

Functional seizures: An evaluation of the attitudes of general practitioners local to a tertiary neuroscience service in London

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Summary

Objective: Functional seizures are a common functional neurologic disorder. Given their chronic nature, and the biopsychosocial factors involved in their etiology, general practitioners (GPs) play a crucial role in the care of these patients. However, little is known about the attitudes of GPs toward, and knowledge of, functional seizures.

Methods: The Atkinson Morley Regional Neuroscience Centre in London provides a comprehensive service to patients with functional seizures. As part of a service evaluation we conducted an online survey among local GPs over a 1-month period assessing their attitudes toward, and knowledge of, functional seizures.

Results: One hundred twenty of 974 surveyed GPs replied to the survey (12.3%). Approximately 75% of GPs readily use the term “pseudoseizures,” and over 50% were not sure or did not think that functional seizures were involuntary. Nearly 30% believed, or were unsure as to whether, functional seizures occur only when patients are stressed. Despite approximately 50% of GPs expressing interest in getting involved in the management of these patients, a similar proportion do not feel confident in dealing with queries from patients with functional seizures. Although most GPs felt that neurology and psychiatry should be the primary caregivers in the diagnosis and management, respectively, of functional seizures, 50% were also of the opinion that neurology should be involved in the management of these patients.

Significance: This survey highlights the attitudes of, and descriptive terms used by, GPs toward patients with functional seizures. Our findings suggest a need for better and clearer provision of information to GPs about this condition.

KEY WORDS

functional seizures, GP attitudes, nonepileptic seizures, pseudoseizures, psychogenic seizures

1 | INTRODUCTION

Functional seizures superficially resemble epileptic seizures but are not associated with ictal electroencephalographic

discharges. They are episodes of impaired self-control associated with a range of motor, sensory, and mental manifestations.¹ A variety of different terms are used to describe these seizures including psychogenic nonepileptic seizures (PNES)

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and nonepileptic attack disorder (NEAD). For the purpose of this article we will continue to use the term functional seizures, recognizing that they are a common manifestation of functional neurologic disorders (FNDs).

Functional seizures are classified by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) as a conversion disorder (functional neurologic symptom disorder)² and by the International Classification of Diseases (ICD-10) as a dissociative disorder.³ Although general practitioners (GPs) in the United Kingdom are not expected to make a diagnosis of epileptic or functional seizures, systematic reviews of prognostic studies indicate that two-thirds of patients diagnosed with functional seizures continue to have chronic seizures after diagnosis, and do not enter remission despite attempts at treatment.⁴ Current GP guidelines highlight that GPs play an “essential role in the management of chronic neurological disability in the community.”⁵ Indeed, given the etiologic complexity in these patients, which encompasses biological, psychological, and social factors, and a GP’s traditionally holistic approach to patient care, GPs are perhaps even more central to the care and management of these patients than they are in other neurologic conditions.

Previous research into the attitudes of GPs toward chronic diseases suggests that GPs would be willing to assume some responsibility for most patients with chronic conditions if specialist advice was accessible when needed.⁶ This approach not only improves patient care, but also has significant health economic benefits.⁷ Although there are studies reporting GP attitudes to common, chronic neurologic disorders such as multiple sclerosis,⁸ and psychiatric disorders, such as anxiety and depression,⁹ only 4 studies have assessed GP attitudes toward patients with functional seizures.^{10–13} Of these studies, only one¹³ concentrated solely on GPs, but was limited to the views of 23 GPs. Indeed, most studies of the attitudes of healthcare practitioners toward patients with functional seizures have concentrated on specialized professionals, particularly neurologists.¹⁴

St George’s University Hospitals NHS Foundation Trust (SGUH), which houses the Atkinson Morley Regional Neuroscience Centre (AMRNC), is one of the largest university hospitals in the United Kingdom, serving a population of 1.3 million across southwest London and the surrounding regions. The presence of a tertiary epilepsy service, a neuropsychiatry department in collaboration with the South-West London and St George’s Mental Health Trust, and a clinical psychologist with an interest in functional neurologic disorders, provides a comprehensive tertiary service to patients with functional seizures. As part of a local service evaluation, we sought to assess the attitudes of GPs based in local clinical care commissioning groups (CCGs), toward patients with functional seizures in terms of their diagnosis and management. This may improve our understanding of the barriers we face in the diagnosis and treatment of these patients.

