



King's Research Portal

DOI:

[10.1016/j.yebeh.2019.106895](https://doi.org/10.1016/j.yebeh.2019.106895)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Asadi-Pooya, A. A., Brigo, F., Mildon, B., & Nicholson, T. R. (2020). Terminology for psychogenic nonepileptic seizures: Making the case for "functional seizures". *Epilepsy and Behavior*, *104*(Part A), 106895. [106895]. <https://doi.org/10.1016/j.yebeh.2019.106895>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Terminology for psychogenic nonepileptic seizures: making the case for “Functional Seizures”

Authors: Ali A. Asadi-Pooya, M.D.^{1,2}, Francesco Brigo, M.D.³, Bridget Mildon⁴, Timothy R. Nicholson, Ph.D., MRC. Psych⁵

1. Neuroscience Research Center, Shiraz University of Medical Sciences, Shiraz, Iran.
2. Jefferson Comprehensive Epilepsy Center, Department of Neurology, Thomas Jefferson University, Philadelphia, Pennsylvania, PA, USA.
3. Division of Neurology, "Franz Tappeiner" Hospital, Merano, Italy; Department of Neuroscience, Biomedicine and Movement Science, University of Verona, Verona, Italy.
4. FND Hope International, CEO, USA.
5. Section of Cognitive Neuropsychiatry, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK.

Address for correspondence:

Ali A. Asadi-Pooya, M.D.

Neuroscience Research Center,

Shiraz University of Medical Sciences,

Shiraz, Iran

Phone/Fax: 98-7136121065

E-mails: aliasadipooya@yahoo.com; dr.francescobrigo@gmail.com; bridget@fndhope.org;

timothy.nicholson@kcl.ac.uk

Running title: Functional seizures

Number of characters in the title: 92; number of characters in the running head: 20; number of text pages: 7; number of words: 2831; number of words in the abstract: 226; number of references: 54; number of figures: 0; number of tables: 2.

Abstract

Purpose: To review the literature on the terminologies for psychogenic nonepileptic seizures (PNES) and make a proposal on the terminology of this condition. This proposal reflects the authors' own opinions.

Methods: We systematically searched MEDLINE (accessed from PubMed) and EMBASE from inception to October 10, 2019 for articles written in English with a main focus on PNES (with or without discussion of other functional neurological disorders) and which either proposed or discussed the accuracy or appropriateness of PNES terminologies.

Results: The search strategy reported above yielded 757 articles; 30 articles were eventually included, which were generally of low quality. "Functional seizures" (FS) appeared to be an acceptable terminology to name this condition from the perspective of patients. In addition, FS is a term that is relatively popular with clinicians.

Conclusion: From the available evidence, FS meets more of the criteria proposed for an acceptable label than other popular terms in the field. While the term FS is neutral with regard to etiology and pathology (particularly regarding whether psychological or not), other terms such as "dissociative", "conversion", or "psychogenic" seizures are not. In addition, FS can potentially facilitate multi-disciplinary (physical and psychological) management more than other terms. Adopting a universally accepted terminology to describe this disorder could standardize our approach to the illness and facilitate communication between healthcare professionals, patients, their families, carers and the wider public.

Key words: Functional; Psychogenic; Seizure; Terminology

Introduction

Psychogenic nonepileptic seizures (PNES) are self-limited events characterized by paroxysmal changes in feelings, responsiveness, movements, or behavior^{1,2}. They may look like epileptic seizures but are not associated with epileptiform changes in the electroencephalogram and therefore with any evidence of any electrical dysfunction of the brain¹. There is increasing evidence of abnormal brain function, yet, the neurobiological underpinnings of this condition remain largely unclear³. Despite current scientific findings pointing to both neurobiological and psychological bases,^{1,3} PNES are often defined in terms of what they are not rather than what they are (i.e., “non-epileptic”) and there is not even a universally accepted/used terminology^{1,4}.

Several different terms have been used in the medical literature to describe PNES⁴.

“Psychogenic nonepileptic seizures” has emerged in recent years as the most commonly adopted term to describe this condition³. For this reason, we have primarily focused on the term PNES in the current manuscript; although, other terms are currently used, especially “dissociative” or “conversion” seizures^{2,4}. However, various international authors, experts, and patients challenge whether “psychogenic” appropriately defines the condition⁵, especially as not all patients have past psychological traumas or current psychiatric problems¹.

