

Fibromyalgia: The Physician's Curse?

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If you spend any time around persons with fibromyalgia (FM), sooner or later the conversation will turn to doctors. After all, for most FM patients physicians play a critical role, first in making an initial diagnosis and later in prescribing a treatment program for what is a very complex and usually frustrating medical condition. Not surprisingly, patients' comments about their medical practitioners run the gamut from enthusiastic, grateful, or respectful to defensive, angry, or incredulous.

Of course, many physicians have strong feelings about FM patients as well. I was reminded of this recently while listening to the audiotapes of two presentations given by rheumatologist Thomas Romano, M.D., Ph.D., at the National Fibromyalgia Partnership's May 2002 conference, *Fibromyalgia: Facing the Future*, in Orlando, Florida. While speaking on the topics of post-traumatic fibromyalgia and alternative medicine, Dr. Romano took time to consider common physician attitudes about fibromyalgia and the reasons for them. If you are not familiar with Dr. Romano or his work, he is one of the leading experts on post-traumatic fibromyalgia in the United States and has years of experience in treating this disorder. He is also a strong advocate for persons with fibromyalgia. For this reason, he is in a unique position to offer insights about the relationships between FM patients and their doctors as will be illustrated in this article. T.L.

Editor's Note: For logistical reasons, the pronoun "he" has used in this article when referring to doctors of both genders. No sleight or insult is intended by this pronoun usage.

Criteria For A Good Fibromyalgia Doctor

It is frequently difficult for persons with fibromyalgia to find a physician who is both experienced in FM diagnosis and treatment and willing to take the time to listen. In addition, it is often challenging for the physician to determine whether a new symptom experienced by a patient is some new manifestation of fibromyalgia or a warning of some other, potentially dangerous malady. Dr. Romano offers interesting insights:

It's important to go to somebody who knows what he's doing. Very important! Doctors are punished for practicing medicine, so good luck! If you find somebody, stick with him, work with him. If you have a disagreement, work it out. If a doctor is willing to see you, willing to work with you, is open-minded and reads the stuff from the internet that you bring in, if he is willing to be your partner in therapy, send him a present at Christmas, give him a kiss, hug him--he needs it!

It's hard to take care of you, by the way. Very hard. The practitioner has to overcome a lot of problems. One perpetuating factor is the environment in which all this treatment takes place. Furthermore, fibromyalgia can mimic other causes of pain. Just because you have FM, you can't blame everything on it.

For example, here is an absolutely true story. I went to see a patient of mine who was admitted to the hospital to have an emergency appendectomy. She had been having pain for a week or so before the operation. Her appendix burst; she became hypotensive; she almost died. So I asked her why it took her so long to get to the hospital. She said: Because it hurt like everything else hurt. Interesting!

You could have other stuff, so don't blame everything on FM. Please be aware that your chest pain may be fibromyalgia; it may not be. You have to get this stuff checked out!

I don't know if you realize this, but doctors are taught how to make mistakes. Of course, they don't want to make mistakes, but if they're going to make them, there's a way to do it. There are two kinds of mistakes that can be made: a Type 1 or Alpha error or a Type 2 or Beta error (these are statistical terms).

A Type 1-Alpha error means you assume something is present, but it's not. An example: chest pain. You go to the emergency room. They strap you down, put a heart monitor on you, put an IV in you, give you nitro under the tongue, and they assume it's a heart attack. It's important that they assume it's a heart attack because if it's a heart attack, you could die. So they monitor you, admit you to the hospital, and two days later, the doctor comes in and says: Luckily it wasn't your heart, it's something else. It could be indigestion; it could be

musculoskeletal, whatever. But that stuff isn't going to kill you. So it's important that doctors make Alpha errors. We check and make sure you don't have the worst thing, and then we can always take our time figuring out what's really going on.

The Beta errors, which we don't want to make, assume something is not there, but it is. An example of a Beta error...Do you know an actress by the name of Heather O'Rourke? Did you ever see Poltergeist? She was the little blonde girl who says, 'They're here!' Well, she's dead. She died because of a Beta error. Her mother took her to the ER, and the doctor diagnosed her as having the flu or something. Well, she ended up having a perforated viscus. I don't know whether it was appendix or some other part of the intestine, but it perforated, and she died.

When I learned medicine, we were told that if you have abdominal pain, you should be admitted for observation unless you know the reason for it. If it's a kidney stone, or if it's stuff that you've had before, and you pretty much know the pattern, that's fine. But if you have really bad abdominal pain, you should be observed. If not there can be Beta errors, and Beta errors can be fatal!

Fibromyalgia Is Not A "Real" Illness

One of the more frustrating situations that FM patients encounter is physicians who refuse to treat fibromyalgia because they believe it is a poorly defined or non-existent medical condition. Dr. Romano had this to say about an encounter he had with such a physician:

I was giving a talk on fibromyalgia, and a neurologist in the front row started giving me a hard time saying: The complaints (of patients) are all subjective; we don't have any tests for it.

So I said, you're a neurologist, right? (Yes.) How many migraine patients do you see in a week? (We see a lot of them, 30-40 in a week.) I said, okay, what's the test for migraines? There is no test for migraines. I then said to him: Apply the criteria that you applied to me to your practice. If you applied those criteria, you'd have to go out of business. You'd have to close your doors and say: We don't have a test for migraine; I can't believe you have a migraine. There's no test for it. So go home.

That's not right! It's okay for them to treat migraines...Neurologists know migraine headaches with a characteristic pattern: an aura, photophobia, having

to be in a dark room, etc., and they treat them with medications. BUT, they will not give the fibromyalgia patient the same courtesy. That's wrong!

Why Doesn't My Doctor Listen To Me?

