



Reflections

I am afflicted with an illness

Physicians and their fibromyalgia patients

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I am afflicted with an illness, but not because I have it. I am afflicted with this condition because I find it so difficult to understand. Why do people have it? How are doctors expected to deal with it when some people do not even acknowledge that it exists? How can you treat it without medicalizing people who could be healthy? Are they ill? How do you judge? I am afflicted with this condition because I do not know the answers to these questions, and yet, I must some day treat hundreds of people with this diagnosis.

I heard about fibromyalgia years before medical school. A friend complained of suffering from it when we were teenagers, while her parents were getting divorced. She did not seem sick to me, and I assumed the diagnosis was an attempt—conscious or not—to focus her parents' energy on her rather than on each other. In my mind, fibromyalgia became synonymous with seeking attention.

That opinion stuck. I cannot recall coming across the subject again, and my association of fibromyalgia with seeking attention followed me into medical school a decade later. Early in my first year, I overheard a conversation in the computer room that reinforced my suspicion. A fourth-year student was describing his elective in the Pain Clinic to a classmate. He said it was an interesting and useful experience because he had had the opportunity to treat patients that were “in a lot of pain...real pain, not ‘fibromyalgia pain.’”

That statement bothered me. I could understand what this student had meant and could relate to his cynicism with regard to fibromyalgia, but it seemed out of place. It struck me that, as professional healers, the judgment he (and I) was making was too cavalier. I felt that we were now responsible for ensuring that we did not feel or think such things without very careful consideration, to avoid harming people because of our visceral biases. That was when I became afflicted with fibromyalgia.

In my second year, I did an elective in rheumatology. On one occasion, a medical student I was working with had interviewed a woman with fibromyalgia, and our rheumatologist preceptor was discussing the patient's presentation with us. He, like the upperclassman in the computer room, was frank but pessimistic about the patient group as a whole. He told us that most of these patients were depressed and frequently had histories of trauma or abuse. Their lives were essentially ruined, and, in spite of their rheumatologic complaints, there was really nothing a rheumatologist could do for them.

Again, I felt that such an approach was too cynical and somehow inappropriate, although I could certainly understand his frustration. Most of the other conditions that we came across in rheumatology were so clear-cut: a joint was hurt, usually by deposits, inflammation, or degeneration. A drug, diet, or physiotherapy referral could minimize the deposits, inflammation, and especially the pain. Patients were grateful and could get on with being productive members of society, and doctors felt useful and fulfilled. This was not the case with the fibromyalgia patients we saw. They complained of pain that could not be explained. They were taking treatments that did not work. They seemed to want far more than we could give them.

Over the course of the year, I had the opportunity to work with several other rheumatologists and I discovered that my first preceptor's frustrations with fibromyalgia were shared by other physicians as well. I began to see how futile it was for these patients to come to rheumatology clinics expecting treatment. These patients clearly needed help, but if specialists thought there was nothing they could do for them, should I also resign myself to hopelessness?

Late in my second year, I entered into a discussion with a family physician about specialists and the relative merits of family medicine. I suggested to him what I perceived to be one possible benefit of family practice: one could always refer to specialists if unsure about a diagnosis. Specialists, however, were the end of the line. The family doctor disagreed. He explained that family physicians, unlike specialists, have the benefit of time and context. They see patients over and over and can observe the course of an illness, which often makes a difference in diagnosis. They also know and understand their patients and are, therefore, in a better position to interpret history and physical findings. For some diagnoses, family doctors are the end of the line.


A few days later, I was reminded of this conversation when I came across a qualitative study about the experience of people with fibromyalgia. In this study, participants described the effects of fibromyalgia on their lives and how they dealt with their condition, on their own and through the health care system.¹ Their comments reminded me of the family doctor's observations about diagnosis. The participants did not make any references to the role of rheumatologists; instead, family medicine was portrayed as the responsible specialty. It appeared that family doctors had usually made the initial diagnosis, and, in addition, had also advised and monitored the treatment regimens. The family physician I had spoken with described the advantage that family doctors have in the *diagnosis* of some conditions. Perhaps fibromyalgia was one of those conditions and perhaps *treatment* of fibromyalgia would also be more appropriately coordinated by family physicians. Interestingly, participants' comments about their interactions with their family doctors were almost all positive.

One study participant stated, "You need to see the same person on a regular basis; you know the doctor and the doctor knows you."¹ Since treatment of fibromyalgia is based almost entirely on lifestyle changes, this assertion made a lot of sense

to me. Another participant agreed, saying, "There is no magic medication...you are going to have to do what is necessary for you."¹ Such individualized and ongoing care would be far more appropriately managed by family physicians, rather than relatively removed specialists. In fact, the statements of these fibromyalgia patients sounded very much like the patient-centred clinical method, elaborated in the four principles of family medicine.²

The researchers also made an observation about treatment of fibromyalgia that reminded me of these principles. According to the principle of family practice as a community-based discipline, physicians must be "stewards" of the health care system and use community resources judiciously. The study researchers mentioned the tendency of health care providers to respond inappropriately to the complaints of patients with fibromyalgia by sending them for numerous unnecessary tests and treatments. They emphasized the importance of family physicians' understanding patients' illness experience, an understanding that leads to early recognition of the characteristics of chronic pain and thereby ultimately avoiding costly, futile, and potentially harmful interventions.¹

The concepts presented in this qualitative study resolved several of the issues that I had with fibromyalgia, but they were only part of my reconceptualization of this illness. While reading the accounts of these patients, I also began to feel empathy for them. This was something I had unconsciously avoided doing up to this point, because of my biases concerning fibromyalgia. The concerns that the study participants raised, such as the importance of continuing to work and be involved in the community without overdoing it, the difficulties of coping with a chronic illness, and the necessity of dealing appropriately with stress to avoid exacerbations, were all issues that I could relate to on a personal level. These people were facing the same challenges that I saw in my own life and in the lives of my friends and family.

From the day we decide to study medicine, we hear how important it is to have empathy. If you do not show empathy, your patients will not confide. If you feel contempt, your patients will naturally be distrustful of your care. On the other hand, empathy requires a degree of acceptance. I had not really tried to find common ground with these patients because of my own premature judgments of the validity of their concerns. Reading about their experiences suggested to me that I might find it in myself to develop some previously lacking, and much-needed, empathy. This embryonic empathy, together with the concept of the family physician as the specialist of choice in diagnosing and treating fibromyalgia, made me feel much more hopeful about my ability to participate effectively in the care of these patients. Where fibromyalgia had initially afflicted me, it now seemed more like a challenge, on par with any chronic illness that I would one day encounter among my future patients. 

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