Developing an international consensus on terminology is important for many reasons, including improved patient-clinician relationships and inter-professional communications, among others⁴. The aim of the current paper was to systematically and critically review the literature on the terminology for the condition to inform several discussions that could influence the decision regarding an optimal term. First, we will discuss the appropriate term to call this condition with regard to its nature (i.e., seizure vs. attack vs. event). Then, we will

discuss what could be an appropriate descriptive modifier. Finally, we make our proposal on the terminology of this condition. **This proposal reflects the authors' own opinions.**

Materials and Methods

First, we did a systematic review (Appendix 1^{6,7}). We systematically searched MEDLINE (accessed from PubMed) and EMBASE from inception to October 10, 2019. In both electronic databases, we used the following search strategy: (“psychogenic” OR “non-epileptic” OR “dissociative seizure”) AND (“terminology” OR “phenomenology” OR “definition”). We restricted the search to these terms, excluding some obsolete names (e.g., pseudoseizure, hysteroepilepsy, etc.³). We included articles written in English with a main focus on PNES (with or without discussion of other functional neurological disorders) and which either proposed or discussed the accuracy/appropriateness of a certain PNES terminology.

The first two authors (AAP and FB) selected the relevant articles after reviewing their titles, abstracts, and full texts. Also included, were some of the references of the selected articles if they were relevant. Retrieved items were independently screened and selected for possible inclusion by two reviewers (AAP and FB); any disagreement was resolved through discussion. The same reviewers independently extracted the following data: study authors, study design and methods, and main results. The methodological quality of included studies was assessed and discussed narratively. Classes of evidence were categorized using the American Academy of Neurology's criteria for studies of causation (Appendix 2)⁸.

Results

The reported search strategy yielded 757 articles. After excluding duplicates (n=251) and reading titles, abstracts and full texts, 30 articles were included in the current review (Appendix 1). Table 1 shows a summary of the included 30 published materials. All studies were of low quality (class IV) evidence. Twelve studies were field study (surveys or observational studies; seven studies investigated patients and five of the articles studied healthcare professionals), seven were reviews and 11 were letters. While, the authors acknowledge that the literature on the terminology of this condition is limited and of generally low quality, “functional seizures” appears to be an acceptable terminology to name this condition (PNES) from the perspective of patients (based on the findings from three studies); “functional seizures” was significantly less offensive terminology than other terms for patients and their care-givers (references 20, 21, and 23 in Table 1). In addition, “functional” is a term that is relatively popular with clinicians, again based on the findings from three studies (references 28, 41, and 42 in Table 1). However, this is based on results described in a few studies out of 30. Therefore, the current manuscript is essentially an opinion piece by the authors. The following text describes and discusses the elements of the terminology for this common condition.

Discussion

There is a shortage of high-quality data on the optimal terminology for this disorder. However, adopting universally accepted terminology to describe this condition is necessary to facilitate communication between healthcare professionals and between such professionals and both patients, their care-givers and the wider public. Authors relied on the results of a systematic review of the literature to provide a formal proposal of terminology. This proposal

reflects the authors' own opinions but takes into account the data from the available literature.

1. Is it a “seizure”, “attack” or “event”?

By definition from Cambridge English dictionary, an “event” is anything that happens, especially something important or unusual (both in English and in American English) ⁹; an “attack” is a sudden and short period of illness ¹⁰; a “seizure” is a very sudden attack of an illness in which someone becomes unconscious or develops violent movements ¹¹.

Semiologically, psychogenic nonepileptic seizures are paroxysmal, time-limited alterations of bodily/mental functions, manifested in movements, responsiveness, behavior, or sensations ^{1,12}. Therefore, the term “seizure” appropriately describes the semiology of this condition in comparison to the terms “event” and “attack” and is more specific.

The term “seizure” may be descriptively modified by the preceding terms such as “epileptic”, “hypocalcemic”, “hypoglycemic”, “febrile”, etc. Hence, the term seizure is not only associated with epilepsy (particularly in English, as some may argue) ¹². In fact, there are many occasions of provoked seizures (e.g., hyponatremic seizures) that are not associated with epilepsy; even though these have electrical brain abnormalities associated with the seizures and some may argue that PNES are outlier with this regard, as the latter do not have any associated electrophysiological changes. Despite this, some professionals and patients alike may associate the term “seizure” with “epilepsy”. Therefore, it is the responsibility of healthcare professionals to educate and explain the condition appropriately for the patients and their families to reduce the possibility of any misunderstanding and confusion ^{12,13}.

