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**What Does the Public Know About Patient Safety and Diagnosis?**

By Susan Carr

With each major anniversary of the Institute of Medicine's *To Err Is Human,*[1] the patient safety community reflects on its progress and future prospects.

In 2015, *To Err Is Human's* 15th anniversary coincided with another significant milestone, publication of *Improving Diagnosis in Healthcare*[2] Published by the National Academy of Medicine (NAM; successor to the Institute of Medicine), the new report presented what was known at the time about diagnostic error, how best to prevent it, and generally improve diagnosis. With the 5th and 20th anniversaries of these reports approaching, most but not all stakeholders believe that progress has been made both on diagnosis and patient safety overall.[3-5] Many also ask why the "needle" indicating advancement has not moved further and faster and what can be done to accelerate future progress.

Now, 5 years since *Improving Diagnosis* was published, how has awareness of diagnostic error changed? The Society to Improve Diagnosis in Medicine (SIDM), which sponsored the report, and the Coalition to Improve Diagnosis continue to enlist healthcare organizations, professional schools, malpractice insurers, and patient safety advocacy groups in efforts to prevent diagnostic error and improve diagnosis in general. Awareness of diagnosis has grown since 2015 among those who were already engaged in patient safety. It is difficult to gauge how much knowledge the general public and even healthcare professionals in general have of diagnosis as a process and its potential for error.

How well patients and the public understand the process is relevant because Goal 1 in the NAM diagnosis report is to "Facilitate more effective teamwork in the diagnostic process among health care professionals, patients and their families."[2(p8)] Teamwork with patients and families, the report suggests, can be enhanced by providing learning opportunities, inviting patient engagement in the diagnostic process, granting access to clinical information, and encouraging patients to share feedback about errors and near misses.

That sounds optimistic in an environment where many people are not aware of diagnosis as a process, much less one they need to participate in.

Researcher and consultant Michael Millenson, who first wrote about medical error in 1997,[6] points out that most people approach information on a "need to know" basis *(personal communication, October 2019).* They are unlikely to study the diagnostic process until they find themselves in the midst of it. And even then, the process itself may not seem like a priority. The

NAM report on diagnosis agrees and includes suggestions to encourage clinicians to address that lack of knowledge with strategies that range from improving clinician communication skills to equipping patients with checklists and scripts. Patients who will engage at that level, however, represent the minority at this time.

**Adding Diagnosis to Patient Safety**

Sue Sheridan, a patient activist who is now director of patient engagement for SIDM, points out that before being able to collaborate, patients and families often need an explicit invitation:

> *It would be very helpful if doctors would take the first step and invite patients to join them: "We need you as part of the team." It would help if they explained that diagnosis is a process: "There will be tests, there may be some referrals, and there may be a couple of different working diagnoses." To doctors, that might sound obvious, but we have found that patients want permission, they want an invitation to participate in their own care (personal communication, October 2019).*

Sheridan has been active in patient safety since the late 1990s. In addition to her current role at SIDM, she has held leadership positions at the Centers for Medicare & Medicaid Services, the Patient-Centered Outcomes Research Institute, and the World Health Organization. She became active following the first of two devastating medical errors in her immediate family—her son, Cal, and husband, Pat. In 1995, Cal suffered a form of brain damage called kernicterus when the severity of his newborn jaundice was misdiagnosed despite his parents' observations and repeated questions. Cal, who lives with significant disabilities, attended college and has become a professional comedian. In 1999, Pat had surgery for a mass in his cervical spine. Pathology tests identified the tumor as malignant but the report was put in a file without have been communicated to the physicians or the Sheridans. Pat's tumor grew, and he passed away three years later, in 2002, following extensive surgeries and cancer treatment.

For years, Sue Sheridan thought of those events as medical errors, not diagnostic errors because

> *…back then, we didn't use that language, we didn't look through that lens. I really never thought of them as diagnostic errors until 2008, when Mark Graber invited me to speak at the very first Diagnostic Error in Medicine conference (personal communication, October 2019).*

As a peer reviewer for *Improving Diagnosis in Health Care*, Sheridan became steeped in process and later Cal's and Pat's diagnostic processes in great detail for engineers at the National Academy of Sciences.

Sheridan says, "Even people who know they've had a medical error don't think about diagnostic error. Patients aren't aware of it—that's our biggest challenge."

**Public Perceptions of Patient Safety**

Ilene Corina also began working in patient safety following personal experience with medical injury. As president and founder of the Pulse Center for Patient Safety Education and Advocacy, Corina has been working to inform people in the general public about patient safety since 1996.

