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Article:

Ludwig, L., Whitehead, K., Sharpe, M. et al. (2015) Differences in illness perceptions between patients with non-epileptic seizures and functional limb weakness. *Journal of Psychosomatic Research*, 79 (3). pp. 246-249. ISSN: 0022-3999

<https://doi.org/10.1016/j.jpsychores.2015.05.010>

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Differences in illness perceptions between patients with non-epileptic seizures and functional limb weakness.

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Keywords: Psychogenic non-epileptic seizures; Functional weakness; Conversion disorder; Epilepsy
Illness perception; Neurology

Word Count excluding abstract and tables: 1590

Abstract 259

Abstract

Objectives

Illness perceptions are considered to play an important role in the onset and maintenance of symptoms in Functional Neurological Symptom Disorder (Conversion Disorder). There has, however, been little work examining differences between subtypes of this disorder. We therefore aimed to compare illness perceptions of patients with non-epileptic seizures (NES) and those with functional weakness (FW) with matching neurological disease controls to examine their specificity.

Methods

The Illness Perception Questionnaire Revised (IPQ-R) was completed by patients with functional limb weakness, non-epileptic seizures and patients with neurological disease causing limb weakness and epilepsy in two separate case control studies.

Results

Patients with FW (n=107), NES (n=40), Epilepsy (n=34) and neurological disease causing limb weakness (NDLW) (n=46) were included in the analysis. Both FW and NES patients reported a low level of personal control, understanding of their symptoms and a tendency to reject a psychological causation of their symptoms. However NES patients rejected psychological causes less strongly than FW patients ($p<0.01$), including the single 'stress' item of the IPQ-R ($p<0.01$). Patients with NES were also more likely to consider their treatment to be more effective ($p<0.01$). None of these differences appeared in a similar comparison between patients with epilepsy and patients with NDLW.

Conclusion

Although patients with NES tend, as a group, to reject psychological factors as relevant to their symptoms, they did so less strongly than patients with functional limb weakness in these cohorts. This has implications for both the way in which these symptoms are grouped together but also the way in which explanations and treatment is approached.

Introduction

Illness perceptions are considered to have an important impact on outcome in functional neurological symptom disorder (FNSD/Conversion Disorder) [1][2]. Compared to patients with similarly disabling neurological diseases, such as multiple sclerosis or epilepsy, patients with functional limb weakness and non-epileptic seizures typically have quite similar illness perceptions regarding the impact of their symptoms but are less likely to endorse psychological factors as causes [3][4][5].

Symptoms of seizures and weakness have always been grouped together within DSM Conversion Disorder because: 1) both present to neurological services, 2) they co-exist in the same patient much more often than chance, 3) there are patients who have intermediate forms of the disorders (e.g. paroxysmal movement disorders that could also be considered 'seizures' or patients whose NES leave them with more persistent functional limb weakness), 4) **both presentations have traditionally been conceptualized to share a similar etiological (psychogenic, conversion) explanation.** However, data comparing these two groups is scarce [6–9] and no previous studies have focused on illness perceptions.

We therefore aimed to compare the illness perceptions of two well-characterised cohorts of patients with NES and FW. Additional disease controls with matching symptoms (patients with weakness caused by neurological disease or with epilepsy) allowed us to investigate whether any differences between groups related specifically to conversion disorder rather than more generally to the experience of having attacks or limb weakness. Data from these two cohorts have previously been analysed to explore differences between patients with functional and neurological limb weakness [4], patients with non-epileptic seizures and their doctors [5], and between relatives of patients with functional symptoms or symptoms of neurological disease [10]. However, none of the previous studies have examined differences between the two different functional symptom groups and the specificity of these.