While, the term “seizure” might best describe the nature of the manifestations of PNES (objective and subjective features) ¹⁴⁻¹⁶, it is unavoidable that some patients with PNES might

not like or adopt to use the term “seizure”¹⁶. By the same token, the term “attack” is also sometimes not accepted by patients and results in some individuals avoiding the term “attack” as well^{17,18}. In fact, many patients may be uncertain what to call their condition¹⁹; this highlights the significant role of healthcare professionals to describe the condition to patients and their families appropriately. Clearly, the explanation should reflect that of a standardized approach rather than a healthcare professional’s personal understanding and attitude toward the condition. Unfortunately, labels can negatively influence how some healthcare providers approach their patients, and in some instances the standard of care which is provided. Furthermore, terminologies may affect how and if a patient can access certain treatments (e.g., physical therapy, occupational therapy, etc.) and if the treatment is a covered service or self-pay.

2. Is it “psychogenic”, “dissociative” or other?

"Psychogenic" means that a condition or illness originates "in mind", with a psychological etiology and the same applies to “dissociative” and “conversion”. These terms can be offensive to patients because they risk being misconstrued as inferring patients are exaggerating or even ‘putting on’ symptoms, i.e. feigning^{20,21}. While the term “psychogenic” is poorly accepted by patients^{20,21}, the reasoning against its use is not simply due to patients’ preference. It can be argued that this term encourages a dualistic representation of disorder (somatogenic vs. psychogenic) that is no longer supported by research and implies the absence of an organic etiology⁵. It is clear that these seizures have a different etiology to epileptic seizures in that they are not associated with electrophysiological epileptiform changes; they have a mechanistic basis that is different from that in epileptic seizures. However, an association of these seizures with organic (physical) brain dysfunction appears to be very likely based on the recent evidence, albeit preliminary, of functional and structural

brain connectivity abnormalities in these patients. There is accumulating evidence that dysfunction of emotion processing areas (e.g., insula), dysregulation of executive control and cognitive processing regions of the brain (e.g., dorsolateral prefrontal cortex, inferior frontal gyrus and parietal cortex), and an increased focus on somatic function (e.g., attributed to the insula, parietal cortex and anterior cingulate) may be involved in the pathophysiology of these seizures^{2,22}. While the term “Functional Seizures” is neutral with regard to etiology and pathology, i.e. whether psychological or physical (i.e. “organic”), other terms are variably so: “dissociative” seizures implies a specific psychological mechanism, albeit one also seen in organic conditions or potentially induced pharmacologically, and both “conversion” (of stress and/or trauma to physical symptoms) seizures and “psychogenic” seizures have clearer positions regarding psychological etiology.

In brief, “psychogenic”, “dissociative”, or “conversion” terminologies can be argued to ascribe a single and specific etiology that falls short of the supportive evidence for a complex and potentially heterogeneous condition, potentially alienating patients for whom a simple psychological cause is not appropriate and therefore does not make sense. On the other hand, the term “functional” points to the above-described potential functional brain dysregulations and permits a more rigorous scientific approach to the study of this patient community by studying neurobiological underpinnings on how functional changes in the brain may produce these seizures. In addition, it opens a prosperous horizon for better engagement of all key stakeholders (e.g., neurologists, psychiatrists, patients, carers, etc.).

On the other hand and based on the evidence, “functional” is a less offensive term for this and other similar conditions than terms such as “dissociative”, “conversion”, or “psychogenic”^{20,21,23,24}. The importance of adopting a term that is most descriptive of the pathophysiology with the least negative connotation is not merely semantic; it could have a significant effect not only on how clinicians view this patient community (e.g., it influences how and if

neurologists feel this realm of medicine falls in their field of expertise), but overall acceptance of the diagnosis and how patients understand and accept the offered therapeutic care²¹. Finally, although psychological factors are identified for the majority of patients with this condition, they are not found in all patients and it is unclear whether and how they are etiologically relevant⁵. Similarly, some patients with this condition do not experience dissociative symptoms. While the term “Functional Seizures” will facilitate the possibility of multi-disciplinary (medical and psychological) treatments, other terms (“dissociative”, “conversion”, or “psychogenic” seizures) do not provide such an opportunity; this may hamper the management process of the patients.

We should keep in mind that adding a term as a descriptive modifier can help to distinguish these seizures from other seizures (i.e., both epileptic and non-epileptic conditions, such as syncope)²⁵. Therefore, considering the above arguments, it seems that the term “functional” is an appropriate descriptive modifier to be used with “seizures” in these patients.

3. Is it necessary to mention “non-epileptic”?

It is clearly not ideal to define a disorder by what it is not. Such negative terms provide no relevant positive information regarding the disorder in terms of what it is⁵. In addition, if we follow the above strategy of providing a clear and appropriate description of the condition to patients and their families, we do not need to be worried about creating any confusion or misunderstanding for them as for the diagnosis. Furthermore, a negative diagnosis, i.e., one of elimination, is understandably poorly accepted by many patients, whereas a positive diagnosis helps to understand and accept the disorder and its treatment better⁵.

