

# Underserved community versus underserved disease

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I was in high school in rural Southwestern Ontario when my mom became sick. She was a healthy and energetic nurse when almost overnight things changed. First, her joints started to swell and then she became so tired she could not get off the couch. Her local rural care providers ordered every test imaginable, but everything was 'normal'. She was seen by specialists, and tried many treatments but nothing addressed her debilitating fatigue.

Over the last 13 years, her energy has fluctuated. She retired early and gave up her volunteer roles. There were times she felt 'okay' and would end up 'overdoing it', resulting in days or weeks on the couch. At times, she was so unwell she needed help with bathing and she would rest on the floor while going from the couch to the kitchen to make a cup of tea. Our family always felt that if only we lived in a bigger centre someone would be able to diagnose and cure my mom.

I graduated high school near the beginning of her illness and pursued medicine hoping to find her a diagnosis. However, nothing I learned in class or saw on rotations explained her symptoms. It was not until another family member developed similar symptoms after a viral illness that the pieces came together. This individual was diagnosed with

myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome.

I now know ME is a complex, chronic illness which the World Health Organization specifies as a post-viral neurological disease.<sup>1</sup> The prevalence is 0.42%–2.8% depending on the case definition,<sup>2</sup> and sources from the United States suspect that 90% are not diagnosed.<sup>3</sup> The hallmark feature is post-exertional malaise, which is the worsening of symptoms after cognitive or physical exertion. It is a clinical diagnosis requiring severe fatigue lasting more than 6 months, post-exertional malaise, unrefreshing sleep and either impaired memory/concentration or orthostatic intolerance.<sup>3</sup> There is no cure for ME. Staples of care include energy management and symptom-based therapies.<sup>4</sup> Patients are known to have a poor quality of life<sup>3,5</sup> and over 25% of patients are bedbound.<sup>3</sup> Unfortunately, the disease has been underfunded for decades and many providers are unaware of this diagnosis, leading to misdiagnosis and mismanagement.

Now that I am wearing the white coat, I know her rural care providers had nothing to hide. There were no secret tests or cures in the city either. Her care providers just did not know, like many doctors across Canada. You cannot diagnose something if you have

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never heard about it. Recently, my mom revisited her symptoms with her new family physician and was finally diagnosed with ME. While the diagnosis does not change her prognosis, it has provided her comfort in better understanding her symptoms and knowing how to manage her limited energy. As rural physicians with broad sets of knowledge and skills we are well-positioned to help these underserved patients, even if we practise in underserved communities. Going forward, I hope more physicians will add this diagnosis to their differential.

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