

Understanding the patient with medically unexplained disorders – a patient-centred approach

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ABSTRACT

Patients with functional or medically unexplained disorders represent a challenge to the general practitioner. Medical school never taught us the art of diagnosis and treatment of subjective symptoms without objective findings. However, functional disorders are not as unexplained as they appear at first sight. Symptoms may originate from stress, lack of control and flexibility at home or at work, from abuse, from monotonous mechanical exertion and long-term toil in low-waged jobs. Bodily habits resulting from such states may for some people predispose symptom development. So far, we do not know who is vulnerable or why. The biopsychosocial model can help us understand, but is often misused to legitimise a one-sided psychologising of the patient's problem. Patients often complain about this. The diagnosis of somatisation may act destructively and should be abandoned. Instead, salutogenic perspectives are important remedies for recovery and hope. Empowerment implies recognition, strengthening, and solidarity. Patient-centredness means that the doctor identifies and gives privilege to the patient's agenda. Shared understanding of the patient's strong

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sides is the foundation of patient-centred salutogenesis in clinical practice. To provide quality care, doctors will have to challenge some myths about functional disorders and the patients suffering from it. Yet, we shall understand more by incorporating new knowledge, perspectives and experiences learned from the patients.

Keywords

Functional disorders, somatisation, patient-centredness, recovery, empowerment

Introduction

In functional disorders, patients experience bodily symptoms such as pain, weakness, disordered sleep, dyspepsia, or hypersensitivity. However, no organ pathology can be diagnosed. The diagnostic terminology is diverse. Descriptive labels, such as fibromyalgia, chronic fatigue syndrome, glossodynia, temporomandibular joint disorder, whiplash disorder or tension headache, are commonly used. Undifferentiated diagnoses like myalgia, neurosis, low back

pain, asthenia, chest pain or functional disorders also belong to this group. Terms such as candida-syndrome, ME-syndrome (myalgic encephalomyelitis), or multiple chemical sensitivity disorder, are sometimes preferred by patients. Doctors may name the condition somatoform disorder, depression or hypochondria, implying that the patient has not understood the real causes of the symptoms.^{1,2,3} Below, I shall apply the term 'medically unexplained disorders', deliberately intending to shift

the reader's attention to the problems arising when medicine does not understand what is going on.⁴

Difficult patients or complex explanations?

Relating to patients with medically unexplained disorders represents a challenge to the general practitioner. People in modern society, including medical professionals, expect cure, and prefer resolution rather than persistence of symptoms.⁵ Doctors assign low status to these conditions.⁶ Un-

explained disorders regularly impose strain on the doctor-patient relationship and may contribute to mutual feelings of anger and hopelessness.^{7,8,9,10} Causal explanations seem complex or cloudy, and contemporary biomedical frameworks offer no simple or universal solutions.

What are doctors supposed to do when we realise that we are not able to relieve the pain, or are perhaps not even able to share the patient's understanding of the problems? These are not the kind of problems that medical school taught us to solve. Unnoticeably, a difficult problem may be transfigured to a difficult patient. Not only is the patient's body in pain, her burden of suffering increases when those who were supposed to help her seem to distrust her. Patients complain of not being taken seriously by doctors^{11,12} and report struggling against the doctor's scepticism and insistence on psychological explanations.¹⁰

An underlying assumption is that health problems present as subjective symptoms accompanied by objective findings. Objective findings are regarded as the keys to diagnosis, which explains the cause and subsequently assigns treatment.¹⁴ Yet, regardless of its alleged subjectivity, the patient's story is actually a more important source of information in clinical diagnosis than findings and lab results.¹⁵ Furthermore, in general practice, symptom diagnoses are more prevalent than

disease diagnoses, which are assigned to only one out of eight patients.¹⁶ Symptom diagnoses are readily accepted for acute health problems of intermediate severity, such as fever, diarrhoea or stomach pain, where the diagnostic task is to judge the seriousness of the condition and find out whether something should be done. In persistent conditions, such as fibromyalgia or chronic fatigue syndrome, a symp-

tom diagnosis announces that the professional does not understand what is wrong. Feelings of helplessness may challenge the doctor's professional identity of being in charge and result in blaming the victim of the 'unexplainedness'.