She and Pulse's volunteers, many of whom work in health care or are retired physicians, nurses, or pharmacists, have reached thousands of people with education and support. Through workshops, community meetings, support groups, and individual consultations, Corina and Pulse have developed a core community of people savvy about patient safety, including diagnostic error. Beyond that group, she's not so sure:

> *How well does the general public understand patient safety? As much as I would love to have an answer to that question, I don't know. (personal communication October 2019)*

According to Corina, public perception is not being measured because research funding has been lacking. With modest grant funding, Corina and Pulse have worked with day laborers, members of the gay and transgender communities, young mothers, and other local groups. Corina observes that the knowledge she has developed about those groups is not the same as would be gained through a broad survey of public perceptions.

**Measuring Public Perceptions of Safety**

Patients' views of safety and quality in ambulatory care, of which there are a limited number of studies, reflect a population more varied than hospital inpatients (more often the subjects of research) though still qualitatively different from the general public.

In 2016, a group of researchers in Germany conducted a systematic review[7] of articles covering the views of patients in primary and ambulatory care regarding adverse events. The review included 19 studies; all but one published between 2004 and 2011. Thirteen of the studies took place in the United States and 1 included the US among other countries.

Across the articles reviewed, patients lacked common terminology and definitions, so their observations give a faceted rather than cohesive view of the quality and safety of care. The authors of the review article observe that most patients combine reports of "mistakes" (preferred by the public over "medical error"), such as medication and diagnostic errors, with reports of unwanted side effects from drugs and quality problems that more often relate to patient satisfaction than patient safety.

They also report that researchers in a number of the studies "recognized service quality problems as…contributing factors to technical medical errors, eg, prescriber-patient miscommunication leads to ambulatory adverse drug events."[7(p4)] And they report that some healthcare professionals and organizations are beginning to understand that poor service and quality may cause patients emotional, if not physical, harm. In time, more research will help develop greater understanding of patients' perceptions of safety and quality, as well as effective ways to learn from patient feedback.

One of the US-based studies[8] in the systematic review stands out for the size and diversity of the population studied. Nearly 1,700 patients with varied demographics across 7 primary care practices in North Carolina were surveyed with four questions about "medical mistakes" in ambulatory care. One of the questions asked, "Has a doctor in a doctor's office made a wrong diagnosis or misdiagnosed you?"[8(p1481)] A random sample of patients who responded "yes" to questions about wrong diagnosis or treatment were selected for personal interviews that explored their memories and perceptions of the errors in more detail. Similar to results of the

systematic review, this study found "access and relationship issues" were often reported as "mistakes," and patients struggled to distinguish treatment from diagnostic errors.

The study also asked patients if they had ever changed doctors after receiving what they perceived to be a wrong diagnosis or wrong treatment, to which 14.1% responded "yes." In interviews, many of those patients said they were reluctant to tell the original physician they felt a mistake had been made.

Separate from efforts to reduce the incidence of medical error, the researchers feel there is a need to address the perception of mistakes with improved communication about diagnostic and therapeutic process, patient expectations, and clinical outcomes. They also note that although the study participants were demographically diverse, they all had a primary care physician and therefore were not representative of the general public.

**Changing the Way We Think**

By drawing back the curtain on safety lapses, *To Err Is Human* profoundly changed the way many people think about medical care, across a spectrum of knowledge and interest. At one end are people who became experts in patient safety science, and that population is steadily growing. At the other end is the general public, which remains largely uninformed. Most healthcare professionals fall somewhere in the middle. It is too early to tell how much effect *Improving Diagnosis in Health Care* will have on the problem of diagnostic error. Surveys of the public and healthcare professionals would be especially valuable to measure this impact but have yet to be funded.

Attracting and holding the attention of the public and the healthcare profession in general to the problems of patient safety and diagnostic error has been challenging and remains a priority for experts in safety and quality improvement.

Two organizations—one public, one private—joined forces recently to study this apparent lack of interest with the goal of learning how to communicate more effectively to a broad audience about the importance of patient safety, including diagnostic error.

The Betsy Lehman Center for Patient Safety, a non-regulatory state agency in Massachusetts, engaged the FrameWorks Institute, a nonprofit research group focused on improving discourse about social and scientific issues, to study currently held beliefs among stakeholders in patient safety. FrameWorks began by studying three groups: the general public, healthcare professionals, and patient safety experts. In results published in late 2017, FrameWorks found clear differences between safety experts on the one hand and healthcare professionals and the public on the other:

> *Our findings reveal that both groups [healthcare professionals and the public] hold deep beliefs about health, health care professionals, systems, and human nature that often contradict what experts in the field know about patient safety.*[9(np)]

The researchers urge experts to "reframe" how they talk about safety and to work with, not against, commonly held beliefs:

> If patient safety leaders and advocates better understand how people think about patient safety, they can anticipate reactions to messages and develop communications that spark a more productive conversation —one that deepens understanding and builds support for solutions.[9(np)]

The FrameWorks research is another reminder to avoid making assumptions about what people know or need to know. Sue Sheridan reminds physicians to begin with a sincere invitation. Ilene Corina observes that we don't have good data for guidance about the general public's views about patient safety. And Michael Millenson points out that we tend to seek information when we need it, not before.

