and complete accounts about patients' diagnostic experiences. Using these methods is a necessary but not sufficient step for more effective learning about patients' perspectives on diagnostic safety.

Understanding patient and family perspectives on diagnostic experiences also requires recognition that the diagnostic experiences being recounted can often be complex and will sometimes never be fully resolved in their own minds, even when viewed in retrospect. But additional research may help further enhance our capacity to learn from patient experiences with diagnostic safety.

Enhancing the Fidelity and Reliability of Narrative Accounts: Several aspects of collecting narratives about diagnosis would also benefit from additional study. The first involves potentially fine-tuning elicitation techniques to learn from experiences of patients in the throes of extended diagnostic odysseys.⁶ For example, these frequently occur for newly emerging conditions (e.g., “long COVID”) or rare conditions, both cases where clinical knowledge is limited and clear protocols for timely diagnosis often remain ill-defined. Comparably extended searches for a diagnosis can, of course, emerge for a variety of conditions when patients present with an unusual combination of symptoms or these symptoms manifest in atypical ways.

These circumstances also challenge patients and families to interpret diagnostic experiences and make it more difficult to attribute delays or other shortfalls in diagnosis to a particular clinician's expertise or thoroughness. Some patients or families will explore the internet to clarify these boundaries, but many patients still rely exclusively on clinicians to inform them about what is known about a given condition.^{vi} Whether elicitation techniques need to be adapted to these circumstances requires further study.

Contexts in which clinicians and patients might have agreed to not aggressively pursue certain diagnoses present a second issue. These situations are not uncommon in the care of older patients and might grow even more prevalent were clinicians and patients to discuss forms of watchful waiting or palliative care more openly.

However common, these circumstances raise the specter of age-related biases inhibiting appropriate diagnoses for some patients,³⁵ and watchful waiting might be viewed very differently by family respondents than by the patients themselves. Precisely because these circumstances are complex and potentially fraught, research is needed to clarify how best to ask respondents to describe and explore them.

A third set of considerations involves the role of organizational or systemic factors that limit the capacity of clinicians to pursue diagnoses in ways they would prefer. Past research on how patients make attributions regarding clinical encounters shows that it is often hard for patients to discern the impact of system-level factors. These factors include organizational constraints on referrals or limitations imposed by health insurers on coverage of out-of-network specialists.¹⁷

Narratives of patient encounters suggest that patients often suspect that these constraints have affected their diagnosis but typically do not discuss these matters with their clinicians to verify this speculation.³⁶ Research is needed to understand how best to learn about these effects and to promote clinician-patient dialogue that clarifies the impact of system-level factors.

^{vi}Our own (unpublished) data suggest that about one-third of all patients prefer to not turn to the internet to augment what their clinician informs them about diagnoses.

Addressing the Limitations of Narrative Feedback: When the diagnostic process goes awry, patients will often experience the consequences in the form of less effective treatments than anticipated. But the efficacy of initial treatment can also be a perfectly reasonable way of “testing” a diagnosis, thereby learning more about the condition in question. That makes it difficult for patients or families to reliably assess the linkage between diagnosis and their subsequent experiences with treatment. It also makes it especially challenging to determine whether initial treatments were sustained too long, leading to inappropriate delays in considering alternative diagnoses.

For all these reasons, the nexus between diagnosis and treatment may remain opaque. Whether something potentially useful can still be learned from patients and families about this nexus remains unclear. That leaves it as a suitable topic for additional study but one that is likely to have relatively limited yield from even the most effective narrative elicitation.

A second and related set of limitations involves assessments by patients and families of diagnostic delays more generally. In this case, a potentially meaningful distinction can be made between narrative feedback that can identify sources of delay and narrative accounts that can determine the magnitude of that delay. (Delays may involve clinicians unwilling to make a referral or test results that are misplaced or for which no one “closed the loop” in terms of followup communication.)

Patient narratives have ample capacity to identify sources of delay, although how prevalent and how reliable these markers of delay are remain in need of additional research. But the capacity to use narrative accounts to calculate metrics of the magnitude of delay appears far less promising, in large part because patients and family have limited capacity to parse out appropriate from inappropriate lags in altering diagnoses.

Third, patients and families sometimes report an absence of effective care coordination (see Exhibit 1 in Volume 1 of this issue brief). But many aspects of care coordination, including sharing information through electronic health records and other forms of interprovider communication, are hard for patients to reliably discern. Therefore, narrative accounts are likely to be a relatively unreliable source of information about all aspects of care coordination.

Patient or family perceptions could readily miss forms of communication or overlook breakdowns in communication. Additional research may help determine the direction of this bias, if any. But here, too, we anticipate that the yield will be limited.

Thus, many opportunities are open for future research that could either enhance existing approaches to narrative elicitation or better define the limits of reliable elicitation. We summarize these options in Exhibit 3.

Exhibit 3. Research priorities related to patient experiences with diagnosis

Questions Meriting Future Research

1. When Might Circumstances Require Adapting Elicitation Methods?
 - Diagnoses for conditions that are poorly understood
 - Diagnoses for patients approaching the end of life
 - Diagnoses affected by organizational or systemic constraints
2. Where Are the Limits of Rigorous Narrative Elicitation?
 - Understanding implications of diagnostic mishaps for subsequent treatment
 - Identifying and assessing the magnitude of delayed diagnoses
 - Identifying impediments to diagnosis associated with lack of coordinated care

Conclusion

Past research already reveals multiple ways elicitation can be improved beyond existing methods. But that is just the start of an extended process of methodological refinements. Once narrative accounts can be more reliably elicited, they may lead to an entirely new family of performance metrics that characterize the prevalence of harms associated with diagnostic mishaps. These metrics may also address the capacity of the healthcare system to assist patients and families who have experienced those harms.

Making this potential a reality calls for an investment of additional resources, applied in multiple stages. As noted above, substantial work is still needed to adapt elicitation methods to the challenges of the diagnostic process, particularly in situations that pose the greatest challenges for patients and families to reliably assess what has occurred. Once these methodological improvements have been made, additional research will be needed to most effectively code narrative content so that actionable feedback can be identified and quantifiable metrics calculated.

Perhaps the most crucial investments will come from healthcare systems and practices, as they experiment with the use of narrative feedback for improving the diagnostic experiences of their patients. Past research suggests that many clinicians will welcome the availability of narrative insights,³⁷ but not all will be accepting. Even those predisposed to learn from patient narratives may find it daunting in practice, when time to review this material is scarce and the autonomy to respond in constructive ways often constrained.

Learning how to most constructively provide narrative feedback is essential. That will depend on our collective capacity to learn from initial experimentation and adapt feedback methods accordingly.

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