

What Can We Learn From Stories of Self-Diagnosis?

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Newsletter Editor

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patients feel abandoned,
left to their own devices, and
at odds with physicians.***

Stories of self-diagnosis, especially about serious or rare conditions that have been missed by physicians, are easy to find on the Internet and often heard at healthcare conferences. In the archetype, patients feel abandoned, left to their own devices, and at odds with physicians. The narratives usually feature patients who are motivated, persistent, and creative in solving diagnostic riddles while their physicians reject the patient's information and knowledge and are ineffective due to cognitive bias, burnout, rote adherence to pathways, and other professional and system problems.

Beyond revealing inadequacies in diagnostic medicine, what lessons do these compelling stories offer? Can they be used to help reduce the incidence of diagnostic error?

- ❖ Martine Ehrenclou had been seriously ill with pelvic pain for more than a year. After extensive research and many specialist consultations, procedures, tests, and medications, she had neither diagnosis nor relief. While helping a sick friend research her symptoms, Ehrenclou stumbled upon a newspaper article that described a woman with symptoms that matched her own.¹ That discovery led to self-diagnosis and successful treatment. Ehrenclou benefited from being an engaged, highly educated, and motivated patient, but luck also played a role.
- ❖ Jessica Barnett's diagnosis was confirmed only after her death at age 17. Doctors in Halifax, Nova Scotia, had been unable to identify the cause of fainting spells she had experienced since age 12.² Two years earlier, Jess's grandmother learned about an in-

herited heart condition called Long QT syndrome (LQTS) and recognized that it might be causing Jess's fainting spells. After dismissing a provisional diagnosis of LQTS, physicians were unable to agree on a definitive diagnosis. After Jess's death, physicians and the hospital settled out of court with the Barnetts, who sued for errors related to the diagnosis³ that relatives, as it turned out, had gotten right and repeatedly shared with physicians while Jess was still alive.

- ❖ When her 4-year-old son was ill with a fever and rash, Deborah Kogan posted photos of him on her Facebook page that showed the progression of his symptoms. As she reported on Slate,⁴ one of her friends recognized the look of Kawasaki disease and helped make the correct diagnosis, which the boy's pediatrician initially missed. Kogan posted on Facebook simply to

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“share” with her friends and did not initially know that the original diagnosis of strep was incorrect. Testing came back as negative for strep just as her son’s symptoms worsened. Kogan was not consciously crowdsourcing for a diagnosis but lucked into it before her pediatrician had a chance.

- ❖ A story dubbed “selfie diagnosis” went viral in June 2014, with tens of thousands of hits online and coverage by major television networks in the United States and Canada. Stacy Yepes had gone to a hospital in Toronto after she experienced what she thought might have been a mild stroke. Doctors attributed her symptoms—weakness and tingling on the left side of her face and body—to stress and sent her home. When the symptoms returned a few days later, she used her smartphone to record a video documenting her symptoms. Doctors viewed the video and confirmed the diagnosis they had earlier rejected—transient ischemic attack. On the *NBC Nightly News*, reporter Ann Thompson asked, “What would you do if doctors didn’t believe you? Stacy took a selfie.”⁵

NBC reviewed warning signs of stroke as part of this story, but the overriding message was that Stacy got the attention she needed by being creative and proactive during a serious medical event. Online commenters observed it would be safer to seek immediate medical attention than to record a selfie under similar circumstances, but it is hard to fault Stacy given her initial experience.

Stories of self-diagnosis often describe unique circumstances; they don’t usually offer a replicable model that others can follow. These stories illustrate imperfect systems, and usually do not offer reliable solutions. There may be lessons here for patients who have lived for extended periods with either a wrong or no diagnosis, but self-diagnosis in these cases is a work-around at best.

Do-It-Yourself Tools for Diagnosis

While these dramatic stories usually involve missed diagnoses, many patients try to self-diagnose by doing research online about symptoms as they emerge, before getting medical attention. The

Pew Research Center’s Internet & American Life Project found that in 2012, 35% of adults in the U.S. had at sometime in the prior 12 months gone online “specifically to try to figure out what medical condition they or someone else might have.”⁶

Whether doing initial research of symptoms or searching for a correct, definitive diagnosis that physicians have not been able to supply, people in search of diagnosis turn to the Internet. According to the Pew Center, 77% of people who seek health information online start with a search engine, such as Google, Bing or Yahoo. Sites that specialized in health information, eg, WebMD, are the starting point for 13%, with just 2% going to Wikipedia, and 1% using social networks such as Facebook.⁶ Medical literature databases, such as PubMed⁷ or specialized portals such as AHRQ’s Patient Safety Network,⁸ offer an organized entry point. Many articles are protected by paywalls; armed with an accurate citation, however, consumers may find that a hospital or public library can obtain the article on their behalf. Consumers and patients also have access to “do-it-yourself” tools, such as the Isabel Symptom Checker, designed specifically to generate a differential diagnosis.⁹

The reliability of information accessed online is often questioned, and research confirms common sense: the accuracy and objectivity of information should always be scrutinized and, whenever possible, verified.¹⁰ While online sources, especially social media, are routinely dismissed as unreliable, it is also dangerous to limit research to any single source of information, even if it is peer-reviewed. Consulting a diversity of sources is most likely to result in a complete search.¹¹

From Self-Diagnosis to Partnership

Stories of self-diagnosis teach us through negative example that the quality of information and the relationship between physicians and patients are central to the diagnostic process. Two factors are especially important: 1) the patient’s storytelling skills and 2) the physician’s listening skills plus willingness to consider and possibly use information the patient may present from outside sources, including the Internet.

