Missing the meaning and provoking resistance; a case of myalgic encephalomyelitis

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**Background.** The interaction between a clinician and a patient who put his problems down to myalgic encephalomyelitis is described. Despite attempting a patient-centred approach, the doctor acted on his own understanding of the meaning of this diagnosis without gaining proper insight into what it meant for the patient. This failure not only led to damaged rapport, it may have contributed to delayed recovery.

**Objectives.** The unsatisfactory nature of this encounter led the clinician to consider more effective consulting techniques.

**Methods and results.** A hypothetical interaction is constructed in which the clinician uses reflective listening statements to understand the patient’s true meaning of this self-diagnosis.

**Conclusions.** Despite well intentioned attempts to be patient-centred through widening the consultation beyond the biomedical to include personal and contextual factors, clinicians may still end up imposing their own medical meaning on patient’s words. Damaged rapport is a signal that another tack could be more fruitful and reflective listening is one strategy which enables clinicians to check that they fully understand the patient’s meaning. Provoking resistance by following strategies which are not appropriate for the patient might then be avoided.

**Keywords.** Physician–patient relations, chronic fatigue syndrome, consultation process.

Introduction

The patient-centred clinical method encourages clinicians to explore patients’ concerns and beliefs about their problems. A clinical, individual and contextual diagnosis is made in an attempt to incorporate all relevant components of the system into a holistic approach to patient care. We present an account of a patient who put his problems down to myalgic encephalomyelitis (ME) and although the clinician attempted to take personal and contextual factors into account, it is clear now that he was being far from patient-centred. The clinician did not fully explore the meaning of the illness for this patient and imposed his own meaning and solutions. This provoked resistance and may have caused the patient to entrench the very behaviours the clinician was trying to change. Damaged rapport is a signal that should have led to a change in tactics, and ‘reflective listening’ is a technique that might have proved helpful in this situation.

The case

A 33-year-old assistant bank manager rushed into his doctor’s consulting room in great distress; he was hyperventilating, had vague chest pains and thought he was having a heart attack. There had been no preceding febrile illness, but he had been getting debilitating pains in his muscles for several weeks.

His clinical records revealed that while at boarding school, he had suffered from recurrent abdominal pain. Two years later, investigations for lower back pain proved negative. Nine months of choking sensations prior to final university examinations prompted a barium swallow. He was then treated for ‘grumbling prostatitis’ despite normal physical, bacteriological and haematological examination. At age 27, when his father died, he was again investigated for abdominal pain and a barium meal was normal.

He was now married to a successful accountant, and had two children under three. For career reasons, the family had moved house four times in as many years. He took no regular exercise, had no hobbies, smoked a pack of cigarettes and consumed more than 20 cups
of coffee in a day and drank at least 100 units of alcohol a week.

His father had suffered from prostatic cancer and had died of a heart attack. His mother suffered from psychiatric problems. She had attempted suicide, been on psychotropics for many years and drank excessively.

Careful physical examination was entirely normal. At this first meeting, the clinician managed to calm the patient down, suggested that this was a stress related episode, signed him off sick for a few days, taught him breathing exercises, advised him to drink decaffeinated coffee, keep an alcohol diary and think about ways he could build some form of recreation into his daily life.

But during the next 20 days he consulted a further six times with clear anxiety and panic type symptoms, including fear of driving a car and leaving the house. He had not kept an alcohol diary or considered the place of stress in his life. He also described a leaden feeling in his arms after exercise, usually associated with pins and needles in his fingers. He felt exhaustion out of proportion to his level of exertion. It took him three days to recover from mowing a small patch of lawn. He was plagued by a sensation of “having been hit by a baseball bat” in his chest. Dizziness, mood swings, irritability, poor sleep, difficulty in recalling names and numbers and “fuzziness in the head in the mornings” were reported.

The following three stage assessment was made. Physical: Panic, fatigue, muscle pains, physiological effects of substance abuse. Personal: Intense work stress, fear of ischaemic heart disease, difficulty coping. Contextual: Loss of social support, family history of anxiety, depression, poor coping and ischaemic heart disease, past history of somatizing, two young children, successful partner.

The clinician attempted to discuss this formulation with the patient who responded by saying he was sure he was suffering from myalgic encephalomyelitis. He was adamant that he was not over-stressed or depressed and that the pains, fatigue and dizziness were not in his mind. Whenever the discussion focused on the possible contribution of work and family pressures, he got angry and accused his doctor of not taking his problem seriously.

The clinician read that cognitive behaviour strategies are useful in such situations. For example, a common assumption is that activity should be avoided by the sufferers because it causes pain which signifies further damage to the muscles. Clinicians can challenge this cognition with evidence from muscle biopsies which suggest that it is inactivity itself that causes the muscles to become painful again, rather than activity causing muscle damage. This patient simply disputed the “scientific evidence” and never acted upon a half-hearted agreement to graded exposure to activities that brought on his symptoms.