Methods

Recruitment

Patients were prospectively and consecutively identified from Clinical Neurology departments with the following diagnoses: functional weakness of a limb (FW), neurological disease causing limb weakness, (NDLW) (Department of Clinical Neurosciences, Edinburgh (1999-2002) [4]), epilepsy

(EP) or non-epileptic seizures (NES) (diagnosed on the basis of video EEG recordings of typical seizures conforming to a 'documented' level of diagnostic certainty, Department Clinical Neurology, Sheffield, 2009-11)[5] [11]. Inclusion criteria were: symptom onset within last two years (FW and NDLW only since the recruitment protocol for NES did not specify a duration); not "partly functional/partly organic diagnosis" / not mixed epileptic and non-epileptic seizures (ES and NES only); age over 16, able to read English. Patients completed the Illness Perception Questionnaire-Revised (IPQ-R)[12] and the Hospital and Anxiety Depression Scale (HADS) [13] after seeing a consultant neurologist but prior to being seen by the research fellow for an assessment (FW and NDLW) or, in the case of Epilepsy and NES, before the outcome of the video-EEG recording had been discussed with them.

Further details of recruitment and other clinical and self-report data can be found elsewhere [4] [5]. Ethical approval was provided by the Lothian Research Ethics committee (FW) and Sheffield Research Ethics Committee (NES).

Measures and Analysis

The IPQ-R is a 38-item self-report questionnaire in order to assess patients' illness perceptions [12]. Eight Subscales are rated on a five-point Likert scale ranging from strongly agree to strongly disagree (for a detailed description please see below, Table 2). We excluded the Identity subscale, a list of physical symptoms, as it was not collected in the seizure samples. Additionally, we grouped a list of 18 possible "causes" into psychological/emotional (items 1,9-12, and 17; "stress", "my mental attitude", "family problems", "overwork", "my emotional state" and "my personality") (Cronbach's α = .864) and non-psychological (items 2-8, 13-16, and 18; e.g. "hereditary", "germ or virus", "poor medical care in the past", "accident or injury").

The Hospital Anxiety and Depression Scale (HADS) [13] is a widely used and validated measure of anxiety and depression in patients with physical symptoms.

We used SPSS Statistics 21 to compare the functional groups (NES vs FW) and the neurological groups (EP vs NDLW) on age, gender, HADS score, and IPQ-R data. We used t-tests where data was normally distributed (Kolmogorov Smirnov test) or non-parametric Mann-Whitney U tests where it was not. Because of multiple testing, we conservatively interpreted two-sided p values of ≤ 0.01 as significant. We calculated Cohen's d effect sizes for significant differences.

Results

We recruited 107 patients with FW, 46 with NDLW (commonest diagnoses multiple sclerosis (n=27), Guillain-Barré syndrome (n=4) and others[4]), 40 with NES and 34 with epilepsy. There were no age or gender differences between FW and NES groups (Table 1). Symptom duration in the NES and Epilepsy groups was significantly longer compared to the FW and NDLW groups in keeping with different recruitment protocols at the two sites. There were no significant differences in anxiety or depression scores between patients with FW and NES or between NDLW and epilepsy.

The IPQ-R results for all four groups are shown in Table 2. Although both NES and FW groups tended to reject psychological explanations, NES patients rejected them less strongly than FW patients ($p < .01$, effect size $d = 0.49$, medium effect). This was also true for the single item asking whether 'stress' was a possible cause of their illness ($p < .01$, effect size $d = 0.56$, medium effect). This item, together with the other 'psychological causation' items are shown in Figure 1 for the FW and NES cohorts.

Although both groups agreed that the conditions had major consequences on their lives, FW patients reported a relatively lower effect of the condition on themselves and their families, compared to patients with NES ($p < .01$, effect size $d = 0.44$, small effect).

NES patients also considered the effectiveness of treatment to be higher than FW patients ($p < .01$, $d = 0.52$, medium effect).

There were no differences between patients with FW and NES in terms of their perception of the cyclical nature or the long duration of their disorders (Timeline), personal control over their condition (Personal control) understanding of their condition (Illness Coherence) or the perceived emotional impact (Emotional representation).

Patients with Epilepsy estimated the degree of personal control as significantly lower than patients with NDLW ($p < .001$, effect size $d = 0.84$, large effect). No other differences were found between Epilepsy and NDLW.

