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Hiding in plain sight – functional neurological disorders in the news

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Title:

Hiding in plain sight – functional neurological disorders in the news

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Abstract

Background: Functional movement and seizure disorders are still widely misunderstood and receive little public and academic attention. This stands in stark contrast to their high prevalence and levels of associated disability.

Objective: In an exploratory observational study we examined whether the relative lack of media coverage of functional neurological disorders is in part due to misidentification in “human interest” news stories.

Methods: Thirteen recent news stories from high-impact English language media outlets that portray patients with complex symptoms either attributed to other diagnoses or presented as medical mysteries were identified using online keyword searches. All selected news stories contained film or images displaying relevant symptoms. Cases were grouped as “movement disorders” or “seizure disorders” and were then independently assessed by 10 respective expert raters. For each group one story of a patient whose symptoms were due to a well-recognised neurological disease was also included. Both the diagnostic category and the respective confidence level were reported by each rater for each case. The interrater agreement was calculated for each group of disorders.

Results: The raters confirmed almost unanimously that all presented news stories except the negative control cases portrayed misidentified functional movement or seizure disorders. The interrater agreement and average diagnostic confidence were high.

Conclusions: Functional neurological disorders are often wrongly considered a rare medical curiosity of the past. However, our findings suggest that while they are largely absent from public discourse, they often appear in the news incognito, hiding in plain sight.

Introduction

There is a reason why functional neurological disorder (FND), also known as conversion disorder and, in the past, hysteria, has not shed its mythology and stigma. Unlike other long misunderstood illnesses, such as epilepsy or AIDS, FND cannot be detected using electroencephalography or immunoassays. Instead, routine laboratory and imaging findings are typically normal, and so for large parts of the medical community and the public, FND has remained an elusive 'medically unexplained' disorder, diagnosed by exclusion, almost indistinguishable from malingering. These assumptions, however, are wrong. Whether it manifests as a movement disorder or seizures, FND can be identified with confidence by physicians on the basis of phenotype-specific clinical signs (see table 1 for examples).{1-3} These tried and tested signs have been incorporated into validated sets of diagnostic criteria. In fact, when the diagnosis of FND is made by a specialist (in around 15% of all neurology presentations) it is accurate, and remains stable over time.{4,5}

This discrepancy is mirrored in a more general misunderstanding of FND by the public. Long marred by social stigma, FND has been a confusing and shameful diagnosis for many patients. It is not surprising, thus, that patients can be reluctant to agree with a diagnosis of FND. Physicians, on the other hand, themselves often uncertain about their "diagnosis by exclusion", will accommodate patients' reluctance by repeating tests and scans until a false positive or unrelated finding redirects the course of treatment. At this point "alternative", less evidence-based explanations can be offered by well-meaning practitioners of different persuasions. Patients with FND can find themselves on tortured journeys through a multitude of clinics, and the eventual diagnosis of FND—especially if explained poorly—is often met with skepticism. Sometimes these patient journeys will appear in social media, where misidentified FND will be showcased unknowingly. On YouTube, for example, two-thirds of the most viewed movement disorders videos uploaded by patients have been found to show functional (psychogenic) movement disorders.{6} Surprisingly, however, news articles portraying and discussing FND are a rarity. Are affected patients shunning the limelight, or are journalists and the public not interested in FND? A few high-profile cases of misidentified functional

neurological disorders in news stories {7-9} have suggested a different interpretation: FND is hiding in plain sight, wrongly attributed to neurological disease or labeled as medical "mystery".{8} To test this hypothesis we conducted an informal observational study.

Methods

News stories were identified through non-systematic online searches using Google's video search and the online search function of news outlets by the study coordinators (S.P., T.R.N., J.S.). Implementing a strictly formulated systematic search strategy was infeasible due to the vastness of online media content and the variability of terminology encountered in such articles. The following criteria were used to select appropriate news stories: English language; major media outlet; content available online; published within the last 5 years; available material (including video or pictures) sufficiently detailed to offer independent experts an opportunity to make a diagnostic judgement; case not already subject to wide public debate; neurological symptoms portrayed likely mostly functional based on positive criteria{1-3}; functional ("psychogenic") etiology not acknowledged. Ultimately, 13 news stories that fulfilled all criteria were selected. The news stories came from the following sources: BBC (4), CNN (3), FOX (1), Las Vegas Review-Journal (1), The Telegraph (1), ABC News (1), Coventry Telegraph (1), and The Guardian (1).

