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

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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.

INTRODUCTION

Unexplained neurological symptoms (UNS) are some of the most common conditions neurologists encounter[1]. Despite this, very little is certain in regards 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-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.

METHODS

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.

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.

Data Analysis

Data was analysed with SPSS 21, using Chi-squared and McNemar's tests. The connotations of "faking" and "imagining" were considered offensive, following Stone et al (2002), but "mentally ill" was not. This represents a departure from Stone et al, who included the connotation of being "crazy" as offensive, which of course it is; our term was the less inherently pejorative "mentally ill", which while doubtless still stigmatised, is nonetheless the accepted classification of unexplained neurological symptoms, and explicitly involved in some of the definitions: were we to have considered this to be offensive in our design then those terms would have been 'automatically' deemed offensive whose explanations involved it. By keeping the term in we were able to see what additional 'offence' it conferred. For each term, the proportion of subjects who responded "yes" to one or more of these categories was deemed hypothetically offended and from this, the "number needed to offend" calculated, following the procedure previously described in Stone et al (2002). This represents the number of patients with whom the term could be used until it would offend one person.

Data were analysed before and after they received the descriptions, and compared; the effect of their understanding was explored by an analysis of whether their responses changed, depending on whether or not they reported they understood the term (a change in the response of those having reported understanding the term suggesting they hadn't understood it after all).

RESULTS

Two hundred and fifty-four people were approached. Two hundred agreed, but forty questionnaires were returned only partially complete and fifteen were not returned at all,

resulting in 185 partially- and 145 fully-completed questionnaires (see figure 1). In all cases, partial completion was due to subjects' clinic appointments being called. The partially completed questionnaires were included for those analyses where the relevant section was complete (for example, when they had indicated initial connotations for all seven terms they would be included in initial NNO calculations). The final response rate was 78.7%; 60.3% of participants were female, with a mean age of 48.2 years (range 18-86). The sample had a relatively high level of education attained, with 42.4% completing their education to a tertiary level, and a further 52.7% completing secondary education.

Reported Understanding

The majority of participants reported they did not know the meaning of most of the terms. Less than half of the participants reported understanding the terms "Psychogenic", "Dissociative Disorder", "Somatic Symptom Disorder" and "Conversion Disorder". Interestingly, the current official term of "Conversion Disorder" had the lowest level of self-reported knowledge, with only 15.1% of participants reporting understanding what the term meant. Conversely, "Medically Unexplained" and "Functional" had the highest levels of reported understanding (Figure 2). Of course, self-reported understanding did not always translate into agreement with the definitions provided (see below).

Ranking the offence of terms

"Functional" was the least offensive term both before and after explanation, with no significant difference from the control term "stroke" (McNemar's $p=0.132$). This term was significantly less offensive than the current label of "Conversion Disorder" (McNemar's

$p=0.001$). “Psychogenic” was consistently one of the more offensive terms before and after explanation. The other terms’ rankings changed after a definition had been provided: the most offensive term before explanation was “Somatic Symptom Disorder”, with a number needed to offend of only 3 patients (Table 1); once an explanation had been provided, “Medically Unexplained” became the most offensive term (Table 2).

The effect of explanation on offence

Explanation had a statistically significant effect on the perception of offence overall ($p<0.05$), with all terms affected except “Stroke” and “Functional”. Once an explanation had been provided, “Conversion disorder”, “Psychogenic” and “Medically Unexplained” became significantly more offensive, with “Medically Unexplained” showing the largest increase in offence (figure 3). Conversely, “Somatic Symptom Disorder” and “Dissociative Disorder” became significantly less offensive once an explanation had been provided, causing “Dissociative Disorder” to become one of the least offensive terms overall, on par with the offence level of “Functional”.

The effect of reported understanding on offence

Reported understanding had an effect on the perceptions of terms. Even when subjects reported understanding a term, explanations made a significant difference to the scores for “medically unexplained weakness” and “somatic symptom disorder”. When reported as not understood, unsurprisingly, explanation made a significant difference to many terms: seeing the definition rendered “Functional” more offensive, for example, while “Somatic Symptom Disorder” and “Dissociative Disorder” became less offensive (Table 3).

