

Disability or symptoms, which comes first?

Once Charles suggested to me that specialists might be defined by the symptoms with which they deal rather than the organs. The idea seemed particularly appropriate where severe symptoms and disability occur where the underlying disease appears to be mild. I read that the Prime Minister has concerns about rising numbers on incapacity benefit. It seemed an opportune moment to resurrect the suggestion with Charles.

‘You remember when we were talking a little while ago you invented the “*symptomologist*”?’

I was fascinated when he interjected, ‘Yes, but on reflection I thought he might be better called a “*disabilitologist*”, indicating that his expertise lies in the assessment of all the mechanisms of disability and its interaction with symptoms, rather than just symptoms.’

‘Rehabilitation experts do exist,’ I suggested.

‘Yes, but most are concerned with mechanical disability.’

‘By no means always,’ I replied. ‘But I do feel that they are sometimes too concerned with late and severe disease and not enough with mild early disability before it is too late to do much good.’

‘Thinking of the early stages: what comes first, symptoms or disability?’

‘One would think that they start and get worse together,’ I replied.

‘That is only true if the impairment is the direct cause of the disability,’ he said.

‘But surely someone who has heart failure and feels tired and weak when he tries to walk has symptoms. Both symptoms and disability reflect the impairment.’

‘Yes, that’s true,’ he said, ‘but what about angina?’

‘In an otherwise fit person, symptom threshold and the amount of vessel disease, the impairment, are fairly well correlated,’ I replied.

‘But is that always so?’ he questioned.

‘Such things as coronary artery spasm may complicate things.’

‘That’s not what I was getting at. Surely some people will stop sooner than others for the same degree of pain.’

‘Yes that’s true,’ I said, ‘and early on disability may depend on whether the person is prepared to “walk through” his angina.’

‘In that case it is the perception of the symptom rather than the underlying disease that determines the level of disability. From what you have told me in the past, with breathlessness, the relationship with the underlying disease may be extremely weak. That suggests to me that it is the symptom of the impairment rather than the impairment itself that causes the disability.’

‘Yes, certainly I do think you have got a point there. Dyspnoea reflects the effort perceived to be necessary to maintain respiration and even allowing for such things as covert wheeze, functional air trapping and stiffness of the chest wall, symptoms may quite disproportionate to the underlying impairment.’

‘That doesn’t surprise me,’ he said. ‘Indeed, I am surprised that most people are not breathless most of the time.’

‘Why?’ I asked.

‘Isn’t it the case that breathing is primarily a mechanical feedback process and both elements of the mechanism, merely modulated by changes in blood gases and acidity?’

‘Certainly, it is true that breath-holding time cannot possibly be explained by metabolic changes. In most people it is less than the circulation time and much shorter in expiration.’

‘Aren’t sensation in the chest wall and movement of muscles of respiration potentially at conscious level? So it isn’t surprising that slight disturbance on the sensory side might cause disproportionate dyspnoea in at least some people with minimal disease. How is it rather than being breathless the whole time, we suppress awareness of respiration for 99.9% of our lives?’

'Ultimately very difficult to explain,' I conceded, adding: 'Indeed sometimes people are severely disabled when there is no structural disease at all and the process is entirely functional.'

'I thought that most doctors thought that functional dyspnoea was hysterical hyperventilation and therefore regard it lightly,' he replied.

'Yes,' I said, 'but paradoxically when there is cardiac or respiratory impairment they regard breathlessness as a very organic symptom. I have been long concerned that both are over-simplifications.'

'The symptomatologist or disabilitologist might be much better at determining when the critical impairment was the symptom itself and when it was due to the underlying organic disease. He would appreciate the danger of an increase in disability arising solely from a vicious circle of increased disability and increased symptoms, without any deterioration in the underlying organic impairment.'

'That is true,' I said.

'He would also be in a better position to understand that if the perception of symptoms varies from individual to individual then the disability caused by any particular level of organic

impairment would also vary from individual to individual. Whilst I am not suggesting that there is no such thing as a malingerer or someone with what used to be called poor moral fibre, no one can be certain of another person's appreciation of symptoms.'

'Agreed. There are layabouts and wimps but do not judge hastily whom they are!'

'Be that as it may, the perception of severity of impairment is more important than the actual severity.'

'Yes, I am sure a subtle change of approach, recognising this more readily, would substantially reduce much unnecessary disability, which is wrongly attributed directly to mild cardiac, respiratory or musculoskeletal disease.'

'Rather than rehabilitation, *habilitation*! "Habilitation" is the old word for the provision of initial capital in the mining industry. Shouldn't we provide capital resources from the start to enable those developing chronic illness to continue to lead full lives?'

Surely the cost implications are horrendous, or are they, Prime Minister? Good fuel for another conversation!

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