4. Our proposal is “Functional Seizures”

It has been argued that an ideal terminology should fulfil multiple criteria^{26,27}. Table 2 shows these criteria for the most commonly used terminology (i.e., PNES)⁴ and the proposed term (i.e., Functional Seizures) for this condition. In our opinion, “functional seizures” appears to be the most appropriate terminology to name this condition (PNES). “Functional” is a term that is relatively popular with both clinicians and the public⁴. It also meets more of the criteria proposed for an acceptable label than other popular terms in the field (Table 2)²⁷.

When presenting the diagnosis of this condition to a patient, a specific and clear label for the seizures should be provided at the beginning of the encounter along with an appropriate description of the condition to the patients and their families¹⁸. Some authors have already adopted this term (i.e., functional seizures) to describe this condition²⁸⁻³⁰.

To anticipate the counter-arguments from neurologists, who may argue that epileptic seizures are, in many cases, “functional” or “network” as opposed to “structural” disorders³¹, we have to say that yes, epileptic seizures are indeed “functional” or “network” disorders as opposed to “structural” problems, in many patients; but, this does not refute that PNES are also a functional disorder^{32,33}. In addition, for epileptic seizures, we have a more specific and more appropriate modifier to describe the term “seizure”, that is “epileptic”; but, for PNES, we do not have a better and more specific modifier to adjoin with the term “seizure”.

Perhaps, more importantly the term “functional seizure” is also in keeping with terminology of other symptoms of the wider disorder that has increasingly become known as Functional Neurologic Disorder (FND), for example functional paralysis and functional movement disorders (e.g., functional tremor or functional dystonia)³⁴⁻³⁶. Therefore, it is possible to apply a universal term to the whole disorder and its subtypes; an abbreviated terminology has recently been proposed with FND subtypes [e.g., FND-seiz (for seizure), FND-par (for paralysis) and FND-movt (for movement disorders)]³⁰. While, patients with PNES do not fit into a single category of the current international classifications, overwhelming majority (if

not all) that are given this label fulfill the diagnostic criteria of Functional Neurological (Symptom) Disorder (DSM-5)³⁷. Finally, it is important to acknowledge that the acronym FND has been universally adopted by the patient groups and charities that have developed and flourished over the last decade³⁸. We have to clarify that by the use of the modifier “functional”, we do not mean that it is a mere disorder of the function of the brain (“the brain or part of it does not work properly”), without evidence of structural abnormalities! Based on the current literature²², presence of subtle structural abnormalities may be expected, at least in some patients with functional seizures. Rather, we adopted this modifier for all the reasons described above.

We acknowledge that this work has some limitations. The arguments about terminology in this article are Anglocentric. We do not know whether the term “functional seizures” translates well in other languages. We should keep in mind that acceptability of terms may change over time and stigma could be attached to any new terms. These issues should be evaluated in the future.

Conclusion

Despite all the above, physicians and other healthcare professionals in different countries and even in different institutions in one country may prefer one term over another to name this condition³⁹⁻⁵⁴. Adopting a universally accepted terminology to describe functional seizures is likely to facilitate better communication between healthcare professionals and critically between such professionals and patients. However, this is a controversial area; some prefer the term “PNES”, while others may prefer “dissociative seizures”, and they who are split between the multiple existing terms in the literature. To definitively conclude these differences necessitates the collecting of opinions from a broad range of stakeholders in the field (neurologists, psychiatrists, psychologists, primary care physicians, patients, healthcare

planners, managers, etc.) in order to maximise the likelihood that the new term will be accepted and used widely. This could be achieved by a mixture of expert-opinion and evidence-based approaches. However, while these various perspectives are important factors to consider, stakeholder opinions should be carefully weighed and scrutinized. Appropriate terminology should take into consideration both our current scientific understanding and limitations, as well as, its influence on diagnosis, management, and future research into the condition. Labels not only define illness but also patients, so it is imperative that every effort is made to eliminate bias and improve overall patient care.

Conflicts of interest

A. A. Asadi-Pooya: Honoraria from Cobel Daruo, Sanofi, and RaymandRad; Royalty: Oxford University Press (Book publication).

F. Brigo received travel support from Eisai, Lusofarmaco and UCB Pharma; he acted as consultant for Eisai, LivaNova, and UCB Pharma.

T. Nicholson is funded by a UK National Institute of Health Research (NIHR) Clinician Scientist Award. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health.

B. Mildon is the CEO of FND Hope International/USA. She has received honoraria from The Cleveland Clinic and runs a free non-profit self-help website www.fndhope.org.

Acknowledgments

None.

