

Functional Seizures: An Evaluation of the Attitudes of GPs Local to a Tertiary Neuroscience Service in London

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Abstract:	Objective: Functional seizures are a common functional neurological disorder. Given their chronic nature, and the bio-psycho-social factors involved in their aetiology, GPs play a crucial role in the care of these patients. However, little is known about GP attitudes to, 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 amongst local GPs over a 1-month period assessing their attitudes to, and knowledge of, functional seizures. Results: 120 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 care givers 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 to patients with functional seizures. Our findings suggest a need for better and clearer provision of information to GPs about this condition.

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Epilepsia Open Page 34 of 55

FUNCTIONAL SEIZURES: AN EVALUATION OF THE ATTITUDES OF GPS LOCAL TO A TERTIARY NEUROSCIENCE SERVICE IN LONDON

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SUMMARY

Objective: Functional seizures are a common functional neurological disorder. Given their chronic nature, and the bio-psycho-social factors involved in their aetiology, GPs play a crucial role in the care of these patients. However, little is known about GP attitudes to, 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 amongst local GPs over a 1-month period assessing their attitudes to, and knowledge of, functional seizures.

Results: 120 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 care givers 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 to 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, pseudoseizures, psychogenic seizures, non-epileptic seizures, GP attitudes



INTRODUCTION

Functional seizures superficially resemble epileptic seizures but are not associated with ictal electroencephalographic (EEG) 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 non-epileptic seizures (PNES), and non-epileptic attack disorder (NEAD). For the purpose of this article we will continue to use the term functional seizures, recognising that they are a common manifestation of functional neurological disorders (FND).

Functional seizures are classified by DSM-5 as a conversion disorder (functional neurologic symptom disorder) ² and by ICD as a dissociative disorder ³. Although GPs in the United Kingdom (UK) 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 aetiological complexity of 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 other neurological conditions.

Previous research into GP attitudes to 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 neurological disorders such as multiple sclerosis ⁸, and psychiatric disorders, such as anxiety and depression ⁹, there have only been four studies assessing GP attitudes to patients with functional seizures^{10–13}. Of these studies only one ¹³ concentrated soley on GPs, but was limited to the views of 23 GPs. Indeed, most studies of the attitudes of healthcare practioners to patients with functional seizures have concentrated on specialised 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 UK's largest university hospitals, serving a population of 1.3 million across southwest London and 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 neurological 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), to patients with functional seizures in terms of their diagnosis and management. This may improve understanding of the barriers we face in the diagnosis and treatment of these patients.

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 GPs used to describe functional seizures, and their

attitudes to the terminology, clinical features and management of functional seizures. The questionnaire was deliberately brief in order to maximise response rates amongst 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 1month. 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.

As this was a descriptive survey, all variables were analysed in an exploratory manner using descriptive statistics, with minimal inferential statistical testing. A threshold of 55 was used to split respondents into two groups, those aged below 55 years ('young') and those aged 55 years or older ('old'). This threshold was chosen because it is the earliest age at which partial retirement can be taken in the UK by medical practioners. Group analyses, using 'young' and 'old' age were statistically analysed using a Chi squared test. When comparing groups, answers from the questionnaire were re-coded into dichotomous scores in order to simplify the analysis as indicated in Table 1.

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 onwards. That data which was available for this respondent was included in the analysis. A total of 65.5% of respondents were female, and 75.7% were aged below 55 years; 89.2% of respondents reported having seen between 1 and 10 patients with functional seizures, while 9.2% reported having seen no patients with this condition; 1.7% reported having seen between 11 and 20 patients with functional seizures (Table 1).

The most popular terms used to describe functional seizures were "pseudoseizures", and/or "non-epileptic 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 non-epileptic seizures", "functional seizures", "pseudo-epileptic seizures" and "non-organic seizures". Dissociative seizures was used by only 13% of GPs while "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' or 'young' GPs.

GP attitudes to the clinical features and treatment of functional seizures was 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 know whether, patients only had functional seizures when stressed. Knowledge of other aspects of functional seizures was better, although rates of incorrect or absent knowledge about functional seizures amongst 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 though not directly life threatening do need treatment based on psychological approaches and not anti-convulsants. Almost all (93.3%) GPs correctly replied that functional seizures resemble but are not equivalent to epileptic seizures, and 88.3% correctly stated 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% v 22% respectively). Otherwise, there were no significant differences in attitudes to functional seizures between younger and older GPs, including whether patients have voluntary control of seizures.

While 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% v 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, while only 34.2% felt 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, while 96.7% of GPs reported feeling comfortable referring patients to neurology, only 50% felt comfortable referring to psychiatry. Moreover, while 72.3% reported feeling

adequately supported by neurology, only 39.5% reported feeling adequately supported by psychiatry in managing these patients. Over 75% of GP would actively welcome a dedicated diagnostic and management service for these patients.

