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Predicting first attendance at psychiatry appointments in patients with dissociative seizures



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ABSTRACT

Purpose: Patients with dissociative (non-epileptic) seizures typically receive their diagnosis from neurologists, but are often referred to psychiatrists, whom they may be reluctant to go and see. We aimed to assess which factors were associated with first attendance at psychiatric services.

Methods: A cohort study of 698 participants involved in the pre-randomisation phase of the CODES trial, a randomised controlled trial assessing the benefit of cognitive behavioural therapy for dissociative seizures when added to standardised medical (including psychiatric) care. Patients diagnosed by neurologists from 27 UK centres provided demographic information and a measure of diagnostic confidence. Neurologists described predominant seizure type and comorbidity with epilepsy. We analysed hypothesised (young age, male, residing in areas of higher deprivation, low belief in diagnosis) and exploratory factors for their association with first attendance with the psychiatrist about 3 months later.

Results: 568/698 (81.4 %) participants attended a psychiatry appointment. None of the following were associated with attendance: Location, age, gender, deprivation score, relationship status, ethnicity, level of education, employment status, receipt of disability benefits, duration, previous diagnosis of epilepsy or mental health problems and degree of confidence in the diagnosis. The only variable differing between groups was having a carer (21.5 % not attending vs 38.6 % attending).

Conclusion: First attendance at a psychiatry appointment after a neurologist had given a diagnosis of dissociative seizures was not associated with any hypothesised predictors, including patient confidence in the diagnosis. Neurologists should put aside any expectations about these variables when referring to and anticipating attendance with a psychiatrist.

1. Introduction

Patients with functional disorders, including dissociative (non-epileptic) seizures (also called psychogenic non-epileptic seizures), are often considered 'difficult to help' by neurologists [1]. There is evidence that consultations in which neurologists explain this diagnosis are often challenging for doctor and patient [2,3]. A range of different issues can contribute to these difficulties. These include factors pertaining to doctors, such as problems communicating the diagnosis, ambivalent attitudes towards the diagnosis, issues around raising the relevance of psychological factors in relation to a condition presenting with physical

symptoms, and the lack of services for further treatment [4,5]. Studies have also highlighted how interactional features such as anger at diagnosis and other negative emotions from neurological assessment can predict worse outcome [6–9].

At present the best evidence for treatment of dissociative seizures is for psychological therapy [10,11]. The vast majority of patients will be diagnosed by a physician specialising in epilepsy, usually a neurologist. Referral to a psychiatrist can be problematic for any condition, because of stigma around mental health in the general population. Arguably, referral to a psychiatrist for a condition that is perceived as 'psychosomatic' can be even more stigmatising, because of the way these

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disorders are often confused in the media [12] or by patients [13,14] with conditions that are “imaginary”, “made up” or even worse, malingered. Studies in the neurology clinic have shown that patients tend to resist psychiatric referral and that doctors tend to anticipate this resistance [2,3]. This may be particularly evident when patients seem to disagree with the diagnosis or where socioeconomic or educational factors may interfere with treatment. However, there have been no studies of which factors are associated with attendance at psychiatric services in patients with dissociative seizures. This data could assist in identifying individuals who may be at higher risk of non-attendance.

Studies of non-attendance after referral to secondary specialist medical care from primary care suggest that young age (16–30), males, low socio-economic status, longer delay to appointment, transport and rapport are factors associated with missed appointments [15,16]. Reasons often given by patients for non-attendance include forgetting, apathy, illness, work commitments and clerical errors [17]. Psychiatric appointments have a higher rate of missed appointments than general medical ones (20 % vs 10 % in one study [17]). Specific reasons related to psychiatric settings include being unhappy with the referral in the first place (5/29 psychiatric new patients in one study [18]), stigma and fear of what might happen during the appointment. One previous study exploring the engagement of patients with dissociative seizures and other functional neurological symptoms with psychotherapy found that 23.4 % failed to attend for any appointment after they had been referred by a neurologist [19]. Non-engagement in that study, which is not the same as attendance, was predicted by being economically inactive [19].

The CODES randomised controlled trial (RCT), comparing the addition of cognitive behavioural therapy to standardised medical care versus standardised medical care alone [20], offered an opportunity to study this question in a large prospective cohort of patients with dissociative seizures across multiple neurological centres. Patients were recruited in 27 centres across the UK from neurology/specialist epilepsy clinics into an observational study that acted as a screening phase for the RCT. The observational study ended with a psychiatric assessment by a neuropsychiatrist/liason psychiatrist to assess eligibility for treatment within the RCT, after approximately 3 months. All patients were encouraged to attend the psychiatry appointment, including those whose seizures had remitted.