Interpretations of terms

Offensiveness was calculated as the “number needed to offend” by imputing either feigning or imaging of symptoms. However, there were other connotations of each term. Overall, all terms were largely regarded as medical conditions, with nearly 100% of participants endorsing “functional” as a medical condition, and even “medically unexplained” was considered a medical condition by 60%. In contrast to this, a low proportion of patients (< 20%) viewed any of the terms as indicative of “faking” their symptoms. The term with the highest endorsement of this connotation was “medically unexplained”, especially after the definition had been provided.

“Mentally Ill” had variable responses, with nearly half of the respondents endorsing “psychogenic” and “dissociative disorder” as a mental illness. There was a significant increase in endorsement of “Somatic Symptom Disorder” and “Conversion Disorder” as a mental illness after explanations had been provided. It is important to note that in this study “mentally ill” was not included as a connotation considered offensive (in contrast with previous studies which included being thought “mad” as part of the offence). However, including it in the offence score did not change the ranking nor change the effect the explanation would have.

DISCUSSION

We explored patients and their carers understanding of, and responses to, commonly used terms for UNS, and whether their responses changed following the terms’ explanation. We

found limited understanding of the majority of terms, and this impacted on how they were perceived. “Functional” was initially the least likely to offend, followed by “conversion disorder” and “dissociative disorder”, but most terms became more offensive once an explanation was provided, notably “medically unexplained” and “conversion disorder”. Indeed, “medically unexplained” became the most offensive term after explanation, even though it was a term most thought they understood: one potential source of dispute is clearly when patients think they have understood the clinician to mean one thing, but which on subsequent probing, or their own investigation, they find to be far less benign (in the case of medically unexplained, for example, that the patient may have no medical condition at all). The tendency of doctors to avoid making their diagnoses explicit when they assume resistance [3, 22, 25] may prove effective in avoiding conflict within the session, but is likely to expose patients to the less controllable information sources of the internet and store up that conflict to later.

The acceptability of “Conversion disorder” to patients has never been assessed, though two studies of neurologists have found it uncommonly used[18, 26]. Concerns about its evocation of alarming Freudian ideas seems overblown, as only a small minority of respondents felt they understood what it meant: it was the least reportedly understood of all the terms, and correspondingly few were initially offended by it. However, the attribution that stress is “converted” into a physical symptom does retain some power to offend: after a definition was provided, it became significantly more offensive, though less than either “psychogenic” or “medically unexplained”.

The least offensive term before and after explanation was “functional”. It appeared to be the clear ‘winner’ in this survey, being commonly understood, and no more offensive than

“stroke”. It is a term that fulfils many of the criteria proposed for acceptable terminology[19], with an implicit mechanism but less implication of aetiology. There have been contrasting views as to its usefulness in clinical practice, however. Though initially strongly discouraged due to its ambiguity [18], it has remained popular amongst clinicians for the same reason[23]. This might mean that once the term was explained the loss of ambiguity would increase the offense - as we found: for those unaware of the meaning, “functional” became significantly more offensive once a definition was provided.

This study had several strengths, including a large, diverse sample and a good response rate, the provision of explanation and examination of its effect, and the inclusion of the official psychiatric terms. Its limitations include the use of a hypothetical situation rather than patients with an actual functional disorder; non-inclusion of other popular terms such as “pseudo-”, “non-organic” and “stress related”; and attributing offence to connotations rather than testing these. Though the response rates were reasonable, the sample cannot be considered representative of the general public (all were in outpatients) or of patients (many would have been relatives or carers).

Three previous studies have looked at patient preferences for terminology used to label unexplained leg weakness or blackouts. These studies have shown that “functional” and “stress related” were preferred above other terms, though “non-epileptic” was favoured for non-epileptic seizures[20, 21, 27]. All considered the word in isolation from its possible explanation, and did not consider psychiatric terms.

Though this study explores the effects of explanation to a degree, it does not do so in a truly ‘ecological’ manner: there is no rapport or trust built up with a diagnosing clinician, and there

is no actual symptom to ponder. Likewise, it does not explore offence directly: it assumes that subjects' endorsements are whole-hearted and that the implications are offensive (this is a forced choice scenario, so these implications may only be marginally endorsed, if at all). The ideal study would explore these factors with direct observation of doctor patient encounters in patients being diagnosed with this condition, and followed up to see the relationship of this with outcome, though clearly that is a much more ambitious undertaking.

Conflicts of Interest and Source of Funding

None declared

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Gender: F/M

Age: _____

Highest Level of Education:

- Primary
- Secondary
- Tertiary



Imagine this scenario:

You have been having ongoing leg weakness, and all the tests have come back negative.

