

Explaining symptoms after negative tests: towards the rational explanation

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Abstract

Many patients undergo diagnostic tests which are normal. In this essay, we consider how clinicians can provide acceptable explanations for symptoms which persist after ruling out known physical disease. We begin by examining explanations from the perspectives of patients and clinicians and consider the different ways of explaining symptoms following negative tests. We then propose the characteristics of an ideal, or rational, explanation. This rational explanation is a pragmatic approach which, while imperfect, makes sense to both doctor and patient and promotes appropriate action.

Introduction

Many patients undergo diagnostic tests which are normal. However, sustained reassurance does not automatically follow from negative diagnostic tests (1), and patients who continue to consult with “medically unexplained” symptoms (MUS) are likely to receive further, possibly unnecessary tests, and treatments from their doctors (2).

In this essay, we argue that clinicians can provide acceptable explanations for symptoms which persist after ruling out known physical disease and that this is a necessary counterweight to the power of diagnostic testing. We will examine explanations from the perspectives of patients and clinicians and consider the different ways of explaining symptoms following negative tests. Building on earlier research (3), we will propose the characteristics of an ideal, or rational, explanation. We will take a pragmatic view that the rational explanation, while imperfect, makes sense to both doctor and patient and promotes appropriate action.

Reassurance and explanations

There is a strong link between explanations and reassurance. Reassurance, for instance after negative diagnostic tests, has two components: emotional and cognitive(4). The emotional component of reassurance (relief) is immediate. It is the response we witness to statements like “Your tests are negative, you don’t have cancer”. However while relief feels good, it is only transient for many people, particularly if symptoms persist. If it occurs repeatedly, it may even lead to a cycle of anxiety and relief-seeking. In contrast, the cognitive component of reassurance (assurance) is longer lasting, and has sustained benefit (5). It accompanies the

recognition that even if symptoms persist, they are not a sign of danger and may be controlled. For at least some patients it means answering the question “So if my tests are negative, what is causing my symptoms?”

As MUS are common, one might expect doctors to be skilled and confident in explaining them to patients. However patients commonly report otherwise (6) and observation indicates that despite giving patients ample opportunity to talk about their “medically unexplained” symptoms, general practitioners do not structure these consultations well and spend little time trying to explain to patients what is happening to them (7). Even experienced GPs have a very limited repertoire of explanatory models and scripts (8).

Patients and explanation

There are several different approaches to the way patients make sense of symptoms. Probably the most widely used model of illness appraisal is the common-sense model of illness (9). It contains five categories of illness representation: identity, cause, timeline, consequences and controllability and suggests that these representations are processed both cognitively and emotionally. It implies that patients seek to identify the name of the condition that causes the symptom, its cause, course and consequences and how to control it. In the case of MUS, all the components of illness representation may be contested between doctor and patient, in a clash of professional expertise against personal experience(6).

Patients’ own explanations and interpretations of symptoms are often sophisticated and complex (3). While most medical explanations invoke physical changes, such as damage, inflammation or wear, many lay explanations are more subtle and dynamic, with ideas of imbalance or disordered function (10). Importantly, patients’

explanations for symptoms often include elements of stress or emotional distress but usually as one factor among many (11).

Clinicians and explanation

When faced with physical symptoms and tests which are normal, or which are ambiguous (such as the finding of age-appropriate degenerative change on X-ray), clinicians can choose from a range of explanatory strategies. We consider these within four categories of explanation: normalising, biomedical, psychosomatic and biopsychosocial explanations; we also consider the idea of non-explanation which is often associated with the idea of needing to accept uncertainty.

Normalisation

Normalising explanations convey the message that the patient's symptoms are within the broad scope of normal experience. They assert that there is nothing seriously wrong, either by indicating the absence of apparent disease or through non-specific explanations such as "probably a virus", "wear and tear", or "doing too much". They draw on the doctor's authority in differentiating disease from normal experience and may emphasise normal test results, despite the fact that reassurance following negative investigation is rarely sustained (1) .

A series of studies of clinical communication about persistent MUS in UK general practice reported three kinds of normalisation from the patient's perspective: dismissal (in which symptoms are played down even though they are persistent), inappropriate explanation (in which explanation is given but fails to engage with the patient's concerns) and constructive engagement (in which the explanation of symptoms is plausible, blame free and facilitates therapeutic partnership)(12). These

features of the constructive engagement form of normalisation are valued by patients and will be used later as a component of the rational explanation.

Biomedical

In conditions with clearly understood pathophysiology, doctors may explain conditions both in terms of diagnostic entities (“your chest pains are due to angina..”), and in terms of pathophysiological process (“... which happens when an artery supplying blood to the heart muscle is narrowed and not enough blood can get through”). This approach becomes more difficult to justify when the findings on investigation are poorly correlated with symptoms (for instance MRI disc lesions and back pain), although many clinicians continue to describe these minor or incidental pathological findings as if they are the root cause of symptoms.