We hypothesised, based on existing studies, that younger, male, patients living in more socio-economically deprived areas and those with lower confidence in the diagnosis would be less likely to attend a first psychiatric appointment. Additionally, we aimed to examine the role of other exploratory variables described below.

2. Materials and methods

2.1. Recruitment

Participants were initially recruited between October 2014 and February 2017 from secondary/tertiary epilepsy/neurology outpatient clinics taking part in the CODES trial [20]. These clinical services were located in England, Scotland and Wales, mainly in London, the South and South-East of England, Leeds, Sheffield, Birmingham, Cardiff and Edinburgh. Patients in the United Kingdom (UK) have access to psychiatric treatment in these centres through the National Health Service (NHS), do not require specific insurance and there is no charge for appointments. As part of the CODES protocol, neurologists who made the diagnosis of dissociative seizures, explained the diagnosis to the individual in simple terms and gave the patient a leaflet (see www.codestrial.org). If a patient met the eligibility criteria (see below) the neurologists invited the patient to consent to have their details passed on to the CODES trial team. A research worker then contacted the patient to explain the trial in more depth, confirm eligibility, obtain consent and collect demographic information. All participants were then referred to the designated liaison/neuropsychiatry service by the

neurologist for an appointment approximately three months later. Some psychiatry services accepted referrals from more than one neurology site. During this period a self-report seizure diary was collected at two-weekly intervals by a research worker. Participants were eligible for up to £25 travel reimbursement to offset any financial burden associated with the attendance of their appointment with the psychiatrist.

Inclusion criteria were: Adults aged at least 18 years old who had experienced a dissociative seizure within the previous 8-week period and whose dissociative seizures had been confirmed by video EEG telemetry or, where this was not undertaken, clinical consensus; no recorded history of intellectual disability; ability to keep seizure diaries and fill out questionnaires; being able to give informed consent.

Exclusion criteria were: Diagnosis of currently-occurring epileptic seizures in addition to DS (where ‘current’ was characterised as an epileptic seizure that had occurred in the previous year); meeting criteria for current alcohol or drug dependence using DSM-IV criteria; being insufficiently fluent in English to fill out questionnaires or subsequently undergo CBT without the assistance of an interpreter; currently attending CBT sessions for another diagnosis, if this treatment would be ongoing when the assessment by the psychiatrist occurred; having previously had a CBT-based intervention for dissociative seizures at one of the centres taking part in the RCT.

All participants provided written informed consent and the CODES study received ethical approval from the London-Camberwell St Giles NRES Committee (Reference number 13/LO/1595).

2.2. Measures

Patient data collected included: demographic information including age, gender, relationship status, ethnicity, level of education, employment status, presence of dependents or a carer and whether they were in receipt of state-related financial disability benefits. The participants’ postcode provided a measure of local area deprivation (Index of Multiple Deprivation (IMD)) from separate databases for England [21], Scotland [22] and Wales [23]). Variables related to participants’ dissociative seizure diagnosis included: age at first seizure, strength of belief in the diagnosis (using the question “How strongly do you believe that you have been given the correct diagnosis of dissociative seizures?” on a Likert scale where 0 = not at all, 5 = somewhat, 10 = extremely strongly), whether there was a previous diagnosis of epilepsy or current prescription of antiepileptic medication, and whether they had sought previous medical treatment for a mental health problem and/or undergone prior cognitive behavioural therapy for dissociative seizures.

Neurologists were asked to record whether the seizures were predominantly hypokinetic or hyperkinetic and whether there was a previous diagnosis of epilepsy.

2.3. Analysis

We aimed to compare the participants who attended the psychiatry appointment with those who did not. Note that this was in the pre-randomisation phase of the CODES trial, and not all those who attended then progressed to the RCT phase (due to eligibility or consent). Descriptive statistics are therefore stratified by participant attendance at psychiatry, presented as n (%) or median (IQR), where appropriate.

Our hypothesised variables based on the literature were: lower age, male gender, living location in a more socio-economically deprived area and lower confidence in the diagnosis. Our exploratory variables based on clinical experience were: variables related to the seizure diagnosis (age of onset, duration, previous diagnosis of epilepsy, type of seizure), differences in treatment centre, previous seeking of mental health treatment, relationship/employment status, ethnicity, whether the individual was living alone, had dependents, a carer and received benefits.

