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Inside medicine: Look at the whole patient

By Dr. Michael Wilkes -

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Disease and illness are not the same thing.

Susan, a 56-year-old nurse, suffers from diffuse body pains. She's no longer able to work and has been unable to play her beloved violin for months. At first, her doctor had hunches about the cause of her symptoms and, over the course of many visits, tried hard to diagnose the problem.

She feels like she's had nearly every medical test possible to the tune of tens of thousands of dollars. But she's still in pain and doctors aren't quite sure why. Perhaps worse than the disabling physical pain is Susan's realization that the more difficulty doctors have had diagnosing her pain, the less they seem to care about her.

In medical school, we teach students to focus on disease -- disturbances in the structure or function of the body -- in other words, a body part or organ system. Medical students memorize anatomical parts, chemical pathways and laboratory normal values -- all of which can be helpful in diagnosing disease.

But, we don't do well teaching doctors to acknowledge the person who has the disease. It is a bit like trying to understand why your tomatoes won't grow by carefully studying the seeds but failing to appreciate the importance of the soil and the environment.

Biology and disease are only part of the story. The other important part, often ignored, is illness -- the subjective feeling of being unwell, often without a biochemical explanation. To understand Susan's disease is to understand some laboratory abnormalities. But to understand her illness is to take the time to know how her life has been impacted by the pain, how she understands the pain, and then being able to anticipate the depression she has slowly slipped into.

Body symptoms -- say severe pain -- can have different meanings and can lead to different degrees of illness and suffering, depending on the context. Pain from cancer can lead to considerable illness that, in part, comes from knowing the cause of the pain is life-threatening and that it will likely continue.

However, the same severity of pain due to, say, childbirth is not usually perceived as an illness. It has a clear endpoint and has a positive outcome (a baby).

Doctors, including psychiatrists, have found no explanation for Susan's pain; and, in the absence of a clear explanation, some think she's fabricating her pain. But they have not suggested she explore other approaches or clinicians who may have something to offer, particularly alternative providers such as acupuncturists or Chinese physicians. Instead, her doctors ignore her and her phone calls, which only leads her to feel angry and rejected.

Her doctors are not callous or uncaring, they just are at the end of their diagnostic ability. They are frustrated they can't help, but they don't have the courage to tell this to Susan.

Caring for illness isn't easy; it takes time, patience, and perhaps a larger community of experts than just medical doctors.

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Phone: (916) 321-1000

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