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Psychogenic Non-epileptic Seizures (PNES) in Children and Youth

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Introduction and definition:

Hi everyone! Welcome to a PedsCases podcast on pediatric non-epileptic seizures. Never heard of this before? Well, what about "pseudoseizure, functional seizure, non-epileptic event or psychogenic seizure?" All these terms have been used in the literature to describe clinical events that resemble epileptic seizures but are not due to abnormal brain electrical activity. For our purposes today, we will refer to these events as "psychogenic non-epileptic seizures" or "PNES" for short. Studies suggest that up to 25% of patients admitted to inpatient epilepsy monitoring units with treatment resistant epilepsy, may have non-epileptic seizures. Thus, it is important to recognize these events so that treatment is tailored.[1] PNES fall under the category of Somatic Symptom Disorders where somatization is the prominent feature. Somatization is the process of experiencing emotions as physical symptoms.[2] Common somatization symptoms include stomach aches before tests or headaches from stress, but there are many symptoms (including seizure-like episodes) that are commonly recognized as somatization.

Let's get started by reviewing our learning objectives for this podcast.

1. **Describe common clinical presentations and features of pediatric PNES**
2. **Develop an approach to the assessment and diagnosis of pediatric PNES**
3. **Review an ideal multidisciplinary treatment plan for pediatric PNES**

Let's jump into our case:

A 12-year old female, Alana, is admitted to the Pediatric Neurology service where you are currently completing a 4th year elective. Her mother reports an episode of abnormal, repetitive right arm and leg jerky movements lasting for four hours. Alana had no warning before the event, her eyes were closed during the event and she did respond to verbal commands. She had similar shorter episodes in the month prior to admission. The events started and ended abruptly and she was not confused or sleepy afterwards.

There was no history of headaches or concussion, but she did have a febrile seizure at 8 months of age lasting 2 minutes.

Alana's mother reports an uncomplicated pregnancy and birth at 39 weeks. Her development was normal other than slightly delayed language affecting articulation. Alana receives learning assistance in school in math and language arts and is very shy. Alana's mother describes that she has always been a perfectionist with her schoolwork and with activities at home.

Alana's 15-year old brother is healthy with no medical conditions, her mother has major depressive disorder, and a maternal uncle has bipolar disorder.

Alana lives in an apartment with her mom, brother, and maternal grandmother. Her parents divorced recently and Alana is not in contact with her father, who lives in another province.

Take a moment and think about the case so far. What other information would you like to know? What is your differential diagnosis for Alana's presentation?

Let's now address our first objective, to describe the clinical presentation of pediatric PNES.

Making a diagnosis of PNES is challenging and the differential diagnosis is considerable. Approximately 50% of children with PNES have a clinically significant neurological history, such as comorbid epilepsy or learning difficulties.[1] It is important to suspect the diagnosis of non-epileptic seizures early as studies have also shown that prognosis is better with earlier diagnosis and treatment.[3]

There are no pathognomonic clinical features of non-epileptic seizures but these seizures are more likely to be frequent, prolonged, occur in specific situations, and occur rarely during sleep. They are rarely associated with urinary incontinence or injury, do not respond to anti-seizure medications and often result in multiple ER visits. There may be a lack of concern or an excessive emotional response to the events and the individual may have a personal experience of epilepsy. In contrast, epileptic seizures are more likely to be associated with eye opening, tongue biting, urinary incontinence and to occur during sleep.[4,5,6,7]

Our patient, Alana, presented with abnormal, prolonged repetitive right arm and leg movements for four hours that on further questioning tended to wax and wane. Non-epileptic seizures tend to last much longer than typical epileptic seizures.[6] In one study, episodes lasted longer than two minutes and tended to wax and wane.[8]

Let's go back to our case. How do we approach patients like Alana? This leads us to our second objective, to **develop an approach to the assessment and diagnosis of a pediatric patient presenting with non-epileptic seizures.**

Firstly, we need to gather a detailed history. Ask for details about the seizure-like episodes including age at onset, pre- and post-ictal features, as well as similarity or differences between events. A full personal developmental, medical, psychological and neurological history should be taken. Medications and interventions tried to date are also useful to know, since patients with non-epileptic seizures may have been tried on anti-seizure medications, especially if they have comorbid epilepsy and did not respond.[9] A detailed family history including febrile seizures, epilepsy, concussion, central nervous system infection, cardiac disease, learning difficulties, mood and psychiatric disorders should be taken. A psychosocial history is very important and includes information about the patient's temperament (what they are like as a person), and any past or current trauma or stressors, such as learning difficulties, family conflict, parental separation, bullying, or recent loss, such as death of a family member or of a family pet. It is also important to know how these episodes have affected the patient's social and academic functioning. A brief screen for mood and anxiety symptoms or other psychiatric conditions is relevant as well.

Following the history, a detailed general physical and neurological examination is performed.

With the widespread use of mobile devices, parents often have recordings of the events in question and careful review is important. The gold standard to make a diagnosis of non-epileptic seizures is recording the typical events during EEG with video which could be during a routine outpatient EEG, or in-patient video-EEG monitoring.[10] The presence of interictal epileptiform discharges on EEG such as generalized spike wave or rolandic spikes is not unusual as these patterns are common in children and can be completely benign or indicate a genetic predisposition to developing epilepsy. During non-epileptic seizures, there is no evidence of epileptiform activity on the EEG. It is important to appreciate that seizures that arise deep within the frontal or temporal lobe may not show an EEG change during the epileptic seizures but the clinical features of these seizures are stereotyped and an epilepsy expert would be able to recognize the difference from non-epileptic seizures. This can be difficult and shows the importance of careful interpretation of the video-EEG findings.

