

## VIEWPOINT

## DIAGNOSTIC EXCELLENCE

## Diagnostic Excellence Through the Lens of Patient-Centeredness

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**Making an excellent consumer product** differs fundamentally from providing an excellent service, such as health care.<sup>1</sup> The former leads to a handoff, such as when an appliance store delivers a refrigerator, whereas the latter is more like a ballroom dance. In health care, a popular term for that dance lately is *coproduction*.

The dividing line is not absolute. A great manufacturer seeks a long-term relationship with customers and has plans and processes for supporting the customer and for redesigning the product according to customer feedback. Surely health care must sometimes be 1 way: resuscitation from a cardiac arrest is not “coproduced.”

During the past half century, health care has moved from a technocratic, professionally dominated framing of “excellence” to one that seeks and incorporates the values, knowledge, context, actions, and power of patients and their loved ones. That shift was recognized in 2001 in the landmark Institute of Medicine (now National Academy of Medicine) report *Crossing the Quality Chasm*,<sup>2</sup> which declared patient-centeredness to be 1 of the 6 dimensions of quality, and included the



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following among its “ten simple rules” for redesign of health care: “[c]ustomization based on patient needs and values” and “[t]he patient as the source of control.” Indeed, patient-centeredness is not only 1 among the dimensions of quality but key to all of them.<sup>3</sup>

For the pursuit of diagnostic excellence, these perspectives of coproduction, patient-centeredness, and a shift of power from clinicians to patients have deep implications.

From the professional vantage point, a core aim of diagnosis is to accurately classify the causes of the patient’s current or impending distress according to up-to-date understanding of biology and psychology. That attribution is layered, from phenomenology (“You have hypertension”) to causation (“You have hypertension secondary to obesity”) to causes of causes (“You have hypertension secondary to obesity, which may be affected in part by your choices of food and activity level, as well as your genetic background”). For the clinician, an excellent diagnosis is a “correct explanation.”

From the patient’s perspective, the aim is not so simple. Patients come with pain, risk, or concern, and

their desire, for the most part, is not only explanation but also relief. Few patients who had to choose between knowing what is wrong and relief of their symptoms and distress would choose the former. Significant relief doubtlessly often does come from the resolution of uncertainty; not knowing can be painful. But the physician’s degree of satisfaction in being able to attribute a patient’s symptom to a cause or a known pattern is an incomplete reflection of the patient’s aims.

There is a juxtaposition in the 1990 Institute of Medicine definition of health care quality: “the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”<sup>4</sup> The phrase “desired health outcomes” reflects interest in patients’ goals, whereas “consistent with current professional knowledge” has far less to do with what patients would regard as excellence. Most patients would probably welcome whatever help works, no matter whose knowledge is used.

The aim of patient-centered diagnostic excellence therefore extends beyond proper classification to the prevention and relief of symptoms and signs. Thus, if proper classification is on the critical path to relief, it is an element of excellence. If it is not, then no matter how much pride, satisfaction, or craft the physician experiences, proper classification may have little to do with excellence from the patient’s perspective.

Patient-centeredness enters the diagnostic process in at least 5 ways: the pursuit of relevant knowledge, verification after diagnosis, temperance in pursuit of diagnosis, interpretability, and alternative attributions and causal theories.

### The Pursuit of Relevant Knowledge

Renowned diagnostician William Osler, MD, is said to have counseled physicians to “[l]isten to your patient; he is telling you the diagnosis.” In Osler’s time, that meant the exact, detailed description by the patient of symptoms, events, and patterns may well have contained the pathognomonic clues to diagnosis. That is still true. But in the age of the internet, Google, and social media, it may also be literally the case that the patient made the diagnosis long before entering the consulting room. Indeed, in the search for relevant biomedical science, patients often have the time and interest to do the research that their physicians could not manage to do. In some studies, 80% of internet users reported that they seek medical information on



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the web, with generally positive effects on the patient-physician relationship.<sup>5</sup>

The value of patient vigilance is a lesson learned painfully in the world of patient safety, where patients or family members often identify trouble long before clinicians do. Students of patient safety know well tragedies in which professionals failed to heed accurate alarms coming from families, such as the 2001 death from dehydration of 18-month-old burn victim Josie King at Johns Hopkins Bayview Hospital despite her mother's pleas for assessment,<sup>6</sup> and the avoidable complications of kernicterus in newborn Cal Sheridan in 1995, whose mother's observations of his jaundice were dismissed until it was too late to treat his hyperbilirubinemia effectively and prevent the consequences.<sup>7</sup> One of the strongest findings in extensive investigation of excess deaths in the Mid Staffordshire NHS Foundation Trust hospital in England between 2005 and 2009 was that patients and families knew the hazards long before hospital executives acknowledged them.<sup>8</sup>