DISCUSSION

This is the largest survey of GPs to explore the attitudes to, 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 were not sure as to whether, functional seizures occur only when patients are stressed, while 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 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 care givers 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 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 practioner attitudes to patients with functional seizures¹⁴ has previously reported that most healthcare practioners use aetiologically 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 specialised healthcare practioners, such as neurologists. This, in contrast, is the first paper 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 upon 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 two 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 amongst the least popular terms used by only 6.3% ¹⁹ and 4.5% ²⁰ of respondents respectively. GPs also commonly used the term "non-epileptic events/attacks/seizures". While this term is more acceptable to patients than pseudoseizures 16,18, and popular amongst 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 amongst 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 two 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, while 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 those of the patients themselves ²². Surveys of other health professionals report similar findings, though to lesser degree. In a postal survey of 349 practicing consultant neurologists in the UK, 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 amongst older compared to younger GPs, and this age difference may reflect more historical, Freudian models of functional seizures. In reality less than 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 non-health 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 the patient has about his or her condition, particularly in the case of a somatoform disorder, and this in turn may impact their behaviour ^{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 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 USA and UK 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, while only 62.5% felt psychiatrists should be similarly involved.

Epilepsia Open Page 46 of 55

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 amongst younger compared to older GPs and may reflect a simple lack of experience. Our survey findings also indicate that while GPs believe 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 two 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, though limited, are more readily available than neuropsychiatric and psychotherapeutic services ¹⁹, while 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, neurological compared with psychiatric services. From a medical viewpoint, on-going neurology follow-up would facilitate the weaning of anti-epileptic medications, ensure that the diagnosis of functional seizures does not change inappropriately, and aid the robust diagnosis and management of the frequent co-morbid conversion disorder and somatisation symptoms that can arise in this patient group ³⁶. Neurologists may also help to mitigate concerns about overlooked neurological 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 followup patients with functional seizures at least until anti-convulsants are withdrawn and seizures controlled, and indeed 20% discharge patients straight after making a diagnosis ¹⁹. A review of studies of the attitudes of healthcare practioners highlights that neurologists see a very limited role for themselves in the management of patients with functional seizures ¹⁴. We suspect 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. Though 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 UK 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 UK especially those working in rural areas. Indeed, GPs in this study work in the catchment area of two neuroscience centres with an interest in this disorder. In addition it is possible that knowledge and attitude of GPs that 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 to patients with functional seizures and their diagnosis and management. While 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 neurological services. We propose that a dedicated multi-disciplinary management service with integrated neurological, 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.

KEY POINT BOX

- 75% of GP respondents use the term "pseudoseizures" to describe psychogenic non-epileptic seizures, and 50% doubt their involuntary nature.
- 50% of GPs report an interest in the management of patients with psychogenic non-epileptic seizures, but do not feel confident in managing these patients.
- One and two thirds of GPs feel unsupported by neurology and psychiatry respectively in the diagnosis and management of these patients.

Epilepsia Open Page 50 of 55

Table 1 – Questionnaire – Questions 1/2 can be seen in figures 1/2. Italicized answers represent dichotomisation of answers for the purpose of group analysis between 'old' and 'young' GPs.

Q3. How many patients have you	seen with this condition? % o	f respondents (number o	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	General	General	General	Neurology and
		alone	practice alone	practice and	practice and	Psychiatry
				Psychiatry	neurology	
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)

Very comfortable/Comfortable/Neutral = Comfortable

 ${\it Uncomfortable/Very\ uncomfortable} = {\it Uncomfortable}$

	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)
	•			•	*

Page 51 of 55 Epilepsia Open

-	Q6. How confident do you/would you feel in managing these patients and dealing with their queries? % of respondents (number of
	respondents)

Very confident/confident/Neutral = Confident

Very unconfident/Unconfident = Unconfident

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)

Very well supported/Well supported/Neutral = Supported

Poorly supported/Very poorly supported = Not supported Not applicable = Not coded

	Very well	Well supported	Neutral	Poorly supported	Very poorly	Not applicable
	supported				supported	
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)

Very high/High/Moderate = Interested

Low/Very low = Not interested

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)

Epilepsia Open Page 52 of 55

		Yes		No	N	eutral
Diagnosis		75.6 (90)		5 (6)	19	.3 (23)
Management		77.3 (92)		2.5 (3)	20	.2 (24)
Q10. What is you	age? % of respond	ents (number of resp	ondents)			
				55 (A	(5.74	75
Q10. What is your 18-24 0 (0)	25-34 10.1 (12)	35-44 28.6 (34)	ondents) 45-54 37 (44)	55-64 21 (25)	65-74 3.4 (4)	75+ 0 (0)



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Epilepsia Open Page 54 of 55

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Epilepsia Open Page 56 of 55

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

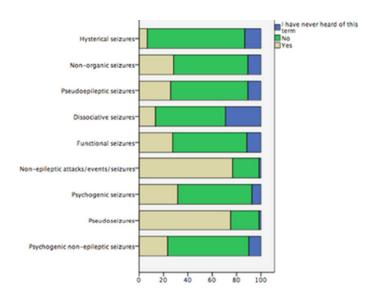
Ethical publication statement

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.

Authorship statement

All co-authors have been have been 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.

Epilepsia Open Page 32 of 55



 $\label{prop:continuous} \mbox{Figure 1: Percentage of GP respondents using various terminology for functional seizures.}$

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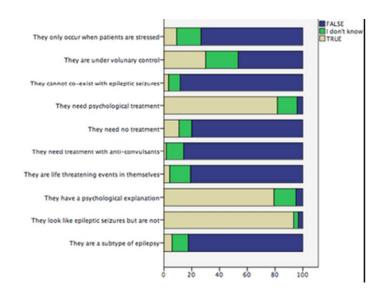


Figure 2: Percentage of GP respondents and their knowledge of functional seizures.

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