A Family and Hospital’s Journey and Commitment to Improving Diagnostic Safety

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INTRODUCTION: ALL AUTHORS

In June 2015, Ethan, an 11-year-old boy whose “light shone from his eyes,” began suffering severe headaches accompanied by fever. Clinicians repeatedly misdiagnosed Ethan over several weeks as migraine headaches. An insidious, more dangerous condition remained undetected despite his parents repeatedly questioning the migraine diagnosis. Below, David and Farren Wyner, Ethan’s parents, describe the missteps in Ethan’s diagnostic journey. Their experience highlights the National Academy of Medicine’s challenge to the health care community to begin addressing diagnostic safety as laid out in Improving Diagnosis in Health Care.1

We share how Children’s Hospital Colorado responded to the challenge, in partnership with the Wyners.

ETHAN’S JOURNEY: DAVID AND FARREN WYNER

When Ethan was ~7 years old, he experienced several sharp, localized, short-lived headaches. A neurologist at Children’s Hospital Colorado (CHCO) diagnosed “ice pick headaches” thought to be related to our family’s migraine history. She explained the headaches may evolve into traditional migraines when Ethan reached puberty.

In late June 2015, Ethan, at age 11, developed another headache with photophobia. His pediatrician examined him and explained he probably had a migraine. She recommended over-the-counter pain medications until the headache resolved.

One week later, Ethan was still experiencing an unremitting headache as well as mild fever. His pediatrician referred us to CHCO’s 24/7 urgent care. The staff took a family history, performed a neurologic examination, and began a “migraine protocol” of intravenous medications and fluids. When the protocol appeared to offer relief, the staff evidently cemented the migraine diagnosis. When we asked staff repeatedly across multiple shifts if migraines could last for weeks without resolution, we were assured they could. Because that assurance contradicted Ethan’s father’s lifelong experiences with migraines, we asked if imaging was warranted. The providers confidently replied that imaging was not indicated, that computed tomography (CT) would expose Ethan to unnecessary radiation, and that he would require sedation for an MRI, something they were hesitant to do. We were discharged, with recommendations to continue over-the-counter medications and follow-up with a neurologist.

When Ethan’s headache continued unabated for another 2 days, we returned to urgent care. Our second experience, including 2 shift changes, was almost exactly like our previous experiences with migraines, we asked if imaging was warranted. The providers confidently replied that imaging was not indicated, that computed tomography (CT) would expose Ethan to unnecessary radiation, and that he would require sedation for an MRI, something they were hesitant to do. We were discharged, with recommendations to continue over-the-counter medications and follow-up with a neurologist.

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In route, Ethan decided to transfer him to the ICU. Over the next 3 hours. The staff condition deteriorated dramatically was moved to a medical ward, his Ethan for observation. Once Ethan that did not help, they admitted exact same migraine protocol. When previous visits. Ethan received the same answers. When the migraine protocol provided no relief, intravenous prednisone was prescribed, leading to a dramatic improvement in Ethan’s discomfort. Rather than considering what other conditions might produce such drastic relief with steroids, the staff was reassured by his improvement. We went home with 5 days of steroids and instructions to return for further treatment if the headaches continued.

On prednisone, Ethan’s headaches minimally improved but persisted. Less than 24 hours after taking his last steroid, Ethan’s headache returned in full force. Now 6 days after the last urgent care visit and nearly a month since the headache began, we went to the CHCO emergency department. The staff assumed the accuracy of the migraine diagnosis that was, by now, written in Ethan’s chart from previous visits. Ethan received the exact same migraine protocol. When that did not help, they admitted Ethan for observation. Once Ethan was moved to a medical ward, his condition deteriorated dramatically over the next 3 hours. The staff decided to transfer him to the ICU. In route, Ethan’s condition deteriorated further, and he underwent emergent CT.

