
The Underlying Psychopathology, Triggers, and Risk Factors

As briefly mentioned in the overview to this treatment guide, the underlying psychopathology of children with PNES, conversion disorder, involves displacement of the tension associated with negative emotions, such as anxiety, anger, fear, frustration, and demoralization onto physical symptoms. Why certain children develop conversion disorder with epilepsy-like symptoms rather than other physical symptoms remains unclear [1, 2]. However, current psychodynamic theories on pediatric PNES and evidence for triggers (see review in [3]) and risk factors [4]) shed light on ways the disorder might develop.

From the research perspective, triggers for pediatric PNES include learning difficulties; social problems; parent marital discord; family dysfunction; unrealistic expectations by the child or the parents for the child to excel at school, sports, or extracurricular activities; bullying and other forms of psychological abuse; and rarely physical or sexual abuse [5–9]. But not every child who experiences these trigger factors develops PNES. Two independent risk factors differentiate children with PNES from their siblings, a somatopsychiatric factor and an adversity factor [10]. In other words, children with medical problems, excessive use of medical services, fearful response to physical sensations, and psychiatric diagnoses—the somatopsychiatric factors—are at risk for PNES. Bullying associated with emotional problems, psychiatric diagnoses, and treatment with psychiatric drugs—the adversity factors—also increase the vulnerability for PNES.

From the psychodynamic perspective, children who develop PNES and other conversion disorders [11] appear to use avoidance when faced with situations that trigger negative emotions (fear, anger, frustration, anxiety, or sadness). In addition to not confronting and/or problem-solving the situation that triggers these negative feelings, these children are often unaware of or deny experiencing negative emotions. Thus, they are avoidant on both the functional and emotional levels. In some cases, the children have language difficulties with impaired use and/or retrieval of words to describe their emotions (alexithymia) (see review in Reilly et al. [3]) and/or

difficulty using sentences to formulate [12] their feelings and thoughts, particularly those involving abstract concepts. As a result, and given their use of avoidance, they do not tune into their negative emotions and/or verbally express or talk about their problems and the associated emotions.

In other cases, the children have intact language skills. However, when they verbalize and express their difficulties or problems to their parents and ask for their help, the parents pay no or little attention to the children's complaints. In some cases, parents misinterpret, scold, criticize, or verbally abuse the children for their difficulties and avoidant behavior. These responses cause the children to back off, not share their difficulties with their parents, and continue to avoid dealing with the problems at hand.

The children's unexpressed negative emotions accumulate when the problem situation(s) does(do) not go away and/or gets(get) worse due to the children's avoidance. Repeat exposure to the problem situation(s) and the lack of problem-solving triggers(s) the children's anxiety, as well as negative responses by others, which, in turn, make the children more fearful. Mounting of their unexpressed negative feelings on the one hand and the practical results of not problem-solving on the other hand result in these children feeling there is no way out. Taylor [13] used the term predicament to describe this situation, which leads to displacement of the growing tension and mounting unresolved problems into physical symptoms.

Because of the attention these children get due to the seizure-like episodes, they are excused from meeting demands in the school, home, and social environment and/or from dealing with other potential stressors or triggers of their condition. Increased attention by parents and others to the child's "seizures," together with continued avoidance of dealing with ongoing problems, difficulties, and/or challenges, is called secondary attention. This inevitable phenomenon reinforces recurrence of the episodes which then take on a life of their own. The more they recur, the more attention the child gets and the more difficult it is for the child to cope with the ongoing problems. Antiseizure medications, also known as antiepileptic drugs (AEDs), can have adverse effects, including fatigue and irritability that further impair the children's ability to problem-solve and reinforce this vicious cycle. In terms of family functioning, the child's symptoms might overwhelm the parents in their efforts to deal with the child's illness and their own ongoing life stressors, such as family discord.

