

The unexplained disorder: A test of stigma, ethics and empathy

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The diagnosis and treatment of difficult-to-measure disorders have long been complicated by stigma from health professionals, the public and even patients themselves. In fact, patients with medically unexplained symptoms, including functional neurological disorders—like fibromyalgia, chronic fatigue syndrome and chronic pain syndromes—are often dismissed as hysterical, deceitful, even dangerous.

Following are highlights from an [article](#) published in the *AMA Journal of Ethics*[®] ([@JournalofEthics](#)). The case commentary was co-written by:

- Benjamin Tolchin, MD, director of the Center for Bioethics and co-chair of the Adult Ethics Committee at Yale New Haven Hospital.
- Dorothy W. Tolchin, MD, an instructor in physical medicine and rehabilitation at Harvard Medical School.
- Michael Ashley Stein, PhD, executive director of the Harvard Law School Project on Disability.

Using the hypothetical case of a woman with tremors who has experienced four years of unsuccessful treatment and feels abandoned by her caregivers, the authors explored the ethical obligations to minimize harms and maximize benefits of diagnosis and treatment of disorders without biomarkers. These include navigating difficult-to-measure, even clinically inexplicable, symptoms.

Know the harms

“Diagnosis of a medically unexplained symptom incurs real risk of harm to patients, most notably in the form of stigma,” the authors wrote, adding that studies of stigma in the health care system identify three pathways through which it can harm patients.

One of those, public stigma, “encompasses negative moral judgments made by others—including clinicians, family members, employers and the general public—about an individual or group with a

specific diagnosis or other characteristic.”

It can lead to discrimination in multiple domains, the authors noted, including housing, employment and health care.

Self-stigma, meanwhile, occurs “when stigmatized individuals internalize and accept negative moral judgments about themselves, leading to diminished self-esteem, self-efficacy, and self-investment, as well as self-caused impediments to the pursuit of life goals.”

Then there’s label avoidance, which “occurs when individuals avoid the health care system in order to avoid a diagnosis associated with negative moral judgments,” the authors wrote, adding that patients with difficult-to-measure disorders and medically unexplained symptoms are at risk through all three pathways.

Also note the opportunities

Providing an accurate diagnosis, the authors noted, requires a physician’s collaboration with both the patient and colleagues, and these interactions should coalesce around the pillars of medical ethics: autonomy, justice, beneficence and non-maleficence.

“As clinician and patient come together to understand the nature and implications of a patient’s symptomatology, a clinician heeds the bioethical principle of beneficence, and a meaningful patient-clinician relationship and clinical approach can emerge,” the authors wrote, adding that “a diagnosis that engenders understanding of a patient’s lived experience can provide benefits, including closure on a prolonged diagnostic period and an end to the risks of diagnostic inquiry.”

A meaningful diagnosis also engenders a strong patient-clinician relationship, in which patients feel understood and stay engaged with the medical system.

“Moreover, as health care systems begin to address systemic ableism, individuals with medically unexplained symptoms will be able more fully to experience the aforementioned benefits of diagnosis,” the authors wrote. “Acknowledging the implications of ableism may help foster opportunities for clinicians and institutions to identify and address biases in care for individuals with all types of disabilities.”

What’s more, diagnoses can help patients become active agents in the management of their illnesses. Affected patients and families have gone on to join or even create patient advocacy organizations.

“Clinicians involved in medical education can also empower patients as teachers,” they wrote, “by inviting them to speak about their experiences to medical students.”

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