The CT revealed a mass, presumably a brain tumor. He was taken straight to the operating room after the CT, without us being able to see him. We learned Ethan was being prepared for emergency surgery. After a shorter-than-expected surgery, we learned the mass was not a tumor but an abscess, likely present for some time. Ethan never regained consciousness after surgery and died 5 days later.

**OUR EXPERIENCE AS PARENTS: DAVID AND FARREN WYNER**

We understand how doctors initially reached the faulty diagnosis. Ethan had a history of headaches. His dad has migraines, as do both of Ethan’s grandparents. His symptoms mimicked migraines. We also understand how rare his true diagnosis was. But it is not the job of medical professionals to blindly accept convenient answers. We acknowledge that we did not hear every conversation that happened between clinicians. We accept that mistakes happen. We know medical professionals are fallible. But this was not a 1-time error made by 1 professional. This was a system-wide failure with multiple components. Numerous clinicians exhibited the same faulty reasoning. We were not provided the opportunity to share in the decision-making about a CT scan. The migraine diagnosis documented in the chart became established fact without being questioned during subsequent encounters. Our opportunities to contribute to the diagnostic process diminished at each encounter as the migraine diagnosis became solidified in the collective consciousness of the system.

Rather than feeling like partners or, at least, valued contributors in the diagnostic process, we felt steamrolled by the army of white coats and scrubs, all apparently eager to corroborate and support each other’s theories. As parents, it is not our job to be medical experts, but it is our job to ask hard questions and push for better answers. Time and again, when we did just that, we felt dismissed by people we relied on to be the experts.

We needed a creative thinker, a maverick, who thought outside the box and who entertained possibilities other than the obvious written into the chart. Had we had a physician who said, “It is probably a migraine, but Ethan’s felt bad for a few weeks. I would really like to know what an MRI would show,” then the outcome may have been different.

In the absence of that maverick (or, maybe, in addition), Ethan needed a system with room for doubt built in, room to question its own biases, that had sufficient checks and balances to explore the possibilities of rare situations. Without that system, all we got was shift change after shift change that simply inherited the previous diagnosis without question. Indeed, the focus seemed to be on confirming that diagnosis, oblivious to the possibility that the reasoning was clouded by confirmation bias. As Ethan’s parents, we were powerless. We were at the mercy of the health professionals. If Ethan had a doctor who thought creatively and autonomously and encouraged by a supportive medical system, he may have come home.

Our goal in partnering with Children’s Colorado is to turn our avoidable tragedy into a meaningful contribution to patient safety. We want Ethan’s story to lead to changes in the way the medical system approaches diagnosis so that no parents have to bury their child because of a diagnostic error.

**ONE FAMILY AND HOSPITAL’S JOURNEY: DRS GRUBENHOF AND BRUMBAUGH**

Improving Diagnosis in Health Care places the patient at the center of the diagnostic team because “[p]atients hold critical knowledge that informs the diagnostic process” and “bear the ultimate risk of harm from a diagnostic error.” This central placement requires the rest
of the diagnostic team to listen actively and communicate effectively to ensure the best outcome from the diagnostic process. Farren and David felt dismissed and disconnected from the process once the clinicians conferred a diagnosis on Ethan. Their experience is not unique.

Ethan’s story exemplifies key barriers to effective partnership with parents previously highlighted in Family Partnerships: fear of being labeled a “difficult parent”; insufficient confidence to understand medical jargon; and exclusion from conversations between clinicians. Knowledge asymmetry between patients and clinicians creates power imbalances that impede effective communication and imply that, once made, a diagnosis is right rather than a working hypothesis. Knowledge and power imbalances that hamper communication are supported by evidence that 50% of patient narratives regarding diagnostic errors involve ignoring the patient’s knowledge (eg, worrisome symptoms and failure to improve). These experiences underpin diagnostic errors for many Americans.