Perhaps the most common complaint voiced by people with fibromyalgia is that they get the fast shuffle in doctors' offices. Physicians hurry through a consultation, are unwilling to read the articles or notes that a patient has prepared, and are impatient to be finished with an appointment. Dr. Romano points out that many physicians, particularly those affiliated with managed care, work under very frustrating conditions:

When you were a little kid, if you brought your report card home to your mom and there were a lot of 'A's' on it, and you got punished, how many times would you bring home 'A's'? ...It seems that the doctors who are the most compassionate and spend the most time are the most punished by managed care. I gave a talk a long, long time ago at the American College of Rheumatology's Annual Meeting, as a poster presentation. The word 'fibromyalgia' was in the title. One of the rheumatologists from Georgia (I forget what part of Georgia) came over and pointed to the word 'fibromyalgia' and said: I hate those patients!

This was seven or eight years ago. I asked him how he could hate his patients. That's crazy! He responded:

"They've got all those problems. Everything's bothering them. They have headaches and musculoskeletal pain. They're tired and fatigued. I hate them! They take so much time!"

So I said to him, if you could spend as much time as you wanted with them in gathering their symptoms and getting their complaints and examining them, and they could spend as much time as they wanted and feel satisfied from the encounter, and you got paid fairly for your time, would you hate those patients? (No) I said, well, you don't hate the patients; you have a problem with the conditions under which you are seeing them.

This is an important point. I think that part of the problem that we have here in America is that reimbursement is an issue, and doctors will not see you if it means going bankrupt...So if you bring internet stuff, books, and book chapters to your doctor, and he takes the time to read them and ends up losing money, he may not do it. It's impractical to ask someone to be punished by doing certain things. We are very simple organisms in the sense that we avoid pain, and we tend to want to go towards pleasure. If it's painful, eventually we'll stop doing it.

I hate to be mundane and pedestrian about this, but I have a private practice. I own a business. I have to be able to pay my staff. I have to be able to earn a living. I believe I charge fairly for my time, and because I don't deal with managed care, nobody punishes me. I take care of patients the way I want to. I find that incredibly liberating.

On the other hand, if you go to a health care provider who is under contract with managed care organizations or whatever, believe me, he will not be paid adequately to evaluate you and do a good exam. A previous speaker talked about using a pressure algometer which is a dolorimeter to test for tender points. No one is going to do this. It takes too much time, and it's not reimbursable. You cannot run an office that way. You'll be driven crazy.

Managed care is your enemy, in my opinion--one man's opinion, and I am entitled to it. If your doctor is told he can see you for 15 minutes once every three or four months, and that's it, and he has to fight to get paid to see you, how desirable are you as a patient? Seriously, he'd much rather see someone with a swollen knee. He takes the fluid out and gives you a shot. (Hey, doc, I feel better! See you in six months!) Believe me, from a physician's point of view--much easier!

...There has to be a reward whether it be the personal satisfaction of seeing someone get better, whether it be financial, whatever. There's got to be some reward for doing a certain action. In our society now, the most compassionate doctors are leaving medicine. I'm seeing it in my community. They can't take it any more. They're overwhelmed with paperwork!

My Doctor Simply Isn't Interested In Fibromyalgia And Could Care Less About Learning More About It

When all of the possible mitigating factors have been ruled out, there are still physicians who just don't believe that fibromyalgia exists. Showing him/her all of the research articles in the world would make no difference. Dr. Romano comments on this phenomenon:

Why don't some doctors diagnose this or appreciate this? Well, maybe they don't keep up or are skeptical. If you're a busy family practitioner in a small town as the only doctor, you'll go crazy trying to figure this out in addition to everything else.

Unfortunately, some people are close-minded. They are. There are close-minded lawyers, close-minded doctors, close-minded butchers, and close-minded bus

drivers. It's not unique to doctors, and it's not unique to patients. Some people are just close-minded.

Remember Max Planck? Max was cool. For those of you who don't know who Max was, he's the physicist who basically invented quantum mechanics. When he first came out with his idea of quantum physics, people said, 'Ah, you're full of it; this is ridiculous. We don't believe you.' He was absolutely right, of course. What he said was that an important scientific innovation rarely makes its way by gradually winning over and converting its opponents. What does happen is that its opponents gradually die out, and the growing generation is familiar with the idea from the beginning. That's usually what happens.

There are some doctors who still don't believe that fibromyalgia exists. Okay, fine. What can you say? There's been literature about this for 20 years now. There was before, but during the last 20 years there has been an explosion of literature regarding this condition. What are you going to do?

What Is The Definition Of A Good Doctor?

When everything is said and done, what should a fibromyalgia patient look for in a doctor? We close with this advice from Dr. Romano:

A good doctor should have a falcon's eye, a girl's hand, and a lion's heart. You have to find a doctor who is going to fight for you. I'm not kidding. In today's health care climate, they have to fight for you. He has to be your advocate (not in court, that's your lawyer's job) but in terms of presenting to you the best medical treatment that he can think of for your treatment.

Dr. Romano is currently in private practice in Martin's Ferry, Ohio. In addition to the material covered in this article, you will find helpful information on post-traumatic fibromyalgia and alternative medicine in the two audiotapes of his Orlando presentations which were referenced in this article: "Post-Traumatic Fibromyalgia: The Scope of the Problem and Practical Solutions," and "Perpetuating Factors in Fibromyalgia: How Alternative Is Alternative Therapy?" Both of these audiotapes are available for purchase in the Online Store of the National Fibromyalgia (NFP) at: www.fmpartnership.org or from the NFP's regular catalog. Write: NFP, P.O. Box 160, Linden, VA 22642-0160.