



## CORRESPONDENCE

## Stigma surrounding functional seizures

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Dear Editor,

As part of the online publication process of our paper, “Incidence rates and characteristics of pediatric onset psychogenic nonepileptic seizures”,<sup>1</sup> printed in the current issue of *Pediatric Research*, something happened that led us to reflect upon the stigma often surrounding psychogenic nonepileptic seizures (PNES), also referred to as functional seizures. For reasons unknown, the word “false” was inserted in the title of the online pre-proofread manuscript so that it read: “Incidence rates and characteristics of pediatric onset psychogenic nonepileptic (false) seizures”. A couple of colleagues including Jon Stone, coauthoring this piece, spotted the title online and contacted us with concerns since the added description of the seizures as being “false” could be perceived as offensive. The word “false” was quickly removed again from the online version of the paper by the editorial staff, but the incident made us think more carefully about the words that are used to describe functional seizures, and the effect they can have on health practitioners and patients.

Words like “false”, “pseudo” and “hysterical” have been used over time to describe PNES. Patients with this condition and their families describe feelings of being both misunderstood, shamed and blamed for the seizures.<sup>2,3</sup> The opposite of the word “false” is “true”; thus, the label “false” conveys an idea that the seizures “are not real” or that they “are made up”.<sup>2,4</sup> This is an attitude that sadly is still prevalent even among clinicians, who might innocently refer to epilepsy as “genuine” seizures.<sup>5</sup> The term PNES is the most preferred label in research terminology, which is why we used this term in our paper printed in this issue.<sup>1</sup> The term PNES may, however, also be problematic. “Psychogenic” is a term that reinforces the dualistic idea that the brain and mind are separate entities, even though modern neuroscience repeatedly indicates the opposite. “Psychogenic” also intrinsically suggests that the disorder is always explained either by underlying psychological causes or stressors, even though in many children and young people neither may be detectable.<sup>6</sup> If our recommended understanding and explanatory model of PNES should be a biopsychosocial one, then a focus and labeling only of psychological and social aspects undermines this message and weakens our alliance with young patients and their parents.<sup>7</sup> Functional neuroimaging studies have identified brain abnormalities in patients with PNES and other types of functional neurological disorders. These are starting to provide a neurobiological basis for understanding the symptoms of functional seizures at a brain network level, which is complementary to and not in competition with cognitive and behavioral theories.<sup>8</sup>

Our primary consideration in choosing a diagnostic label should be to consider how well it describes the disorder, rather than its popularity with patients and relatives. Nonetheless, a study of 146 parents of children with PNES demonstrated a preference for the terms “functional seizures”, “nonepileptic events” or “non-epileptic attack disorder (NEAD)”.<sup>2</sup> Some have argued that the term “functional seizures”, although criticized for being too general,

allows better integration of these neurobiological processes and does not force an etiological framework into the name of the condition. The term “dissociative seizures” is arguably also a primarily mechanistic rather than etiological term, which describes the nature of the period of impaired awareness (an episode of dissociation) without presupposing its cause or attempting to separate it into a mental or physical event, although an older understanding of the term dissociation from a psychological etiological perspective could occur. Thus, “functional seizures” could be preferred as a more neutral label producing less stigma to the disorder and supporting a biopsychosocial approach.