From the behavioral perspective, how parents respond when their child reports physical symptoms acts as positive or negative emotional reinforcers. As such, they can influence how much their child complains about aches, pains, and not feeling well. The wide range of parental responses includes a lack of response, a neutral concerned response, or an excessive anxious response for the child to receive immediate medical attention. In some families, parents only pay attention to their children when they are sick or have physical complaints. Children whose parents are overly anxious when their children have somatic complaints and children of parents who pay attention to them only when they are ill are at high risk for somatization and conversion disorder [14, 15].

Table 2.1 DSM-5 diagnostic criteria for conversion disorder

Conversion disorder
One or more symptoms of altered voluntary motor or sensory function
Physical findings provide evidence of incompatibility between the symptom and recognized neurological or medical conditions
The symptom or deficit is not better explained by another medical or mental disorder
The symptom or deficit causes clinically significant distress or impairment in social, occupational, or other important areas of functioning or warrants medical evaluation

The Gold Standard Diagnosis

Confirmation of PNES is based on two essential components. The first component is a prolonged video-EEG (vEEG) in which the child has seizure-like episodes without EEG evidence for ongoing epileptic activity. The second component is that the child meets criteria for a conversion disorder or, more rarely, a dissociation disorder, based on a comprehensive psychiatric evaluation. This treatment guide focuses on treatment of children with PNES who have a conversion disorder. Table 2.1 lists the DSM-5 diagnostic criteria for this disorder [16].

Why Is It Difficult to Diagnose PNES in Children?

Medical Reasons

PNES Mimics Epilepsy

In most cases, physicians confirm a diagnosis of seizures due to epilepsy based mainly on reports by parents, family members, or other observers of the seizure manifestations. An EEG finding of epileptic activity helps confirm the diagnosis. However, EEG electrodes on the scalp do not pick up epileptic activity from deeper regions in the brain. Therefore, the lack of epileptic activity during a routine EEG when a patient is not experiencing a seizure does not rule out a diagnosis of epilepsy. Most epilepsy patients usually do not have a seizure in the doctor's office. So, when a child first has a non-epileptic seizure, even if a routine EEG is normal, physicians do not usually consider the possibility of a non-epileptic seizure.

PNES Occurs in About One-Third of Children with Epilepsy

In children with epilepsy whose seizures were controlled, the parents and physicians assume that the child has had a breakthrough of seizures when NES symptoms occur. In children with new-onset seizures, when seizures continue despite a trial of at least two AEDs, physicians assume they are dealing with intractable or treatment-resistant epilepsy. They, therefore, increase the AED dose, add an AED, or change to another AED in their effort to control seizures.

AED Adverse Effects

Since these drugs do not control seizure-like symptoms unrelated to epilepsy, the child's episodes continue. High doses of multiple AEDs can cause adverse behavioral and cognitive effects (see review in Caplan [16]). Parents might interpret medication side effects, such as inattention, spacing out due to tiredness, and irritability, as ongoing seizures. This, in turn, can lead physicians to further increase AED doses and/or number of drugs to control the "seizures."

Parental Behavior

As previously described above in "The Underlying Psychopathology, Triggers, and Risk Factors", parents' behavior when their children let them know about problems they are experiencing influences if and how the children share their difficulties with the parents and do or do not problem-solve. Features of parent behavior, described below, can make it difficult for physicians to reach a PNES diagnosis.

Denial of Psychological Problems

Some parents of children with PNES have difficulty recognizing or accepting that their children have learning, social, or psychological difficulties. These parents typically deny that their children have any problems other than seizures when physicians ask about problems.

Misinterpretation of Children's Behavior

As mentioned in section "The Underlying Psychopathology, Triggers, and Risk Factors", parents might unwittingly misinterpret their children's call for help as evidence for laziness, attention seeking, shyness, and/or lack of assertiveness, depending on the nature of the domain in which the child is having a problem. So, when physicians ask these parents if their children have any problems, they might respond with one of the above features, which are typically regarded as normal behavior.

Attention to Physical Symptoms

Parents are unaware that the attention, they do or do not give to their children's episodes, can perpetuate these symptoms.

Child Behavior

Many children with PNES deny that they have problems other than seizures. Others might acknowledge feeling sad or mad but not about the stress, difficulties, and problems they actually face.