Key Points

- Seventy-five percent of GP respondents use the term “pseudoseizures” to describe psychogenic nonepileptic seizures, and 50% doubt their involuntary nature.
- Fifty percent of GPs report an interest in the management of patients with psychogenic nonepileptic seizures, but do not feel confident in managing these patients
- One-third and two-thirds of GPs feel unsupported by neurology and psychiatry, respectively, in the diagnosis and management of these patients

2 | METHODS

Three authors with a specific expertise in epileptology, functional seizures, and functional neurological disorders (MY, MM, and ME) designed an 11-item questionnaire to survey the terms that GPs used to describe functional seizures, and their attitudes toward the terminology, clinical features, and management of functional seizures. The questionnaire was deliberately brief in order to maximize response rates among busy GPs. All questions offered predefined answers, and respondents could select more than one answer for some of the questions.

Links to the online questionnaires were emailed to all individual GPs in those CCGs for which the AMRNC is the tertiary neuroscience unit (Wandsworth, Kingston, Sutton, Surrey Downs, Croydon, Merton), using an online survey tool. Three reminders were sent on a weekly basis to those GPs who had not completed the online questionnaire, and the survey remained on-line for 1 month. At every stage GPs could opt out of the survey by clicking on the appropriate link within the emailed invitation. Response and completion of the survey was taken to be consent by participating GPs. This project was registered and approved with the hospital audit and governance lead as a service evaluation.

Because this was a descriptive survey, all variables were analyzed in an exploratory manner using descriptive statistics, with minimal inferential statistical testing. A threshold of 55 was used to split respondents into 2 groups, those younger than 55 years (“young”) and those 55 years or older (“old”). This threshold was chosen because it is the earliest age at which partial retirement can be taken in the United Kingdom by medical practitioners. Group analyses, using “young” and “old” age were analyzed statistically using a chi-square test. When comparing groups, to simplify the analysis, answers from the questionnaire were re-coded into dichotomous scores, as indicated in Table 1.

TABLE 1 Questionnaire - Responses to questions 1 and 2 can be seen in Figures 1 and 2. Italicized answers represent dichotomization of answers for the purpose of group analysis between “old” and “young” GPs.