Table 1. Demographic and HADS scores in all four groups.

Overall Condition	Functional Neurological Disorders			Neurological Disorders		
	Non-epileptic seizures (NES) (n=40)	Functional weakness (FW) (n=107)	Two sided p-value	Epilepsy (n=34)	Neurological Weakness (NDLW) (n=46)	Two sided p-value
Age (yrs, mean, range) ^a	37.0 (18-66)	39.1 (17-67)	.41	33.2 (17-64)	39.3 (18-63)	.02
% female ^b	62.5%	79.4%	.053	79.4%	82.6%	.717
Median duration of primary symptom (months, range) ^c	24 (0-504)	9 (7-27) ^e	< .001	108 (12-456)	11 (1-30) ^e	< .001
Mean (s.d.) HADS anxiety score ^{a,d}	10.2 (5.6)	8.6 (5.3)	.141	7.9 (4.1)	7.2 (4.7)	.500
Mean (s.d.) HADS depression score ^{a,d}	7.8 (5)	7.6 (5.1)	.843	5.5 (3.5)	5.8 (4.4)	.765

^a t-test

^b Pearson's chi-squared test

^c Mann-Whitney U test

^d data missing for FW n=11, NES n=6, NDLW n=6

^c FW (n=2, 25+27 months) and NDLW (n=1, 30 months) had weakness duration over 24 months

Table 2. Comparison of adapted IPQ-R scores for all patients with Non-Epileptic Seizures (NES) compared with Functional Weakness (FW), and Epilepsy (EP) compared with neurological disease causing limb weakness (NDLW). All scores are normalised to a 1-100 scale. t-test unless otherwise specified.

IPQ-R subscales	Interpretation of higher score	IPQ-R score, mean (s.d.) and statistical comparison between NES and FW			IPQ-R score, mean (s.d.) and statistical comparison between EP and NDLW		
		Functional Neurological Disorders			Neurological Disorders		
		NES (n=40)	FW (n=102)	Two sided p-value	EP (n=34)	NDLW (n=43)	Two sided p-value
Psychological causal attributions	Greater endorsement of six psychological causes	36 (24)	25 (21)	.009	39 (19) ^b	35 (20)	.403
Stress (single item)	Agrees with stress as a cause of illness	54 (36)	34 (33)	.004 ^a	67 (30)	59 (29)	.241 ^a
Consequences	Condition has great effect on patient and family	71 (19)	62 (21)	.019 ^a	68 (19)	68 (17)	.947
Treatment control	Treatment is effective for condition	61 (15) ^b	53 (15)	.004 ^a	54 (18)	53 (18)	.819
Timeline (cyclical)	Condition is cyclical	60 (20)	55 (25)	.257	63 (17)	54 (22)	.048
Timeline (acute/chronic)	Condition will have long duration	58 (16)	51 (21)	.041 ^a	63 (21)	69 (25)	.250
Personal control	Patient has high level of control over condition	42 (19)	46 (17)	.167	35 (19)	52 (20)	.000
Illness Coherence	Greater understanding of the condition	32 (26) ^b	24 (19)	.160 ^a	44 (25)	50 (24)	.290
Emotional representations	Greater emotional impact on patient	62 (27) ^c	56 (22)	.261	60 (24)	62 (19)	.746

