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When Pain Remains

What should patients do when doctors can't figure out how to treat their suffering?

Q. & A.

The Big Hurt

This week in the magazine, Jerome Groopman writes about reflex sympathetic dystrophy, a type of intense chronic pain, and how a better understanding of R.S.D. might help to explain certain fundamental aspects of the nervous system. Here, with Ben Greenman, he discusses the topic.

BEN GREENMAN: What first interested you in R.S.D.?

JEROME GROOPMAN: Several people I know developed it, and they saw a number of physicians until the correct diagnosis was made. Along the way, they were given a lot of misinformation and misdiagnoses. I became intrigued. I didn't know much about it myself. And, the more I looked into it, the more I realized that it was important. It was not that rare a condition. And thinking about pain in this new way had the potential to give us a window into a new understanding of the central nervous system.

How much is known about pain in general? In medicine, obviously, it's managed all the time, for surgical procedures and terminal illnesses and everything in between. But pain itself seems poorly understood. Why is one of the most common conditions also one of the most elusive?

I think that, in classic medical education, pain has either been overlooked or disliked. It's the kind of situation that is often very frustrating to doctors. The therapies are not easy or pleasing. Until recently, it did not have its own specialty. In the past, physicians would just write a prescription for a narcotic and hope that the patient found enough relief not to come back and bother them. A lot of the patients in my article, the ones suffering from R.S.D., would have entered a medical purgatory, where they were largely shunned by the medical establishment. More recently, two things have happened. There's been increased understanding of the biology of pain, and I talk about that in the article. Also, there are very committed physicians who believe that this is an important clinical issue, and they have begun to devote themselves to the care of these patients.

One of the things about pain that you mention in the article, and that people intuitively understand, is that it's subjective. When you take a history of a patient's pain, you have an essentially subjective complaint. Thresholds are different, and there aren't always visible or measurable symptoms—although, in R.S.D., there is skin-temperature increase and inflammation. The subjectivity of pain must be something that thwarts and frustrates physicians.

I just got off the phone with a close friend who fell yesterday and smashed her arm. Luckily, nothing's broken, but she has an extraordinary pain threshold. She does not take Novocain when she goes to the dentist, and it's not because she's a masochist; it just doesn't bother her that much.

So is that the kind of person who might, in theory, have a low-lying case of chronic pain?

Well, there are some pains that wouldn't register with her. But I think that what's interesting about R.S.D.—and what distinguishes it from any other pain syndromes—is that it can affect anyone. It's not predicted based on people's prior pain thresholds. For example, the woman who is the main figure in this week's piece, whom I call Barbara, is someone who's very athletic and active. She doesn't have the "classic pain personality," which physicians have portrayed in the literature: people who don't want to work, people who are not motivated, people who are terrible complainers, people who have a little bump and think it's the end of the world. This is a woman who has been thrown from a horse, fallen down a flight of stairs, torn her hamstring, and hardly complained about any of her injuries. Then R.S.D. came along and affected her the same way it affects everyone—it's debilitating. So the mystery of this is that the psychological predisposition to reacting to pain doesn't seem to be determinative.

Can you explain the difference between adaptive and maladaptive pain?

Adaptive pain is pain that assists the body in healing or protects the body. So, classically, you'll withdraw your hand from a flame, or you'll have surgery and the area will become inflamed and swollen and painful, and you'll be forced to rest it, so that healing can occur. It's either protective or it fosters the natural healing process. Maladaptive pain—and R.S.D. is a severe version of it—is essentially a neurological disease. You develop circuits in the spinal cord and in the brain which are signalling continual pain, despite the fact that there is no painful stimulus. Or you develop circuits in the spinal cord and in the brain in which peripheral nerves—nerves from your fingers or feet or legs, which normally carry innocuous or even pleasant sensations, like a breeze fluttering or a soft touch—now send signals that are interpreted in the brain as being painful. That's maladaptive. It gives no benefit to you, and actually is extremely destructive.