Q1. Many synonymous terms are used to describe nonepileptic seizures in patients. Do you readily use the following terms in these patients? (more than one answer possible)						
Q2. What is your understanding of nonepileptic seizures?						
Q3. How many patients have you seen with this condition? % of respondents (number of respondents)						
None	1-10	11-20	21-30	>30		
9.2 (11)	89.2 (107)	1.7 (2)	0 (0)	0 (0)		
Q4. Which speciality do you think should be responsible for the DIAGNOSIS (A) and MANAGEMENT (B) of this condition? % of respondents (number of respondents)						
	Neurology alone	Psychiatry alone	General practice alone	General practice and psychiatry	General practice and neurology	Neurology and psychiatry
Diagnosis	18.3 (22)	0 (0)	(0)	1.7 (2)	19.2 (23)	60.8 (73)
Management	2.5 (3)	3.3 (4)	3.3 (4)	45 (54)	11.7 (14)	34.2 (41)
Q5. How comfortable do you/would you feel about making the initial referral of these patients to NEUROLOGY (A) and PSYCHIATRY (B) services for diagnosis and management? % of respondents (number of respondents) <i>Very comfortable/Comfortable/Neutral = Comfortable</i> <i>Uncomfortable/Very uncomfortable = Uncomfortable</i>						
	Very comfortable	Comfortable	Neutral	Uncomfortable	Very uncomfortable	
Neurology	50 (60)	42.5 (51)	4.2 (5)	2.5 (3)	0.8 (1)	
Psychiatry	10.8 (13)	16.7 (20)	22.2 (27)	38.3 (46)	11.7 (14)	
Q6. How confident do you/would you feel in managing these patients and dealing with their queries? % of respondents (number of respondents) <i>Very confident/Confident/Neutral = Confident</i> <i>Very unconfident/Unconfident = Unconfident</i>						
Very confident	Confident	Neutral	Unconfident	Very unconfident		
0 (0)	15.1 (18)	37 (44)	40.3 (48)	7.6 (9)		
Q7. How well supported do you feel by NEUROLOGY (A) and PSYCHIATRY (B) services when managing these patients? % of respondents (number of respondents) <i>Very well supported/Well supported/Neutral = Supported</i> <i>Poorly supported/Very poorly supported = Not supported</i> <i>Not applicable = Not coded</i>						
	Very well supported	Well supported	Neutral	Poorly supported	Very poorly supported	Not applicable
Neurology	1.7 (2)	24.4 (29)	46.2 (55)	17.6 (21)	4.2 (5)	5.9 (7)
Psychiatry	0 (0)	6.7 (8)	32.8 (39)	39.5 (47)	14.3 (17)	6.7 (8)
Q8. What is your level of interest in managing these patients? % of respondents (number of respondents) <i>Very high/High/Moderate = Interested</i> <i>Low/Very low = Not interested</i>						
Very high	High	Moderate	Low	Very low		
0 (0)	4.2 (5)	45.4 (54)	38.7 (46)	11.8 (14)		
Q9. Would you welcome a dedicated DIAGNOSTIC (A) and MANAGEMENT (B) service for patients with this diagnosis? % of respondents (number of respondents) <i>No/Neutral = No</i> <i>Yes = Yes</i>						
	Yes	No	Neutral			
Diagnosis	75.6 (90)	5 (6)	19.3 (23)			
Management	77.3 (92)	2.5 (3)	20.2 (24)			

(Continues)

TABLE 1 (Continued)

Q10. What is your age? % of respondents (number of respondents)						
18-24	25-34	35-44	45-54	55-64	65-74	75+
0 (0)	10.1 (12)	28.6 (34)	37 (44)	21 (25)	3.4 (4)	0 (0)
Q11. What is your sex? % of respondents (number of respondents)						
Male			Female			
34.5 (41)			65.5 (78)			

3 | RESULTS

The survey was sent to 974 local GPs and 120 responses were received, resulting in a response rate of 12.3%. All responses were complete, apart from one, which was incomplete from Question 6 onward. That data that were available for this respondent was included in the analysis. A total of 65.5% of respondents were female, and 75.7% were younger than 55; 89.2% of respondents reported having seen between 1 and 10 patients with functional seizures, whereas 9.2% reported having seen no patients with this condition, and 1.7% reported having seen between 11 and 20 patients with functional seizures (Table 1).

The most popular terms used to describe functional seizures (Figure 1) were “pseudoseizures,” and/or “nonepileptic events/attacks/seizures,” which were used by 75% and 76.7% of GPs, respectively. The next most popular terms used by between 20% and 30% of GPs were “psychogenic seizures,” “psychogenic nonepileptic seizures,” “functional seizures,” “pseudoepileptic seizures,” and “nonorganic seizures.” Dissociative seizures was used by only 13% of GPs, whereas “hysterical seizures” was the least popular term, with only 6.7% of GP reporting that they used it. There was no difference in terminology between “old” and “young” GPs.

