Reading, writing, and revalidation

What should we say to patients with symptoms unexplained by disease? The "number needed to offend"

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Most doctors make a diagnosis and offer treatment to patients whose symptoms turn out to be unexplained by disease. In such cases a diagnostic label is important in signifying to the patient and family that the doctor is taking the problem seriously and accepts the complaints as real. Some diagnostic labels, particularly those that sound "psychological," can be perceived by patients as offensive by implying that the patients are "putting on" or "imagining" their symptoms or that they are "mad."

Various potentially suitable diagnoses are available to doctors. "Hysteria" was the traditional term and is still sometimes used. "Functional nervous disorder" was used in the late 19th century to denote symptoms arising from disordered nervous functioning,³ but in the 20th century this was superseded by terms that implied psychogenesis, such as psychosomatic.⁴ In the past 20 years more neutral descriptive terms such as "medically unexplained symptoms" have gained in popularity.¹

Despite their importance in the doctor-patient relationship, the implications to patients of these labels have received remarkably little attention. We explored the differing connotations and potential offensiveness of 10 different medical labels for the symptom of weakness.

Participants, methods, and results

The study received local research ethics approval. Two medical students (WW and DD) interviewed 86

consecutive new patients attending a general neurology outpatient clinic in Edinburgh, before patients saw the doctor. Twenty four other patients declined to take part (most because they were in a hurry), and three further interviews were incomplete. We asked patients, "If you had leg weakness, your tests were normal, and a doctor said you had [diagnosis] X, would he or she be suggesting [implication] Y?" The table shows the 10 diagnostic labels for weakness (X) and five potential connotations (Y). We coded patients' responses "yes," "no," or "don't know" for each diagnosis and each connotation.

The diagnoses of multiple sclerosis and stroke always had fewest negative connotations and "symptoms all in the mind" the most. The diagnoses ranked in between were of greater interest. We calculated an "offence score" for each diagnosis as the proportion of patients who endorsed one or more of the following connotations, which we deemed offensive: "putting it on," being "mad," or "imagining symptoms." We then used this value to calculate a "number needed to offend"-that is, the number of patients who can be given this diagnosis before one patient is offended (see figure on bmj.com). This value assumes an ideal world in which no one is ever offended, and we used standard calculations for number needed to treat.5 A comparison of "medically unexplained weakness" and "functional weakness," two of the most popular labels in use, revealed that "functional" was much less offensive

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"If you had leg weakness, your tests were normal, and a doctor said you had 'X' would he be suggesting that you were Y (or had Y)." Percentage responses among 86 new neurology outpatients, offence score, and "number needed to offend"—that is, number of patients who would have to be given this diagnostic label before one patient is "offended"

	Connotations (Y) (No (%) of patients)						
Diagnoses (X)	Putting it on (yes)	Mad (yes)	Imagining symptoms (yes)	Medical condition (no)	Good reason to be off sick from work (no)	Offence score (%)*	Number needed to offend (95% CI)†
Symptoms all in the mind	71 (83)	27 (31)	75 (87)	57 (66)	60 (70)	93	2 (2 to 2)
Hysterical weakness	39 (45)	21 (24)	39 (45)	28 (33)	36 (42)	52	2 (2 to 3)
Psychosomatic weakness	21 (24)	10 (12)	34 (40)	18 (21)	24 (28)	42	3 (2 to 4)
Medically unexplained weakness	21 (24)	10 (12)	27 (31)	32 (37)	35 (41)	35	3 (3 to 5)
Depression associated weakness	18 (21)	6 (7)	17 (20)	13 (15)	24 (28)	33	4 (3 to 5)
Stress related weakness	8 (9)	3 (6)	12 (14)	14 (16)	20 (23)	20	6 (4 to 9)
Chronic fatigue	8 (9)	1 (2)	9 (10)	16 (19)	12 (14)	15	7 (5 to 13)
Functional weakness	6 (7)	2 (2)	7 (8)	7 (8)	17 (20)	12	9 (5 to 21)
Stroke	2 (2)	4 (5)	4 (5)	5 (6)	10 (12)	12	9 (5 to 21)
Multiple sclerosis	0 (0)	1 (1)	3 (3)	3 (3)	7 (8)	5	22 (9 to ∞)

^{*}Proportion of patients who responded "yes" to one or more of "putting it on," "mad," or "imagining symptoms." †Calculated according to the offence score.



(P<0.05 for all categories of negative connotation, McNemar's test).

Comment

Many diagnostic labels that are used for symptoms unexplained by disease have the potential to offend patients. Although "medically unexplained" is scientifically neutral, it had surprisingly negative connotations for patients. Conversely, although doctors may think the term "functional" is pejorative, patients did not perceive it as such. As expected, "hysterical" had such bad connotations that its continued use is hard to justify, although it is the only term in this list that specifically excludes malingering.

Diagnostic labels have to be not only helpful to doctors but also acceptable to patients. Many of the available labels did not pass this basic test, but "functional" (in its original sense of altered functioning of the nervous system³) did. This label has the advantage of avoiding the "non-diagnosis" of "medically unexplained" and side steps the unhelpful psychological versus physical dichotomy implied by

many other labels. It also provides a rationale for pharmacological, behavioural, and psychological treatments aimed at restoring normal functioning of the nervous system.⁴ We call for the rehabilitation of "functional" as a useful and acceptable diagnosis for physical symptoms unexplained by disease.

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A paradigm shift in the medical literature

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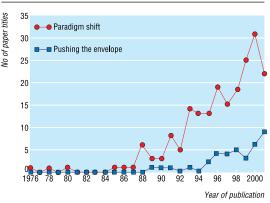
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Medical literature is expanding massively. More and more journals are appearing and an increasing amount of research and comment is being produced to appear in these journals. Funding for universities is decided on the amount and quality of research produced, and therefore more pressure is placed on researchers and clinicians to (publish or perish). A piece of research needs to be sound in method and results, but the title needs to be appealing to attract the attention of editors and catch the eye of the reader. Titles including words suggesting results of great impact will cause more interest and tempt journal subscribers to read beyond the title or abstract—this one did, didn't it!

Papers with catchy titles work best. Titles need to contain phrases that are in popular use and suggest innovation and exploration. I examined the use of two such phrases that are, or have been, in popular use: "paradigm shift" and "pushing the envelope."

Method and results

I used PubMed (www.ncbi.nlm.nih.gov/entrez/query. fcgi) to search for published articles containing the words for the two phrases. Searches were limited to "paradigm and shift" and were limited to title words. The database was searched for a 25 year period, 1976-2001. The same search strategy was repeated for "pushing and the and envelope." This search does not determine the word order in the paper title, but for the words to make sense in a sentence, the word order will have to remain grammatically correct and the sense remain approximately the same.



Number of papers published with the words "paradigm shift" or "pushing the envelope" in the title

I found 201 paper titles for 1976-2001 for the phrase "paradigm shift" and 37 for "pushing the envelope." The figures shows the results of the searches. As a phrase for inclusion in the title of published medical research, the phrase "paradigm shift" had low popularity in the early years of the study but picked up in the mid-1980s and began to rise exponentially before seeming to drop in the past year or two. In contrast, "pushing the envelope" remained dormant for most of the period of study but in the early 1990s has picked up and seems to be mirroring the success of "paradigm shift."

Comment

According to www.dictionary.com, an online dictionary and thesaurus, the word "paradigm" has three defini-