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"Functional disorders": one of medicine's biggest failures

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About a third of patients attending neurological and gastrointestinal, or almost every outpatient clinic—have functional disorders, meaning that they do not have a physical cause that can be detected with a microscope, scanners, or blood or genetic tests. These are patients whom medicine has failed more than almost any other group.

I've been reading Suzanne O'Sullivan's *The Sleeping Beauties: And Other Stories of Mystery Illness*, a book that was recommended by a doctor colleague because it had had a big impact on him. It's now had a big impact on me and probably will on you if you read it. O'Sullivan is a Queen Square neurologist who specialises in functional disorders and a gifted writer who is acutely aware of the limitations of her medical craft. Her book tells the stories of outbreaks of mass psychogenic illness, including the young asylum seekers in Sweden who have been "asleep" for years, the American diplomats in Havana and Beijing suffering symptoms attributed to a sonic bomb weapon, and several others. The stories make excellent reading, but the value of the book to doctors is that it can benefit their practice and deepen their understanding of medicine.

Language, as always, is part of the problem. Functional disorder is perhaps the best term for these conditions, but psychosomatic, psychogenic, conversion disorder, and in the past hysteria have all been used. Hysteria, with its association with women, is clearly unacceptable, and the prefix "psycho" is unhelpful. As O'Sullivan writes "Every medical problem is a combination of the biological, the psychological, and the social. It is only the weighting of each that changes." Medicine was cursed when René Descartes divided the mind from the body.

Almost any symptom, perhaps every symptom, can result from functional disorder. O'Sullivan lists paralysis, blindness, headache, dizziness, coma, tremor, skin rashes, breathlessness, chest pain, palpitations, bladder problems, diarrhoea, stomach cramps, and so on and on. I might add fatigue, abdominal pain, diarrhoea, cough, backache, pain in any part of the body, and a gamut of symptoms that have no known physical cause.

We are all aware that mental activity or emotion can cause bodily symptoms like tears and blushing, but most of us find it hard to accept that mental activity could cause something as extreme as a coma, fits, or blindness. If no physical cause can be found then people are tempted to think that the symptoms are "not real," "all in the mind," or that the patient is faking them. These are serious mistakes to make: the symptoms are as "real" as with any physical cause and just as severe; they are not "all in the mind" because the body is clearly affected and the division between mind and body is not helpful; and there is no fakery. It's also a mistake, writes O'Sullivan, to attribute them to "stress."

Our understanding of how people develop these symptoms is poor, but the starting point is distress of some kind. "Embodied cognition" is the theory that sensory and motor systems are integrated with cognitive processing. As O'Sullivan writes: "The body is awash with white noise, so symptoms can always be found if a person looks hard enough." "Looking hard," implies a conscious action, which is probably not what she intended. Those symptoms are then linked with illnesses, even diseases, we know about. "Illness is a socially patterned behaviour, far more than people realise," writes O'Sullivan, "How a person interprets and reacts to bodily changes depends on trends within society, their knowledge, their education, their access to information and their past experience of disease." Modern medicine offers an increasing range of diseases for people to unconsciously connect with.

The philosopher Ian Hacking has described a phenomenon he calls "Making up people." New classifications "bring into being a new kind of person" who have the classification attached to them or attach it to themselves. Their symptoms may then be added to the new classification, changing, and expanding it. "The classification changes the person, who in turn changes the features of the classification," which has been called "the looping effect."

Past experiences can be important in developing functional disorders. O'Sullivan uses the example of patients who have lost their voices after a severe bout of laryngitis. The next time the patients develop sore throats, perhaps milder ones, the prior experience may lead to the patients losing their voices again. "The top-down priors overwhelm the sensory input."

Our understanding is, it seems to me, limited, and the theories and mechanisms that O'Sullivan discusses are unfamiliar to most doctors.

Just as culture dictates how we try to make sense of symptoms it also dictates how we respond. Our usual response is to see a doctor, and the doctors feel obliged to exclude physical disease. The patient undergoes a barrage of tests, and some of those tests may suggest something wrong both because of false positives and because "normal" is often defined as being within two standard deviations of the mean, which means 5% of results will be "abnormal" by mathematical definition. Patients are understandably made anxious by tests that suggest that something may be wrong, and more tests are needed to exclude disease, giving further opportunities for misleading results. Many patients will conclude that "Something must be seriously wrong if the doctors are doing all these tests."

The patients may then begin the merry-go-round of specialists. Only the crass will say "there is nothing wrong with you" because the patient clearly has something wrong. Indeed, after all the tests and anxiety he or she may be feeling worse. When no physical cause is found the patients may be referred to psychiatrists, with at least the implication that the patients have a psychological problem. Because of the stigma unjustly attached to psychological problems this can cause distress and offence and is anyway to fall into the trap of thinking the physical and psychological separate.

O'Sullivan worries about this: "Like many Western doctors, I medicalise feelings and behaviour. People come to me so that I will do that for them—give them a medical explanation for their suffering—but, in truth, I worry all the time that what I'm doing, faithful as it is to my training and welcome as it may be to my patients, is wrong and potentially harmful."

O'Sullivan finds herself attracted to some of the conditions that western medicine calls mass psychogenic illness. Grisi siknis occurs only among the Miskito, an indigenous people from the coast of Nicaragua and Honduras. The sickness begins with mild symptoms but progresses to irrational behaviour, convulsions, and hallucinations. Patients, who are mostly young and female, see a dark figure that they know to be the devil.

The condition does not attract blame but rather community support, and it usually passes. O'Sullivan writes: "I found a great deal in grisi siknis that I could admire. It can be a very effective culturally agreed means of expressing distress. It is an acceptable way to exteriorize and deal with personal and social conflict. It is also a useful one, because it comes without blame. The demon infiltrator presents an external cause that removes the focus from the individual. It also provides something at which to aim treatment."

She draws a contrast with people with functional disorders exposed to modern medicine. Not only must they undergo many tests and pick up "diagnoses" along the way but they may also become permanent patients. Worse still, the patients may find themselves in battles with the medical establishment.

People recover from functional disorders, but treatment is difficult. Doctors and patients in conflict is the worst outcome for everybody. O'Sullivan concludes her book by emphasising the role of community: "I also learned that the best chance of recovery comes when you surround yourself with a community that allows patients and their doctors to find that common ground. A community that can listen without judgement. A community that provides support. A community that can tolerate imperfection and failure, and which has the humility to put aside its vested interests. A community that is able to take a holistic view of health."

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