GP attitudes toward the clinical features and treatment of functional seizures were variable. Around half of GPs (53.3%) agreed that, or did not know whether, patients had voluntary control over their functional seizures. Moreover, 26.7% agreed that, or did not know whether, patients had functional seizures only when stressed. Knowledge of other aspects of functional seizures was better, although rates of incorrect or absent knowledge about functional seizures among GPs were still approximately 20% (Figure 2). Knowledge gaps included the fact that functional seizures are not a subtype of epileptic seizures, but instead have a psychological explanation, and although not directly life-threatening do need treatment based on psychological approaches and not anticonvulsants. Almost all GPs (93.3%) correctly replied that functional seizures resemble but are not equivalent to epileptic seizures, and 88.3% stated correctly that epileptic and functional seizure could co-exist. Older GPs tended to believe that, or not be sure whether,

functional seizures only ever occur when patients are stressed, as compared to younger GPs (41% vs 22%, respectively). Otherwise, there were no significant differences in attitudes toward functional seizures between younger and older GPs, including whether patients have voluntary control of seizures.

Although 50% of GPs expressed an interest in managing these patients, 48% also reported a lack of confidence in dealing with their queries. Younger GPs were more likely to be very unconfident or unconfident in managing patients with functional seizures compared with older GPs (54% vs 28%, respectively). In total 98.3% and 62.5% of respondents felt that neurology and psychiatry, respectively, should be involved in some way in the *diagnosis* of functional seizures. This pattern was reversed when GPs were asked about the *management* of patients with functional seizures. In this context, more GPs reported that psychiatry (82.5%) should be involved at some level in the management of these patients compared to neurology (48.4%). Specifically, 60.8% of GPs felt that neurology and psychiatry together should be responsible for the diagnosis of patients with functional seizures, whereas only 34.2% felt that both specialities should be responsible for the management of these patients. Instead, the majority (45%) felt that general practice together with psychiatry should be responsible for the management of these patients. However, although 96.7% of GPs reported feeling comfortable referring patients to neurology, only 50% felt comfortable referring to psychiatry. Moreover, although 72.3% reported feeling adequately supported by neurology, only 39.5% reported feeling adequately supported by psychiatry in managing these patients. More than 75% of GPs would actively welcome a dedicated diagnostic and management service for these patients.

4 | DISCUSSION

This is the largest survey of GPs to explore the attitudes toward, and the terminology, clinical features, and management of patients with functional seizures. At least 75% of GPs readily use the term “pseudoseizures,” and over 50% of GPs did not agree with, or were unsure about, the involuntary nature of functional seizures. Nearly 30% believed or

