

That sinking feeling

A patient-doctor dialogue about rescuing patients from fibromyalgia culture

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When your fibromyalgia patients arrive, does your heart sink? We want to show you how to understand these patients better, and make the experience of treating them more rewarding.

Who are we? I am Baraa Alghalyini, a family physician who wants to pilot an interprofessional approach to fibromyalgia management. Margaret Oldfield, a researcher, wants to share her experience of beating fibromyalgia and her insights into fibromyalgia culture. The following dialogue between us presents our different points of view:

BA: When my fibromyalgia patients walk in the door, my heart sinks.

MO: Why?

BA: Fibromyalgia is a condition characterized by multiple nonspecific symptoms. When I see a patient with vague musculoskeletal complaints, fibromyalgia is always in my differential. Once the diagnosis is made, my first obstacle is explaining the pathophysiology, natural history, and treatment options to patients in simple language, keeping in mind that we as doctors strive to find answers ourselves in order to better understand this entity.

Occasionally, patients disagree with my diagnosis and insist on seeing a specialist, despite a reassuring baseline investigatory workup. The dilemma here is to balance the use of appropriate resources, for example referrals, with patients' satisfaction.

Because I treat many patients with fibromyalgia and have a growing interest in their condition and culture, I can anticipate what they will experience: denial in the beginning; followed by diligent searching for medical or nonmedical second opinions; and eventually leading to, in most cases, inadequate compliance with recommendations—whether they relate to prescribed medication or exercise routines—from doctors and other health care team members. When this happens, I feel helpless and wonder if I should've done something else.

MO: Maybe my experience can help your patients.

BA: What do *you* do to keep fibromyalgia at bay?

MO: I exercise vigorously every second day. I do aquafit to loosen my muscles and play winter and summer

sports. I travel by bicycle, on foot, or transit. I stretch as soon as my muscles feel tense and during baths and showers. And I monitor my posture.

I get massages regularly, which not only relax me but also help me to learn where in my body I hold tension. My bed is super-comfortable, so I have restful sleeps. I try to live a low-stress life. And having my lifelong depression treated was essential. When I'm in pain, I look for causes other than fibromyalgia—like middle age. Most important, I stay away from fibromyalgia culture.

BA: It is important to understand the profile of illness behaviour in patients with fibromyalgia. Could you elaborate on the culture of fibromyalgia?

MO: It's essentially the commonalities I saw in the programs I attended, among the women I met, and in the self-help and medical literature I read. The culture's fundamental message is that fibromyalgia is incurable; the best you can hope for is to cope with it. Without hope of recovery and influenced by literature that catalogues fibromyalgia symptoms, patients obsess about the pain and compare their conditions with one another, often pathologizing common middle-age complaints. I think this is unwise. Obsessing about pain increases its intensity. If you expect a symptom, you'll get it.

Medical and self-help literature claim that fibromyalgic muscles repair slowly after exercise, so we should exercise gently; otherwise, we'll hurt 2 days later. This creates fear of any exercise that's vigorous enough to increase fitness. Although exercise programs have been shown to reduce pain in patients with fibromyalgia, patients might be reluctant to try exercising for fear of more pain.

BA: So, Margaret, what do you recommend doctors do for patients with fibromyalgia?

MO: Give them hope for recovery. By *recovery*, I mean getting better, not necessarily being cured. The latter doesn't really matter; it's feeling better that counts.

Use words like *recover* and *feel better* instead of *chronic* and *disease*. Address patients' fears and any fibromyalgia myths they've heard. Reassure them that they can get better if they follow your advice. Focus on ability rather than disability. Suggest distractions from pain. If patients don't have good social support

networks, you should refer them to social workers who can help them build these.

BA: What should doctors do for those fibromyalgia patients who were diagnosed a while ago and have immersed themselves in fibromyalgia culture?

MO: Work with these patients to create recovery plans with achievable goals. Encourage them to believe that they will get better and not simply learn to cope with their symptoms.

BA: I believe that we need to take a team approach to treating fibromyalgia. To do that we need more funding for physiotherapists and social workers, and for doctors to spend more time with patients. For starters, we need to come up with a fibromyalgia exercise prescription—a practical tool that doctors can provide to patients, especially those who can't afford uninsured health services.

MO: Great idea! It'll help if you present exercise as a fun activity that can be integrated into daily life.

BA: When patients ask us to sign disability forms, we should reconsider. Taking short-term disability leave might be necessary to allow for recovery, but going on long-term disability will make fibromyalgia worse.

MO: Right. The last thing you want is for your patients to leave the work force permanently. Working gives patients

a reason to get up each day and provides social interaction and physical activity—all of which can distract patients from symptoms. Maybe doctors can suggest patients work part-time or job-share during recovery.

BA: Doctors need to be convinced that fibromyalgia is a bona fide medical condition. When patients complain, we shouldn't dismiss their complaints as psychosomatic. We should validate our patients.

MO: That's extremely important. Patients with fibromyalgia desperately look for people who understand their symptoms. If they don't trust that their doctors believe them, they'll look for others who do; then they'll get trapped within fibromyalgia culture.

BA: Poverty is a huge barrier for some of my patients. There are cultural barriers, too. I have a patient who recently immigrated to Canada; she tells me she is always tired, headachy, and achy all over. She's expected to stay home, cook, and care for her children. Her husband works 2 shifts and, when he's home, has no time to talk to her. How can I motivate her to go to a gym or even go for a walk in a shopping mall before the stores open?

MO: You can suggest an exercise program in a neighbourhood community centre; she can meet other women she'll feel comfortable with and feel less isolated.

BA: So, in a nutshell, here's my advice for family doctors: Base your diagnosis on more than a "tender points" score; consider fibromyalgia in any patient with chronic diffuse musculoskeletal pain. Avoid burnout by collaborating with allied health team members in treating patients with fibromyalgia. This, in fact, is a very promising avenue for an interprofessional care approach to family medicine. And, choose your pharmacologic and physical interventions carefully—a "one size fits all" approach is less likely to be true in fibromyalgia.

What's your advice, Margaret?

MO: Validate patients' symptoms; then help them let go of symptoms. Try to keep your patients out of fibromyalgia culture. Work with your patients to create recovery plans; encourage and motivate them as they realize their plans. Above all, give your patients hope that they will get better.

We hope this dialogue has helped you better understand your patients with fibromyalgia and that it increases your success in treating them. Good luck! 🍁

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Competing interests
None declared

Resources

Fibromyalgia Impact Questionnaire, www.myalgia.com/FIQ/fiq.pdf

Associations

- Ontario Fibromyalgia Association, www.hwcn.org
- National Fibromyalgia Association, www.fmaware.org
- American Fibromyalgia Syndrome Association, www.afsafund.org

Further reading

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