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Learning From Patients' Experiences Related To Diagnostic Errors Is Essential For Progress In Patient Safety

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Abstract

Diagnostic error research has largely focused on individual clinicians' decision making and system design, while overlooking information from patients. We analyzed a unique new data source of patient- and family-reported error narratives to explore factors that contribute to diagnostic errors. From reports of adverse medical events submitted in the period January 2010–February 2016, we identified 184 unique patient narratives of diagnostic error. Problems related to patient-physician

interactions emerged as major contributors. Our analysis identified 224 instances of behavioral and interpersonal factors that reflected unprofessional clinician behavior, including ignoring patients' knowledge, disrespecting patients, failing to communicate, and manipulation or deception. Patients' perspectives can lead to a more comprehensive understanding of why diagnostic errors occur and help develop strategies for mitigation. Health systems should develop and implement formal programs to collect patients' experiences with the diagnostic process and use these data to promote an organizational culture that strives to reduce harm from diagnostic error.

Diagnostic errors pose a significant risk to patient safety, affecting an estimated twelve million US adult outpatients annually¹ and leading to 6–17 percent of all adverse events reported in hospitalized patients.^{2,3} The 2015 National Academies of Science, Engineering, and Medicine report titled *Improving Diagnosis in Health Care* defined *diagnostic error* as “the failure to (a) establish an accurate and timely explanation of *the patient's* health problem(s) or (b) communicate that explanation to *the patient*.”^{2(p xiii)} This definition signals a shift in focus that includes the patient's perspective in diagnostic error literature and highlights the fact that communication of a health issue to the patient is a fundamental part of the diagnostic process, as patients bear the most risk for harm.² Within the diagnostic process, patient-centered care requires strong communication; a willingness to engage patients as participants; and the ability to be responsive to patients' preferences, needs, and values.² Continued movement away from disease- or physician-centered care toward more patient-centric care models can foster a trusting and healing relationship between clinicians and patients.⁴

Involving Patients Is Central To Improving Diagnosis

Diagnostic errors are often underreported or poorly reported.² Underlying causes may be difficult to ascertain or hidden by the unrecorded details of individual cognition and patient-clinician interactions. Patients' reports of their experiences of diagnostic errors can provide information that traditional measurement mechanisms often fail to capture.^{5–7} Given the absence of diagnosis-specific experiences in most surveys and patient-reported outcomes, the only current way to capture patients' experiences of diagnostic error is via patient complaints. However, complaints are often viewed as satisfaction matters rather than safety signals,⁸ despite evidence to the contrary.^{9,10}

In addition to system factors and individual clinical reasoning, diagnostic decision making can often be affected by complex factors involving patient-physician interactions, many of which remain elusive. Patients' experiences may highlight how “soft” factors,¹¹ including patients' and clinicians' judgment and specific behavioral and interpersonal factors, can affect diagnostic safety. For instance, clinicians' negative attitudes and behaviors can affect diagnostic performance¹² and decision making and lead to delayed or missed diagnoses. Patients' experiences with the diagnostic process could serve as a rich data source about these factors. To gain insight into factors that could contribute to diagnostic error, specifically those related to patient-physician interaction, we examined narratives from a new database that collects patient and family stories on perceived diagnostic error.

The Empowered Patient Coalition, a nonprofit organization that promotes patient advocacy and health care safety, began this data collection to learn about safety events from the patient's point of view and to advance patients' role in improving the quality and safety of their health care.¹³ Patients, family members, and caregivers voluntarily submit data to report their care experiences by responding to questions and using narrative free text. We evaluated data from 465 patients or family members who reported a diagnostic error to the database in the period January 2010–February 2016¹⁴ and included a written narrative of their experience.

All participants selected one or more of the following categories of safety issues: delay in diagnosis or treatment; misdiagnosis; proper tests not ordered; test results lost, misplaced, or disregarded; and laboratory or pathology error. We used the National Academies' definition to identify those stories that seemed to describe diagnostic errors and conducted a thematic analysis to identify patterns or themes across the stories.¹⁵

We found 184 relevant narratives, which were about evenly split between patient and family member reports. About two-thirds of the patients involved were female, and the average age was 52.4 years (exhibit 1). Most of the reported diagnostic errors (79.9 percent) took place in the hospital setting. While more than half of the participants said that they had reported the incident to the institution where the incident occurred or to a governing body, only 9 percent said they were satisfied with the response (exhibit 2). About three-quarters of the narratives reflected what we identified as a problematic clinician behavior related to the diagnostic process and not consistent with patient-centered care.¹⁶ In all, we identified 224 such instances that reflected four themes of problematic behavior: ignoring patients' knowledge, disrespecting patients, failing to communicate, and engaging in manipulation or deception. Below we discuss each of these themes in greater detail.