^aMann-Whitney U test

^bdata missing for n=1

^cdata missing for n=2

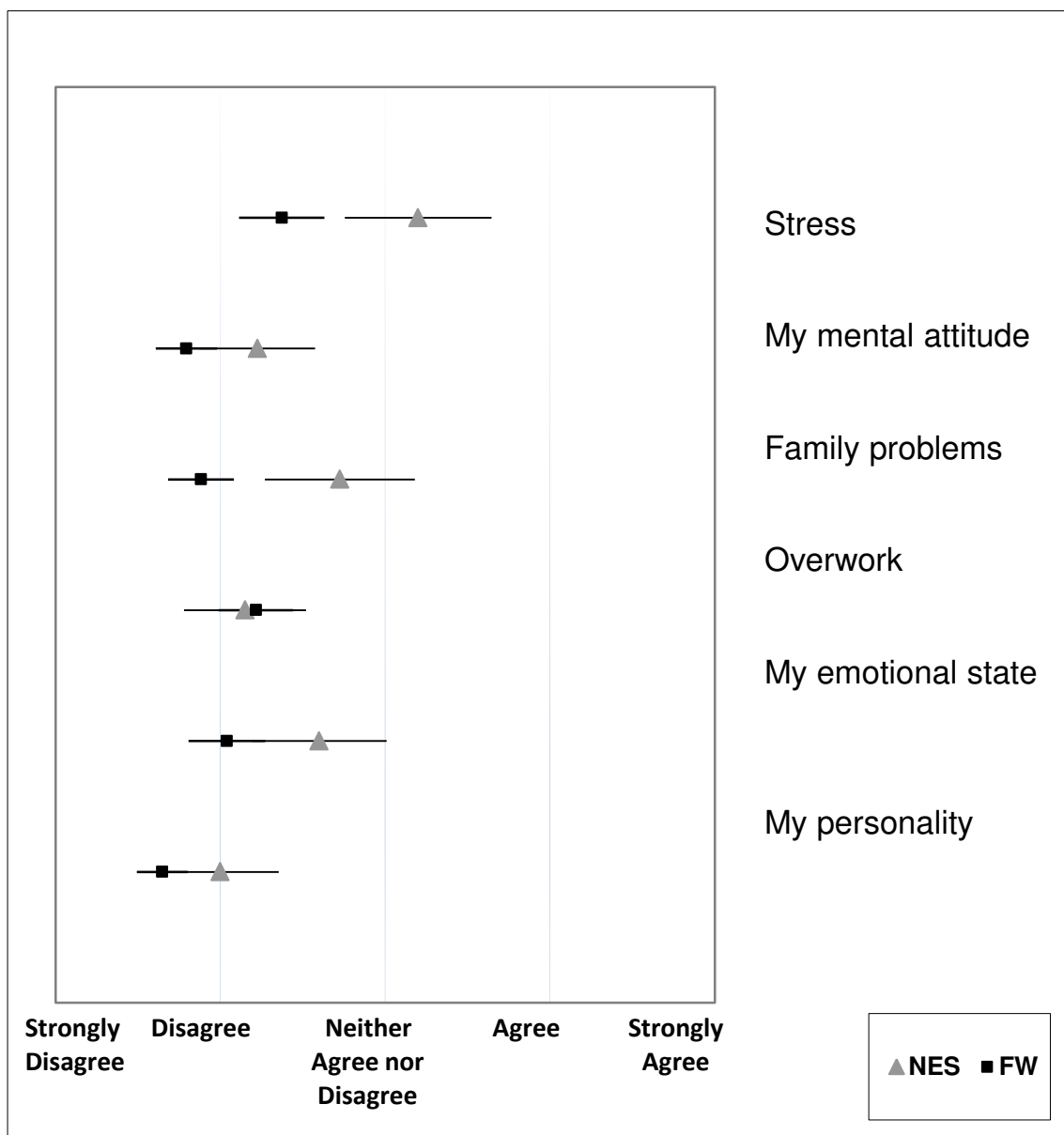


Figure 1. Differences in illness perceptions about psychological causes among patients with Functional Weakness (FW) and Non-Epileptic Seizures (NES)

FW n=102, NES n=40

Discussion

Several previous studies have shown that patients with both NES [3][5] and FW [4] tend to reject psychological factors as potentially causal factors [14][15]. Reasons for this may include the stigma of associated psychological factors when there is no validating disease label and a possible tendency of some patients to deny or not to be able to perceive psychological factors of potential relevance [16,17]. However, the data here suggests that of these two patient groups, those with FW are even more reluctant to endorse psychological factors than those with NES.