Most stories of self-diagnosis feature patients who are sophisticated and articulate in describing their symptoms and resourceful in finding the information and expertise they need. Regardless of who arrives at the definitive diagnosis first, the details of the patient’s symptoms, history, and daily life often supply the deciding, pivotal clue.¹²

Tales of self-diagnosis, such as Jessica’s story,²

ImproveDx is a bimonthly publication of the not-for-profit Society to Improve Diagnosis in Medicine (SIDM). The opinions expressed in this publication are not necessarily those of the Society to Improve Diagnosis in Medicine or its Board of Directors.

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often include physicians who scoff at information supplied by the patient or family members. This is a common theme of stories about patient harm due to errors in treatment and care, where family members, such as Helen Haskell¹³ and Sorrel King,¹⁴ know that their children (the patients) are in trouble but are not able to convince clinicians to take their concerns seriously. In *When Doctors Don't Listen: How to Avoid Misdiagnoses and Unnecessary Tests*, Wen and Kosowsky coach both sides of the relationship; they encourage patients to work together with clinicians and physicians to renew their curiosity and acumen for partnering with patients.¹⁵

The lasting lessons of these stories demonstrate more about how to avoid the circumstances that lead some patients to diagnose themselves than about how to use methodologies and tools for self-diagnosis. It is not surprising that effective communication is the central lesson. When patients are able to report their symptoms honestly and accurately and to offer additional worthwhile resources, and physicians are available to hear the details and nuance in patients' stories and are willing to learn as well as teach, the diagnostic process is most likely to be efficient and accurate.

Merging Policy, Practice and Technology: Paths to Improve Diagnosis

In-depth, pre-conference sessions on Sunday, Sept. 14:

- Teaching the Teacher
- Clinical Decision Support—Bedside Tools for Better Diagnosis
- Introduction to Diagnostic Errors
- Patient Summit: How to Reduce Chances of Misdiagnosis
- Reducing Diagnostic Error through Improvement of Laboratory Test Utilization

For more information, visit www.DEM2014.org

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Engaging Patients in Reducing Diagnostic Error

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Engagement Committee

The SIDM Patient Engagement Committee creates strategies to inform and empower patients to help reduce diagnostic error. The Committee engages a growing network of more than 40 patients to make specific contributions to the Diagnostic Error in Medicine (DEM)/SIDM community.

The Committee has organized sessions and activities at each of the DEM conferences, including keynote addresses by prominent patient activists and panel sessions featuring patients. One of these panels, “The Patient Is In,” served as the genesis for an article on patient involvement in medical encounters, delivery system improvement, and policy formation.¹

SIDM partnered with the National Patient Safety Foundation (NPSF) on the 2014 Patient Safety Awareness Week (PSAW),² which adopted error in diagnosis as its theme. The Patient Engagement Committee contributed the content of the first PSAW webinar, one of the best-attended webinars in NPSF history. Committee network affiliate Ilene Corina of PULSE New York sponsored a PSAW seminar featuring SIDM’s president. Our committee worked on check-

Currently, committee members are working with researchers on a study about patient experience of diagnostic error and partnering with medical librarians on a pilot service for patients.

lists, factsheets, and “The Patient’s Toolkit for Diagnosis,” which rolled out as part of PSAW online resources.³

Currently, committee members are working with researchers on a study about patient experience of diagnostic error and partnering with medical librarians on a pilot service for patients. In addition, the 2014 DEM conference in Atlanta plans to feature an educational workshop to give patients information on ways to prevent or respond to misdiagnosis and a plenary session examining “deep root causes” of diagnostic error from the patient/family perspective.

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NEWS FROM THE FIELD

June Issue of SIDM Journal, *Diagnosis*, Available Online

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The second issue of SIDM’s peer-reviewed journal, *Diagnosis* (ISSN:2194-802X), offers the latest research and commentary about advancing the practice of diagnosis. The issue includes commentaries, editorials, and original research.

David Newman-Toker et al. studied records of inpatient discharges and emergency department (ED) visits to estimate the incidence of missed diagnosis of stroke. To their knowledge, this is the first large-scale, national study of stroke misdiagnosis in EDs. Using data from nine states, they estimate that between 15,000 and 165,000 strokes are misdiagnosed each year in the United States. Among other findings, they report that odds of misdiagnosis of stroke are higher among women, non-white patients, and those between the ages of 18 and 45. Newman-Toker and others have been engaged in a lively discussion on the

SIDM listserv focused on this research and an article in *The Washington Post*¹ about rising rates of stroke in young people.

Also in the June issue, James Reilly et al. describe fishbone diagrams that have been modified specifically to address the challenge of analyzing the root causes of diagnostic error. The modified tools have been used at two institutions—Maine Medical Center and the University of Pennsylvania—to analyze diagnostic failures. The authors invite further discussion and modifications.

Emilie Powell et al. report on a failure mode effects and criticality analysis (FMECA) of sepsis resuscitation in emergency departments, which they conducted at three hospitals. They, too, modified the tool they used—FMECA—to address diagnostic error, with a focus on cognitive processes.