The clinician felt frustrated. Having made what he thought was an adequate three stage diagnosis, there was precious little he could do to engage the patient on problems at the contextual and personal level and he began to dread the patient’s visits. At times, their discourse went something like this:

Patient: I need to rest because its the only thing that helps with ME.
Clinician: ME?
Patient: Yes, fatigue caused by a viral infection of the muscles and nervous system. Activity makes it worse.
Clinician: You say its a viral infection, but endless researchers have tested for the so called virus that is said to cause it, and they have come up with virtually nothing. I’ve got a feeling that hunting for a physical cause for your problems might just delay your recovery. Unless you begin to consider the place of stress in your life, you will never get back to work.
Patient: I know stress can sometimes be important, but I’m telling you, pain and exhaustion like I’ve got is not caused by stress. What I’ve got is ME and its caused by a bloody virus, and they have proved it. When is someone going to take my problem seriously?

Over the months, despite the poor rapport, the patient continued to consult frequently, probably mainly to get sick notes. His symptoms waxed and waned with an overall tendency towards improvement. He cut down his drinking, stopped smoking, and felt calmer. The clinician’s exhortations to get back to work became ever more insistent, as he believed the patient may have been entrenching phobic symptoms. After eight months of being off sick the patient eventually agreed to a graded programme of increasing time at work, but at the end of his first day back, he fell into a ditch and fractured his tibia and fibula.

Discussion

This patient and his doctor became stuck in a Mexican stand-off on either side of a mind–body divide with disastrous consequences for the patient and their relationship. The clinician made a fundamental mistake by failing to clarify the personal meaning of the patient’s words. He realized too late that ME probably meant a way out of an intolerable situation which preserved self esteem. The patient wanted to avoid any suggestion that his problems were associated with not coping or personal weakness; he had simply been the unlucky victim of a nasty infection. Disputing this biomedical view meant challenging his defences.
For this clinician however, ME meant a serious malaise made worse by avoiding activity. He was also aware of the association between prognosis and patients' belief in a viral cause.4 The doctor could see no solution other than to challenge the patient and this provoked resistance to the point where the clinician felt almost physically threatened at one point. In effect, the clinician had told the patient the cause of his problem and attempted to direct him down the road of the doctor's choosing to a medical definition of recovery. For the patient this meant going back into the firing line, and he had already established that he wanted to be elsewhere. When the clinician 'pushed' him back to work, the patient fell and broke his leg. It was as if he was taking the clinician by the lapels, giving him a good shake, and saying, "Do you now see that I need a physical reason not to go back to this particular job?"

It is well known that solutions imposed from outside are less likely to be as effective as those based on intrinsic motivation and perceived as owned by patients.5 If the doctor had made sure that he understood the meaning the diagnosis had for the patient, he may have been able to create the climate in which creative solutions might have emerged from the patient.

Confusion about meaning may arise at various stages in the process of communication. First, the way a speaker codes meaning into words may be inaccurate. Second, the listener may not hear the message correctly, and third the listener may also decode the meaning incorrectly.6 In this case, there were problems both in the patient's verbal coding of his meaning (ME meant far more than just a virus causing debility), and in the doctor's decoding of the message (the clinician imposed his assumptions about recovery onto the patient's words).

Reflective listening is a technique which helps prevent such misunderstandings, consequent blocks and breakdown in rapport.6,7 The listener is required to check his perception of meaning against the speaker's own meaning, usually by making a statement that invites clarification.

Had the clinician used reflective listening statements, their discourse may have gone more like this:

Patient: I need to rest because that is the only thing that helps ME.

Clinician: ME?

Patient: Yes, fatigue caused by a viral infection of the muscles and nervous system. Activity makes it worse.

Clinician: Going back to work will make it worse.

Patient: Yes, if I exert myself in any way it could set me back even further.

Clinician: You have an infection that is preventing you from getting back to work.

Patient: Yes, and it could take quite a long time before I get better.

Clinician: The problems of your work sound pretty long term and quite worrying.

Patient: I've got a lot of pressure on me because of the family, but I know that the job is damaging my health . . .

In this fantasy exchange, there is no opportunity for the patient to 'yes but' the clinician and resistance is not evoked in the patient. By clarifying meaning in this non-challenging way, and by refraining from leaping in and providing interpretations and solutions, clinicians avoid putting 'road blocks' in the way of patients elucidating for themselves the many conflicting aspects of their predicaments.

Experience in the addictions field suggests that resistance to advice cannot be attributed solely to patient characteristics.7 Far from being a symptom of a patient's 'denial', resistance may be the product of consulting styles which deny patients the opportunity to articulate factors they see as relevant to their motivation. This case illustrates that imposing medical meaning and solutions can damage the doctor-patient relationship and entrench in the very sort of behaviour that the clinician was trying to change. Emerging resistance in response to strategies which challenge patients’ cognitions should be a clear signal to the clinician to change tack, and clarifying meaning through the use of reflective listening may be a good place to start.7

This case raises another interesting question: The importance of listening, reflecting and exploring individual meanings has been well established in psychotherapeutic teaching, and the application to general practice has been widely known and well developed over decades.8-11 Why is it that a reasonably well trained and hopefully well intentioned clinician found himself in a position of having to rediscover the invention of the patient-centred, reflective wheel? Perhaps we all find it hard to move from the action and solution oriented hospital milieu where most of our training took place to a situation of continuing care where the therapeutic value of relationships, time and patients constructing their own evaluations and solutions achieve greater importance. Do our experiences within the time pressured parameters of primary care reinforce our destructive behaviours? Whatever the reason, this clinician clearly discovered an uncomfortably large gap between what is known about effective consulting and his actual behaviour.

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References