References

1. Asadi-Pooya AA, Sperling MR. Epidemiology of psychogenic non-epileptic seizures. *Epilepsy Behav* 2015; 46: 60-65.
2. American Psychiatric Association. Diagnostic and statistical manual of mental health disorders: DSM-5. 5th Ed. Washington, DC: American Psychiatric Publishing; 2013.
3. Allendorfer JB, Nenert R, Hernando KA, DeWolfe JL, Pati S, Thomas AE, et al. FMRI response to acute psychological stress differentiates patients with psychogenic non-epileptic seizures from healthy controls - A biochemical and neuroimaging biomarker study. *Neuroimage Clin* 2019; 24: 101967.
4. Brigo F, Igwe SC, Ausserer H, Nardone R, Tezzon F, Bongiovanni LG, et al. Terminology of psychogenic nonepileptic seizures. *Epilepsia* 2015; 56: e21-5.
5. Barron E, Rotge JY. Talking about "psychogenic nonepileptic seizure" is wrong and stigmatizing. *Seizure* 2019; 71: 6-7.
6. Hutton B, Salanti G, Caldwell DM, et al. The PRISMA extension statement for reporting of systematic reviews incorporating network meta-analyses of health care interventions: checklist and explanations. *Ann Intern Med* 2015; 162: 777-784.
7. Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009; 6: e1000097.
8. Gronseth GS, Cox J, Gloss D, et al. on behalf of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology. 2017. Clinical Practice Guideline Process Manual, 2017 ed. Minneapolis, MN: The American Academy of Neurology.
9. <https://dictionary.cambridge.org/dictionary/english/event/> accessed on 06/11/2019.
10. <https://dictionary.cambridge.org/dictionary/english/attack/> accessed on 06/11/2019.

11. <https://dictionary.cambridge.org/dictionary/english/seizure/> accessed on 06/11/2019.
12. LaFrance WC Jr. Psychogenic nonepileptic "seizures" or "attacks"? It's not just semantics: seizures. *Neurology* 2010; 75: 87-88.
13. Benbadis SR. Psychogenic nonepileptic "seizures" or "attacks"? It's not just semantics: attacks. *Neurology* 2010; 75: 84-86.
14. Asadi-Pooya AA, Bahrami Z. Loss of responsiveness in psychogenic non-epileptic seizures. *Epileptic Disord* 2019; 21: 192-196.
15. Asadi-Pooya AA, Bahrami Z. Auras in psychogenic nonepileptic seizures. *Seizure* 2019; 69: 215-217.
16. Reuber M, Brown RJ. Understanding psychogenic nonepileptic seizures- Phenomenology, semiology and the Integrative Cognitive Model. *Seizure* 2017; 44: 199-205.
17. Plug L, Sharrack B, Reuber M. Seizure, fit or attack? The use of diagnostic labels by patients with epileptic or non-epileptic seizures. *Appl Linguist* 2010; 31; 94-114.
18. Monzoni CM, Reuber M. Psychogenic Non-epileptic Seizures: How Doctors Use Medical Labels when they communicate and explain the diagnosis. In: M O'Reilly & J N Lester (eds.), *The Palgrave Handbook of Adult Mental Health*. London: Palgrave McMillan UK, 2016, 209-226.
19. Rawlings GH, Reuber M. What patients say about living with psychogenic nonepileptic seizures: A systematic synthesis of qualitative studies. *Seizure* 2016; 41: 100-111.
20. Stone J, Campbell K, Sharma N, Carson A, Warlow CP, Sharpe M. What should we call pseudoseizures? The patient's perspective. *Seizure* 2003; 12: 568-572.
21. Morgan LA, Dvorchik I, Williams KL, Jarrar RG, Buchhalter JR. Parental ranking of terms describing nonepileptic events. *Pediatr Neurol* 2013; 48: 378-382.

