



Reflections

A disability paradox

Merete Jørgensen, MD

As a GP for many years in Copenhagen, Denmark, I have met a lot of different patients. I am amazed by how well some patients cope with enormous strain, while others seem unable to cope at all. When it comes to chronic illness, this disparity is even more evident. Why do some patients continue life as if nothing has happened, while others find their whole life collapsing? Why do some patients with a severe chronic disease not consider themselves to be ill? Is it an inborn talent? Is it influenced by upbringing and social circumstances? Can we as doctors learn something from these patients that will help others to cope with chronic diseases?

Can GPs make a difference?

As doctors we are used to focusing on loss and disability. Could shifting focus to things that patients still *can* do help them to restructure a life with chronic disease? I am not talking about deadly diseases, where the situation is quite different, but patients you see every day in your clinic with chronic diseases and disabilities.

Can patients gain from having chronic diseases?

One of my patients, a 47-year-old single father, says: "There is one good thing about my getting a pension. I know I have a bad heart and I know it is serious, but if I move around slowly I do not feel ill at all, and I have the opportunity to be here when my son comes home from school." Why

does he not feel ill? I would if I were in his shoes. Do symptoms alone mean illness to him, more than the possibility of having a heart transplant? Or does he just live from one moment to the next? Perhaps he denies the whole situation. As I have known him for many years, I do not find denial a likely explanation.

Can chronic disease mean relief?

Another patient, an 80-year-old woman, suffers from postpolio syndrome. I have known her for 20 years. As we discussed the trouble she had moving around, she explained: "Well, I love to read books and watch television. Now I have a good excuse for staying at home and doing that. My children used to press me to leave the house. 'It is good for you to come out of the house,' they would say. But now I tell them I cannot; I have got a syndrome! Am I ill? Not at all."

Are you ill if you have a chronic disease?

A 52-year-old woman with rheumatoid arthritis had more or less the same answer. "Ill? Me? No, I am just not perfect." I would have considered her ill, with her severe pain and stiff joints.

Are you afraid of the future?

A 60-year-old woman suffered from severe osteoarthritis. From my point of view she had annoying symptoms but nothing to be afraid of. She burst into tears

when I asked why it worried her so much. She had seen a lot of people her age in wheelchairs and she was sure she would end up like that. This was something that I, with my medical background, found unlikely and would not have worried about. Once I had explained this to her, she accepted the situation and decided that she could certainly have been suffering from a much more serious disease.

Can you believe the doctor?

Lower back pain can be a nuisance for busy women, but it is even more troubling when medical explanations do not coincide with patients' perception of the problem. "I know what I feel; it is *my* body. I do not believe the doctors when they say the pain comes from my pelvis; I can feel it comes from my spine." Who knows best? In this case, it turned out that she was right. She had a herniated disk. Mutual understanding is necessary and important.

What can doctors do?


Many things influence the way people perceive chronic disease. Some we probably cannot change. But we could try to explore patients' perspectives of disease. We can ask questions. Do they understand the nature of the disease, or do they not want to? Is it important to them to understand? Do they feel that they control the disease themselves, or do they trust the doctor to take care of them? What feelings does the disease arouse in them? Anger, sadness, incompetence, loss of self-respect, dependence, humility? Or do they simply fear complications, the future, and impending disabilities? If their job is the most important aspect of their life, are they afraid of losing it? A marathon runner who

cannot run any more will feel much more disabled by a chronic leg injury than an 80-year-old man who would not dream of running.

Are we listening?

Another patient of mine, a 27-year-old man suffering from epilepsy, told me: "They never listened to what I said. I tried so hard to make them understand what I really felt having epilepsy—what it meant to me. They just said 'take more pills,' while I tried to tell them pills did not help. I had the cramps anyhow." It is important to meet the human person behind the patient and ask what the disease means to that person. Could my patient find a way to live the life of a young man with untreatable cramps? Or could he learn to avoid situations that provoke fits? What can we, as doctors, do to help him? And are we listening to him?

So what now?

A patient-centred approach brings us a long way toward helping patients restructure their lives around chronic disease. But there is still something to be sorted out. Why do some patients with severe chronic disease perceive themselves to be healthy, when I, as a doctor, find them to be ill? It is really a disability paradox. What can we learn from them that could help other patients? 

Dr Jørgenson is a general practitioner and an Associate Teaching Professor in the Department of General Practice at the University of Copenhagen in Denmark.

References

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