To test whether these news stories indeed portrayed unacknowledged or misidentified FND, they were presented to a group of expert raters. The news stories were split into two groups, 'seizures' and 'movement disorders'. One news story was featured in both categories (case 5 in 'seizure' group and case 2 in 'movement disorders' group), since both symptoms were reported and portrayed. For each category, a news story showing a relatively rare, but presumably 'organic' neurological disease was also added as a negative control case to counteract the inherent rater bias of participating in a study on FND in media. These control cases were otherwise chosen using the same selection criteria (sources: FOX and KGW). Raters were told that there would be "at least one" news story with a presumed 'organic' underlying disease to encourage critical consideration of competing etiologies.

Ten movement disorders specialists and ten epileptologists representing a broad field of clinical and research expertise were asked to participate in the study as expert raters. Each rater was independently given a form with instructions and a table including 8 news stories (7 per group including one case that had both movement disorder and seizures; plus one control case). Raters were asked to judge whether the symptoms seen in each news story were most likely functional (psychogenic) or due to a neurological disease such as primary dystonia or epilepsy. Information from the article text could also be considered. Since dual pathology is possible, the task was to decide which etiology was most likely to explain the symptoms to a large extent or completely, and provide a dichotomous answer. Raters were then asked to indicate their diagnostic confidence on a numerical 0-10 confidence scale (0 – no confidence; 10 – absolutely confident) for each case. Lastly, raters were asked to freely report specific signs or features that influenced their diagnostic decisions in order to encourage decisions on the basis of identifiable positive clinical signs.

Although all patients presumably gave consent to be portrayed in publicly accessible media outlets, a re-diagnosis without face-to-face consultation, while clinically possible in some cases, is ethically problematic{9}; thus we are not publishing the source details of the specific news stories. The original rating forms including the sources of news stories (URL links) were made available to the journal editors and peer reviewers, but are not referenced in this article. No clinically obtained patient data was used in this study, so ethics committee approval was not sought.

To calculate interrater agreement, Cohen's Kappa (κ) was calculated according to the Fleiss-Cuzick extension{10} using StatsDirect statistical software (Cheshire, UK) and interpreted as 'poor', 'fair', 'moderate', 'good' or 'very good' according to categorization by Landis and Koch.{11}

Results

Table 1 provides a summary of the news stories in the 'movement disorders' category. In 6 of the 7 cases with presumed functional movement disorders, agreement among raters was 100% with an average confidence rating of 9.3 out of 10. In 1 case, there was disagreement, with 9 of 10 raters

judging it to be a functional movement disorder with an average confidence rating of 7.8/10. The 'negative control' (case 8) was unanimously identified as 'organic' (mean confidence rating 9.5). The overall interrater agreement for the 'movement disorders' category including the control case was κ = 0.89 ('very good'; 95% CI: 0.79 – 1.00; $p < 0{,}0001$).

Table 2 provides a summary of the news stories in the 'seizure' category. In 5 of the 7 cases with presumed dissociative attacks, agreement among raters was 100% with an average confidence rating of 8.9 out of 10. In 2 of cases, there was some disagreement, with 9 of 10 raters judging cases 1 and 6 to be 'psychogenic' with average confidence ratings of 8.6 and 5.7 respectively. The 'negative control' (case 8) was unanimously identified as 'organic' (mean confidence rating 8.5). The overall interrater agreement for the 'seizure' category including the control case was κ = 0.80 ('very good'; 95% CI: 0.70 – 0.91; $p < 0.0001$).

Discussion

Our study identified 13 highly probable cases of FND in news media stories which were not recognized as such and, in eleven of these cases, were reported as other medical conditions. Cases were divided into two categories (seizures and movement disorders) and presented to raters along with one 'negative control case' to counteract bias. In both groups, raters confidently and mostly unanimously judged that cases indeed showed FND, and not, as often suggested in the news stories, neurological symptoms caused by diseases such as Lyme disease or epilepsy.