To formally compare the difference between groups, we performed the Wilcoxon rank-sum test (Mann–Whitney two-sample statistic) or

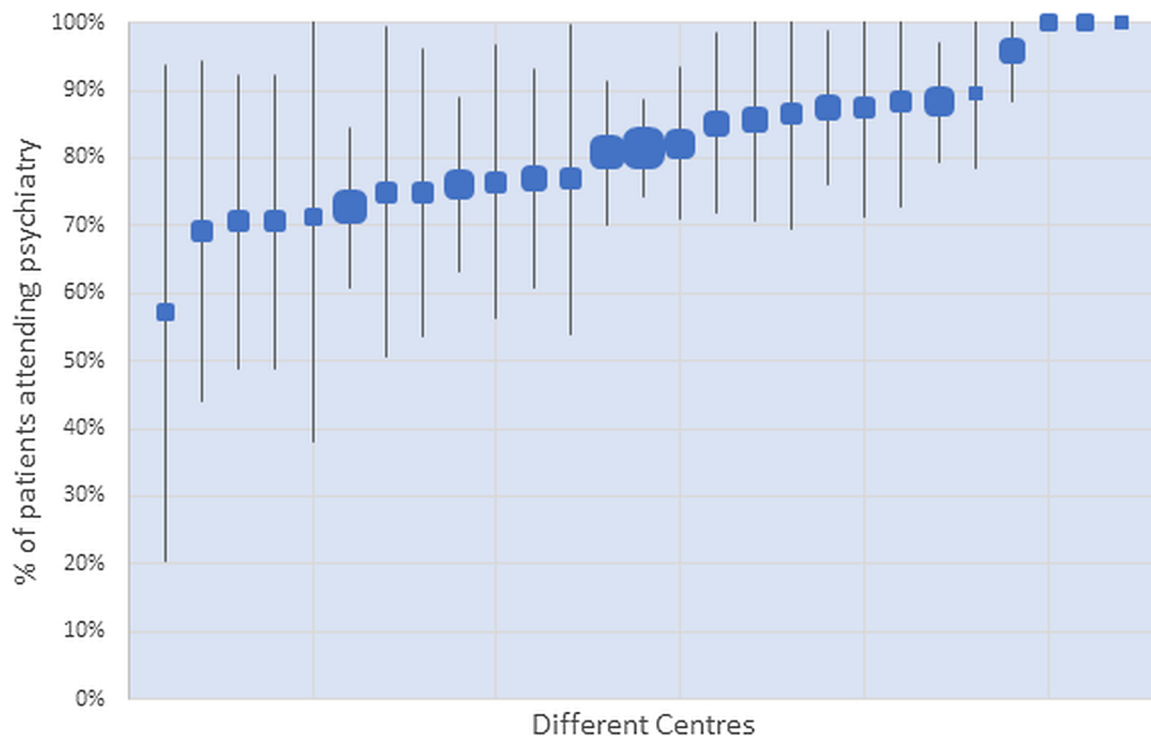


Fig. 1. Percentage attendance at psychiatry by 27 Neurology referral centres –Size proportionate to number of patients recruited at each referral centre; error bars are 95 % confidence intervals.

Fisher's exact test for parametric or non-parametric variables, respectively. We used an initial significance level of $\alpha = 0.05$ to reject the null hypothesis (no difference between groups), and then used Bonferroni correction ($\alpha/23$) to reduce the chance of false positive results from multiple testing. All variables were chosen a priori, and only Bonferroni-adjusted p-values are presented.

3. Results

A total of 901 patients were identified in neurology/specialist epilepsy clinics for the CODES trial over a period of 29 months. Out of those identified, 845 met the eligibility criteria to enter the screening phase and were contacted by researchers; however, due to patients either not wanting to participate (85, 9.43 %) or being uncontactable (61, 6.77 %) the number of patients recruited and thus offered a psychiatry appointment was 698. A detailed analysis of the demographics of these 698 patients has been presented elsewhere [24].

Of the 698 patients, the overall percentage who did not attend a psychiatry appointment was 18.6 % (130/698). There was no obvious centre effect with respect to attendance with no individual trial site having higher or lower subsequent attendance rates for psychiatry (Fig. 1 shows the range in anonymised centres).