Insights

Ignoring Patients' Knowledge

The most salient theme across the narratives concerned information transfer from patients or family members to clinicians. We found ninety-two narratives that mentioned instances where patients or families felt clinicians ignored or dismissed their reports of clinical clues such as worrisome symptoms, changes in patient status, or failure to improve, resulting in a diagnostic error. Many participants used words and phrases such as “dismissed,” “ignored,” “would not listen,” “did not pay attention,” and “did not take seriously” to describe how they felt they had been treated.

In one case, a participant indicated to the care team that “after five days post op, my husband was getting worse. We told the doctor [surgeon] for the next [three] days that something was wrong. The doctor thought it was an ileus, was always rushed, always arrogant, and always brushed us off.” During hospital rounds, the oncologist “saw the stats [and] called for an ICU [intensive care unit] stat team. My husband's blood pressure was almost nothing, heart rate was off the charts, and he had a temperature.” Feeling helpless and unheard, the woman watched her husband deteriorate from sepsis over three days following colon resection, according to the narrative.

For many families, the ramifications of feeling unable to make themselves heard extended beyond the immediate medical experience. Family members and caregivers expressed feelings of helplessness, failure, and guilt at being unable to convince the care team to listen and act on their concerns. One said: “I was her first-born child, had worked in a major teaching hospital for years and thought I could manage her care, and make certain she was well taken care of.... I found I was unable to do so, since I was continually ignored.... I failed her.”

Disrespecting Patients

This theme focused on how the manner in which clinicians communicated with patients and families may have contributed to diagnostic error. Participants reported several types of disrespectful behaviors: belittling, mocking, and behaving rudely to the patient and stereotyping patients. A number of these reports centered on insensitive or impolite use of language. In one especially egregious case reported by a family member, a patient who had experienced abdominal pain over three years was humiliated by a clinician: “One physician even had the audacity to ‘listen’ to her chest with his stethoscope and NOT put the ear pieces in his ears.... [T]hey were around his neck and then he patted her on the shoulder and told her she was fine and walked out of the room.” She was later diagnosed with advanced metastatic colorectal cancer, according to the narrative.

Though less common, disrespect also took the form of stereotyping or labeling patients, behavior that was reported by twenty-five participants. This included accusing patients of drug-seeking behavior, attributing pain to a mental health issue, and age-related bias. A family member who was a retired nurse told of bringing her daughter to an emergency department for a seizure: “She [the patient] was groggy and unsteady on admission and without listening to our description of the incident, [the patient] was accused of drug abuse and we were refused treatment. We tried to talk about the event, symptoms and the other symptoms leading up to our coming in but to no avail. A doctor did come but she just basically agreed with the judgmental and disrespectful staff that admitted us.” The narrative reported that the patient had a grand mal seizure while waiting in the emergency department and was kept overnight. After waiting some time to be seen and being told the neurologist on call had been contacted, the family said they contacted the neurologist directly: “He was very distressed and asked about [the patient], asked me if I thought she could travel the 20 min[utes] to his office and we said yes and left.” This patient was later diagnosed with a seizure disorder, according to the narrative.

Failing To Communicate

This theme focused on how clinicians communicated information to the patient or family. Descriptions ranged from ineffective communication styles to outright refusal to speak with patients and families. Narratives included instances of clinicians being unresponsive to questions, not responding to telephone calls or inquiries or requests, and failing to communicate directly with patients and families (ignoring requests to come to the bedside to speak to patients or communicating through a junior or trainee provider). One example of inadequate communication involved a family member who tried to contact a clinician following kidney surgery: “On Monday, the patient was [in] respiratory distress, could

hardly breathe or talk, and [was] put on a respirator on the surgical/kidney patient floor. Caregiver called the doctor on the second day and had no response.”

Engaging In Manipulation Or Deception

This theme, present in fifteen of the narratives, included two subcategories: using fear to influence patient or family decisions and misleading or misinforming patients. Participants told stories of being frightened into taking a clinician’s advice despite feeling unsure or wanting a second opinion. In one exemplary narrative, a radiologist believed that the patient had an ascending aortal tear. The patient’s own cardiologist did not agree and recommended further testing at the hospital. Upon the patient’s arrival at the hospital, the patient asked to get a second opinion but was told she would die with any further delay. She said the radiologist indicated that “the scan was definitive and that more testing was unnecessary. I begged and pleaded for them to do more tests but all they wanted to do was operate. The staff and doctors all said that I was going to die any minute unless I agreed to the heart surgery.” The patient said she felt “desperate and hopeless.” After the surgery, the surgeon “laughed and said how ‘lucky’ I was that I didn’t have a torn aorta.” The patient’s narrative revealed how using fear to influence the patient’s decision resulted in emotional, physical, and financial consequences.