When encountering a diagnosis of functional seizures in a health-care setting, young people and their families often describe a sense of confusion and uncertainty.<sup>9</sup> Many young people have previously been diagnosed with epilepsy and undergo a long and difficult journey including trials of ineffective medication before reaching the correct diagnosis of functional seizures. The switch from an epilepsy diagnosis to a diagnosis of functional seizures is often described as demanding and overwhelming. Common experiences include feelings of abandonment with the message that “nothing is wrong” and “all the tests are normal”, or feelings of loss of legitimacy with functional seizures communicated as “not as severe” or as “serious” as an epilepsy diagnosis.<sup>9–11</sup> The confusion experienced by young patients and their families is often a reflection of similar uncertainty and confusion among their health-care professionals regarding both name, diagnosis, etiology, diagnostic management and treatment.<sup>5,12–14</sup> This lack of consensus among clinicians is also reflected by discrepancies and failings in our international diagnostic classification systems. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5)<sup>15</sup> defines “Conversion disorder (Functional Neurological Symptom Disorder)” by focusing on clinical neurological findings typical of the disorder, for example, prolonged episodes during which there is hyperventilation, or the patient’s eyes are closed. In contrast to this, the International Classification of Diseases (ICD-11)<sup>16</sup> classifies the seizures as “6B60.4 Dissociative neurological symptom disorder, with non-epileptic seizures”, and with criteria based on the absence of consistency with other neurological or psychiatric conditions, thus making it a diagnosis of exclusion.

The importance of effectively sharing the diagnosis of functional seizures with patients and their families as a platform for further treatment has been highlighted in previous literature.<sup>17</sup> The diagnosis of functional seizures should not be delivered as a diagnosis of exclusion, but should instead be a positive diagnosis based on an explanation of, which clinical features of the seizures themselves that support the diagnosis and not based on psychological risk factors, even if relevant. This is especially important in cases where epileptic and nonepileptic events occur in the same person, and where patients, families, doctors and caregivers will need to differentiate between events. This is not an easy diagnosis for patients and families to gain confidence in, but without that confidence, subsequent multidisciplinary treatment and especially psychological therapy may be jeopardized.<sup>18</sup> Functional seizures do not need a “special” type of explanation compared to other diagnoses such as epilepsy. In fact, it is the way that health professionals often do something strange with explaining this diagnosis, especially overemphasizing what the

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diagnosis is not and jumping to conclusions about the etiology that often erodes trust with patients and families. Instead, explanation can follow a normal pattern: naming the disorder, explaining the positive features that allow the diagnosis to be made, describing something about the mechanism: e.g., a problem called dissociation—a “trance-like” state that keeps happening in a reflex way because of something like a short circuit in the brain, as well as use of analogy: “a problem with the software of the brain rather than the hardware”.<sup>7,19</sup> A focus on mechanism allows relevant psychological and neurobiological factors to be brought in as secondary etiological predisposing, precipitating and perpetuating risk factors. Many qualitative studies of people with functional seizures emphasize the fact that being believed is a key issue in coping with functional seizures and being able to engage with treatment.<sup>14,20</sup>

How can we further reduce the stigma still surrounding functional seizures? A fundamental step is acknowledging the importance of language. We must stop using diagnostic labels and language that actively stigmatize, especially in creating dichotomies of seizures that are “false vs true” or “fake vs real”. Functional seizures should be recognized as a severe health problem that typically needs involvement from both physical and mental health care in close collaboration. Evidence-based clinical guidelines as well as formal training of clinicians regarding the assessment and management of functional seizures are needed to continue altering attitudes in order to decrease stigmatization. Furthermore, distributing information to the patients, their families as well as the lay people can also increase the awareness of functional seizures and help reduce stigma related to lack of knowledge about the disorder. Webpages have been developed with information targeting both the adult population (e.g. [www.neurosymptoms.org](http://www.neurosymptoms.org), [www.nonepilepticattacks.info](http://www.nonepilepticattacks.info)) as well as children and their parents (e.g. [www.pnes.au.dk](http://www.pnes.au.dk), [www.neurokid.co.uk](http://www.neurokid.co.uk)), and further awareness of this material is needed. Challenging the stigma takes understanding and education to make a change of attitudes. As professionals we need to consider carefully which words we use and avoid using stigmatizing labels in our communication. This is an essential key to help the patients understand their diagnosis and benefit from treatment.

## AUTHOR CONTRIBUTIONS

A.S.H. wrote the initial draft and revised the manuscript. R.E.N. and J.C. contributed to the revision of the manuscript. J.S. and C.U.R. contributed to the drafting as well as revision of the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

## ADDITIONAL INFORMATION

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