When examining differences between patients who did and did not attend psychiatry appointments, 'having dependents' and 'having a carer', both exploratory variables, were the only demographic variable that differed significantly between groups. The only variable to survive a Bonferroni adjustment was whether the patient had a carer (Table 1). If a patient had a carer, they were more likely to attend the psychiatry appointment (Odds Ratio 2.26 (95 % confidence intervals 1.44–3.54), $p < 0.001$).

Variables related to the seizures also showed no difference between groups (Table 2). Notably, median agreement with the diagnosis was identical in both groups. To ensure these median values did not hide important variation, and because generally there was a high level of agreement with the neurological diagnosis, we carried out a post-hoc analysis of the proportion of patients disagreeing with the diagnosis.

The proportion of participants scoring 0–4 was remarkably similar in both groups: 9 % who did not attend (11/127) and 7 % who did attend (39/565). There were 12 participants in total who said '0=not at all,' which corresponds to 2.4 % of those who did not attend, and 1.6 % of those who did attend. Thus, nine participants who totally disagreed with their diagnosis still attended the appointment arranged for them.

4. Discussion

In a large sample of 698 patients with dissociative seizures referred from a neurologist to a psychiatrist, none of our hypothesised variables including age, gender or deprivation assessed by location, were associated with first attendance at psychiatry assessment. Perhaps most surprisingly, we found no relationship between attendance at a psychiatric appointment and the participant's agreement with the neurologist's diagnosis, even though other studies have suggested that this may be a poor prognostic factor [6].

Our exploratory variables including those related to the seizures, comorbidity with epilepsy or mental health were also non-significant. There was no effect of referring centre even though some centres had been involved in dissociative seizure research for many years and others had not. The only associated factor (after Bonferroni correction) related to whether the participants identified themselves as having a carer. This may simply indicate that someone is more likely to attend if they have someone interested in their welfare and able to support their attendance at hospital appointments (including transport), come from a more stable home situation or possibly in some cases need to be seen to co-operate with treatment regardless of motivation for change. It is also possible that 'having a carer' is a marker of disability or severity of disorder or comorbidity, although receiving disability benefits was not predictive of attendance suggesting this is less likely. This finding may also indicate that it is helpful to include a carer in the consultation. A study of carer beliefs in dissociative seizures showed that they tended to have views which were likely to be more conducive to psychological treatment than the patient [25].

Our overall level of non-attendance at a psychiatry appointment

Table 1
Demographic variables in those attending and not attending a psychiatry appointment after a diagnosis of dissociative seizures.

Variables		Patients who DID NOT attend psychiatry appointment (n = 130)	Patients who attended psychiatry appointment (n = 568)	Difference between the groups*
Age median (IQR)		31 (24 - 44) Range: 18-75	35 (24 - 48) Range: 18-84	NS
Gender n (%)	Female	99 (76.2)	416 (73.2)	NS
	Male	31 (23.8)	152 (26.8)	
Index of Multiple Deprivation score England Quintiles n (%)		(n = 95)	(n = 462)	
	1. Least deprived	11 (10.4)	46 (10.0)	NS
	2	7 (6.6)	59 (12.8)	
	3	22 (20.8)	82 (17.7)	
	4	38 (35.8)	140 (30.3)	
	5. Most deprived	28 (26.4)	135 (29.2)	
Index of Multiple Deprivation score Scotland Quintiles n (%)		(n = 21)	(n = 92)	
	1. Least deprived	3 (14.3)	12 (13.0)	NS
	2	2 (9.5)	17 (18.5)	
	3	3 (14.3)	16 (17.4)	
	4	5 (23.8)	19 (20.7)	
	5. Most deprived	8 (38.1)	28 (30.4)	
Relationship status n (%)	Single	60 (46.2)	242 (42.6)	NS
	Married/living with partner	62 (47.7)	274 (48.2)	
	Separated	4 (3.1)	15 (2.6)	
	Divorced	3 (2.3)	26 (4.6)	
	Widowed	1 (0.8)	11 (1.9)	
Ethnicity n (%)		(n = 130)	(n = 567)	NS
	White	118 (90.8)	498 (87.8)	
	Asian	2 (1.5)	13 (2.3)	
	Black	2 (1.5)	12 (2.1)	
	Mixed	6 (4.6)	31 (5.5)	
	Other	2 (1.5)	13 (2.3)	
Currently living alone/with others n (%)	Alone	22 (16.9)	83 (14.6)	NS
	Others	108 (83.1)	485 (85.4)	
Qualifications n (%)		(n = 129)	(n = 558)	NS
	None	22 (17.1)	85 (15.2)	
	Secondary	35 (27.1)	145 (26.0)	
	Vocational	32 (24.8)	160 (28.7)	
	Further	25 (19.4)	86 (15.4)	
	Higher	15 (11.6)	82 (14.7)	
Employment status n (%)		(n = 130)	(n = 564)	NS
	Not employed or in education	84 (64.6)	383 (67.9)	
	Employed or in education	46 (35.4)	181 (32.1)	
Have Dependents, n (%)		52 (40.0)	170 (29.9)	NS
Have a Carer n (%)		(n = 128)	(n = 565)	< 0.001
		28 (21.5)	219 (38.6)	
Receiving disability benefits and not working (those aged under 65 years only), n (%)		(n = 78)	(n = 368)	NS
		58 (74.4)	267 (72.6)	
Receiving disability benefits and working (those aged under 65 years only) n (%)		(n = 46)	(n = 159)	NS
		11 (23.9)	29 (18.2 %)	

