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Education and debate

Managing patients with inexplicable health problems

Baruch Fischhoff, Simon Wessely

People need to rationalise their health problems, and those with medical mysteries will find some explanation. The best way to manage such patients is unclear, but the principles described in this article should help improve the satisfaction of both patients and doctors

The causes of many health problems remain a mystery despite the advances of modern medicine.[1] When a medical explanation is slow in coming, patients often infer that events (and perhaps people) are responsible for their condition. They may then judge harshly anyone who does not take their condition and inferences seriously. Physicians, officials, and companies often bear the brunt of this anger.[2] For example, in the controversies surrounding chronic fatigue syndrome, Gulf war sickness, and cancer clusters, authorities who denied sufferers' claims met with scorn and contempt.

Public unease, such as caused by the current threat of terrorism, is likely to make medical mysteries more common.[3] We therefore need a disciplined public health response for dealing with inexplicable health effects. In this article, we discuss how illness beliefs arise and suggest principles for dealing with patients.

Summary points

- Without a medical explanation, patients are likely to attribute their illness to events
- Terrorist threats are likely to increase the number of unexplained health problems
- Doctors need guidance to avoid alienating such patients
- Communication should be focused on patients' concerns
- Relief of symptoms should be the priority
- Risks should be given numerically and scientific uncertainty acknowledged

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Development of illness beliefs

Any widescale medical intervention will coincide with the development of medically unexplained symptoms. The intervention may then be seen as a putative cause.[4] Currently, smallpox vaccinations are an obvious target for such attributions, given the publicity surrounding them and their high level of side effects.

Patients naturally want explanations and treatments for their ill health. Professionals, on the other hand, want to be sure about the diagnosis before acting, fearing the monetary and health costs of treating hypothetical conditions. But however justified hesitation may be medically, it can seem callous to patients. They may begin to doubt the integrity of doctors and see them as indifferent to their plight.[5]

The ensuing anger of patients will add to the mutual misunderstanding. No one wants to be distrusted. It is therefore only human for doctors and scientists to want to pull back from a hostile public or to view the public as foolish, uncomprehending, hysterical, or malingering.[6–8] If such professionals speak less, or less respectfully, to the public, their credibility may decline further. They may eventually avoid health problems associated with hostile patients, expensive lawsuits, and government inquiries. This allows opportunists to fill the void, fanning patients' discontent and hawking dubious remedies.[9]

The uncertainty surrounding each medical mystery reflects its unique properties. However, these social and psychological dynamics occur in other contexts where the stakes are high, the trade-offs difficult, and the uncertainties large (such as many environmental conflicts).[6 8 10 11] We can use the experience from these diverse crises to guide us in dealing with mysterious illnesses.

Focus communication around patients' concerns

Communication is essential to maintain trust and credibility. However, the window of opportunity is limited, especially with an already stressed audience. Messages that seem irrelevant or disrespectful can make people less likely to listen, especially if vital information seems to have been hidden. Doctors must focus on the facts that matter most to patients, which requires thinking hard about their predicament:

- What decisions face them?
- What concerns weigh on them, including non-medical issues (for example, insurance, family)?
- What conflicting claims, beliefs, and observations confuse them?

- What information, and misinformation, do they have already?
- Which knowledge gaps and misconceptions provide the greatest barrier to understanding?

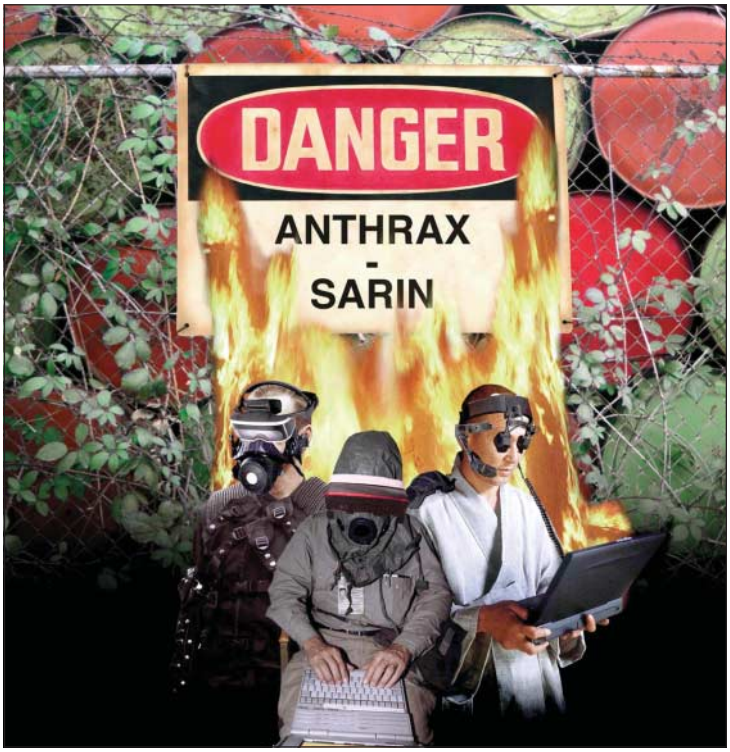
Of course, few clinicians have the resources to conduct decision analyses for individual patients. However, researchers could examine recurrent issues in general form, summarising the scientific literature (and its attendant uncertainties) in terms relevant to patients and summarising common beliefs of patients in terms that are relevant to doctors.[10–15]

Organise the information coherently

People can hold only about seven things in their mind at any one time.[16] That may be too few for some complex medical problems. The way around this cognitive limit is "chunking," organising the information into coherent units. Creating such mental models enables people to integrate new information with existing beliefs and respond to new situations and claims.[17] A good story also provides a narrative for explaining your condition and a feeling that progress is possible.[18]