Please circle “yes” or “no” to show whether you think your doctor would be suggesting each of the following if he/she said your symptoms were:

“Psychogenic “

- I’m imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Functional “

- I’m imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Stroke”

- I’m imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Medically Unexplained”

- I’m imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Conversion Disorder”

- I’m imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“ Dissociative Disorder”

- I’m imagining my symptoms Y/N

- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Somatic Symptom Disorder”

- I'm imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

Please indicate by circling “y” or “n” whether you think you have a fair idea of what each of those terms mean:

- 1) Psychogenic Y/N
- 2) Functional Y/N
- 3) Stroke Y/N
- 4) Medically Unexplained Y/N
- 5) Conversion Disorder Y/N
- 6) Dissociative disorder Y/N
- 7) Somatic Symptom Disorder Y/N



Your doctor now explains each of the terms. With the explanation in mind, please indicate again whether you think your doctor would be suggesting the following:

“Psychogenic “

Your weak leg is psychological in origin

- I’m imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Functional “

Though there is no problem with your brain or nerves, there is a problem with the way they are working

- I’m imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Stroke”

A blood clot has damaged the part of your brain that moves your leg

- I’m imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Medically Unexplained”

We can’t find any medical problem that could explain your weak leg

- I’m imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Conversion Disorder”

Psychological stress has been converted in your brain into the physical symptom of leg weakness

- I'm imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Dissociative Disorder”

Your weak leg has been caused by a separation between information in different parts of your brain

- I'm imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

“Somatic Symptom Disorder”

Your weak leg is part of a psychiatric disorder in which you experience excessive physical symptoms

- I'm imagining my symptoms Y/N
- I am mentally ill Y/N
- I am faking my symptoms Y/N
- I have a medical condition Y/N

Conflict of Interest

The authors have no conflicts of interest to declare.