Previous studies comparing these two subgroups of patients have examined demographics, psychiatric comorbidity, life events and a history of abuse but not illness perceptions [6–9]. Three studies have shown that NES patients are on average younger at onset [6–8] and one highlighted a higher female percentage in NES[8] (whereas we found no significant difference). Two found higher rates of previous abuse and stressful life events in NES vs FW patients [6,7], but none have shown convincing differences in the frequency of psychiatric comorbidity. We have not found prior studies comparing illness perceptions of patients with a motor disorder such as stroke and epilepsy.

Possible explanations for the observed differences between NES and FW patients include: (1) the experience of cognitive symptoms such as fear, derealisation or depersonalisation during NES [18,19] or the experience of triggering which may be more likely to be recognised as ‘psychological’ (2) It is also possible that NES *is* a problem in which psychological factors are especially relevant for symptom triggering and maintenance as suggested by studies of prior life events and abuse [6,7] and studies of threat perception[20]. (3) FW is continuous whereas NES is episodic, making psychological factors more plausible (i.e. patients with FW may have weakness all the time but are unlikely to feel stressed or upset all the time). (5) Differences may be due to a selection bias since patients were seen in different locations and times and had different durations of symptoms, any or all of which may have been the principal shaping factor in their perceptions (rather than the nature of their symptoms). Somewhat against this is the lack of any similar differences in the disease control groups, which shared these potential confounding issues.

The last explanation is also one of several limitations of this study. In addition, the NES patients represent only the subgroup of NES patients who had typical seizures during a video-EEG recording. A previous study has suggested that there may be systematic differences between those patients with NES who experience a NES during such a brief video-EEG test and those who do not [21]. Differential severity of the symptoms could also confound differences in illness perceptions irrespective of symptom type. We also note that the patients with seizures contributing to this study had had symptoms for longer than those with weakness.

Despite these limitations, the study offers for the first time a comparison of illness perceptions in subgroups of patients with functional neurological symptoms with substantial sample sizes, with additional disease controls to examine the specificity of the differences identified. In this study both NES and FW groups tended to reject psychological factors as relevant to their symptoms, NES patients did so less strongly than patients with FW. If this data does reflect a genuine difference between groups it may map on to the common experience of clinicians treating these disorders, that it appears easier (although not much easier) to introduce ideas regarding psychological factors and use these in treatment in patients with NES compared to FW. Higher dropout rates in a trial of psychotherapy for motor disorders [22] compared to a trial for NES [23] lend support to this observation. The data also contribute to the debate regarding whether all functional neurological symptom disorders should be lumped together or considered separately [24]. **Future studies examining a range of other potential predisposing, precipitating and perpetuating factors would help inform this debate.**

Acknowledgements

The data on weakness were funded by the Chief Scientist, Scotland (Grant number K/OPR/2/2/D379).

References

- [1] Edwards MJ, Adams RA, Brown H, Pareés I, Friston KJ. A Bayesian account of “hysteria”. *Brain* 2012;135:3495–512.
- [2] Sharpe M, Stone J, Hibberd C, Warlow C, Duncan R, Coleman R, et al. Neurology out-patients with symptoms unexplained by disease: illness beliefs and financial benefits predict 1-year outcome. *PsycholMed* 2009:1–10.
- [3] Stone J, Binzer M, Sharpe M. Illness beliefs and locus of control: a comparison of patients with pseudoseizures and epilepsy. *J Psychosom Res* 2004;57:541–7.
- [4] Stone J, Warlow C, Sharpe M. The symptom of functional weakness: a controlled study of 107 patients. *Brain* 2010;133:1537–51.
- [5] Whitehead K, Kandler R, Reuber M. Patients’ and neurologists’ perception of epilepsy and psychogenic nonepileptic seizures. *Epilepsia* 2013;54:708–17.
- [6] Stone J, Sharpe M, Binzer M. Motor conversion symptoms and pseudoseizures: a comparison of clinical characteristics. *Psychosomatics* 2004;45:492–9.
- [7] Driver-Dunckley E, Stonnington C. Comparison of psychogenic movement disorders and psychogenic nonepileptic seizures: is phenotype clinically important? *Psychosomatics* 2011;52:337–45.
- [8] Hopp JL, Anderson KE, Krumholz a, Gruber-Baldini a L, Shulman LM. Psychogenic seizures and psychogenic movement disorders: are they the same patients? *Epilepsy Behav* 2012;25:666–9.
- [9] Strutt A, Scott B, Ferrara J, York M, Jankovic J. Psychosocial profiles of psychogenic movement disorder patients with non-epileptic seizures and other abnormal motor manifestations. *Neurology* 2011;76(Supp 4):A591 (abstract only).
- [10] Whitehead K, Stone J, Norman P, Sharpe M, Reuber M. Differences in relatives’ and patients’ illness perceptions in functional neurological symptom disorders compared with neurological diseases. *Epilepsy Behav* 2015;42:159–64.
- [11] LaFrance WC, Baker G a, Duncan R, Goldstein LH, Reuber M. Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: A staged approach: A report from the International League Against Epilepsy Nonepileptic Seizures Task Force. *Epilepsia* 2013:1–14.
- [12] Weinman J, Petrie KJ, Moss-Morris R, Horne R. The illness perception questionnaire: a new method for assessing the cognitive representations of illness. *Psychol Heal* 1996;11:431–45.
- [13] Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta PsychiatrScand* 1983;67:361–70.

