AMA Journal of Ethics®
October 2025, Volume 27, Number 10: E733-736

MEDICAL EDUCATION: PEER-REVIEWED ARTICLE

How Should Students and Trainees Be Taught to Support Patients With Undiagnosed Conditions?

Mylynda B. Massart, MD, PhD and Erika N. Dreikorn, PhD

Abstract
Patients with undiagnosed conditions often experience frustration and lose trust in health care. This article suggests how faculty in academic health centers can prepare their students and trainees to respond with care to the vulnerabilities and needs of patients seeking accurate diagnoses. Specifically, this article suggests the importance of clinicians' roles in validating patients' knowledge claims about their illness experiences. Such validation during clinical encounters can happen when clinicians prioritize symptom management, acknowledge uncertainty as an emotionally painful part of a patient's illness experiences, articulate limitations of clinical knowledge, and express values such as care, partnership, and compassion in their relationships with patients.

The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit™ *available through the* AMA Ed Hub™. *Physicians should claim only the credit commensurate with the extent of their participation in the activity.*

Finding Diagnoses

When caring for patients with chronic, undiagnosed conditions, the first author (M.B.M.) has learned 2 challenging but essential lessons: how to live with the limits of science and medicine and how to be a caregiver when certainty is out of reach. Medicine trains us to collect facts, assemble data, make a diagnosis, and design a treatment plan. But what happens when that sequence breaks down? When the facts are unclear, the data incomplete, and the diagnosis elusive, how do we continue to confidently care for our patients? Early in her training, M.B.M. believed that if she read enough textbooks, attended enough lectures, and reviewed enough journal articles, she could overcome this uncertainty. But, instead, she has found the edge of what we know. Medicine is incomplete; science is imperfect. Despite how far we have come, despite remarkable advances in technology, artificial intelligence (AI), big data, and precision medicine, we are still limited in fully understanding the masterful complexity of human health. While AI will bring more facts to our fingertips than ever before, the true distinction between AI and physicians will always be the art of medicine—the human act of caregiving itself, which is what called M.B.M. to this profession in the first place. And so, as M.B.M. pursues answers as relentlessly as her patients seek them, she also wrestles with how to be the caregiver they need today, even when certainty is just beyond her grasp. This is the tension—and the beauty—that drives both the scientist and the clinician within her.

Patients with undiagnosed conditions often have extensive clinical experiences characterized by inconclusive testing, specialist consultations, and many unanswered questions. When we health professionals find that evidence to support a diagnosis is absent or murky at best, we do not question the scientific process or our diagnostic tools. Instead, we diagnose the patient with anxiety, or we conclude that their obesity is causing "functional" symptoms that do not fit nicely into our algorithmic and evidence-based boxes. Perhaps we conclude that the patient does not match our specific "-ology" and should go see a different "-ologist" instead, as they might be a better fit for the black boxes over there.

These experiences leave patients feeling blamed or shamed for their own unanswered health questions as they travel to the next clinician and the next. Of course, patients will have anxiety about what is unknown, and this anxiety can morph into trepidation about the next consultation: Will the physician listen, or will it be another unsatisfying experience? Eventually, patients will feel gaslit, and they could be accused of "doctor shopping." If their symptoms involve pain, they might be viewed as drug seekers, further compounding the blame and shame they experience. Many will give up and fall into an abyss of disillusionment. In the modern era of digital access, patients often become their own physician-scientists, scouring the internet for answers and finding solidarity in their shared experiences. They must jump hurdles of information and misinformation available to everyone now on the internet. When patients share with their physician a potential solution that they have found and wish to explore, physicians often feel burdened by this additional and seemingly extraneous information.

Adapting Curricula

To achieve better care of patients with undiagnosed conditions, the authors propose 3 adaptations of medical education. Educators must teach physicians to (1) understand that medicine and science are not perfect, (2) validate patients' experiences and partner with patients in their medical journeys, and (3) use their knowledge and skills to manage symptoms when they cannot make a diagnosis.

Traditional medical training emphasizes definitive diagnoses and treatment plans yet lacks focus on managing uncertainty. By its very nature, medicine is not an exact science, and its limitations are often overlooked or poorly understood. M.B.M. remembers being told by educators in medical school that 50% of what they are teaching is wrong, but they don't know which 50%. Clinicians are not taught to recognize the imperfections of medical science or how to handle situations in which no diagnosis can be made. In her medical career, M.B.M. has seen long-held beliefs within evidence-based medicine reversed and watched as the profession changed course. Simultaneously, medical school curricula have evolved significantly to emphasize humility, empathy, and effective communication, thereby equipping future physicians with clinical communication skills. However, failure to implement these skills is still apparent when physicians care for patients who have unknown conditions.