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Figures and Tables

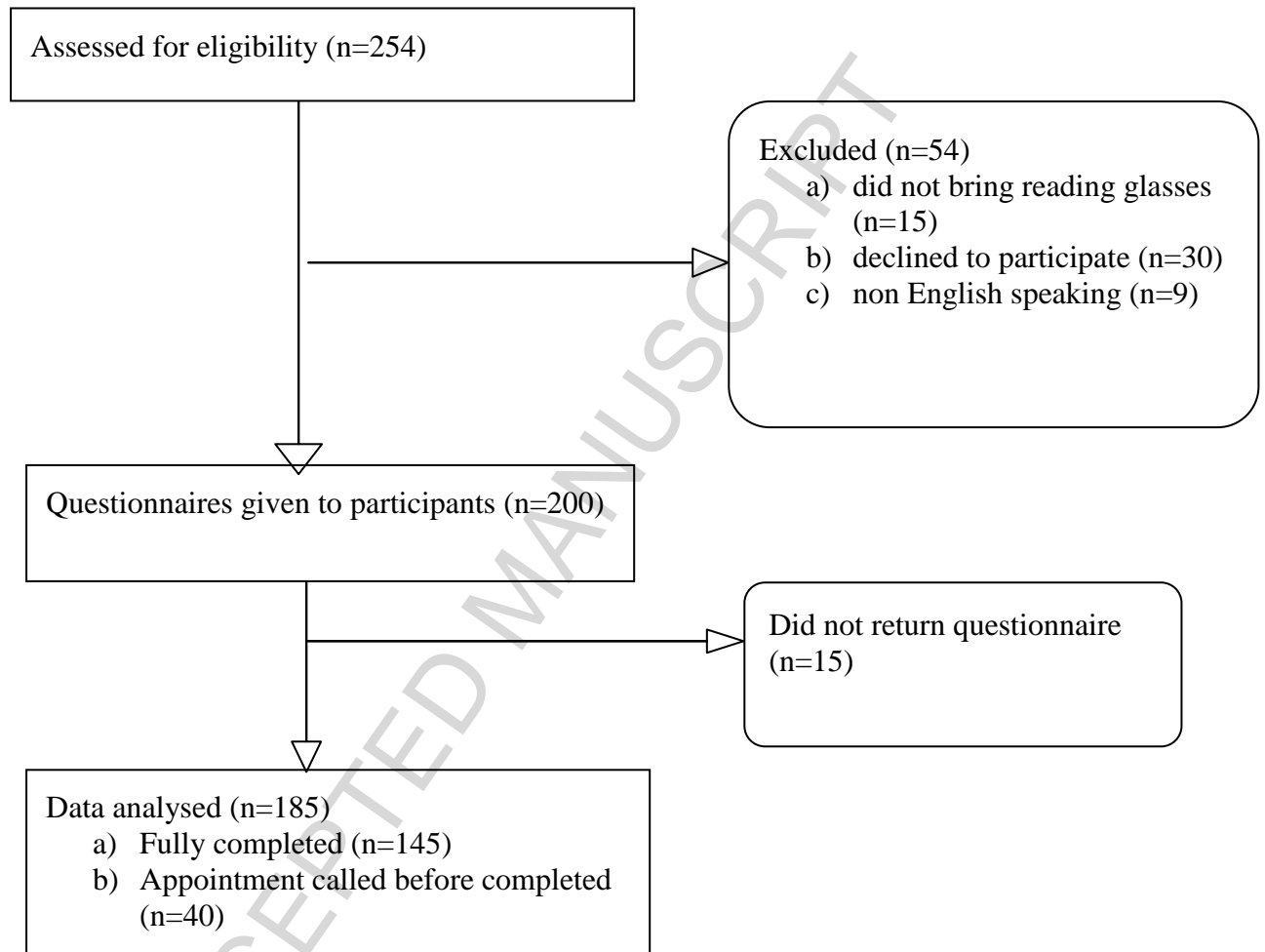


Figure 1: Recruitment flowchart

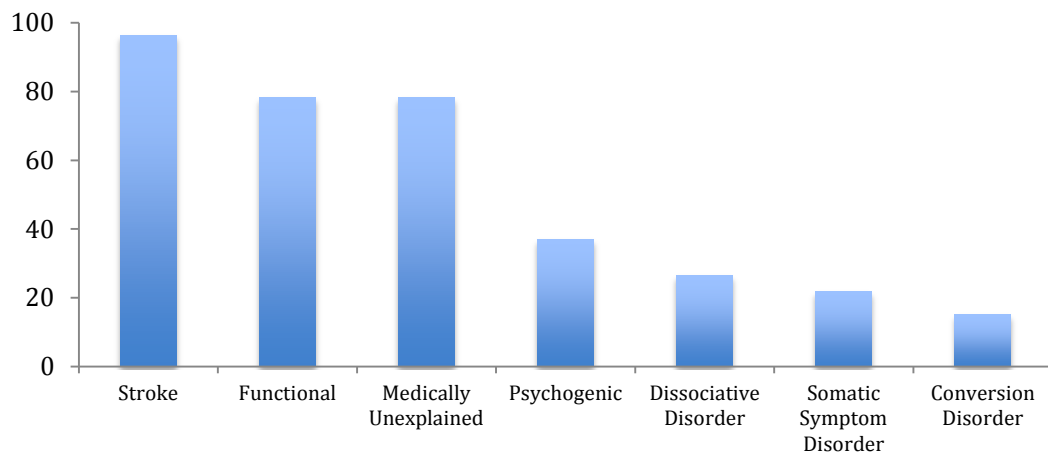


Figure 2: Percentage of participants reporting understanding of each of the terms (%)

