Explaining functional disorders in the neurology clinic: a photo story

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There is an increasing understanding and interest in functional disorders among neurologists. These are common problems that make up a large proportion of a neurologist's workload.[1] Nonetheless many doctors are still apprehensive about this area as they find explanation and treatment challenging.[2 3] However, a successful explanation is generally regarded as an essential platform for further treatment.[4] There is evidence that a successful consultation can resolve symptoms in some patients[5 6] and is associated with improved patient's outcome.[7 8]

Here we explore some issues in explaining the diagnosis of a functional disorder using the unconventional medium of the photo story (figures 1–4). We chose this format to make the article accessible and thought provoking, not because it is a light-hearted topic; far from it.

There is no 'one size fits all' method for every patient, but there are some approaches to the consultation that, we have found, help our practice. Our approach is based as much as possible on how neurologists might explain other conditions in the neurology clinic, such as Parkinson's disease: giving a clear diagnosis, explaining transparently how that diagnosis has been made and something about 'how' the problem occurs even if the 'why' can often be speculative and can be left for later consultations. In an accompanying article, Jon Stone explores the question of whether it is possible to turn a neurological assessment into treatment for the patient with a functional disorder.[9]

Even neurologists who are keen to help patients with functional disorders sometimes find themselves in avoidable situations that can have a negative impact on outcomes. This cartoon highlights some of these common pitfalls: making or explaining the diagnosis because the tests were normal (instead of using positive features); denying the patient a diagnosis ('no neurological disease') and focusing prematurely on psychiatric comorbidity when present can create unnecessary misunderstandings. We also illustrate the potential benefits of demonstrating positive physical signs of functional disorders to patients and the importance of providing written information where possible.[10]

While we use the term 'functional' in this article, we don't think the 'label' chosen is of prime importance. Indeed in a first draft of this article we found ourselves going round in circles discussing the pros and cons of various labels using arguments that have been rehearsed ad nauseam.[11 12] Eventually we realised that the 'label debate' was obscuring what we really wanted to say.

We would argue that it is more important in delivering the diagnosis of a functional disorder that the doctor can show that (1) they are taking the problem (and associated disability) seriously, during the history taking and during diagnostic discussion; (2) there actually is a diagnosis that is familiar and has a name; (3) there is some rationale for the diagnosis; (4) there is some explanation of 'how' the symptom arises (even if 'why' is more complicated); (5) it is potentially reversible and treatment may help; (6) there is written information to help understand the problem; and (7) there is a willingness to triage the patient for further treatment and follow-up as required.

(1) Taking the problem seriously

This basic human skill is sometimes the hardest aspect of all. Neurologists often find patients with functional symptoms 'difficult'.[2 13] But it helps to remember that some patients have prior experience of doctors (and sometimes other people in their lives) being dismissive and not taking them seriously; this can lead to an expectation of being treated with contempt and a feeling they must have to

Figure 1 Photo story part 1.

fight to get what they think they need. The simplest way of handling this is to be kind, polite and interested. You could make good eye contact, use language that demonstrates understanding, and show empathy with suffering and physical disability. It may help, paradoxically, to use humour where appropriate (eg, during the examination of reflexes) or even to say explicitly during the assessment, "This is all familiar, I'll explain at the end" or, "This is a genuine problem/ I believe you" when giving the diagnosis. With these simple steps, in our experience, patients become aware that they are being taken seriously, and the consultation can turn into a collaborative effort that is more rewarding for both parties.

There is a problem here though. Regardless of the techniques used, the doctor who fundamentally doesn't believe that functional disorders are a genuine problem that is the responsibility of a neurologist, will struggle. Patients can usually 'smell a rat' when the words are right but the sentiment is not. This is a conundrum that is worth further thought but which we cannot solve for you.

(2) Making it clear that there is a diagnosis

There comes a moment in the consultation, usually after the examination, when the patient, quite reasonably, expects to be given a diagnosis and some explanation of what that diagnosis means. In our view, it is helpful to do so, although a failure of this most basic step is an outcome that remains common for several reasons.[14]

One is a feeling that this is 'not my problem' and can be dealt with by simply saying, 'There is no neurological disease'. Sometimes this approach arises through ambivalence about the possibility of malingering or exaggeration.[15] Conversely, some doctors, particularly non-neurologists, worry that the diagnosis is not robust. There is good evidence, though, that the diagnosis of a functional neurological disorder can be made accurately by those with an advanced understanding of neurological disease.[1] This means that neurologists are best placed to give and explain the diagnosis.

In the absence of positive evidence of malingering, we suggest that communicating to the patient only that they have 'no neurological disease,' when you know that there is a functional diagnosis, is an abdication of responsibility. The patient with a paralysed leg is not likely to simply think 'that is okay then' and wander home satisfied, any more than a neurologist taking their broken down car to the garage is going to be happy to only be told that the radiator is fine—no problems there; we want our car to work again and the patient wants the same for their leg.