With regard to MUS, there is increasing recognition that a range of physiological mechanisms may be implicated in symptoms. These include alterations in autonomic function, endocrine regulation, immunity and the group of neurophysiological processes termed central sensitisation. They may lead to changes in, or altered perceptions of, processes such as gastrointestinal motility, balance, musculoskeletal activity or pain. None of these has yet been found to be a sufficiently strong explanation to be the sole pathophysiological mechanism for any of the MUS syndromes, however they are likely to play a role, to varying degrees, in many patients and may be useful as components of constructive explanations.

Psychosomatic

Psychosomatic explanations, and the related concept of somatisation, imply that the root cause of MUS is some form of unresolved or unexpressed mental distress.

Simple explanations of this type include suggesting stress as a cause of tension type

headache. More complex explanatory models may seek to reframe physical symptoms by making a link between mental problems and physical symptoms, for instance in the timing or severity of symptoms. This was most clearly formalised in the approach known as reattribution, which despite its widespread use, may have little benefit when used within conventional brief consultations (13).

Psychosomatic explanations are often unhelpful. Patients frequently perceive them as threatening and resist them. Even when patients consider that stress might play a part in their symptoms, they want to be sure the doctor is not jumping to conclusions and they worry that conceding psychosomatic cause for one problem may set a precedent for future symptoms (14). Patients wish to control when and how clinical communication includes their emotional world (15) and deploy a range of discursive tactics in order to preserve their identity as a legitimate patient (16). Patient's resistance to including psychological components in explanations may be reduced when doctors propose a physiological mechanism for symptoms (hormone changes or sustained autonomic arousal) as a process which can also be influenced by stress (17).

Biopsychosocial

More sophisticated biopsychosocial explanations involve a range of interacting components(18) . These may include the autonomic, endocrine and immunological mechanisms described earlier, combined with psychological processes such as somatosensory amplification, catastrophisation and symptom focus. These biopsychosocial models avoid a simple psychosomatic causal pathway and underpin Cognitive Behavioural Therapy which has been shown to be effective for patients with persistent MUS (19), as well as for explained symptoms such as fatigue in neurological diseases. Such models often seek to identify and separately address

components which act within different timescales, for instance a transient physical illness may set up a state of sustained autonomic arousal which is perpetuated by cognitive or behavioural factors.

MUS are associated with substantial psychological co-morbidity: anxiety and depressive disorders are both common in patients who have had even a small number of referrals for MUS and it is important that doctors are sensitive to this. Biopsychosocial models allow anxiety and depression to be included in the explanation, sometimes as a consequence rather than a cause, especially when the patient volunteers pointers to them.

Non – explanation, accepting uncertainty

The fact that we cannot be certain (and sometimes simply do not know) why symptoms are present means there is an argument for simply telling patients this. Some doctors prefer this approach with patients: for example in the statement “Your test is negative, there is no sign of serious disease; I see many people with symptoms like this which I cannot explain”. Some doctors will go further, suggesting that the patient should accept that some things, including an explanation of their symptoms, are unknowable. While the simplicity of this approach is attractive, it ignores the fact that there is much we do not know about many “explained” conditions (for instance migraine) which doctors are otherwise happy to explain. More importantly, it fails to engage with the patient’s own sense-making frameworks or needs.

Working together to explain

We take the view that doctors have a responsibility to assist patients in making sense of symptoms. In the absence of a positive diagnostic test, over which both

doctor and patient can agree, there is a need for explanation which makes sense to both parties. This involves bringing together both the patient's account and the doctor's inevitably incomplete medical knowledge to suggest an explanation which is acceptable to both (3). This creative mixing of the patient's lived experience with a biologically plausible account is a form of personal doctoring which exemplifies what Schei has called "clinical leadership" (20).

Towards the rational explanation

The ideal, or rational, explanation must therefore reflect both clinician and patient factors. It should make sense to both patient and doctor, which means being compatible with current medical knowledge. While it may be incomplete (for instance it may focus on symptom-generating mechanisms rather than root causes) it should be practically useful in terms of guiding treatment or adaptation. It is thus rational in offering plausible mechanisms by which symptoms may arise, and rational in its purpose of helping the patient make sense of their experience and promoting therapeutic action and partnership.

While the evidence we have presented is limited, and there is a need for more research into effective explanations for MUS, we propose six criteria for the rational explanation. These are based on the constructive normalisation type of explanation, the common sense model and the principle of personal relevance. 1) it is plausible (to both doctor and patient; 2) it does not imply weakness or fault on the part of the patient; 3) it promotes therapeutic partnership or action; 4) it applies a descriptive label (which need not be a specific diagnosis); 5) it addresses causation, although this may be through perpetuating mechanisms rather than root cause; 6) it is created through dialogue between doctor and patient. Figure 1 contains two examples of

rational explanation – the brief format means neither is presented as arising through dialogue, though ideally both would be.

Conclusion

Doctors need to become more skilled in suggesting explanations for persistent symptoms after negative diagnostic tests. Our proposed rational explanation can be used as a guide, with which doctors can help their patients find meaningful explanations.

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The Authors declares that there is no conflict of interest

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