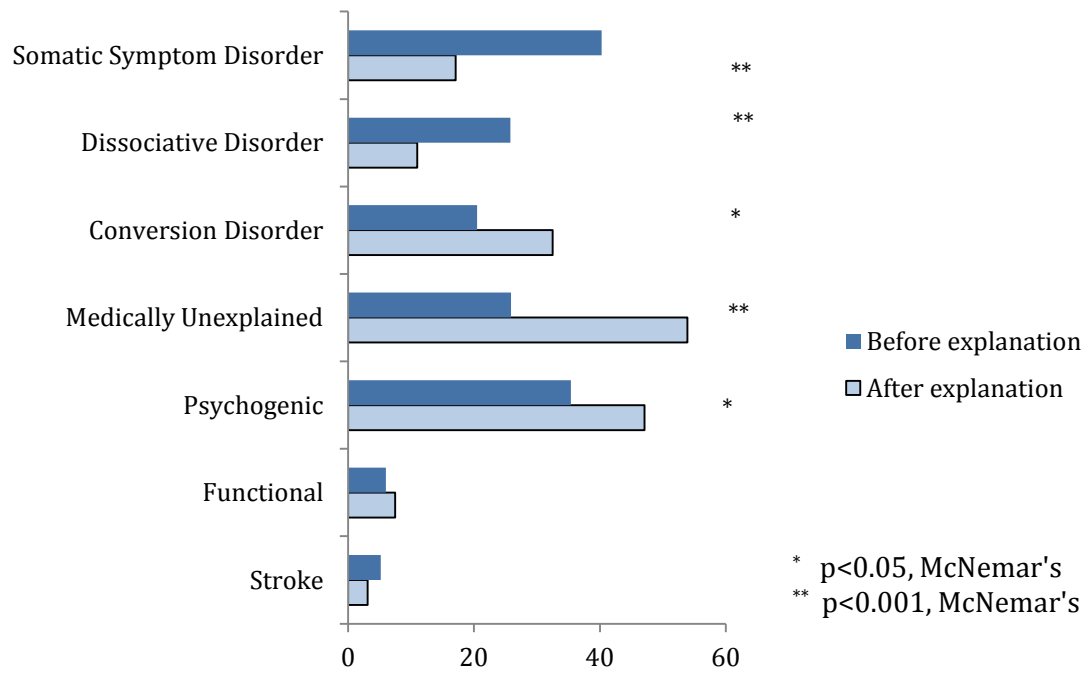


Figure 3: Percentage of subjects offended by each term before and after explanation

Table 1: Offence of each term before explanation was provided: the doctor would be implying that I was “imagining” or “faking” my symptoms if this diagnosis was provided.

<u>BEFORE</u>	<u>Connotations Endorsed (% of patients)</u>					
<u>DIAGNOSIS</u>	<u>Imagining</u>	<u>Faking</u>	<u>Mentally</u> <u>Ill</u>	<u>Medical</u> <u>Condition</u>	<u>Offence</u> <u>Score (%)</u>	<u>Number</u> <u>needed to</u> <u>offend</u>
Stroke	2.3	3.4	2.3	92.8	5.2	19
Functional Weakness	4.1	1.8	4.7	89.5	6.0	17
Conversion Disorder	15.9	7	15.9	66.2	20.5	5
Dissociative Disorder	23.7	4.5	31.2	54.8	25.8	4
Medically Unexplained	21.7	12	9	60.6	25.9	4
Psychogenic	33.9	4.8	32.1	5.8	35.4	3
Somatic Symptom Disorder	34.8	11.6	16.3	56.8	40.3	3

Table 2: Offence of each term after an explanation was provided: the doctor would be implying that I was “imagining” or “faking” my symptoms if this diagnosis was provided.

<u>AFTER</u>	<u>Connotations Endorsed (% of patients)</u>					
<u>DIAGNOSIS</u>	<u>Imagining</u>	<u>Faking</u>	<u>Mentally</u> <u>Ill</u>	<u>Medical</u> <u>Condition</u>	<u>Offence</u> <u>Score (%)</u>	<u>Number</u> <u>needed to</u> <u>offend</u>
Stroke	3.8	0	3.8	97.5	3.1	32
Functional Weakness	7.5	1.3	6.9	92.5	7.5	13
Dissociative Disorder	10.3	3.2	28.6	76.8	11.0	9
Somatic Symptom Disorder	17.1	2.6	53.9	65.1	17.1	6
Conversion Disorder	32.5	3.2	28.6	58.2	32.5	3
Psychogenic	46.2	6.4	26.1	52.8	47.1	2
Medically Unexplained	48.4	20	9.6	40.6	53.9	2

Table 3: Effect of understanding on change in offence for each term

TERM	Change in offense if there was reported understanding (McNemar's)	Change in offense if there was no reported understanding (McNemar's)
Stroke	No	No
Functional Weakness	No	More offensive $p < 0.001$
Psychogenic Weakness	No ($p = 0.057$)	More offensive $p = 0.004$
Medically Unexplained Weakness	More offensive $p < 0.001$	More offensive $p < 0.001$
Conversion Disorder	No	More offensive $p = 0.044$
Dissociative Disorder	No	Less offensive $p < 0.001$
Somatic Symptom Disorder	Less offensive $p = 0.003$	Less offensive $p < 0.001$

Highlights

Previous studies have shown that patients find “functional” to be the least offensive term, but this has not been compared to the current term of “Conversion Disorder”, nor have previous studies explored patient understanding.

This study has found that patients have poor understanding of the majority of terms for unexplained neurological symptoms, and that defining them typically makes them appear more offensive. This was particularly true of “conversion disorder”.

“Functional” remains the least offensive term, though this may be partially attributed to poor understanding of its meaning.