Give risk as numbers

Professionals often use verbal quantifiers such as "rarely" and "unlikely" to describe risk because they believe the public is innumerate. Although such terms are an effective shorthand in familiar situations ("It rarely rains in the summer here"), they can cause confusion in unfamiliar ones (how frequent is a "rare" side effect?).[19 20] Vague terms give no perspective on experiences outside the normal range. To understand their risk of infection in an anthrax attack, for example, people need to know both the numerator (estimated number of casualties) and the denominator (number of exposed people). Even if initially unfamiliar, quantitative estimates of risk can (and must) acquire meaning through repeated exposure. Although people prefer to express themselves in verbal terms, they prefer the added precision of numbers from other people.[21] When they try to use numbers, most people seem to use them at least as well as verbal quantifiers.[22]



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Chemical and biological attacks may produce mysterious symptoms as well as direct injuries

Acknowledge scientific uncertainty

Patients and policy makers may apply understandable pressure for clear answers. Yielding to that pressure is, however, a trap when scientific uncertainty is great. People note and remember when firm promises are violated by subsequent evidence, as has happened in the controversies over bovine spongiform encephalopathy and hormone replacement therapy. Such apparent violations of trust may open the door for less circumspect individuals to offer their own strong claims. When scientists overstate their case, it becomes harder for the public to distinguish science from non-science.[23]

Uncertainty need not mean paralysis. Rather it defines the gamble associated with any action or inaction. Faced with the same uncertainties, people may prefer different gambles. It is therefore essential for them to know what their (uncertain) options are.[12 14 24]

Use universally understood language

We should all know to avoid polysyllabic jargon. Less obvious is avoiding everyday terms whose meaning varies across groups. Psychological diagnoses often do that. Objective medical descriptions, such as depression, carry negative connotations for many people. As with other areas of communication, there is no substitute for knowing your audience, which may require systematic, empirical study.[25 26]

One challenge arises when patients have named their condition in a way that leaves doctors uncomfortable, as occurred with chronic fatigue syndrome. It may seem that adopting the lay label endorses the implicit causal theory and reinforces the perceived disability.[27] For better or worse, the medical profession has lost the monopoly on naming conditions, and rejecting lay terms can needlessly alienate patients.[28] A compromise strategy is "constructive labelling," expanding on the lay name. It would mean treating chronic fatigue syndrome as a legitimate illness, acknowledging that it may have a viral trigger (as many patients report), while gradually expanding understanding of the condition to incorporate the psychological and social dimensions. The recent adoption by the UK Medical Research Council and the chief medical officer's report of the term chronic fatigue syndrome/myalgic encephalitis reflects such a compromise, albeit an uneasy one.[29]

Focus on relieving symptoms

If patients feel better, explaining their condition becomes less essential. Explanation is still important for satisfying curiosity, improving the efficiency of treatment, and preventing future problems. But these are all less urgent tasks and hence less stressful. Focusing on symptoms shows compassion and responsibility. It allows doctors to listen to patients' personal histories without having to evaluate them. It reduces

the risks of appearing disrespectful and the associated conflict and stress.[30 31] Of course, if the outcome cannot be guaranteed, treatment needs to be accompanied by realistic assessments of the uncertainty surrounding it.[2]

Unifying doctors' behaviour

Translating principles into action is rarely straightforward. Doctors need protocols for dealing with potentially angry patients with mysterious conditions.[14] The principles we have described above could be used to develop such a protocol. Any protocol should also include empirically evaluated examples of respectful responses to patients' concerns. Doctors could then use these examples to protect against the natural tendency to regress under pressure to a simplistic, intuitive response. In addition to its immediate benefits, each successful response to stressed patients increases the public goodwill that professionals will need in future crises.

Public goodwill and trust will be essential if the current threat of terrorism is realised. Terrorists hope to create fear, confusion, and distrust. In addition to direct injuries, chemical, biological, and radiological weapons can produce mysterious symptoms, as can some measures of prevention and treatment (such as mass vaccinations). The Gulf war and public exposure to Agent Orange, sarin, and anthrax have all produced such fallout. Each such crisis feeds off, and adds to, the erosion of public trust in societal institutions. We can therefore expect a continuing stream of medical mysteries. Our preparation for these eventualities should include creating communication policies and protocols that meet citizens' need to understand and manage their health in deeply uncertain situations.

Competing interests: None declared

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When we use a word

A 63 year old man with pneumonia was admitted three weeks after he had been discharged after investigation and, ultimately, a diagnosis of an aggressive inoperable lung cancer. The next evening I was asked to review him on the ward because he had become increasingly breathless and uncomfortable.

Before going into his side room, I sat and read the notes for this and his previous admission. In the clerking for his current admission it was stated that he had "refused" any further treatment. However, it was quite clear from his notes that, after long discussion, he had decided that the potential benefit of palliative chemotherapy or radiotherapy did not overcome the potential discomfort from their side effects. He had been in contact with the palliative care team, and arrangements for hospice care, when necessary, had been made.

The use of the word "refused" implies that the patient was considered to be displaying a degree of stubbornness or foolishness in going against the advice of the doctors. As doctors, we sometimes find it hard to "do nothing" for our patients, even when whatever we can do is going to be of little benefit. This difficulty expresses itself in our notes and letters and can lead to a patient being erroneously labelled as "difficult."

Horses "refuse" at a jump, badly behaved dogs refuse to obey their masters. Our patients, I hope, make decisions.

This patient was transferred to the hospice the next morning and died comfortably that afternoon.

Richard Kingston *specialist registrar in medicine, London*

We welcome articles up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake,* or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.