Explanations are available, although complex

Functional disorders are not as unexplained as they appear at first sight. Empirical research has demonstrated different causal explanations interacting in the individual patient on various levels.⁴ In some patients the

condition is related to stress, with lack of control and flexibility at home or at work.^{17,18} Women constitute the majority of patients with medically unexplained disorders.⁴ Violence and abuse leave permanent bodily tracks and wounds, often invisible.¹⁹ Monotonous mechanical exertion and long-term toil in low-waged jobs providing service and care influence muscle physiology.²⁰ Many women live their lives in bodily readiness, eager to meet the needs of other people. Bodily habits resulting from such states may predispose towards symptom development. We do not know who is vulnerable or why. Women's dual workload is not

necessarily the cause of illness, to the contrary, holding several significant roles may actually promote health. But when the roles impose limited control over everyday life, health may suffer.

Symptoms may also be caused by disease not yet discovered by the doctor either due to inadequate professional quality or neglect, or because many diseases simply are difficult to diagnose.²¹ Some may even not yet be invented.

Maybe the doctor forgets to think about the body when psychosocial problems are obviously apparent? Could the medical gaze possibly be looking in the wrong direction or have an unclear focus?

Biopsychosocial understanding today and in the future

Previously, psychosomatic disorders were regarded as secondary bodily consequences of primary psychological disturbances. Engel's biopsychosocial model seems more adequate, portraying a circular collaboration between body, soul and context.²² The model

fits well into recent neuropsych-immunological theories about bodily loops of feedback systems influenced by emotions and behaviour.²³ Neuropeptide reactions are adequate acute responses to physical or emotional trauma perceived as a threat of tissue damage. However, nociceptive systems change their sensitivity over time, and thus maintain pain through central nervous system signals, transforming the experience into chronic pain.

Yet, many doctors still stick to the parochial interpretation of somatisation as pure psychopathology, *'it is all in her mind'*.²⁴ The biopsychosocial model is often used to legitimise a one-sided psychologising of the patient's problem, approaching the personality and life situation of the patient, while neglecting bodily processes. Many doctors see their task as to explain the relationship between symptoms and stress, and several treatment programmes have been developed to help the patient re-attribute her understanding of her condition.²⁵ But when the patient actually perceives the doctor's understanding of the situation as unwarranted psychologising, the diagnosis of somatisation may act destructively and oppressively.^{3,11,12} Furthermore, psychiatric diagnoses are not

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suitable as passive conclusions when we do not have other explanations.

Several of the functional disorders overlap¹, indicating potentially common underlying mechanisms of disease. However, many of the conditions clustered in crude categories today may represent different conditions appearing from various biopsychosocial dynamics. This explains why patients with the same diagnosis respond differently to the same treatment. Some of these conditions might represent diseases not yet inscribed on the medical map of 2002. Maybe within five years they will have been given a medical name, perhaps even associated with a gene, an enzyme, or a bacteria, providing some understanding of why some people are struck by conditions of life tolerated well by others. The history of peptic ulcer, changing its status from psychosomatic disorder to helicobacter infection, should remind us that medical truths are objects of change. We do not extend understanding by insisting that what we do not understand must be a mental disorder.

Understanding the patient and her suffering

Diagnosis, treatment and understanding of functional disorders require that the doctor is able to find out how the patient experiences her symptoms.^{4,11,13,26,27} Negative attitudes in doctors may function as iatrogenic placebos. Patients frequently report that their own knowledge is not assigned validity.^{3,11} The patient is violated when the doctor questions her credibility or morals. Endless negotiations about what the illness 'really' is, may obstruct the possibility of common understanding by creating conflicts between doctor and patient. Epstein, Quill and McWhinney therefore suggest that we abandon the term somatisation, which in its present conceptualisation does not include the patient's perspective.²⁸

The perception of pain is an entirely subjective experience. Ac-

knowledging this, the pain of a person cannot be contested. Yet, interpreting the meaning of bodily pain is a common component of discussion, negotiation, and conflicts in clinical practice. The patient frequently holds an adequate understanding of the mechanisms underlying her symptoms. A respectful patient-doctor relationship is necessary for the doctor to be able to access the patient's causal explanation or expectations about action. The doctor does not have to agree. Our role is to explore all relevant sources of knowledge, putting together the pieces of the puzzle to form a meaningful picture, meaningful also for the patient. Recognition and acknowledgement is not the same as giving in to the patient.