Figure 2 Photo story part 2.

The other common reason for not providing a diagnosis may lie in reattribution techniques, which have been the backbone of general practice and psychiatry teaching in this field over the last 25 years. This way of thinking encourages the doctor to help the patient come to his or her own understanding of the problem using discussion to 'broaden the agenda' and then help the patient 'make the link' between their physical symptoms and emotional state. Doctors trained in this model feel they should approach the problem in this way but are aware that, especially in secondary care, patients often do not welcome this approach. This may lead doctors to abandon all attempts at explanation or conversely to 'formulate' excessively (as studies using conversation analysis found).[16] There are aspects of this that we would support for the purposes of treatment in some cases but adopting a biopsychosocial model means that you have to be prepared to be 'bio' as well as 'psycho' in your world view. This may mean accepting that in some patients, psychological or biological factors are more important than in others. The data for functional disorders do show higher rates of psychological factors but not in everyone.[17] In our experience it is far better to make a clear and positive diagnosis—to focus on a shared understanding as a foundation—before leaping to conclusions about aetiology. Our experience is backed up by trial evidence that does not support reattribution as an effective technique, despite its popularity.[18]

At this point we are often asked 'but what should we actually say?'. In general we favour, as a default position, an explanation along a functional model for reasons we have rehearsed elsewhere,[12] but we do not apply this inflexibly. If we agree with a patient who thinks their symptoms relate primarily to an anxiety disorder but who just wants to make sure there is no sinister cause, we will discuss that openly. A diagnostic label is essential to signify that the symptoms are not a mystery, to communicate with family, friends and health professionals and to signpost further treatment. Ideally that label should concur with the doctor's own model of what the symptoms are, and should not do harm or obstruct treatment. It should preferably indicate what the diagnosis is, and not what it is not. In the absence of evidence you should decide for yourself what is best. Ultimately, though, it is probably true that 'it ain't what you say, it's the way that you say it'.

(3) Demonstrating the rationale for the diagnosis

Many patients with functional disorders have a general feeling that their symptoms are a mystery;[19 20]