To help physicians succeed, we medical educators must continue to take their curricula to the next level. Medical students and residents need to practice applying empathy and communication skills in a more formal manner, while simultaneously acknowledging the unknown in science and medicine. We must teach future doctors how to explain the limitations of current medical diagnostics to patients and how to approach caregiving in the absence of a clear diagnosis and treatment plan. Students can practice validating a patient's experience and acknowledging the patient's journey and frustration. M.B.M. has found that doing so only takes a simple sentence: "I agree that something is going on with your health, and I hope we can get to the bottom of these symptoms, provide a diagnosis, or at least start managing the symptoms to optimize your quality of life." Frequently, she will tell patients that "while science and medicine may not have all the answers yet, we can still do our best to eliminate many of the possible causes and then focus on symptom management." While this approach can be implemented with standardized patients, the authors encourage medical schools to bring in more real patients to share their stories with students. The students will remember these stories long beyond their lectures on anatomy or biochemistry. During the clerkship years, educators should encourage students to take their time and learn from patients, instead of rushing through to meet the busy demands of clinical schedules. Clerkship should be a time for medical students to have the luxury of really listening to and learning from patients. This is a luxury they will not have in the future, and it is the perfect time for them to practice these skills. In M.B.M.'s experience, students given this experience and time will often learn valuable information that helps M.B.M. take better care of her patients.

Medical education can also train students to recognize and accept the limitations of medical science. Physicians must understand that uncertainty is not a reflection of their own competence; it is a reality of practicing in a continually evolving field. Once medical students face the imperfection of their future craft and recognize that medicine and science are incomplete, they then need to learn how to explain these limitations to patients in a way that builds confidence in their medical skill set without reflecting negatively on themselves. "Not having all the answers" is not a reflection of personal failure. We physicians are experts at finding information if it exists, but there are some cases in which the necessary information just does not exist. When we see patients and work with them, we must prepare them for uncertainty ahead, knowing that we won't always find the answers. If we do not set these expectations, patients will continue to seek specialist after specialist, hoping to check every unturned stone to find their missing answers. This is the actual failure: our feeding into and propagating a futile cycle.

Patient Collaborators

With these skills, we can better collaborate with patients. We can apply our empathy and communication skills to recognize patients as persons needing support and validation, even without a clear diagnosis. M.B.M. has repeatedly heard from patients that they just want to be seen and heard. This approach shifts the physician's role from "fixing" patients to bearing witness to their lived experience and championing their understanding and comfort. We can reassure our patients that we see and hear them, that we are still their caregivers, and that we will support them by prioritizing symptom management. We can learn from and apply the principles of palliative care in these scenarios, emphasizing pain and symptom management, emotional and spiritual support, and overall optimizing of quality-of-life goals. When we don't have all the answers, we still have many tools. These tools will range from treatment to management, depending on the symptoms. Our tools can significantly alleviate the physical and emotional suffering that accompanies a long diagnostic odyssey. We can support our patients through advocacy: assisting with accommodations at work or school and with paperwork to document the impact of their illness or symptoms on daily functioning or to help them access supportive care resources that might be challenging to obtain in the absence of a diagnosis. We can also encourage our patients to participate in research and contribute to a scientific knowledge base that could one day help other patients. Ultimately, everyone wants answers. Applying our tools as best we can while managing symptoms reinforces the care given to our patients and eases their journey.

Until we can fully realize the vision of understanding all human diseases, we can learn how to tell patients "I don't know," while validating their lived experience and partnering with them to access support and manage their symptoms. We can train future physicians to manage the dual responsibility of recognizing the limits of medical science while delivering compassionate care. By doing so, we can transform the patient's journey from one marked by frustration and isolation into one rooted in hope and partnership, thereby ensuring that no patient is left behind due to the boundaries of current medical knowledge.

Mylynda B. Massart, MD, PhD is a family medicine physician in the Primary Care Precision Medicine Clinic at the University of Pittsburgh School of Medicine and UPMC in Pennsylvania. Her clinical practice focuses on patients with complex, often undiagnosed, conditions, many of whom have felt misunderstood or stigmatized. Her research interests include precision medicine, the integration of genomics into primary care, centering community and patient lived experience in research, and improving patient experiences in navigating diagnostic uncertainty.

Erika N. Dreikorn, PhD is the director of research and communications for the Primary Care Precision Medicine Clinic at the University of Pittsburgh Medical Center in Pennsylvania.

Citation
AMA J Ethics. 2025;27(10):E733-736.

DOI
10.1001/amajethics.2025.733.

Conflict of Interest Disclosure
Contributors disclosed no conflicts of interest relevant to the content.

ISSN 2376-6980