Red Flags for Pediatric PNES

Child's Medical History

The following information in the child's history should alert you to the possibility of PNES:

- A change in the typically stereotyped clinical manifestations of children who have confirmed epilepsy, with and without seizure control.
- Children with new-onset seizures who also have a history of multiple nonspecific physical symptoms.
- Every child with a history of intractable seizures.
- Traumatic brain injury can lead to the development of epilepsy particularly in children with moderate and severe head injury [18]. Most children who experience mild head trauma do not develop epilepsy [19]. If they present with seizures 6 or more months after their head injury, however, they are more likely to have PNES than posttraumatic epilepsy [20].

Clinical Manifestations

Although the symptoms below suggest possible pediatric PNES, they are not specific to this condition. The previously described gold standard diagnostic method is essential to confirm a PNES diagnosis:

- Children with PNES have an inconsistent or changing pattern of symptoms rather than the consistent and stereotypic symptom pattern found in seizures due to epilepsy.
- The episodes of PNES are typically prolonged and last for more than 5 min. The lack of tiredness and confusion following these events differentiate them from the prolonged seizures of status epilepticus.
- PNES episodes begin with a gradual buildup often associated with hyperventilation.
- Children with PNES have clear consciousness following an episode.
- The episodes typically do not occur when the children are alone.
- The children do not sustain injury during episodes.
- Incontinence for urine and feces are rare.

Epilepsy Model

A relative, neighbor, or friend with epilepsy might serve as a model for the displacement into seizure-like behaviors of the negative feelings involved in the child being in a "predicament."

“The Only Problem Is the Seizures”

During the diagnostic interviews, described below, if the child and/or the parents deny any problems other than seizures as well as the possibility of stressors, other than the episodes themselves, rule out the possibility of a PNES diagnosis.

Techniques for the Child Diagnostic Interview

Ideally, the psychiatric/psychological assessment to determine if the child has PNES should be done in parallel with the neurological evaluation and vEEG. The three main goals of the diagnostic interview are to rule in or out a diagnosis of conversion disorder (or dissociative disorder), identify the child’s stressors, and determine if the child has comorbid anxiety disorders and/or depression. See Table 2.2 for the recommended content and order of the interview. Although these children often deny any problems other than their seizures, use the techniques in Fig. 2.1 to encourage them to talk.

Table 2.2 Pediatric PNES psychiatric diagnostic interview guidelines

Topic	How to
Interview goal	Tell the child that epilepsy is not an easy illness to have and that it can affect different things in a child’s life
	To understand how seizures are affecting the child’s life, you would like to first ask the child to tell you about the seizures and then find out about the child’s home, school, friends, mood, and other things
	If you feel you have good enough rapport with the child, mention that you know from other children with epilepsy that when they are stressed their seizures get worse
NES episodes	Ask the child to describe the episodes. If the child refers you to the parents for this information, ask the child what the parents have told the child that happens during a seizure
	Find out how the episodes have impacted different parts of the child’s life including school, extracurricular activities, home, and friends
	Express empathy for the episodes and the impact they have on the child’s life. This helps establish rapport with the child
Stress	Find out what things seem to make the child’s seizures worse and what seems to make them better
	If the child denies any stressors, and you do not feel that the rapport you have with the child is good enough, go on to another topic. Mention that you know from other children with epilepsy that when they are stressed their seizures get worse.
	You might learn about the child’s stressors during the rest of your interview. If not, you can try to bring up this topic again at the end of the interview. The best way to do it would be to tell the child you just want to make sure you understood what the child had said about different things that are stressful
	How does the child cope or has coped with the stressors, problems, and difficulties that the child mentions? If it is difficult to get information on coping or problem-solving strategies, avoidance might be the child’s main way of problem-solving.

