



Letter to the Editor

What's in a name?



To the Editor

There is growing confusion about the nomenclature for the disorder currently known by many names including psychogenic nonepileptic seizures, functional seizures, dissociative seizures, and psychogenic nonepileptic attacks [1–4]. Clinicians and researchers agree that this condition is a subtype of functional neurological disorder (FND), diagnosed based on history, semiology, and video-electroencephalographic evaluation of typical events. Education and psychotherapy are well-accepted primary treatments. As demonstrated by the lengthy list of names above, in recent years, the terminology used to communicate the diagnosis to patients and to discuss the disorder in the medical literature has become increasingly fragmented. Well-intentioned but uncoordinated efforts to popularize specific terms – including efforts by the present authors – have only exacerbated the problem. Each term has certain advantages and disadvantages, but the failure to consistently use a single term has led to confusion among all constituencies including patients, caregivers, clinicians, advocacy groups, researchers, and funding agencies.

The negative consequences of this confusion are most apparent to – and most often experienced by – the patients, who are already receiving an unfamiliar diagnosis, often after having been incorrectly diagnosed for years or even decades with treatment-resistant epilepsy. The stigma and bias directed toward patients with neuropsychiatric disorders and especially FNDs already make this a difficult diagnosis for patients to accept. Lack of clarity on the part of the diagnosing and treating clinicians contributes to patients' difficulties in accepting the diagnosis, which limits treatment engagement and contributes to poor outcomes. Inconsistent terminology also impedes public awareness advocacy and the development of new treatments through clinical research. If we ever want the disorder to be taken seriously, coordinated efforts to create a unified nomenclature must be a priority. Most importantly, considerable progress will be made in de-stigmatizing this disorder if healthcare professions can unify around an agreed-upon name that is also easy to understand, acceptable, and not stigmatizing to patients.

There are numerous legitimate goals that might motivate the selection of a consensus name for this disorder. These considerations might include but are certainly not limited to the following:

1. Helping patients and family members to understand and engage with the diagnosis and its available treatments;
2. Streamlining the process from diagnosis to treatment, helping patients and clinicians to more easily access appropriate treatment resources;
3. Connecting the disorder clearly to the broader overarching category of FND;

4. Identifying a putative etiology of the disorder;
5. Maintaining agnosticism regarding the mechanisms and etiologies of a disorder that remains poorly understood;
6. Reducing the risk for iatrogenic physical and psychological harm through unnecessary medications, intubations, and other interventions directed at the treatment of epileptic seizures.

Unfortunately, not all of these goals can be fully or even partially served by a single name. Some of these goals may be directly contradictory. In order to arrive at a consensus nomenclature, stakeholders must weigh and prioritize disparate goals. We need to agree on what we are trying to accomplish with a name.

Reaching agreement on our goals and on a single name will require a coordinated effort by the clinical, patient advocacy, and research communities to select and popularize a single uniform nomenclature. This effort must also engage broad input from all stakeholders (e.g., the International Classification of Diseases (ICD), Systematic Nomenclature of Medicine Clinical Terms (SNOMED CT), healthcare providers, insurers, and healthcare billing organizations), with patients, caregivers, family members, and advocates at the forefront of consideration. The members of the American Epilepsy Society's Committee on Psychosocial Comorbidities and the Special Interest Group in Nonepileptic Seizures propose to conduct a moderated teleconference symposium during the American Epilepsy Society's annual meeting next December in Seattle, Washington. There, we propose to discuss (rather than debate) the disparate goals underlying various candidate nomenclatures and to plan a fair and inclusive process by which the community can advance current efforts to identify a single "not perfect, but reasonable" term for this disorder on which many of us have focused our academic careers. The challenge will require participants not to "defend" or justify a name, but rather think about what a term should offer to patients, caregivers, and the involved healthcare professionals. If you are interested in participating in a constructive town hall forum, please watch the Functional Neurological Disorders Society website (fndsociety.org), where we will post announcements and links to the online component of the symposium. Consider joining the Functional Neurological Disorders Society if you have not already done so. Through open, respectful dialogue and coordinated action, we can ease the confusion and improve patient outcomes, decrease stigma, and increase coordinated research to better help patients worldwide.

Declaration of competing interest

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