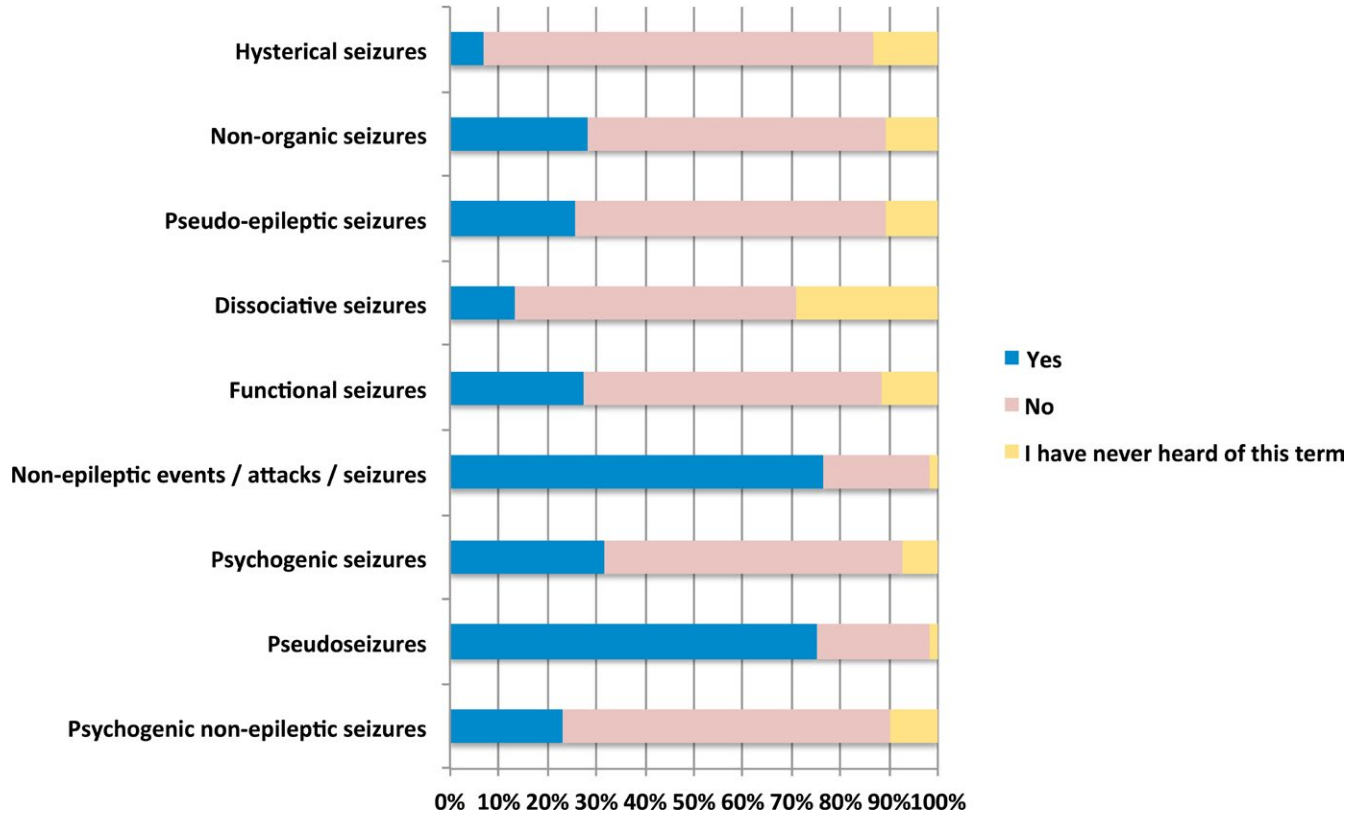


FIGURE 1 Percentage of GP respondents using various terminology for functional seizures