22. Asadi-Pooya AA. Neurobiological origin of psychogenic nonepileptic seizures: A review of imaging studies. *Epilepsy Behav* 2015; 52: 25625-9.
23. Ding JM, Kanaan RA. What should we say to patients with unexplained neurological symptoms? How explanation affects offence. *J Psychosom Res* 2016; 91: 55-60.
24. Edwards MJ, Stone J, Lang AE. From psychogenic movement disorder to functional movement disorder: it's time to change the name. *Mov Disord* 2014; 29: 849-852.
25. Bodde NM, Brooks JL, Baker GA, Boon PA, Hendriksen JG, Mulder OG, et al. Psychogenic non-epileptic seizures-definition, etiology, treatment and prognostic issues: a critical review. *Seizure* 2009; 18: 543-553.
26. Creed F, Guthrie E, Fink P, Henningsen P, Rief W, Sharpe M, et al. Is there a better term than "medically unexplained symptoms"? *J Psychosom Res* 2010; 68: 5-8.
27. Ding JM, Kanaan RA. Conversion disorder: A systematic review of current terminology. *Gen Hosp Psychiatry* 2017; 45: 51-55.
28. Wichaidit BT, Østergaard JR, Rask CU. Diagnostic practice of psychogenic nonepileptic seizures (PNES) in the pediatric setting. *Epilepsia* 2015; 56: 58-65.
29. Yogarajah M, Child R, Agrawal N, Cope S, Edwards M, Mula M. Functional seizures: An evaluation of the attitudes of general practitioners local to a tertiary neuroscience service in London. *Epilepsia Open* 2018; 4: 54-62.
30. Pick S, Goldstein LH, Perez DL, Nicholson TR. Emotional processing in functional neurological disorder: a review, biopsychosocial model and research agenda. *J Neurol Neurosurg Psychiatry* 2019; 90: 704-711.
31. Mahoney JM, Mills JD, Muhlebner A, Noebels J, Potschka H, Simonato M, et al. 2017 WONOE appraisal: Studying epilepsy as a network disease using systems biology approaches. *Epilepsia* 2019; 60: 1045-1053.

32. Asadi-Pooya AA. Psychogenic nonepileptic seizures: a concise review. *Neurol Sci* 2017; 38: 935-940.
33. Asadi-Pooya AA. Psychogenic nonepileptic seizures are predominantly seen in women: potential neurobiological reasons. *Neurol Sci* 2016; 37: 851-855.
34. de Schipper LJ, Vermeulen M, Eeckhout AM, Foncke EM. Diagnosis and management of functional neurological symptoms: The Dutch experience. *Clin Neurol Neurosurg* 2014; 122: 106-112.
35. Edwards MJ, Stone J, Lang AE. From psychogenic movement disorder to functional movement disorder: it's time to change the name. *Mov Disord* 2014; 29: 849-52.
36. <https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2fid%2fentity%2f629477838/> accessed on 12/5/2019.
37. Brown R J, Reuber M. Psychological and psychiatric aspects of psychogenic nonepileptic seizures (PNES): A systematic review. *Clin Psychol Rev* 2016; 45: 157-182.
38. <https://www.fndhope.org/> accessed on November 20, 2019.
39. Mayor R, Smith PE, Reuber M. Management of patients with nonepileptic attack disorder in the United Kingdom: a survey of health care professionals. *Epilepsy Behav* 2011; 21: 402-406.
40. Rawlings GH, Reuber M. Health care practitioners' perceptions of psychogenic nonepileptic seizures: A systematic review of qualitative and quantitative studies. *Epilepsia* 2018; 59: 1109-1123.
41. Aatti Y, Schwan R, Maillard L, McGonigal A, Micoulaud-Franchi JA, de Toffol B, et al. A cross-sectional survey on French psychiatrists' knowledge and perceptions of psychogenic nonepileptic seizures. *Epilepsy Behav* 2016; 60: 21-26.

42. Sahaya K, Dholakia SA, Lardizabal D, Sahota PK. Opinion survey of health care providers towards psychogenic non epileptic seizures. *Clin Neurol Neurosurg* 2012; 114: 1304-1307.
43. Shneker BF, Elliott JO. Primary care and emergency physician attitudes and beliefs related to patients with psychogenic nonepileptic spells. *Epilepsy Behav* 2008; 13: 243-247.
44. LaFrance WC Jr, de Marinis AJ, Webb AF, Machan JT, Rusch MD, Kanner AM. Comparing standard medical care for nonepileptic seizures in Chile and the United States. *Epilepsy Behav* 2012; 25: 224-229.
45. Scull DA. Pseudoseizures or non-epileptic seizures (NES); 15 synonyms. *J Neurol Neurosurg Psychiatry* 1997; 62: 200.
46. Reilly C, McWilliams A, Heyman I. What's in a name? 'Psychogenic' non-epileptic events in children and adolescents. *Dev Med Child Neurol* 2015; 57: 100-101.
47. Tannemaat MR, van Dijk JG. The terminology of psychogenic nonepileptic seizures: a historical perspective. *Epilepsia* 2015; 56: 978-979.
48. Labate A, Gambardella A. Why should we change the term psychogenic nonepileptic seizures? *Epilepsia* 2015; 56: 1178-1179.
49. Brigo F, Tinazzi M, Trinka E. In Response: Terminology of psychogenic nonepileptic seizures—a Babel of different names? *Epilepsia* 2015; 56: 1179-1180.
50. Ramos VF, Ramos ML, Ramos HM. Psychogenic nonepileptic "seizures " or "attacks"? It's not just semantics: attacks: psychogenic nonepileptic "seizures" or "attacks"? It's not just semantics: seizures. *Neurology* 2010; 75: 2135-2136.
51. Cowan RB. Psychogenic nonepileptic "seizures " or "attacks"? It's not just semantics: attacks: psychogenic nonepileptic "seizures" or "attacks"? It's not just semantics: seizures. *Neurology* 2010; 75: 2135-2136.