Cases of misinforming or misleading patients or family members included stories of clinicians not being straightforward and not communicating the seriousness of a situation. In one narrative, a family was told that the patient would be fine despite not waking up after surgery: “We had 6 other doctors come in saying she was fine and would wake up. On Wed[nesday] morning, one week after surgery, mom still not awake, and no report for why she was not awake. Demanded answers from doctor, who avoided answering questions. At that time, nurse took me to mom’s room, closed [the] door and told me mom was brain dead and they [had known] since Friday.”

Insights From Patients Can Inform Error Reduction Efforts

Our review of a large number of patient- and family-reported diagnostic error narratives revealed clinician behavioral and interpersonal factors that contributed to diagnostic errors. The reported errors met the National Academies’ definition of *diagnostic error*, and participants recounted strikingly similar patterns of experiences related to problematic clinician behaviors. These behaviors were described as related to or causing the diagnostic errors and caused participants to experience feelings of guilt, fear, and loss of trust. In prior research, patients’ perspectives have shown the breadth of communication problems^{17,18} and clinician behaviors that can threaten patient safety.^{19–21} Behaviors uncovered in our analysis were reportedly associated with subsequent diagnostic errors through the simple process of shutting down communication and limiting the patient input needed to achieve an accurate diagnosis.

Nearly two decades after the publication of *To Err Is Human*, health systems still struggle with identifying and remedying patient safety issues.²² *Improving Diagnosis in Health Care* emphasized the creation of learning organizations through monitoring the diagnostic process, as well as identifying and reducing diagnostic errors as part of an organization’s

overall safety and quality programs.² Patients' observations and complaints, especially in high numbers, have been found to correlate with higher numbers of malpractice claims.^{9,23,24} While patients' and families' experiences are gradually being recognized as sources of valuable information that can help improve safety and quality,^{5,25,26} there are no current policy or practice initiatives to supplement patient safety data using patient-reported experience and patient information and feedback.^{6,27-31} Using patient-generated information is essential, because patients and families are able to identify safety events that might not be identifiable on incident reports or in medical records.^{6,27,28} Thus, providing new information not captured by other error-identification strategies.^{5,7,32,33} Because of care fragmentation and the gradually unfolding nature of diagnosis, patients are in an optimal position to communicate details about their diagnostic journey, observe clinicians' performance, and identify factors that contribute to diagnostic errors.

Undesirable behaviors often go undocumented, and, unsurprisingly, we have little empirical evidence on how to address them—which leaves patients vulnerable to harm. Nevertheless, developing a culture of respect is a precondition for safe care.³⁴ After the publication of *To Err Is Human*, many institutions approached handling adverse events by focusing less on assigning personal blame and more on understanding how system design contributes to errors and redesigning systems to reduce error. Although a systems approach to patient safety does not preclude assigning individual responsibility,³⁵ the shift away from blame may have resulted in the perception of reduced accountability for undesirable behaviors.³⁶ Clinicians may find it challenging to speak up about their colleagues' behaviors.²⁰ Patients may be more motivated to report experiencing or witnessing undesirable behaviors, if they are given a way to do so. Institutions must identify and address individual accountability and a workplace culture that perpetuate these behaviors,^{35,36} especially when they threaten safety. Patients' reports can help institutions do this.

Unprofessional, disruptive, and disrespectful behaviors are well documented among clinicians³⁷⁻⁴⁰ but less well studied when directed toward patients. Systemically identifying and addressing clinician accountability in diagnostic error could help reduce preventable diagnostic harm related to these behaviors.^{36,40} Despite requirements from regulatory and professional bodies,⁴¹ institutional processes to document and address unprofessional behavior²¹—even those related to diagnostic errors—remain variable and often ineffective.³⁹ These behaviors can be disturbingly frequent.²¹ A study of unsolicited patient observations found that surgeons described as disrespectful by patients had higher rates of complications.⁴² Furthermore, clinicians' reports of disruptive behavior by their colleagues and its impact on patient care indicate a linkage between these behaviors and adverse events or patient harm,^{43,44} which underscores the need for interventions in this area.

