Between illness and disease

Reflections on managing medically unexplained symptoms

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Illness is "a perception of something being wrong, a sense of unease in the functioning of the body or mind," while disease is "a theoretical construct, a unit in the taxonomy of scientific medicine."[1] In the 2011 Harveian Oration "Divided We Fail," Iona Heath describes the role that family physicians play in distinguishing between illness and disease. As the first point of access to the medical system for many patients, family physicians are in the unique position of "see[ing] much more illness than disease."[1] Most of our daily work is to "[hold] the border between subjective illness and the disease categories recognised by biomedical science"—to protect our patients from the labels of disease only until "such labelling will be positively useful to them."[1] But are we adequately trained to patrol these vague boundaries? Should we carry such immense responsibility? And how do we know when our patients cross quietly over such borders? It was here, in these uncertain territories, that I found myself struggling when I first encountered a patient with medically unexplained symptoms (MUS).

Medically unexplained symptoms, also known as *persistent unexplained physical symptoms* or *somatic symptom disorder*, are defined as "symptoms that last at least three months and are insufficiently explained by a medical condition after adequate examination and investigation."[2] Patients with MUS can present with a variety of symptoms, including fatigue, back pain, headache, and weakness,[3] and account for up to 10% of presentations.[4] The literature shows MUS to be a frequent cause of overinvestigation and to be associated with extensive health care costs.[3] Despite their prevalence and effect on the health care system, studies have shown that MUS are a source of anxiety for many family physicians, who often feel inadequately trained to manage these patients, citing difficulties in excluding medical diseases, fear of missing a diagnosis, patient frustration, and concern.[3,5,6] Reading these studies, I realized I was not alone in feeling inept at dealing with Tina's challenging case.

Tina's case

Tina is a 64-year-old white woman who first presented to my clinic with a 6-month history of fatigue. Her past medical history included resected thyroid cancer, hypertension, type 2 diabetes, dyslipidemia, and depression, all of which were well controlled on appropriate medications. She ran a business with her husband but her fatigue was limiting her ability to work. During this visit, a comprehensive review of systems produced no findings. There were no pertinent findings on physical examination that suggested a cause. Depression screening results with the 9-item Patient Health Questionnaire and the Montreal Cognitive Assessment were negative. Results of bloodwork including complete blood count, electrolyte levels, glucose level, hemoglobin A_{1c} level, thyroid-stimulating hormone level, ferritin level, and renal function were all within normal limits.

During the next 6 months, she described progressive fatigue. Her ability to work continued to be negatively affected. Repeat history taking and physical examination at subsequent visits failed to reveal any further clues. Additional blood testing was done (including liver function tests, extended electrolyte levels, autoimmune testing, and infectious disease screening), the results of which were negative.

With every visit, I grew anxious about what Tina was experiencing. I had no idea what was causing her symptoms, and meanwhile they were getting worse. Like every physician who faces MUS, I ruminated over what I was missing. Was there a symptom I had not asked about? Was there a test I had not ordered? At the same time, I also worried that I was subjecting her to overinvestigation. At what point does one reach a diagnosis of exclusion such as MUS? Maybe I did not have the appropriate skills to manage this case and should involve another specialist. If so, which one? And most important, what could I do to help her feel better?

Accepting a diagnosis of MUS

When I searched the literature on MUS, what I read did not answer my questions. Sure, there were many articles on the principles of MUS management—on the importance of establishing a good therapeutic relationship, of limiting the number of tests ordered, and of providing good follow-up care, among other strategies. But all of that was contingent on my acceptance of MUS as the diagnosis, which I was not ready to do. Instead, I needed to read about how to let go of my search for an answer to her symptoms. I was looking for an "approach to" accepting that there was no alternative explanation. I wanted to read about physicians' experiences with reaching a diagnosis of exclusion such as MUS but, surprisingly, I found few articles that explored perspectives on this conflict.

Reflecting on my care of Tina, I realized that my struggle boiled down to navigating between illness and disease, harking back to Dr Heath's oration. We are tasked to patrol these borders, and yet, at no point in our medical training are we given the manual on how to do so. It was a deeply uncomfortable position to occupy—filled

with fear of misdiagnosis and self-doubt and without the tools to address those feelings. And so I needed to find my own way.

First, I carefully examined Tina's entire chart with a fine-toothed comb, going back more than 15 years. I looked for possible causes and asked myself if I ever came across any red flags. I reviewed her case with my preceptors and mentors, who offered their clinical recommendations. When I was able to systematically rule out most diagnoses, I started to feel more confident that there were no stones unturned.

Second, I discussed Tina's case with her in great detail. Together, we reviewed my detective work and I cautiously explained why I thought her symptoms fit the definition of MUS. To my surprise, she was actually pleased that this was where we found ourselves. She was comforted that there was nothing "more serious" wrong with her and she was grateful that I had been so thorough and open. Her reaction gave me immense relief and helped me let go of some of my anxieties.

Finally, we agreed that we would see each other routinely to discuss whether her symptoms were changing, to determine whether any new symptoms were developing, and to review how she was functioning. Thankfully, she began to feel better about 9 months after our initial visit—likely in part because she felt heard and taken seriously, but also because she felt that she could finally move on with her life. Knowing that her health was not in danger allowed her to recover from her symptoms—including returning to work. In her own words, she realized there was "nothing to be feared anymore."

Conclusion

Medically unexplained symptoms are frequently encountered by family physicians, who often feel inadequately trained in their management. Caring for a patient with suspected MUS can be a daunting task—one that might cause great discomfort and anxiety as one navigates the borders between illness and disease. Unfortunately, an exploration of these experiences is lacking in the current research literature. Persistence in uncovering the truth (even if that truth is medically unexplained), transparency of process, and maintaining a strong therapeutic relationship with the patient were the key tools that helped me reconcile my self-doubt and manage this challenging case.

Dr Lum was a family medicine resident at Women's College Hospital in Toronto, Ont, and is now in her first year of practice.

Competing interests
None declared

References

1. Heath I. Divided we fail. *Clin Med* (Lond) 2011;11(6):576-86.
2. Den Boeft M, Claassen-van Dessel N, van der Wouden JC. How should we manage adults with persistent unexplained physical symptoms? *BMJ* 2017;356:j268.
3. Sirri L, Grandi S, Tossani E. Medically unexplained symptoms and general practitioners: a comprehensive survey about their attitudes, experiences and management strategies. *Fam Pract* 2017;34(2):201-5.
4. Houwen J, Lucassen PLBJ, Stappers HW, Assendelft PJJ, van Dulmen S, olde Hartman TC. Medically unexplained symptoms: the person, the symptoms and the dialogue. *Fam Pract* 2017;34(2):245-51.
5. Nham B, Williard A. Why medically unexplained symptoms and health anxiety don't need to make your heart sink. *Med J Aust* 2018;208(4):188.
6. Den Boeft M, Huisman D, van der Wouden JC, Numans ME, van der Horst HE, Lucassen PL, et al. Recognition of patients with medically unexplained physical symptoms by family physicians: results of a focus group study. *BMC Fam Pract* 2016;17:55.

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