The nature of chronic disorders means that cure is not an appropriate goal for management. Chronic disorders require objectives and strategies for management, which are very different from those applied to transient or curable conditions.^{27,29,30} The progress of medicine in the period of modernity has made people believe that any illness can be cured and that suffering is no longer necessary.

In medically unexplained disorders, the major challenge for both doctor and patient is to obtain a resourceful balance between the painful realities of permanent disability and the hopeful expectations of a future life.³¹ It is about coming to terms with the consequences of illness, without being resigned to the belief that nothing can be done. Medical school training does not prepare doctors for the tasks of walking along the course of an illness, witnessing suffering together with the patient, while at the same time tolerating problems that do not disappear.⁴ The doctor should be reminded that the patient is carrying the heavy burden of this task.

What can be done?

The action-prone doctor may easily feel lost in cases where cure is not uniformly or easily available. However, the myth that nothing can be done with apparently unexplained disorders can be put to rest. Several modalities of medical care are available, and must be thoroughly assessed together with the patient.³²

The management of chronic pain patients is more than drug prescription and simple procedures. Collaboration with other health care providers, referral

to specialist care and multidisciplinary clinics may be useful in many cases. Overtreatment may also occur, however sometimes with severe consequences like drug addiction or postoperative complications. On the other hand, there is a danger of being nihilistic in one's approach as 'yet another' patient seems to be caught in a position of no cure, chronicity and pessimism.

Deciding what would benefit the patient is not a task for the doctor alone. The patient-centred clinical method suggests different approaches, all of them presuming a long lasting relationship between doctor and patient where the patient can feel safe and acknowledged.³³ Thus resignation and despair can be turned into recognition and hope. Approaching recovery, maintaining an understanding of the patient as the main character of the plot, is the core challenge. Joining and supporting the strengths and resources of the individual is an important contribution for the general practitioner who accompanies patients with medically unexplained disorders through the years.²⁷ Achieving this is partly a question of attitude and partly a question of practical action.

Treatment programmes confirming the strong sides of the patient and counteracting oppression within and beyond the doctor's office may pre-

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vent resignation and passivity.^{29,30,34,35} Many patients find cognitive therapy useful, often combined with cross-disciplinary programmes for rehabilitation.³⁶ Communication is a strong agent for gendered interaction, and the consultation may reproduce socio-cultural patterns of power, leaving limited voice for the patient who is in a subordinate position.³⁷ Empowerment means to redistribute power and strengthen the underprivileged. According to critical theory, empowerment for personal and political liberation can be promoted by communicative action. In my own research I have systematically elaborated my communication style. Aiming to expand the empowered space for the patient in a more conscious way, I have turned intuitive talk into a clinical method.^{38,39,40} New dialogues may provide new explanations.

Care versus cure

The impact of treatment, in the sense of cure, should not be overestimated. Care is often more important than cure when it comes to chronic disorders. However, talk and support can never replace the effect of specific treatment based on a thorough physical examination in which minor components contributing to bad cycles can be identified and remedied. Maybe the pain in the patient's left shoulder is not as unexplained as the rest, but turns out to be the symptom of a supraspinatus tendinitis. A steroid injection may provide magic relief and break a bad circle of dysfunctional pain spreading between muscle groups. Imaging may show calcification for which surgery is appropriate. With these matters I want to give some reminders about patient-centred care as the negotiated sum of patient's and doctor's agenda.⁴ While the former is often neglected, bodily aspects have a tendency to disappear when extensive psychosocial problems are dominant. Never forget that new diseases

may appear in patients who have previously been comprehensively investigated. Recurrent symptoms may sooner or later provide some diagnostic findings!

Communicative empowerment implies more than understanding disease and risk factors. The attitudes of contemporary medicine, labelled as the risk epidemic, may contribute to blaming the victims of disease, neglecting individual and collective strengths. Antonovsky challenged this view of health and disease by introducing the concept of 'salutogenesis' (genesis = origin, saluto = health), looking for resources that keep people healthy.⁴¹ Behavioural and psychoimmunoneurological medical research substantiates the self-healing potentials and their relationship to the internal and external context of the person. In the process of chronic disease, such as medically unexplained disorders, salutogenic perspectives are important remedies for empowerment, acknowledgement and hope in the pursuit of a revised notion of being healthy, even in a life of pain.