Dissociative seizures (also known as psychogenic nonepileptic seizures [PNES]) and functional (or "psychogenic") movement disorders and are common forms of FND. The reliability of video-based remote diagnosis has been investigated for both disorders. Experienced epileptologists can correctly identify dissociative seizures in about 85% of cases from video alone.{13,14} The more experience physicians have with dissociative seizures, the higher the rate of correct diagnosis via video.{15} The diagnosis of functional movement disorders is based on positive clinical features such as distractibility, inconsistency and incongruence with neurological diseases, and can be aided by

phenotype-specific signs such as give-way weakness or tremor entrainment.{1,3} Interrater agreement on video-based diagnosis has been variable and appears to be dependent on the difficulty of cases.{16,17} However, there is yet no laboratory test to serve as 'gold standard' and validate clinical judgment of experts.{18} Our specifically pre-selected videos/articles can be assumed to represent more "clear-cut" cases of functional movement disorders, which probably explains the high interrater agreement in our study. Similarly, a study in which experts rated functional movement disorders in popular YouTube videos yielded very high interrater agreement.{6}

There are various potential reasons for the misrepresentation of FND in news media. A major factor is probably the high rate of underdiagnosis of these disorders by physicians. Around 30% of patients seen at epilepsy centers for refractory seizures will not have epilepsy, and a large portion of those have dissociative seizures.{19} The high rate of misdiagnosis is furthermore evident in the exceptionally long diagnostic latency of about 5-10 years for those that are eventually recognized correctly as dissociative seizures.{19,20} While there are no studies quantifying the rate of misdiagnosis of functional movement disorders as 'organic' diseases, FND in general regularly figure in statistics of misdiagnoses of other neurological disorders. In a study of 110 patients misdiagnosed as having Multiple Sclerosis, the underlying reason was FND in 11% and fibromyalgia in 15%.{21} In stroke medicine, FND account for 28-47% of all retrospectively recognized stroke mimics mistakenly treated with intravenous tissue plasminogen activator.{22,23} Naturally, when FND is missed by neurologists, who typically worry more about missing structural than functional disorders, neither patients nor journalists should be expected to identify it in human interest stories. In addition, patients with unresolved diagnoses are arguably more likely to seek redress or validation through the media.

Even when FND is correctly recognized by a physician, patients can often be left unsure or unaccepting about the essence and certainty of their diagnosis.{24} Neurologists often hold negative views on FND,{25} find little about FND in their textbooks or curricula,{26} have concerns about diagnostic certainty or malingering,{27} and often assume a pre-emptively defensive stance when communicating the diagnosis.{28} Patients are often presented with outmoded or overly narrow

versions of psychosomatic models which are liable to be interpreted in offensive terms.{29} Many wonder why there is no radiologic or laboratory "proof" of diagnosis, and some hold on to strong views about alternative diagnoses.{24,30} Crucially, physicians and therapists need to help patients and the public understand the central role of positive clinical signs in the diagnostic process.{1-3} High-tech brain scans and novel antibodies make for impressive headlines, but they are not how movement disorders or seizures are primarily diagnosed. Neurologists need to communicate the reliability of clinical signs and syndrome classification in order to bring across why a functional neurological disorder is not a “dustbin” diagnosis, but a common, well-recognized and potentially treatable condition. Finally, the lack of established treatment services in many places might also explain why FND patients are prone to seek help and validation online or through news media.{6} Possibly underlying some of the above issues, and certainly a factor on its own, there has traditionally been a distinct absence of positive or neutral public awareness of FND. Thankfully this is beginning to change.

FND Hope (www.fndhope.org) and FND Action (www.fndaction.org.uk) are newly established patient-led organizations promoting awareness of the disorder and its treatment. In a few rare instances, individuals with FND have recently been profiled in informed and positive news stories.{31-33} The Movement Disorders Society has a new Functional Movement Disorders Study Group to aid international collaboration, and the International League against Epilepsy has an active Psychogenic Non-Epileptic Seizures Task Force. The Functional Neurological Disorder Society will be inaugurated shortly, and provide a platform and resource for all healthcare professionals, scientists, students, and members of the lay public who are interested in FND. Lifting the stigma and mystery surrounding FND will require a shift in attitudes, both medical and societal. Psychiatrists, neurologists, psychologists, physiotherapists, occupational therapists and everyone else who is involved in caring for patients with FND need to work together towards improving health care provision for this common and disabling disorder. The medical community needs to engage in interdisciplinary and collaborative publicity efforts with patients, artists, journalists, and policy

makers in order to break the cycle of misconceptions and misrepresentation, and lead FND back out of hiding.