Implications For Training, Clinical Practice, And Policy

While there are existing medical curricula to teach patient-centered communication techniques, previous evidence has shown a trend toward less positive attitudes toward patient-centered care among medical students as they move from the classroom into clinic settings.^{45,46} Adding requirements for ongoing and lifelong communication training that helps clinicians respectfully elicit and respond to patients' input in the context of diagnosis

could lead to reduction of diagnostic error. For instance, physicians and patients often approach their interaction with different expectations and perceptions,⁴⁷ these interactions determine the type of language used and information communicated. Mismatched expectations can lead to miscommunication that lowers patient satisfaction and understanding,⁴⁸ which in turn poses risks to patient safety. Lifelong learning strategies could include training on managing patients' expectations, including factors that build or damage rapport through discourse, and the importance of shared expectations for patient safety.⁴⁹ Current medical educational programs for physicians could include this type of training. Adding more content on communication skills, professionalism, and safety knowledge to maintenance of certification and continuing medical education processes would ensure that clinicians routinely refresh their knowledge and skills in these areas.

Our findings also suggest the need to develop programs for collecting and analyzing patient-reported data on safety.²¹ For this to succeed, health systems and providers must include patients as partners in improving care and must allow patients who might not be comfortable voicing their concerns to designate others to speak for them.⁵⁰ Institutions can encourage patient engagement by actively and systematically collecting patients' observations of behaviors that threaten patient safety. For example, the Vanderbilt Patient Advocacy Reporting System systematically collects and codes unsolicited patient and family complaint narratives (all types of complaints can be reported).⁵¹ These reports are reviewed and scored, and, for those with higher scores a graduated intervention is initiated to encourage individual clinicians to change their behavior.^{51,52} Patient reports that similarly identify unsafe clinician behaviors related to diagnoses—such as consistently ignoring patient symptoms that produce harm from delayed diagnosis—could result in interventions focused on improving clinicians' patient-centered communication and engagement behaviors.^{51–54} These data analyses and error identification processes should include corroboration of the patient report of error via the medical record or other independent review or analysis.

Additionally, hospitals and health systems should incorporate patients' reports of diagnostic error into systematic learning processes and patient safety programs.^{8,18,55} There is a need to develop optimal methods to collect and process actionable information from patient complaints.⁵⁵ New federal policies or accreditation initiatives will be needed to encourage health systems to account for patients' experiences in the diagnostic process and promote an organizational culture of effective communication and safe diagnosis.

Conclusion

Insights from patients can be valuable in gaining a comprehensive understanding of diagnostic errors and informing strategies for mitigation. Health systems should proactively develop and implement formal programs to collect patients' experiences, including interpersonal and clinician behavioral issues. These programs could facilitate more equitable relationships between clinicians and patients and positive patient-centered communication behaviors that engage patients, families, and caregivers in the diagnostic process and help prevent diagnostic harm.

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Exhibit 1:

Characteristics of patients who experienced a diagnostic error

Characteristic	Number (percent)
Age, mean (years)	52.4
Sex	
Female	125 (67.9)
Male	59 (32.1)
Setting of reported error	
Hospital	147 (79.9)
Emergency department	29 (15.8)
Outpatient	46 (25.0)
Other	33 (17.9)
Type of diagnostic error	
Delay in diagnosis or treatment	140 (76.1)
Misdiagnosis	120 (65.2)
Proper tests not ordered	89 (48.4)
Test results lost, misplaced, or disregarded	33 (17.9)
Laboratory or pathology error	13 (7.1)
Types of nondiagnostic error ^a	
Adverse medication event	103 (56.0)
Surgical or procedure-related error	100 (54.3)
Hospital-acquired infection	85 (46.2)

SOURCE Authors' analysis of 184 patient narratives reported via Survey Monkey on the Empowered Patient Coalition website, 2010–16. NOTE Participants were able to select more than one category of response for some characteristics, so categories may add up to more than 184.

^aExperienced by patients that had diagnostic errors.

Exhibit 2:

Participants' reporting of errors

	Number (percent)
Did the patient or family report the adverse event?	
No	60 (32.6)
Yes	121 (65.8)
Missing	3 (1.6)
To what agencies and institutions was the adverse event reported?	
Institution where incident occurred	82 (44.6)
State health department	35 (19.0)
State medical, nursing, or other licensing board	38 (20.7)
Joint Commission	28 (15.2)
Medicare or Medicaid	17 (9.2)
Ombudsman or Patient Relations	14 (7.6)
Other	54 (29.3)
Were you satisfied with the response of the institutions or agencies to which you reported?	
No	70 (38.0)
Yes	11 (6.0)

SOURCE Authors' analysis of 184 patient narratives reported via Survey Monkey on the Empowered Patient Coalition website, 2010–16. NOTES Participants were able to select more than one agency or institution to which they had reported the adverse event. Forty of the participants who reported the adverse event did not indicate whether or not they were satisfied with the institution or agency response.

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