What are the effects of defining something like R.S.D. as a disease, as a neurological condition in which signals are crossed or distorted?

By focussing on the authentic biology and casting it as a neurological disease, it takes away the negative stigma and elicits not only sympathy but concentrated clinical attention.

The cases cited in the article seem to involve truly excruciating pain. One woman who was a friend of Barbara's has committed suicide, and Barbara admits that she has considered it. If someone is afflicted with R.S.D. in a foot, would amputating the foot help?

The stump would still be excruciatingly painful.

So the pain remains whether or not the limb does?

Correct.

And the effect seems to be to drive people out of their minds, and out of their lives.

That's exactly what it does. The only analogy that I can think of is being under constant torture. For people who were in concentration camps or at prisons under Saddam—those kinds of places where every day you are subjected to excruciating pain, with no guarantee that it is ever going to be alleviated—their lives would have become empty, and not only empty but torture.

Traditionally, as you say, pain has been treated with narcotics, and there are often side effects—addiction to painkillers being the most obvious. As you point out in the piece, therapies like nerve blocks are used to treat R.S.D. as it becomes better understood. Are there also cases where old, blunt, and not so efficient therapies are being abused? Or, for that matter, are there crank therapies?

It's interesting. These people generally don't have a very high addiction problem, because they don't have what's called an "addictive personality." They have terrible pain, and they use their medicines very judiciously. In fact, a lot of them don't even want to use their medicines, because they don't like the side effects. So they're not psychologically predisposed to addiction. I think there is still a tremendous need for better therapies. As the biology has become better understood, there are drugs emerging that target specific neurotransmitters, specific channels, and so on, which can help these people. The more extreme interventions, with nerve stimulators, for example, are a relatively recent development—in some cases the results are tremendous, and in others the technique doesn't succeed. I haven't seen a lot of crank therapies, because there is not much placebo effect here. You tend to see crank therapies proliferate where the placebo effect is profound. But the kind of pain that these patients are having is not amenable to suggestion or emotional state.

Do you have any sense of how common something like R.S.D. is? There seem to be diseases that crop up more and more often—because of the way people live now, or because of environmental conditions. Carpal tunnel is one. Is there any sense of whether R.S.D. belongs in this category?

I wrote a piece for The New Yorker a while ago about fibromyalgia, and how, historically, there have been poorly understood pain syndromes that were related to the introduction of new technology. For example, there was something called railway spine, chronic and disabling injuries sustained as a result of minor railway accidents, often, when railroads were first introduced, in the nineteenth century, and clearly that's gone. This is different. To me, it was fascinating to trace this back to the Civil War. And I'm sure it antedated that as well. This doesn't, to my knowledge, have any cultural or sociological overlay.

So this has probably existed with the same prevalence as long as there have been people but has only recently been better classified and understood?

That's right. And I think there are large numbers of people who aren't diagnosed. Some of them are fortunate, because in the acute setting, in the initial setting, if you can tolerate the pain to some degree and keep functioning, the nervous system may be able to rewire itself. Other people, unfortunately, who are not diagnosed, who have chronic R.S.D., just go from pillar to post, basically, and suffer terribly.

As this particular syndrome is better understood, is it likely that the medical community will develop a deeper understanding of larger neurological issues?

If you're asking whether more attention to this will lead to a proliferation of diagnoses, what distinguishes this from other pain syndromes is that there are objective findings. If you look at the limb of a person with R.S.D., it's not as though someone has carpal tunnel or someone has railway spine and they're complaining of pain and there are no objective clinical findings. Here, there are really impressive and bizarre clinical findings. You touch the person with cotton and they're on the ceiling. I hope that one of the consequences of the article will be that people who have this will realize they have it, and physicians like myself, and even specialists who were never formally schooled in this, will be more alert to it. It'll be on the radar screen, so that patients can be referred to get help by specialists, and also so that the research that's done on this condition may lead to better treatments.