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TABLE 1: Movement disorders portrayed in selected news media stories[a]

				Rated functional		Rated 'organic'		
Case	**Year**	**Age, sex**	**Diagnosis in news story**	**% of raters**	**mean confidence[b]**	**% of raters**	**mean confidence[b]**	**Selected positive signs[c]**
1	2016	36 M	dystonia, dystonic storms	100%	9.4	0%	-	asynchronous clonic movements; rhythmic pelvic movements; variable tremulous movement; abnormal movements seem activated by a light tactile stimulus
2	2012	16 F	Lyme disease	100%	9.9	0%	-	non-economic posture while walking, extreme variability; incongruence; attention modulation
3	2016	n/a M	tremor, medication-induced	100%	9.9	0%	-	whack-a-mole sign; tremor in different directions; volitional control to stop tremor
4	2017	27 F	dystonia, drug-induced	100%	9.7	0%	-	lip-pulling sign; huffing and puffing sign; crouched gait; mixed and incongruent phenomenology
5	2017	n/a F	unnamed condition	100%	7.9	0%	-	huffing and puffing sign; clenching fist in absence of spasticity/parkinsonism; gasping for air but not during speech; dragging gait; bilateral fixed ankle posturing with inversion; fixed dystonia
6	2013	41 F	dystonia	100%	9.2	0%	-	"other Babinski" sign; lip-pulling sign, symmetry of platysma contraction
7	2016	n/a F	surgery-induced tremor	90%	7.8	10%	8.0	variability of frequency and amplitude of tremor; pause with ballistic movement; distractible
8[d]	2015	35 M	dystonia	0%	-	100%	9.5	striatal postural deformities; patterned dystonic postures; scoliotic dystonic trunk abnormality

[a] n/a=information not available; M=male; F=female

[b] numerical 0-10 confidence scale (0 – no confidence; 10 – absolutely confident)

[c] Raters were prompted to report any signs that influenced their diagnostic decision; selected signs identified by one or more raters are listed here.

[d] control case

TABLE 2: Seizures portrayed in selected news media stories[a]

				Rated 'psychogenic'		Rated 'organic'		
Case	**Year**	**Age, sex**	**Diagnosis in news story**	**% of raters**	**mean confidence[b]**	**% of raters**	**mean confidence[b]**	**Selected positive signs[c]**
2	2015	35 F	epilepsy	100%	9.4	0%	-	eyes closed; waxing/waning; body thrusting; movements mild with no suggestion of increased tone
3	2016	23 M	unknown disease	100%	7.6	0%	-	side to side head shaking, forced eye closure; rolling side to side; markedly variable manifestations; semi-purposeful movements
4	2015	21 F	clinically dead due to POTS	100%	9.4	0%	-	buildup of the event with hyperventilation; prolonged floppy unresponsiveness
5	2012	16 F	seizures due to Lyme disease	100%	9.5	0%	-	ictal crying; asynchronous low amplitude tremulous shoulder movements
6	2016	16 F	seizures	90%	5.7	10%	2.0	sudden loss of consciousness with intense emotion; prolonged unresponsiveness; no apparent premonitory symptoms or signs
7	2015	21 F	seizures due to mast cell disease	100%	8.4	0%	-	closed eyes; asynchronous side to side head and shoulder movements
8[d]	2016	10 F	seizures	0%	-	100%	8.5	eyes open; eye deviation to the side; rhythmic, synchronous tonic clonic movements

[a] POTS=postural orthostatic tachycardia syndrome; M=male; F=female

[b] numerical 0-10 confidence scale (0 – no confidence; 10 – absolutely confident)

[c] Raters were prompted to report any signs that influenced their diagnostic decision; selected signs identified by one or more raters are listed here.

[d] control case