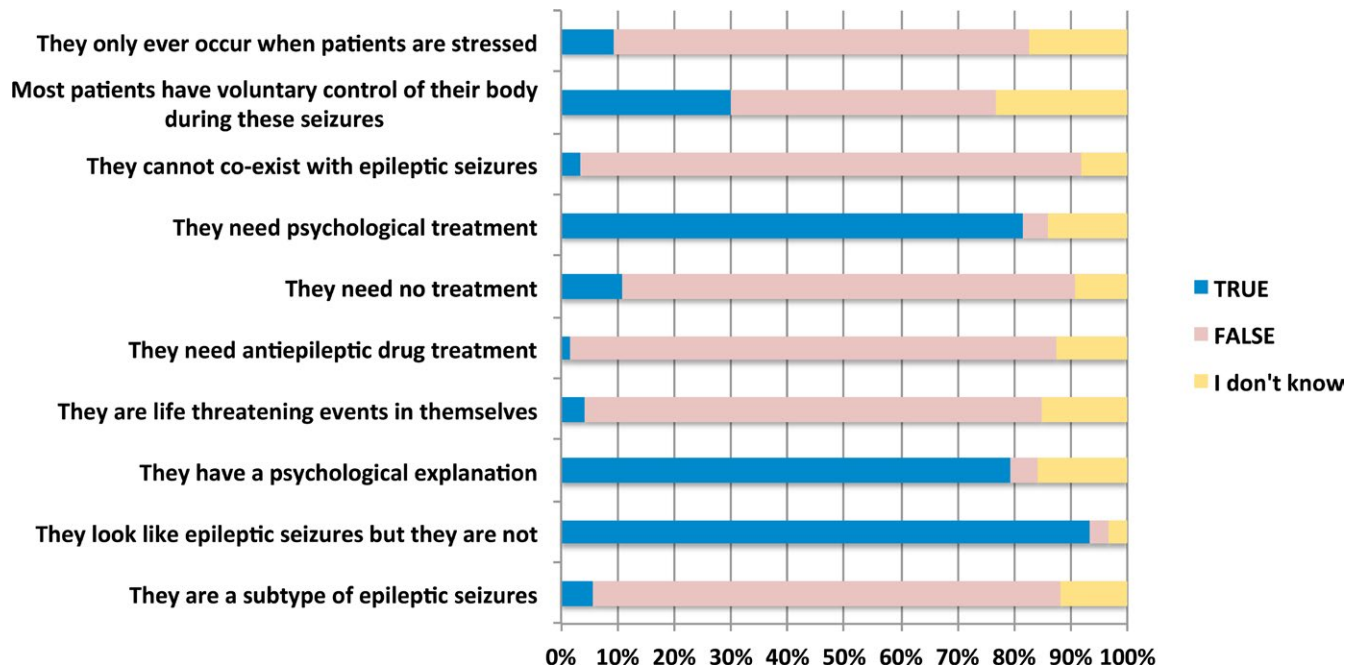


FIGURE 2 Percentage of GP respondents and their knowledge of functional seizures

were not sure as to whether functional seizures occur only when patients are stressed, whereas approximately 20% had some evidence of gaps in their understanding of functional seizures. Despite approximately half of the respondents

expressing interest in getting involved in the management of these patients, a similar proportion did not feel confident in dealing with queries from patients with functional seizures. Although most GPs felt that neurology and psychiatry should

be the primary caregivers in the diagnosis and management, respectively, of functional seizures, nearly 50% were also of the opinion that neurology should be involved in the management of these patients. Indeed, many GPs felt uncomfortable referring patients to psychiatry, and approximately one-third and two-thirds felt unsupported by neurology and psychiatry, respectively. Most GPs would welcome a dedicated management service for these patients.

A review of healthcare practitioners' attitudes toward patients with functional seizures¹⁴ has reported previously that most healthcare practitioners use etiologically neutral terminology, rather than any terms that reference mechanisms potentially underlying functional seizures. However, this review also points out that most of these studies assess the attitudes and opinions of highly specialized healthcare practitioners, such as neurologists. This, in contrast, is the first study to assess the terminology used specifically by GPs to describe functional seizures. The variability in terminology used by GPs to describe functional seizures is unsurprising given that neurologists and epilepsy specialists who diagnose and manage these patients can themselves not agree on common terminology.^{15–17} However, patient views on terminology are also important. The term “pseudoseizures” was a popular term used by GPs in this study and has been assessed in 2 studies of patient preferences.^{16,18} In both patient studies, respondents found the term offensive. This may be because the prefix “pseudo” implies falsehood, and the term itself implies what the attack mimics rather than what it is.¹⁶ Indeed, in national surveys of British and American neurologists and epileptologists, “pseudoseizures” was among the least popular terms used by only 6.3%¹⁹ and 4.5%²⁰ of respondents, respectively. GPs also commonly used the term “nonepileptic events/attacks/seizures.” Although this term is more acceptable to patients than the term pseudoseizures,^{16,18} and popular among neurologists and epileptologists,^{17,19} it is nonetheless a “negative” diagnostic term, which focuses on what the patient does not have, rather than giving the patient a positive explanation for their symptoms. Systematic reviews have shown that the most popular term among patients (and clinicians) for conversion disorder is “functional,”²¹ and studies that have assessed its use in patients specifically with seizure disorders corroborate these findings.¹⁶ However, in this survey, only 28% of GPs used this term. Ultimately, although the debate over terminology is unresolved, based on our findings, education for GPs regarding patient perceptions of different terms would be relevant.

