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What should we say to patients with unexplained neurological symptoms? How explanation affects offence

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ABSTRACT

Objectives: Unexplained neurological symptoms (UNS) are common presentations in neurology but there is no consensus as to what they should be called. This is important, as patient acceptance is a predictor of outcome and there is evidence that patients are unhappy with the terms used. Patient understanding of these terms may be limited, however, and, once explained, the terms may seem more or less offensive. We sought to elicit patients' views of 7 frequently used terms for UNS, and whether these changed once definitions were provided.
Methods: 185 participants were recruited from a medical outpatients' waiting area. They were given questionnaires outlining a hypothetical situation of leg weakness, with 7 possible labels. Participants were asked whether they endorsed 4 connotations for each label and the "number needed to offend" (NNO) calculated, before and after definitions were given.
Results: It was found that "functional" was significantly less offensive than other terms used (NNO 17, compared with "Conversion Disorder" NNO 5, $p < 0.001$). Reported understanding of the terms was generally low, however, and many terms became significantly more offensive once definitions were provided. Participants' reported understanding had a significant effect, with low understanding causing terms to be viewed as more offensive after explanation.
Conclusion: Much of the 'offence' in UNS lies not in the terminology but in the meaning those terms carry. This study replicated previous findings that "functional" was less offensive than other terms, even after explanation, but in common with most terms this was partly due to patients' limited understanding of its meaning.

1. Introduction

Unexplained neurological symptoms (UNS) are some of the most common conditions neurologists encounter [1]. Despite this, very little is certain in regard to their aetiology, diagnosis and treatment. On the most basic level, they are understood to be neurological symptoms where there is no evident "organic" neurological lesion [2]. However this condition is clearly more than the mere absence of organic pathology, and the implicit or explicit aetiological inferences to psychiatric causes or malingering may contribute to the unhappiness many patients display when given the diagnosis [3]. It has been suggested that the diagnostic labels used may be part of the problem and from that perspective there have been calls to change the condition's name [4–6]. The equivocal label "Conversion Disorder (Functional Neurological Symptom Disorder)" adopted in DSM 5 illustrates the unique challenge this presents to both clinicians and patients.

Some of this difficulty may arise from the uncertainty of UNS' aetiology and, perhaps consequently, in how best to approach the diagnosis. Originally termed "hysteria", it was attributed to a wandering uterus until at least the 17th century [7], but the failure to find a neurological explanation led to suspicions of feigning [8] – those suspicions partly relieved by the Freudian theory that these effects were subconscious [9]. As Freudian theory has declined in popularity, there is again no consensus on aetiology, conferring significant uncertainty in diagnosing this condition [9], as the diagnosis can sometimes be reliant on neurologists and psychiatrists having confidence in their interpretations. Apart from the understandable concern of misdiagnosis [10], clinicians are often very wary in their approach to these patients due to interactional aspects of the diagnostic encounter where an aetiology is disputed [11]. This has been described as a "crisis for neurology" [12]. Patients describe feeling rejected and unheard [13] and worry they are viewed as fraudulent [14] to the extent that they may disengage from health services [15], or seek alternative opinions [16]. Their rejection of the diagnosis is a key prognostic factor [17].

While there will be multiple influences on a patient's reaction to their diagnosis, there has been a focus on terminology as a key component. This has diverged in parallel with the divergence in aetiology. Surveys of clinicians have found "psychogenic" and "functional" to be popular terms [18], while proposals for the characteristics of an "ideal" term resulted in vocal clinician debate regarding the relabelling of the disorder [19]. There has been surprisingly little research into patient perspectives directly, however. Two surveys revealed a preference for 'functional' for weakness and 'non-