52. Sethi NK, Sethi P, Torgovnick J, Arsura E. Psychogenic nonepileptic "seizures " or "attacks"? It's not just semantics: attacks: psychogenic nonepileptic "seizures" or "attacks"? It's not just semantics: seizures. *Neurology* 2010; 75: 2135.
53. Karam C. Psychogenic nonepileptic "seizures " or "attacks"? It's not just semantics: attacks: psychogenic nonepileptic "seizures" or "attacks"? It's not just semantics: seizures. *Neurology* 2010; 75: 2135.
54. Brigo F, Tinazzi M, Trinka E. In response: Terminology of PNES over time--the terms they are a-changin'. *Epilepsia* 2015; 56: 979-980.

Table 1. A summary of the included manuscripts.

| Study | Methods | Main results | Class of evidence |
|----------------------------|--|--|--------------------------|
| Stone 2003 ²⁰ | Interview of 102 consecutive general neurology outpatients from the UK | “Stress-related seizures” and “functional seizures” were significantly less offensive. | IV |
| Shneker 2008 ⁴³ | 159 physicians from the USA responded to a survey | 85% of surveyed physicians reported the term pseudoseizure was appropriate to use. | IV |
| Plug 2010 ¹⁷ | Assessed 21 patients’ own preferences to a doctor’s use of different labels through the qualitative and quantitative analysis of doctor–patient interactions in the UK | “Seizure” is a particularly popular diagnostic label, while “attack” is dispreferred. “Fit” and “blackout” are even more preferable in patients with PNES. | IV |
| Mayor 2011 ³⁹ | 130 responses to an Internet survey of clinicians from the UK and the Republic of Ireland (66% neurologists) | A majority used the term non-epileptic attacks (62%); psychogenic nonepileptic seizures (7.9%) and psychogenic seizures (4.8%) were not | IV |

| | | | |
|-----------------------------|--|---|----|
| | | popular. | |
| Sahaya 2012 ⁴² | 115 health care providers from the USA responded to a survey | One-third of respondent favored “non-epileptic seizure” as the preferred diagnostic term. This was the most preferred term by both neurologists (56%) and primary care physicians (40%). Other terms included ‘stress related’, ‘functional’ and, ‘fake’ seizures. | IV |
| LaFrance 2012 ⁴⁴ | Results from 96 Chilean respondents were compared to results from 307 US clinicians. | “Nonepileptic seizures” was the term most often used both in Chile (n = 34; 36%) and in the US (n = 180; 60%). In Chile, this was followed by the terms “pseudoseizures” (n = 29; 31%) and “psychogenic seizures” (n = 15; 16%); in the US, “spells” (n = 32; 11%) and “psychogenic seizures” (n = 23; 7%). | IV |

| | | | |
|------------------------------|---|--|----|
| Morgan 2013 ²¹ | Surveys from 146 parents or guardians from the USA | “nonepileptic events”, “functional seizures”, and “nonepileptic attack disorder” were the least offensive labels; whereas “it is all in his or her head”, “hysterical seizures”, and “psychogenic seizures” were the most offensive terms. | IV |
| Wichaidit 2015 ²⁸ | 61 pediatricians from Denmark responded to a survey | There was no consensus on which terminology and diagnostic codes to use; the terms most frequently stated to be the most appropriate to use were functional seizures (34%) and PNES (25%). | IV |
| Ding 2016 ²³ | 185 participants were recruited from a medical outpatients' waiting area from Australia | “functional” was significantly less offensive than other terms used (compared with “Conversion Disorder”). | IV |
| Monzoni 2016 ¹⁸ | Video-recorded | Patients rarely choose the | IV |