### Verification After Diagnosis

A diagnosis is a hypothesis to be tested and verified over time. Autopsy may be the ultimate revealer of truth. But for the patients who live, diagnoses may be proven right or wrong according to what happens subsequently. **No party has more information on outcomes than the patient.** Diagnostic excellence therefore requires reliable follow-up with patients over time—in some cases, for a very long time. **However, compartmentalization of care, fragmented payment systems, and frail data systems may deter consistent follow-up.**

### Temperance in Pursuit of Diagnosis

The quest for diagnosis is an investment with both costs and potential returns in health and well-being. **Patients know a great deal about the value and the cost.** It is patients who may spend precious hours in medical facilities and who experience the physical and emotional discomfort of diagnostic procedures, and it is patients who may know best when to stop the evaluation (ie, when obtaining an answer is not worth the cost to the patient or family). **Patient-centered thinking would strongly weight the time, cost, discom-**

**fort, and other burdens imposed on the patient,** which could lead to a different testing strategy than if these losses were ignored.

### Interpretability

Diagnosis raises a communication challenge. The clinician's label (eg, "You have hepatitis C," "It's migraine") is little more than a mystic incantation if the patient has no mental map for the words. **Understanding, in the patient's mind, does not end with a diagnosis; it begins with one.** Labeling leads to the ongoing exploration of what that label means: "What do we do about it?" "What will happen to me?" and "What caused this?" Diagnostic excellence ought to incorporate the duty to help patients learn what they wish to learn, and to master the new information in their own language and in ways they can explain to themselves and others.

### Alternative Attributions and Causal Theories

The clinician's diagnosis lands in a terrain full of preexisting theories and labels: the patient's life context, with all of its beliefs, social norms, and values. In the extreme, these context-dependent attributions can even contradict the diagnosis.<sup>9</sup> Diagnostic excellence means more than a victory of the medical model of attribution over other epistemic frames. **It should include the challenging process of integrating the scientific attributions of clinical medicine with the patient's cultural circumstances, worldviews, and knowledge.** In the words of 2 pioneers of such a biopsychosocial model of care, caring (and therefore diagnosis) should be "an exercise in relating social science knowledge and clinical action."<sup>10</sup>

Diagnostic excellence is an accurate and complete understanding of a patient's condition that, from the vantage point of patient-centeredness, (1) embraces the patient's knowledge (not just the clinician's); (2) ensures long-term follow-up and ongoing verification, including the patient's reports; (3) monitors and moderates the level of investment in pursuit of explanations; (4) ensures interpretability and the growth of knowledge for the patient; and (5) whenever possible, melds the language and understanding of the patient with that of the clinician. Excellence in diagnosis means that the needs of the patient, for solace and relief, come first.

#### ARTICLE INFORMATION

**Published Online:** November 18, 2021.  
doi:10.1001/jama.2021.19513

**Conflict of Interest Disclosures:** None reported.

#### REFERENCES

- Batalden M, Batalden P, Margolis P, et al. Coproduction of healthcare service. *BMJ Qual Saf.* 2016;25(7):509-517. doi:10.1136/bmjqs-2015-004315
- Institute of Medicine (US) Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century.* National Academies Press; 2001.
- Berwick DM. What "patient-centered" should mean: confessions of an extremist. *Health Aff (Millwood).* 2009;28(4):w555-w565. doi:10.1377/hlthaff.28.4.w555
- Institute of Medicine (US) Committee to Design a Strategy for Quality Review and Assurance in Medicare. *Medicare: A Strategy for Quality Assurance.* Lohr KN, ed. National Academies Press; 1990.
- Tan SS, Goonawardene N. Internet health information seeking and the patient-physician relationship: a systematic review. *J Med Internet Res.* 2017;19(1):e9. doi:10.2196/jmir.5729
- King S. *Josie's Story: A Mother's Inspiring Crusade to Make Medical Care Safe.* Grove Atlantic Press; 2009.
- Centers for Disease Control and Prevention. Cal Sheridan's journey with jaundice and kernicterus. December 8, 2020. Accessed November 8, 2021. <https://www.cdc.gov/ncbddd/jaundice/cals-story.html>
- National Patient Safety Advisory Group. *A Promise to Learn—A Commitment to Act: Improving the Safety of Patients in England.* Dept of Health; 2013.
- Fadiman A. *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures.* Farrar Straus & Giroux; 1997.
- Stoeckle JD, Barsky AJ. Attributions: uses of social science knowledge in the "doctoring" of primary care. In: Eisenberg L, Kleinman A, eds. *The Relevance of Social Science for Medicine.* Springer Publishing; 1981:223-240. doi:10.1007/978-94-009-8379-3\_10