As soon as the neurology team thinks that the episodes may be non-epileptic, they will involve a multi-disciplinary team. The team members may include psychologists, psychiatrists, and social workers. These team members will help complete a thorough psychological and psychiatric assessment.

Once a diagnosis is made, an informing meeting is very useful to convey the diagnosis and formulation (or understanding) to the patient and family, as well as interdisciplinary provider meetings, where experts from the specialties involved can achieve consensus on the diagnosis and individualized patient management.[2]

It is useful to follow an agenda for the informing meeting. The pediatrician or pediatric neurologist reviews the history, investigations and clinical findings that led to the

diagnosis of PNES and somatization. The psychologist or psychiatrist then discusses the concept of somatization and the mind-body connection. These team members will help families understand that somatization is common and real, but at times can be very powerful and interfere in a youth's daily life. The whole team also reinforce that somatization is very treatable. Patients and their families are given helpful resources, (such as the BC Children's Hospital's Kelty Mental Health somatization website.)[11] The family should be given ample time to ask questions.

Education about somatization for family members helps to reinforce that non-epileptic seizures are real and not due to "faking" physical symptoms. Many families find a diagnosis of a somatic disorder difficult to understand and may fear that an underlying medical cause for symptoms has been missed.[12] Discussing the mind-body connection can help parents understand that what their child is going through is real.

Going back to our case, here is an example of how a team member involved in Alana's care might speak with Alana's mother about the mind-body connection (adapted from a patient friendly mind-body discussion script).[2]

> Alana's mother: "I don't actually understand… how can Alana's body be working okay but then she has these reactions? Doesn't this mean that she's faking them?
>
> Team member: "Many families ask the same questions and have similar concerns. It can be hard to understand how the mind and body interact to produce physical symptoms. The brain and body communicate all day and night long, with the body automatically sending messages up to the brain, and the brain automatically sending messages to the body. Have you heard of something called the "fight-flight-freeze" response before?"
>
> Alana's mother: "Hmm, I think so. Could you explain it to me, please?"
>
> Team member: "Of course. So, during the "fight-flight-freeze" response, the brain senses danger of some kind and automatically sends a message relaying this to the body. This message causes the heart to beat faster, the lungs to breathe faster, and the muscles to tense up. Once the danger is gone, the brain tells the body that it can relax. This cycle is our body's response to stress and shows us how the mind-body connection is very real. This is how the mind and body can interact to manifest emotions or stress as physical symptoms, like Alana is experiencing."

After answering patient and family questions about the diagnosis, the team will develop a multidisciplinary treatment plan with the family. **For our third and final objective, let's review a treatment plan for pediatric PNES.**

Treatment of pediatric PNES is complex and individualized. A multi-disciplinary approach including mental health support, such as a psychologist or psychiatrist, in addition to a pediatric neurologist and school support are paramount to successful treatment.[13]

Key short-term goals in the treatment of PNES include developing strong rapport with the patient and family, contributing to educating the patient and their family about somatization and the mind body connection, working with the family towards symptom control, and re-establishing return to normal routines, such as school and extracurricular activities.[14]

At BC Children's Hospital, a model for treating pediatric somatization is used to develop a multidisciplinary and comprehensive treatment plan. The components of treatment include symptom management, paced return to function in a step-by-step way, counselling to understand emotions and develop coping strategies, and treating any other medical or mental health conditions.[15]

When it comes to symptom management, a behavioural approach is used. This involves parents not reinforcing non-epileptic seizure episodes by actively not paying too much attention to the episodes. This helps to reduce the number of episodes, as it decreases the associated positive gain.[13] Reducing the number of episodes helps children and their families taper back to a regular schedule (which, if you recall, was another one of the treatment goals!) Families and children are encouraged to limit stressful activities and take small steps going back to regular activities.

Another aspect of treatment is medical rehabilitation. This can be considered when a child or parents are struggling with PNES being a psychological disorder. Using a medical approach can be helpful for these families, and concurrently can help comorbidities, such as movement or gait abnormalities.[13]

One major long-term goal is to help patients develop adaptive coping skills, to identify their stressors, and to understand how stressors and coping skills relate to the non-epileptic seizure episodes. A therapist who has rapport with the patient and their family is a vital player in this aspect of treatment. Counselling sessions can help patients notice, label, express and manage difficult emotions, as well as develop confidence in responding to difficult emotions.[15]

Another aspect of treatment is addressing comorbid psychopathology. This may include PTSD, depression, anxiety, suicidal thoughts, amongst others.[8] Most patients receive out-patient psychiatric treatment, but inpatient treatment may be needed in certain instances. This includes uncontrolled PNES episodes, PNES for longer than one year or away from school for more than 3 months with psychiatric comorbidities, such as PTSD or suicidal thoughts.

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I hope you learned something new today and have a better understanding of pediatric PNES. Before we end, let's summarize our objectives:

- Pediatric non-epileptic seizures are seizure-like events that have a variety of clinical presentations, such as abnormal limb movements, and are more likely to be frequent and prolonged compared to epileptic seizures.[8] The gold standard for diagnosis is a video-EEG recording of a non-epileptic seizure event showing a lack of epileptiform activity.
- The work-up for non-epileptic seizures includes a detailed personal medical and psychiatric history, family history, social history and thorough judicious medical investigations.
- Finally, early diagnosis in pediatric non-epileptic seizures is vital,[16] as well as early involvement of a multidisciplinary team, involving mental health from the beginning to reduce the stigma associated with mental illness.[2]

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