| | | | |
|----------------------------------|--|--|----|
| | encounter between 3 neurologists and 17 patients in the UK | term “attack”. | |
| Aatti 2016 ⁴¹ | 963 French psychiatrists were included | 44% used the term “psychogenic nonepileptic seizures”. The terms “functional /dissociative /conversion seizures” were also commonly used (37%), while 16% used terms such as “pseudoseizures”(12%) or “hysteroepilepsy”(4%). | IV |
| Yogarajah 2018 ²⁹ | Online survey of 120 general practitioners in the UK | Approximately 75% of participants readily use the term “pseudoseizures”. | IV |
| | | | |
| Bodde 2009 ²⁵ | A critical review | In their opinion, the term “psychogenic nonepileptic seizures” (PNES) is the preferred term. | IV |
| LaFrance, Jr. 2010 ¹² | A review | The author argues in favor of the term “seizure”. | IV |
| Benbadis 2010 ¹³ | A review | The author argues against the term “seizure”. | IV |

| | | | |
|-----------------------------|---|---|----|
| Brigo 2015 ⁴ | Information prevalence values for the occurrence of different terms related to PNES were obtained | The wide spectrum of synonyms used to refer to PNES in the literature reflects a lack of internationally accepted uniform terminology for this condition. | IV |
| Rawlings 2016 ¹⁹ | A systematic synthesis of qualitative studies | Many patients shared a sense of uncertainty surrounding PNES, often resisting psychological explanations. | IV |
| Reuber 2017 ¹⁶ | A narrative review | The authors adopted the term seizure as “seizure” well describes the nature of the manifestations of PNES (objective and subjective features). | IV |
| Ding 2017 ²⁷ | Conversion disorder: A systematic review of current terminology | Most neurologists favored “functional” and “psychogenic”, while laypeople were comfortable with “functional”, but viewed “psychogenic” as more | IV |

| | | | |
|---------------------------|--------|--|----|
| | | offensive. | |
| | | | |
| Scull 1997 ⁴⁵ | Letter | The author discusses that adopting a uniform terminology to refer to psychogenic nonepileptic seizures is necessary. | IV |
| Ramos 2010 ⁵⁰ | Letter | The authors argue in favor of the term “seizure”. | IV |
| Cowan 2010 ⁵¹ | Letter | The author argues against the terms “psychogenic” and “seizure”. | IV |
| Sethi 2010 ⁵² | Letter | The authors argue in favor of the term “seizure”. | IV |
| Karam 2010 ⁵³ | Letter | The author argues against the terms “psychogenic” and “seizure”. | IV |
| Brigo 2015 ⁴⁹ | Letter | The authors discuss that adopting a uniform terminology to refer to psychogenic nonepileptic seizures is necessary. | IV |
| Reilly 2015 ⁴⁶ | Letter | The authors discuss that neurologists, psychiatrists, and others need to work | IV |

| | | | |
|------------------------------|--------|---|----|
| | | together to reach a consensus regarding what to call this phenomenon. | |
| Labate 2015 ⁴⁸ | Letter | The authors discuss that adopting a new term to refer to psychogenic nonepileptic seizures is not necessary. | IV |
| Tannemaat 2015 ⁴⁷ | Letter | The authors argue in favor of the term “psychogenic nonepileptic seizures” | IV |
| Brigo 2015 ⁵⁴ | Letter | The authors discuss that adopting a uniform, unequivocal terminology to refer to psychogenic nonepileptic seizures is necessary. | IV |
| Barron 2019 ⁵ | Letter | The authors discuss that: "Psychogenic" is wrong, "Psychogenic" is stigmatizing, and "Nonepileptic" is meaningless and rejecting. | IV |

Table 2. Criteria for an ideal terminology: Psychogenic nonepileptic seizures (PNES) vs. Functional seizures (FS).

| | Psychogenic nonepileptic seizures (PNES) | Functional seizures (FS) |
|--|---|---------------------------------|
| It is acceptable to patients. | No ^{20,21,23} | Yes ^{17,18,20,21,23} |
| It is acceptable and usable by doctors and other healthcare professionals. | Yes ^{28,41,44} | Yes ^{28,41,42} |
| Does not reinforce unhelpful dualistic thinking. | No (personal opinion) | Yes (personal opinion) |
| Can be used readily in patients who also have a pathologically established disease (e.g., epilepsy). | Yes (personal opinion) | Yes (personal opinion) |
| Can be adequate as a stand-alone diagnosis. | Yes (personal opinion) | Yes (personal opinion) |
| Has a clear core theoretical concept. | Yes (personal opinion) | Yes (personal opinion) |
| Will facilitate the possibility of multi-disciplinary (medical and psychological) treatment. | No (personal opinion) | Yes (personal opinion) |
| Has similar meaning in different cultures. | Should be investigated | Should be investigated |
| Is neutral with regard to | No (personal opinion) | Yes (personal opinion) |

| | | |
|---|----|-----|
| etiology and pathology (neutral as to mental or organic backgrounds). | | |
| Has a satisfactory acronym. | No | Yes |