The FrameWorks Institute urges patient safety proponents — and by extension, the diagnostic error community — to use explanatory language that ties solutions to the problem when inviting the public and not-yet-enlisted healthcare professionals to join them.

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**American College of Healthcare Executives Strives for Zero Patient Harm**

The American College of Healthcare Executives (ACHE) represents more than 48,000 members focused on advancing healthcare management excellence. ACHE works to improve patient safety and strives to achieve zero patient harm through educational programs and events for healthcare leaders. ACHE joined the Coalition to Improve Diagnosis in May 2019, and they were quick to include Coalition members in their safety education initiatives to help executives make diagnostic quality a priority.

"SIDM's partnership with ACHE amplifies both organizations' shared goal of creating a world where no patient is harmed," said Deborah Bowen, Chief Executive Officer at ACHE. "We are happy to join other members of the Coalition to Improve Diagnosis in taking an active role in improving diagnosis and reducing patient harm."

In September, ACHE and the Society to Improve Diagnosis in Medicine (SIDM) hosted a complimentary webinar entitled, "Addressing Diagnostic Error: A Top Source of Preventable Harm and Cost." During the webinar, SIDM Chief Executive Officer Paul Epner, MBA, MEd, and Director of Patient Engagement Sue Sheridan, MBA, MIM, discussed diagnostic error prevention and the implications that these errors have on patient safety.

More than 220 participants gained useful insights they can implement at both the direct care and organizational levels to reduce the impact of diagnostic error. View the webinar recording online to learn more.

In addition to this webinar, each year, ACHE hosts the Congress on Healthcare Leadership, bringing together more than 4,000 healthcare leaders to collaborate, network, and learn. This year, the 2020 Congress on Healthcare Leadership will be held on March 23-26, 2020 in Chicago, Illinois, where Harry Hoar III, MD, associate designated institutional official at Baystate Medical Center, and Suz Schrandt, senior patient engagement advisor at SIDM will present the latest information on diagnostic practices.

Dr. Hoar and Suz Schrandt will focus on the actions that organizations can take to help reduce harm from delayed and missed diagnoses. They will discuss the usage of "Improving Diagnosis in Medicine: Diagnostic Error Change Package," a tool to help reduce patient safety incidents caused by actions during the diagnostic process. Developed with input from clinical practices and organizations, and contributions from subject matter experts, patients, and families, this change package is designed to help users identify the circumstances under which diagnostic errors can occur and engage all team members, especially patients and families. It includes a menu of strategies, change concepts, and specific actionable items that any hospital can implement. At the session, participants will learn to adapt current patient safety processes, to identify error and learn from it, and to institute change as new ideas for diagnostic improvement are discussed.

ACHE's Congress will also feature a new offering called "Conversations in Safety," co-hosted by ACHE and the Institute for Healthcare Improvement's Lucian Leape Institute, where participants will engage with top experts in safety culture during informal conversations focused on essential safety topics.

For more information on the 2020 Congress on Healthcare Leadership, visit its webpage. Learn more about ACHE's initiatives to reduce patient harm on the ACHE website.

**New DxQI Seed Grant Program to Promote Creativity in Diagnostic Field**

The Society to Improve Diagnosis in Medicine (SIDM) has been awarded a $4.5 million grant from the Gordon and Betty Moore Foundation. With this funding, SIDM has established the DxQI Seed Grant Program to engage healthcare organizations in efforts to identify, develop, and test interventions aimed at improving diagnostic quality and reducing harm from diagnostic error.

Over the course of four years, this program will enable SIDM to support a minimum of 60 sub-grantees to carry out 12-month diagnostic quality and safety improvement projects.

The application process for the inaugural year will open in January 2020. The first cohort will consist of 20 grants of up to $50,000, to be awarded in Spring 2020. The program will support two additional annual grantee cohorts in 2021 and 2022.

"SIDM's DxQI Seed Grant Program will stimulate innovation in the field of diagnostic quality, an area where practice improvement activity is lagging," said Paul Epner, CEO and co-founder of SIDM. "Through engaging health professionals in developing and testing promising approaches, the program will lay the groundwork for a multitude of strategies to improve diagnostic quality and safety and unleash the creativity of the healthcare community."