*Bonferroni adjusted p-value. Index of deprivation for Wales (n = 16) not shown and not included in analyses due to small numbers. NS: not significant at the $\alpha = 0.05/23 = 0.00217$ level.

(18.6 %) was at a level that is similar to other studies of referral to mental health services [17], a study in the US of attendance of 123 patients with dissociative seizures referred in the US (20 %) [26] and a previous study of patients with functional neurological disorders referred by neurologists to psychiatrists [19], but higher than levels of non-attendance to general medical services (which tend to run at 5–10 %).

This data was obtained in the course of recruiting patients to an RCT reducing the generalisability to general neurological practice. For instance, patients were only entered in this study if they met its inclusion/exclusion criteria. The trial also enforced a specific route to intervention (randomisation to standardised medical care or standardised medical care plus CBT) of which participants were fully aware. Thus, they could only progress to treatment in the trial if they saw a psychiatrist, although they were able to access treatment outwith the trial if they preferred. In the context of the study, neurologists were asked to provide a diagnosis of dissociative seizures in a standardised way which

emphasised the following and was backed up by a detailed factsheet [20]: i) what dissociative seizures are, explaining they are common, genuine and can cease; ii) providing a diagnostic label and drawing particular attention to positive aspects of the diagnosis; iii) explaining something of the mechanism of dissociation. Neurologists were not required to provide a detailed account of the aetiology of dissociative seizures. Indeed, we found much higher levels of acceptance of the diagnosis than we were expecting. This may have been related to our study protocol and the explanations and factsheet given to participants. The median rating of strength of agreement was 8 out of 10 and may mean that this sample was atypical in this respect.

As part of the CODES project, neurologists were given advice on how to constructively refer patients to psychiatry to optimise attendance. The findings of our study may have been affected by the fact that, because of the prescriptions of the trial pathway, neurologists had to refer participants to psychiatry after providing their initial explanation of the diagnosis. They could not, as they may have done

Table 2
Seizure variables in those attending and not attending a psychiatry appointment after a diagnosis of dissociative seizures.

Variables	Patients who DID NOT attend psychiatry (n = 130)	Patients who attended psychiatry (n = 568)	Difference between the groups (Bonferroni adjusted p-value)
Age at first seizure median (IQR)	(n = 115) 27 (19–38) Range: 8–74	(n = 554) 28 (19–42) Range: 1–80	NS
Number of years with DS median (IQR)	(n = 115) 3 (1–6) Range: 0–45	(n = 554) 3 (1–7) Range: 0–65	NS
Strength of Belief in diagnosis score median (IQR) *	(n = 127) 8 (6–10) Range: 0–10	(n = 565) 8 (6–10) Range: 0–10	NS
Previous diagnosis of Epilepsy (participant response) n (%)	(n = 129) 39 (30.2)	(n = 568) 172 (30.3)	NS
Previous diagnosis of Epilepsy (neurologist response) n (%)	37 (28.5) (n = 35)	151 (26.6) (n = 144)	NS
Current comorbid epilepsy (no epileptic seizure in past year)	3 (8.6)	12 (8.3)	
Previous epilepsy diagnosis correct, but now only has Dissociative Seizures	3 (8.6)	17 (11.8)	
Patient was previously misdiagnosed with epilepsy	13 (37.1)	67 (46.5)	
Not possible to determine the validity of earlier diagnosis of epilepsy	16 (45.7)	48 (33.3)	
Current prescription of anti-epileptic drugs n (%)	(n = 129) 35 (27.1)	(n = 567) 180 (31.7)	NS
Previously sought medical help for a mental health problem n (%)	(n = 129) 87 (67.4)	(n = 568) 366 (64.4)	NS
Previous CBT for dissociative seizures n (%)	(n = 129) 3 (2.3)	(n = 567) 13 (2.3)	NS
Predominant Seizure type	(n = 127)	(n = 565)	NS
Hyperkinetic	34 (26.8)	187 (33.1)	
Hypokinetic	93 (73.2)	378 (66.9)	

