

Issues

How I stopped worrying and learnt to love the bomb!

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We all have them: patients with symptoms suggesting disease, but who have no diagnosis to explain their ill health.

About a quarter of rheumatology referrals are for aches and pains, fatigue and tiredness that defies clinical and laboratory investigation for rheumatic disease.

In response to this situation you can diagnose arthritis (cervical and lumbar spondylosis, subclinical lupus or some such), send them on an expensive and invasive series of investigations you know will not lead anywhere and then, your job done, tell them to go away because there is nothing wrong.

Rheumatologists have invented the term fibromyalgia syndrome to describe this group. What does it represent?

Fibromyalgia is a common response to stress. Most have experienced the symptoms when overloaded with the pressures of life. Usually there are several factors operating, some beyond our control. Work-related stress, a failing relationship, bereavement, money problems, trouble with the law, physical or emotional trauma. The result is poor sleep, physical symptoms of anxiety and tiredness. Fortunately we can usually identify the sources of our distress and do something about it; get out and get fit, pass the exam, wait for time to heal our grief.

Patients with fibromyalgia are unable to sort out their problems and regain their health. They are demanding and emotionally draining, but why? They stress us because they make demands we cannot answer.

Cognitive behavioural theory holds that it is not the situation that is stressful, it is what we tell ourselves about it that produces the stress reaction. How does this approach relate to dealing with patients with medically unexplained illness?

Most patients come to us to try and make sense of their experience and as doctors we feel charged with alleviating their distress. Sometimes this means making a diagnosis and offering remedial treatment to correct dysfunction. Sometimes, there is no medical disease and we are left feeling helpless. We become stressed because we don't

understand what is going on and do not know how to proceed. Our power is threatened and we react with hostility and rejection; unacceptable feelings to express in the doctor-patient relationship.

Our medical training does not help us deal with 25 per cent of our patients!

Perhaps if we changed the way we thought about them we might not find it so stressful?

Suffering without disease

Conventional teaching informs that symptoms are rooted in disease or injury. If there is no disease, there can be no symptoms, so the patient is either mad or malingering. Our stress response may come from the belief that the patient does not deserve our attention and care, or the health dollars.

A popular idea is that fibromyalgia does not exist.

This is correct in the sense that it is not a disease with a definable pathological basis. But that people with "non-disease illness" are in distress and experience disability in relation to role fulfilment and social disadvantage is undeniable. Doctors are charged with alleviating suffering and distress in the community they serve, and cannot hide behind the idea that because we can't define the pathology we have no responsibility toward the people who come to us for help. Can an alternative model of health, disease and illness help us to understand our patients and alleviate our stress and emotional drain?

This is my prescription for dealing with medically unexplained illness:

Change the doctor-patient relationship. Treat them as "adult" not "child", no matter how they seek to put you in the "parent" role. This is what "shifting the locus of control" means. It is about who takes responsibility for the patient's suffering. Let go of the idea you can explain and fix everything and the self-demand that your patient must not be distressed. This releases you from responsibility for things beyond your control.

Understand the mind-body connection. Science is catching up with the human experience and will be able to explain psychoneurohumoral phenomena. Meanwhile, adopt a metaphysical philosophy that acknowledges that to be healthy we need a balance in mind, body and spirit; that loss of wellbeing in one disturbs the others; that to be ill you do not have to have disease.

Examine your own beliefs and attitudes to health, illness and disease. Maybe they are the reason you are stressed. Where did those ideas come from? What is the evidence they are true? Are there issues you have not resolved that prevent you dealing with your patients?

Get help. Link with other health professionals: nurse, counsellor, occupational therapist, physiotherapist, to help educate and encourage the patient in self- management.

Share ideas with your team about concepts of health. Recognise that this is a journey for all of you.

Do not forget to be the doctor. Holistic medicine can go too far; people with functional illness can develop disease and they will not forgive you for missing it.