Inaccurate or delayed diagnosis is the most common, catastrophic, and costly type of medical error. According to recent research from Johns Hopkins University School of Medicine and CRICO, 34% of all malpractice cases that result in death or permanent disability are caused by diagnostic errors, with 74% of such cases stemming from sources known as the "Big Three": cancer (38%), vascular events (23%), and infection (13%). Applicants to the program will be asked to identify the emphasis of their interventions, and at least 50% of selected projects will be focused on the Big Three. Additionally, SIDM will build a DxQI online community to support shared learning across sites and to receive counsel from an improvement advisor.

"Three clinical categories—vascular events, infections, and cancers—are responsible for a disproportionate share of serious harm and preventable death because of sub-optimal diagnosis. The Moore Foundation is excited to partner with SIDM on this initiative emphasizing diagnostic improvement for these conditions," said Daniel Yang, MD, program officer for the Moore Foundation's Diagnostic Excellence Initiative. "We believe this investment in diagnostic excellence is timely and goes beyond avoiding errors, including consideration of cost, timeliness, accuracy, and patient experience. Designing an optimal quality improvement intervention will require a careful balancing among these competing demands."

Organizations interested in the *DxQI Seed Grant Program* may sign up to receive notification when the request for proposal is issued.

**From the Field: Understanding and Reducing Diagnostic Error**

In partnership with Medscape, the Society to Improve Diagnosis in Medicine (SIDM) has developed a free, online learning module that provides an overview of diagnostic error and how to address it. The module, "Understanding and Reducing Diagnostic Error," covers what we know about the incidence of diagnostic error in practice today, focusing on how these errors arise from the complexity of the diagnostic process and the shortcomings in our systems and clinical reasoning, as well as the steps clinicians and patients can take to reduce the chances of error. This module is presented by Mark Graber, MD, FACP, chief medical officer and co-founder of SIDM, and can be accessed on the Medscape website.

"Diagnostic errors are common—they happen in every healthcare setting and may arise from the complexity of the diagnostic process and shortcomings in clinical reasoning and our healthcare systems," says Dr. Graber. "We've learned a great deal about diagnostic error from studying malpractice cases, including that many of these errors are preventable."

Dr. Graber uses the real-life example of Rory Staunton, a 12-year-old boy whose symptoms of streptococcal sepsis caused by a scrape were missed until it was too late, to illustrate the areas in the diagnostic process that need work and how the health system failed Rory. The module also cites the 2015 National Academy of Medicine landmark report "Improving Diagnosis in Health Care" and the Johns Hopkins University School of Medicine and CRICO 2019 study of malpractice cases published in the peer-reviewed journal *Diagnosis* as evidence that diagnostic error is both a big problem in health care and largely preventable.

The course is appropriate for students, trainees, and clinicians in every specialty, and provides a great opportunity to earn CME/ABIM MOC/CE credit through September 23, 2020. Physicians who complete this module will earn up to 0.50 AMA PRA Category 1 Credits and may qualify for 0.50 MOC points in the American Board of Internal Medicine's (ABIM) Maintenance of Certification (MOC) program. Nurses – RNs and APNs – may earn 0.50 contact hours of continuing nursing education. All others will receive a Letter of Completion that the activity was certified for 0.50 AMA PRA Category 1 Credits.

Any questions or comments about the module can be directed to Dr. Graber at Mark.Graber@ImproveDiagnosis.org.

**From the Field: New SIDM Online Community**

The Society to Improve Diagnosis in Medicine (SIDM) recently launched a new community platform that allows users to start conversations, discover and share resources, and network with peers. The change comes as SIDM develops more effective ways for people from different backgrounds to connect and communicate.

SIDM's discussion board community is open to patients, researchers, clinicians, and anyone interested in improving diagnostic error. The online community allows users to:

- Participate in conversations on the latest research and new efforts to improve diagnosis,
- Collaborate with other members of the SIDM community and build a network of peers,
- Access a community-built library of resources, where users can share files, including multimedia,
- Participate either online or directly by email by replying to threads or starting their own discussion.

There is already lively discussion on the platform, ranging from clinicians asking for advice (Where should we focus efforts to improve education – new trainees, or clinicians in practice?) to researchers sharing articles they have found or written. Others can easily join the conversation and offer input or advice.

Join the new community by navigating to community.improvediagnosis.org and signing in with the same credentials you use to log in to your SIDM account. If you're new to SIDM, you can create an account to start participating.

Once logged in, users can join the community and sign up for real-time, daily, or weekly email digests of current conversations they can respond to on the platform.

For more information or troubleshooting, contact SIDM Digital Content Manager Amanda Staller at Amanda.Staller@improvediagnosis.org.



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