Approximately 20% of local GPs had had some evidence of gaps in their understanding of functional seizures. More significantly, just over 50% of local GPs either agreed with, or were unsure about, the statement that most patients had voluntary control over their seizures. This result is similar to the results of the 2 other published surveys of GPs exploring the same issue. In one study, which included 49

GPs, 31% believed that patients faked or had voluntary control over their functional seizures,¹⁰ whereas in the other study, 38% of 60 GPs believed patients had control over their functional seizures.¹² However, these views about the degree of control patients have over their functional seizures are at odds with both expert consensus, and the views of the patients themselves.²² Surveys of other healthcare professionals report similar findings, although to lesser degree. In a postal survey of 349 practicing consultant neurologists in the United Kingdom, 44% of neurologists thought conversion overlapped with feigning, including 13% who thought that all their conversion patients were feigning or vice versa.²³ A similar level of doubt about the involuntary nature of functional symptoms was highlighted in a questionnaire-based study of 68 specialist neuroscience nurses. About 16% of nurses felt that the symptoms patients experienced were not real, and that patients were simulating them.²⁴ In a French study, 10% of 963 psychiatrists who completed an online questionnaire believed that patients had voluntary control of their functional seizures.²⁵

Nearly one-third of GPs agreed with, or were unsure about, the statement that patients only ever have functional seizures when stressed. This finding was more common among older compared to younger GPs, and this age difference may reflect more historical, Freudian models of functional seizures. In reality <50% of patients report feeling stressed before functional seizures, and in many cases patients do not identify obvious triggers.¹ Patients with functional seizures are more likely than those with epilepsy to consider their problem “somatic” rather than “psychological,” and to deny significant nonhealth stresses in their lives.²⁶

The information provided by GPs to their patients is a product of their perception and knowledge of functional seizures. This will greatly influence the feelings that the patient has about his or her condition, particularly in the case of a somatoform disorder, and this in turn may impact their behavior.^{27,28} It has been shown that the outcome in patients with symptoms unexplained by disease is correlated with the attitude of the treating doctor, such that the poorer the attitude, the worse the outcome.²⁹ The discrepancy in illness perceptions between a patient and their GP can affect how accepting a patient is of psychological treatment and prognosis, and lead to inappropriate healthcare use.³⁰ We therefore propose that educational attempts should be made to ensure that local GPs seeing these patients have a basic understanding of functional seizures, especially around the issue of feigning. This should be relatively straightforward to implement using simple measures such as basic information sheets,^{31,32} and clear, consistent language when communicating and explaining the diagnosis to GPs.³³

The International League Against Epilepsy (ILAE) has recently published a consensus document outlining expert

recommendations for the diagnosis and management of patients with functional seizures.³⁴ Neurologists are best placed to diagnose functional seizures, as they often need to distinguish functional from epileptic seizures, and national surveys in the United States and the United Kingdom demonstrate that they accept this role.^{19,20} This central diagnostic role of the neurologist is reflected in the findings reported in this study, where 98.3% GPs felt neurologists should be involved at some level in making the diagnosis, whereas only 62.5% felt psychiatrists should be similarly involved.