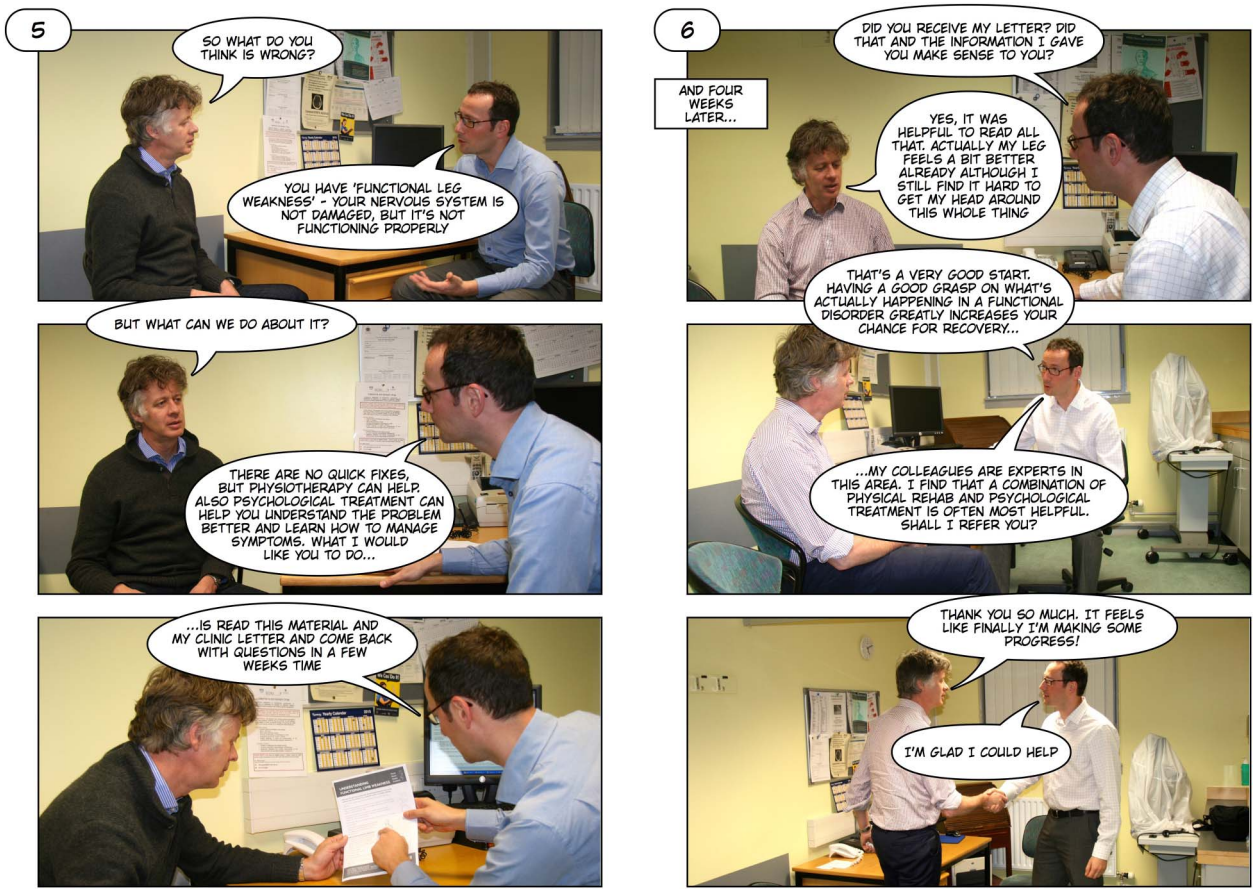

Figure 3 Photo story part 3.

not least because a number of previous doctors have often failed to give a diagnosis. One of the best ways to overcome this is to explain how the diagnosis has been made, for example by showing the patient their Hoover's sign, their entrainment test for functional tremor or by talking them through the positive features of their dissociative (non-epileptic) attack. Functional disorders should not be a diagnosis of exclusion and they may coexist with neurological disease. Asking during the consultation if there were any specific conditions the patient or their family were wondering or anxious about and then explaining why they aren't the case is often helpful. This can all lead on to discuss that this is a common complaint and you have seen it many times before.

(4) Discussing mechanism rather than cause

Clinicians often focus and speculate heavily on the cause when giving patients explanations for functional disorders in a way that they don't, for instance, in discussing migraine.[21]

The reality is that we often have little idea 'why' patients have the symptoms they have. Sometimes there are clear associations with physiological or psychological factors but formulating the problem in this way is fraught with error and speculation. It can be acceptable initially to say simply, "I am not sure why this has happened to you at this point in time". During the initial consultation we would try to redirect questions about 'why' in to questions about 'how'. For example patients with dissociative (non-epileptic) attacks may have an initial event that is syncopal but then it recurs a bit like a panic attack before becoming 'habit-forming'. Discussions like this don't really explain why the attack happened again or the underlying vulnerabilities but provide a more solid basis for understanding the nature of the disorder. Speculation about possible causes is, in our opinion, best left until you have established a proper relationship with the patient and a mutual understanding of the diagnosis. Endlessly seeking evidence of psychological problems or attempting a psychological formulation may be akin to badgering someone about whether they smoke in a TIA clinic. It may be a reasonable question to ask but if they do smoke you won't base your whole treatment of the episode on that fact and if they don't smoke, you will let it go and move on.

(5) Conveying the potential for reversibility and that treatment can help

Figure 4 Photo story part 4.

Instead of philosophically bereft Cartesian discussions about whether the symptoms are neurological or psychological, in the brain or in the mind, try to move the discussion on to whether the symptoms are potentially reversible or potentially irreversible. Feelings of irreversibility can be engendered or misinterpreted by any diagnostic label including functional ('something in the brain I can't do anything about') and psychogenic ('it's down to you and your personality, there's no changing that'). Regardless of label, getting across the point that the symptoms have the potential for improvement, are 'software not hardware' appears crucial with respect to prognosis and attempts at rehabilitation.

(6) Providing written information

The contents of most medical encounters are easily forgotten by patients, especially when conveying complex and new information.[22] Experience with sharing letters and notes with patients is generally favourable, in terms of increasing recall and also improving adherence to treatment recommendations.[23] A clinic letter copied to the patient, which has tailored information combined with generic condition-specific information using a leaflet or website (eg, http://www.nonepilepticattacks.info or http://www.neurosymptoms.org) appears to enhance a good consultation and sometimes rescues an average one.[24]

(7) Triage for further treatment

Ideally the neurological assessment and explanation has been the start of treatment itself.[9] But what happens next? Arguably for a patient with complex symptoms who is trying to understand a diagnosis they have never come across before this should involve a follow-up visit with the person who made the diagnosis. A neurologist is also in a good position to triage patients for psychological and physical treatment, when available, and, if they have sufficient training, to decide which is most likely to help, and when.

CONCLUSION

Regardless of what model or terminology a doctor wishes to use, we would argue that a conventional format of explanation for patients with functional disorders that mirrors what we already do for conditions such as migraine or Parkinson's disease allows for better consultations for patient and doctor.

Some of the issues regarding initial neurological explanation of functional disorders could be subject to randomised clinical trials (eg, which term? what type of information? Does it make any difference if you use a diagnostic label or not?), but some, like treating people decently and being transparent about the diagnostic process should probably never be.

Key points

- Neurologists often find it difficult explaining a diagnosis of functional disorder.
- Follow the normal rules of explanation: tell the patient what it is, not what it isn't.
- Show the patient the positive rationale for the diagnosis (eg Hoover's sign).
- As with any neurological condition start by explaining the mechanism in preference to aetiology.
- Give the patient written information and share the letter you write to their general practitioner.
- Take responsibility for follow up and onward triage.

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