The general practitioner is in the privileged position of being able to observe the power of the human body's capacity for repair and restoration. The patient-centred clinical method highlights the voice of the patient as a valid source of medical knowledge. 'The health resource/risk balance' model is a strategy for a salutogenic and patient-centred consultation model that shifts

the attention from objective risk factors to patients' self-assessed personal health resources.⁴² This model, elaborated from the original patient-centred clinical method, invites the doctor to identify and combine the agendas of pathogenesis and risk factors with salutogenesis and health resources, as well as the agen-

das of doctor-assessment with patient-assessment.

Patient-centred rehabilitation and recovery

Rehabilitation is more than bringing temporarily sick or disabled people back to work – it is about rearranging the practical, physical and social life for persons who had their plans or futures dramatically distorted. Multidisciplinary collaboration between physiotherapists, occupational therapists, social workers, psychologists, medical specialists (most often from rheumatology or neurology) and care providers are needed.³² Health insurance systems and social welfare officers are often involved, and sometimes also the patient's employer and co-workers. To coordinate these efforts is the complex but important task of the general practitioner. Overview of systems, understanding of competence within other professions, as well as communication and negotiation skills are required. In a patient-centred approach, the patient is an active participant of this collaboration network, not an object being managed by professionals.

The doctor cannot achieve recovery upon or on behalf of the patient. Recovery is a personal process. Patient-centredness means that the doctor identifies and gives priority to the patient's agenda so that management can enhance recovery. Seeing the patient as a whole person may help the general practitioner realise why hope disappears temporarily or permanently.^{27,31} Perhaps the structural conditions of the patient's workplace impose pressure and loads upon her, beyond what she feels she can stand. She may not be in charge of change or control. Perhaps her husband repeatedly discounts her, humiliates her, and sometimes beats her. Her economic situation may not allow her to contemplate divorce. The patient may be

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an unemployed man whose chances for a permanent job are doomed because of his pain problems. Or he may feel his body betrays him and turns him into an old man, although he just turned forty. One solution is to become hard at heart.³¹ This is not a good recovery strategy. Eliciting and recognising the patient's agenda, the doctor may be able to prevent a common feeling of hopelessness, and instead explore and encourage the patient's strong sides and resources.⁴²

According to Antonovsky, general resistance resources, such as social class and network, facilitate health in most people.⁴¹ 'Self-assessed personal health resources' denote the individual's subjective experience and perception of qualities or strategies which s/he thinks maintain her health, irrespective of empirical evidence about health effects.^{40,41,42} Self-assessed health resources can only be obtained through an individualised

approach. Shared understanding of the health resources observed by the doctor and the patients' self-assessed health resources are the foundation of patient-centred salutogenesis in clinical practice.

The medical task of mobilising hope

Patients suffering from disabling symptoms and repeated disempowerment, deserve enthusiastic doctors and more support from their surroundings. The ups and downs may be more or less

frequent, the amplitude between good and bad days may vary among individuals, and provocative factors cannot always be predicted. Yet, there is hope on many levels that can be identified and mobilised.

On the other hand, a diagnosis perceived by the patient as derogatory will not enhance dignity and hope.²⁸ An important challenge, therefore, deals with the meeting between presumed experts; the patient who suffers from pain and

worries, and the doctor who is supposed to solve the medical mystery.

Realising that the diagnostic question has no clear-cut answer, the doctor must lean towards the additional cues provided by the patient to compose the clinical knowledge needed to understand what is wrong and what can be done. Finding common ground, one of the hallmarks of the patient-centred clinical method, is vital for diagnosis as well as management.³³ But this is not always an easy task, even for a doctor who is committed to patient-centred care. The medical gaze may easily cut through contradictions by omitting the view of the patient. At a surface level, patient perspectives sometimes appear to mess up the easy conclusions, while they actually may be required to understand the complex reality of lives in pain. Quality care requires that doctors dare to challenge some of the old myths about functional disorders and the patients who suffer from them, and understand more by incorporating new knowledge, perspectives and experiences learned from their own patients.

The general practitioner is in the privileged position of being able to observe the power of the human body's capacity for repair and restoration

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