The ILAE consensus document also highlights that the management of patients with functional seizures should include referral for psychiatric assessment and instigation of psychotherapeutic treatment where appropriate.³⁴ This is again reflected in this survey, where 82.5% of GPs reported that psychiatry should play a role in the management of these patients. The role of neurologists in the management of patients with functional seizures is less clear. The consensus document highlights a need for “doctors” to play a role in “treatment maintenance” in a proportion of patients but does not specify the nature of these doctors. Although half of the GP respondents in this survey expressed a moderate or high interest in managing these patients, a similar proportion reported feeling unconfident or very unconfident in managing them and dealing with their queries. This is in keeping with other studies where GPs report confidence levels of 4/10 to 5/10 in managing patients with functional seizures,^{12,13} and are much less confident, compared to neurologists and nurses.¹² This finding was more common among younger compared to older GPs, and may reflect a simple lack of experience. Our survey findings also indicate that although GPs believe that psychiatrists are crucial to the management of these patients and see a role for themselves in the management of these patients, a substantial proportion also feel that neurologists also have an important role to play in the management of these patients. This is in keeping with 2 other studies that have assessed GP opinions regarding the management of patients with functional seizures. In both studies GPs felt it was primarily the role of GPs *and* neurologists, or neurologists *and* psychiatrists to manage patients.^{12,13} Neurologists, rather than GPs or psychiatrists, may indeed be well placed to take on this role of “treatment maintenance” for both practical and medical reasons.^{35,36} From a practical standpoint, neurology services, although limited, are more readily available than neuropsychiatric and psychotherapeutic services,¹⁹ whereas general psychiatrists have little interest or expertise in the management of these patients,^{37,38} and access to appropriate psychological treatments can be limited.¹⁹ These resource limitations, and the fact that neurologists tend to make the diagnosis of functional seizures, may explain why GPs felt more comfortable referring to, and better supported by, neurologic compared with

psychiatric services. From a medical viewpoint, ongoing neurology follow-up would facilitate the weaning of antiepileptic medications, ensure that the diagnosis of functional seizures does not change inappropriately, and aid the robust diagnosis and management of the frequent comorbid conversion disorder and somatization symptoms that can arise in this patient group.³⁶ Neurologists may also help to mitigate concerns about overlooked neurologic symptoms, and in doing so help patients to come to terms with their diagnosis and to engage in forms of psychological treatment.^{35,39} Despite these advantages, and the fact that GPs reported being better supported by neurology compared to psychiatry, 21.8% of GPs still reported being very poorly or poorly supported by neurology services. This is not surprising because nationally 53% of neurologists do not follow-up patients with functional seizures, at least until anticonvulsants are withdrawn and seizures controlled, and indeed 20% discharge patients directly after making a diagnosis.¹⁹ A review of studies of the attitudes of healthcare practitioners highlights that neurologists see a very limited role for themselves in the management of patients with functional seizures.¹⁴ We suspect that this is in part related to resource limitations, and the inherent challenges in managing patients with functional seizures.¹⁴

Our results should be considered, bearing in mind the following limitations. All internet-based questionnaire-based studies are limited by selection bias, and the results reported here can only be considered truly representative of those who are technologically literate and chose to respond to the survey. Although the response rate in this survey of 12.3% is superior to the 5.8% rate reported in an internet survey of neurologists managing patients with functional seizures in the United Kingdom,¹⁹ it is still low, and limits the generalizability of any findings reported here. This survey was conducted in a densely populated metropolitan area and it is not representative of the general population of GPs in the United Kingdom, especially those working in rural areas. Indeed, GPs in this study work in the catchment area of 2 neuroscience centers with an interest in this disorder. In addition, it is possible that the knowledge and attitudes of GPs who did not respond to this survey are even more limited and negative. This may in part limit the generalizability of our findings.

In conclusion, this study has highlighted the knowledge of, and attitudes of, GPs toward patients with functional seizures and their diagnosis and management. Although most GPs are happy to help manage these patients, there are clear shortcomings in their knowledge of this relatively common disorder, which can affect the prognosis of patients. Compounding this problem, most GPs feel unsupported by psychiatric and to a lesser extent neurologic services. We propose that a dedicated multidisciplinary management service with integrated neurologic, neuropsychiatric, and psychological care, and

better education and clear communication with GPs, may help to alleviate these problems, and would also be welcomed by GPs, as demonstrated in this survey.

DISCLOSURE

None of the authors has any conflicts of interest to disclose. 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.

AUTHOR CONTRIBUTION

All coauthors were substantially involved in the study and/or the preparation of the manuscript. No undisclosed groups or persons have had a primary role in the study and/or in manuscript preparation. All co-authors have seen and approved the submitted version of the paper and accept responsibility for its content.

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