*Response to the question ‘How strongly do you believe that you have been given the correct diagnosis of dissociative seizures: 0=not at all, 5=somewhat, 10=extremely strongly); NS: not significant at the $\alpha/23 = 0.00217$ level.

under non-trial circumstances, refer the patient at a later stage. The participants’ attendance rate may also have been influenced by being in a trial, both negatively, because of these factors, and positively because they had been contacted by a research worker interested in their condition who was staying in contact with them, asking them to complete a seizure diary and reimbursing them for travel to the appointment. A previous study has suggested that this sort of contact with patients could have benefits in terms of psychiatry appointment attendance after referral from neurology [27]. Notably, attendance rates were unlikely to have been influenced by the more typical variation in NHS waiting times for appointments as the pathway was designed to ensure a psychiatry appointment after three months, often but not always shorter than normal appointment waiting times. We could not include data on participants who were not eligible for this screening phase of the study because of the exclusions listed above. This could have increased the frequency of first psychiatric attendance. The range of data available was also limited and we also did not include a prediction from the neurologist about whether the participant would attend, or measures of other somatic comorbidities that may have led to physical difficulties attending appointments. Finally, some of the patient characteristic data was self-report, including whether they had previously sought medical help for a mental health problem or had CBT.

Clinical experience after the end of the trial also indicated that the reasons for non-attendance were heterogenous. We do not have numerical data, but we encountered anecdotal evidence from participants at a later date that they did not attend because: their seizures had improved; they felt guilty they had not completed a seizure diary for the study; they were agoraphobic or too distressed to attend; or they were not keen on the idea of psychiatric assessment because of stigma. Finally, it should also be noted that this is only a study of attendance and not of engagement with psychiatric services or of treatment outcome. A study of 123 patients with dissociative seizures scheduled for 4 psychiatric visits found that although 80 % attended the first appointment, 42 % attended the second, 24 % the third and only 14 % the fourth [26]. The authors subsequently demonstrated improved adherence with a randomised controlled trial of motivational interviewing

[28].

5. Implications

Neurologists often express expectations about which patients will and will not attend clinic appointments. Our clinical experience is that some patients are potentially denied psychiatric referral because of a perception that they will not attend or engage in treatment due to symptom duration, disagreement with the diagnosis or demographic factors.

This study suggests that such perceptions are often inaccurate. All patients with dissociative seizures should be considered for onward referral.

Ethical publication statement

We confirm that we have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines. Ethical approval was granted by the London-Camberwell St Giles NRES Committee (reference number 13/LO/1595).

Alan Carson reports being a paid editor of the Journal of Neurology, Neurosurgery and Psychiatry, and is the director of a research programme on functional neurological disorders; he gives independent testimony in Court on a range of neuropsychiatric topics (50 % pursuer, 50 % defender). Jon Stone reports independent expert testimony work for personal injury and medical negligence claims, royalties from UpToDate for articles on functional neurological disorder and runs a free non-profit self-help website, www.neurosymptoms.org. The remaining authors have no conflicts of interest to declare.

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Declaration of Competing Interest

Alan Carson reports being a paid editor of the Journal of Neurology, Neurosurgery and Psychiatry, and is the director of a research programme on functional neurological disorders; he gives independent testimony in court on a range of neuropsychiatric topics (50 % pursuer, 50 % defender). Jon Stone reports independent expert testimony work for personal injury and medical negligence claims, royalties from UpToDate for articles on functional neurological disorder and runs a free non-profit self-help website, www.neurosymptoms.org. The remaining authors have no conflicts of interest to declare.

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