- [14] Monzoni CM, Duncan R, Grünewald R, Reuber M. Are there interactional reasons why doctors may find it hard to tell patients that their physical symptoms may have emotional causes? A conversation analytic study in neurology outpatients. *Patient Educ Couns* 2011;85:e189–200.
- [15] Monzoni CM, Duncan R, Grünewald R, Reuber M. How do neurologists discuss functional symptoms with their patients: a conversation analytic study. *J Psychosom Res* 2011;71:377–83.
- [16] Dimaro L V, Dawson DL, Roberts N a, Brown I, Moghaddam NG, Reuber M. Anxiety and avoidance in psychogenic nonepileptic seizures: The role of implicit and explicit anxiety. *Epilepsy Behav* 2014;33C:77–86.
- [17] Goldstein LH, Mellers JDC. Ictal symptoms of anxiety, avoidance behaviour, and dissociation in patients with dissociative seizures. *J Neurol Neurosurg Psychiatry* 2006;77:616–21.
- [18] Reuber M, Jamnadas-Khoda J, Broadhurst M, Grunewald R, Howell S, Koepp M, et al. Psychogenic nonepileptic seizure manifestations reported by patients and witnesses. *Epilepsia* 2011;52:2028–35.
- [19] Hendrickson R, Popescu A, Dixit R, Ghearing G, Bagic A. Panic attack symptoms differentiate patients with epilepsy from those with psychogenic nonepileptic spells (PNES). *Epilepsy Behav* 2014;37:210–4.
- [20] Bakvis P, Roelofs K, Kuyk J, Edelbroek PM, Swinkels W a M, Spinhoven P. Trauma, stress, and preconscious threat processing in patients with psychogenic nonepileptic seizures. *Epilepsia* 2009;50:1001–11.
- [21] McGonigal A, Oto M, Russell AJC, Greene J, Duncan R. Outpatient video EEG recording in the diagnosis of non-epileptic seizures: a randomised controlled trial of simple suggestion techniques. 2002.
- [22] Kompoliti K, Wilson B, Stebbins G, Bernard B, Hinson V. Immediate vs. delayed treatment of psychogenic movement disorders with short term psychodynamic psychotherapy: Randomized clinical trial. *Parkinsonism Relat Disord* 2013:7–10.
- [23] Goldstein LH, Chalder T, Chigwedere C, Khondoker MR, Moriarty J, Toone BK, et al. Cognitive-behavioral therapy for psychogenic nonepileptic seizures: A pilot RCT. *Neurology* 2010;74:1986–94.
- [24] Stone J, LaFrance WC, Brown R, Spiegel D, Levenson JL, Sharpe M. Conversion disorder: current problems and potential solutions for DSM-5. *J Psychosom Res* 2011;71:369–76.