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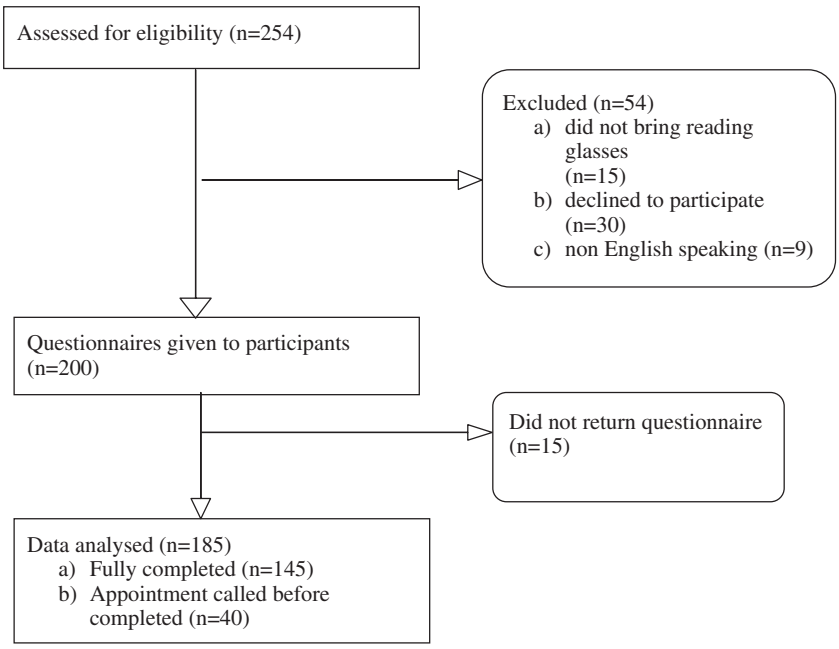

Fig. 1. Recruitment flowchart.

epileptic' for seizures [20,21] but they did not compare acceptance of these to the official psychiatric label of "conversion disorder". More importantly, they did not explore whether and what patients understood by the terms. This presumes that what is offensive is the label itself, yet patients may have little understanding of what the labels mean, and in most clinical encounters the label will be given along with an explanation – which is likely to be at least as important to the patient as the label [22]. It may be that the explanation defuses patient misunderstanding – or it may be that the explanation reveals the offence that the label conceals [23]. This study aimed to determine patients' responses to current terminology, official and otherwise, and if these changed once explanations were provided.

2. Methods

2.1. Questionnaire design

A literature review and consultation with expert members of the UK Functional Neurological Symptoms Group [24] was undertaken to choose the terms and definitions. Consensus definitions for the terms were sought among the group, but as no consensus was achieved we instead opted for definitions for each term provided by a clinician who preferred that term. The questionnaire was piloted and approval by the Austin hospital research ethics committee was obtained before commencement of subject recruitment, with completion of the questionnaire taken as consent.

The questionnaire collected brief demographic data before presenting a hypothetical situation: "Imagine this scenario: You have leg weakness, and all the tests have come back negative. Your doctor may use the following terms to explain your condition." They were then presented with seven terms that could be used for their symptoms ("functional weakness", "psychogenic weakness", "medically unexplained weakness", "somatic symptom disorder", "dissociative disorder", "conversion disorder" and "stroke" - as a control term), and four possible connotations of these: that these would imply they were "imagining symptoms", "faking symptoms", "mentally ill" or had a "medical condition". They were asked to choose as many connotations as they felt applied to each term. They were then asked whether they felt they understood each term (yes/no). Finally, they were given brief definitions for each of the seven terms, and again asked to select the connotations that they felt were appropriate. The full questionnaire, including all instructions, is in the Appendix A.

Participants were recruited from a general hospital outpatient waiting room at the Heidelberg Repatriation Hospital, a hospital in Melbourne's inner suburbs, from February to May 2015. They may have been patients, their carers, friends or family. They were approached by JMD with the request to fill out the questionnaire. Those excluded were only those where capacity was in question or who did not speak English.

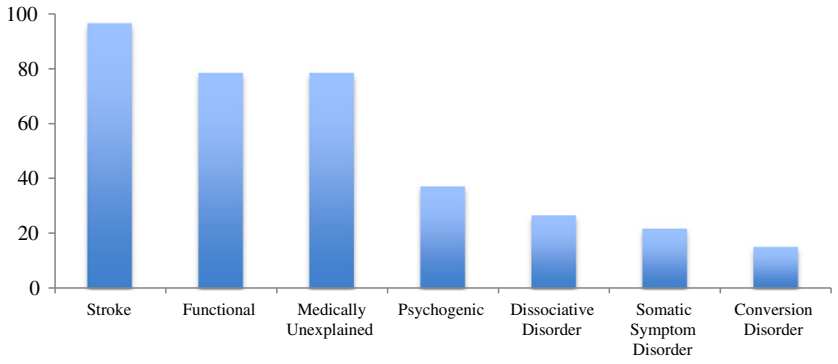

Fig. 2. Percentage of participants reporting understanding of each of the terms (%).