The first step in our journey addressed a culture reticent to discuss diagnostic errors. Dr Grubenhoff and the Wyners have presented the consequences of not acknowledging parents’ contribution to the diagnostic process to clinicians, nurses, administrators, and a national patient safety organization. We have also recorded an educational video that relays Ethan’s story, followed by introduction of concepts, including cognitive bias and diagnostic safety, that has been shared locally and nationally. A patient’s outcome cannot be dependent on “mavericks” comfortable challenging confirmation bias and diagnosis momentum when parents ask tough questions about the accuracy of diagnoses. Diagnostic safety requires being receptive when asked tough questions and welcoming of improvement opportunities. However, clinicians must ask uncomfortable questions about our diagnostic errors, even when patients and families feel unable to speak up. Through the Wyner’s partnership, CHCO has begun asking tough questions about failures in the diagnostic process at both individual and institutional levels.

However, awareness does not necessarily prompt change. The commitment CHCO made to Ethan’s parents mandates taking an honest look at our diagnostic performance as a system. A year after Ethan’s death, CHCO invited David and Farren to share their experience during a hospital-wide collaborative case review (CCR) as part of a 2-day kickoff to discuss strategies to improve culture surrounding diagnostic errors conversations. CCR can promote system-wide improvements and may be better than root cause analysis (RCA) for identifying opportunities to improve the diagnostic process. Now held quarterly for 3 years, CCR focuses on how systems, communication, infrastructure, and vulnerabilities in human reasoning create risks to diagnostic safety. During our regular diagnostic safety program updates with the Wyners, they challenged us to incorporate the patient perspective in CCR. We now include patient liaisons in these conferences to provide the patient and family voice. Feedback from participants consistently confirms that we have created psychological safety for the difficult task of reviewing human contributions to misdiagnosis.

After CHCO disclosed the diagnostic error in Ethan’s case to Farren and David they asked: “Is this going to happen to someone else’s child?” As Chief Medical Officer and Medical Director for Diagnostic Safety (DB and JAG), we wish we could definitively answer, “No!” An inherent barrier to reducing diagnostic errors lies in the relative obscurity of latent vulnerabilities to reliable diagnostic performance. Although CCRs and RCAs identify highly impactful diagnostic errors, the rarity of such tragic cases potentially leads safety leaders to focus on the wrong threats. The risks that expose patients to more frequent but less severe consequences remain hidden. Diagnostic errors compose only a small fraction of medical errors reported to passive incident reporting systems. To address this, we now review all admissions occurring within 10 days of an emergency department or urgent care visit to screen for potential diagnostic errors. This has unearthed patterns repeated in multiple patient encounters allowing recognition of diagnostic safety improvement opportunities. For instance, we discovered nearly a dozen cases like Ethan’s. None were reviewed by CCR or RCA. Aggregating cases previously considered isolated events reveals repetitive patterns of misdiagnosis. This knowledge informed a migraine clinical care pathway that specifically excludes patients like Ethan. Such institutional learning opens new possibilities for identifying possible diagnostic missteps amenable to systematic improvement efforts.

Although less tangible than specific programs, the Wyners’ partnership has proved invaluable for maintaining our hospital’s commitment to diagnostic safety. Patients want clinicians to accompany them on their journey after adverse events helping them better understand what has happened “to allow patients to ... feel support and empathy from healthcare providers”; patients also desire trust from their clinical companions. The Wyner’s partnership continually renews our commitment to diagnostic safety.
CONCLUSION: ALL AUTHORS

Our journey and partnership have only begun. As the Wyeners point out, a culture persists that marginalizes patients and families to recipients of a diagnosis rather than engaging them as coequal members of the diagnostic team. Partnership with patients and families requires humility and active listening from health care providers and committed engagement to find solutions together. Ethan’s, it turns out, was not as rare a situation as any of us had hoped. But partnering with David and Farren preserves our accountability to the commitment we made 6 years ago to ask hard questions and push for better answers.

ABBREVIATIONS

CCR: collaborative case review
CT: computed tomography
NAM: National Academy of Medicine
RCA: root cause analysis

REFERENCES

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