Table 2.2 (continued)

Topic	How to
Comorbid psychiatric disorders	Inquire about symptoms of mood disorders, anxiety disorder, attention deficit hyperactivity disorder (ADHD), learning disorders, psychotic disorders, eating disorders, conduct disorder, oppositional defiant disorder, substance abuse, autism spectrum disorders, and trauma. For young children and those with language or intellectual difficulties, see [21] for guidelines on how to ask about these topics
Conversion disorder	When you inquire about stressors, problems, or difficulties, does the child say that the only problem is the seizures? If the child is able to share some difficulties with you, what negative feelings do they arouse in the child?
	When you ask about sadness, anger, anxiety, and fear, does the child deny them?
	Has the child been bothered in the past or currently by physical symptoms?

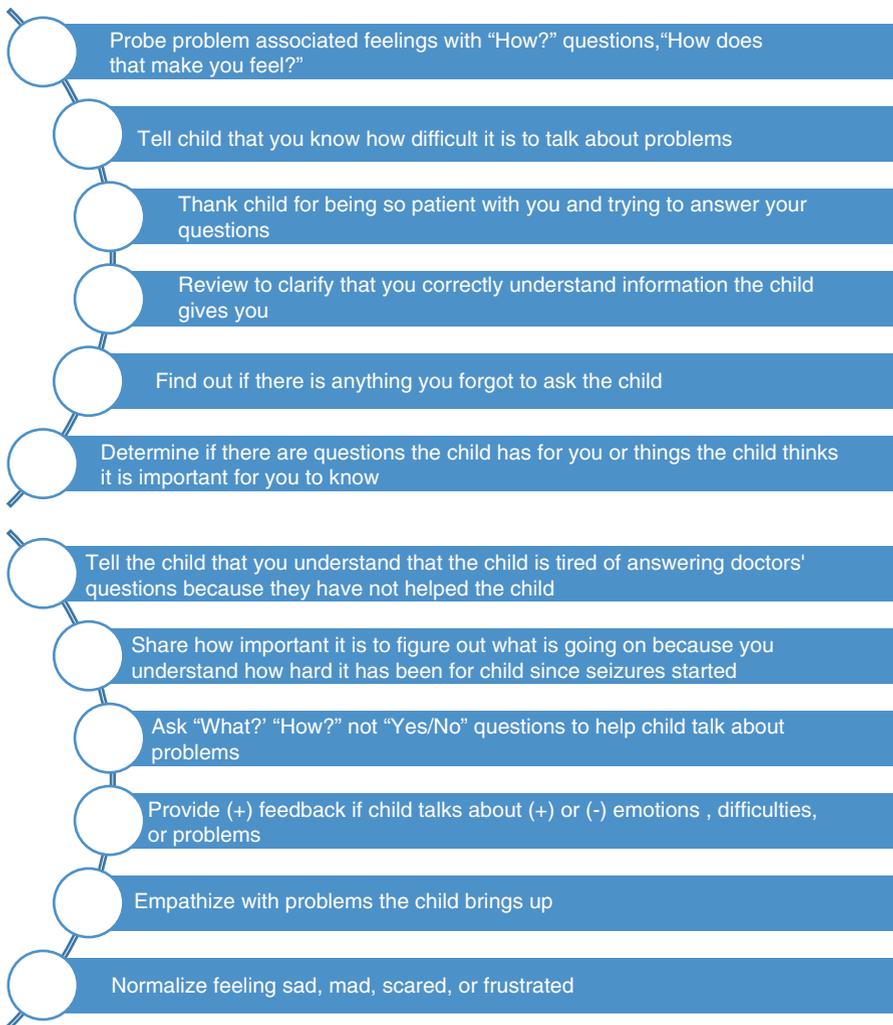


Fig. 2.1 Techniques to encourage children with PNES to talk about their problems

In terms of the interview format, interview the child without the parents to ensure that the child will be able to speak as freely as possible. If the patient is an adolescent, interview the adolescent before the parents. Always gauge where the child is at developmentally both in terms of mental age and language skills and modify the language you use accordingly to ensure that the child understands you. This is particularly important because the child might have subtle receptive and expressive language difficulties [22]. Use concrete rather than abstract language for younger children and those with language difficulties.

Confidentiality, Diagnosis, and Treatment Plan

At the end of the interview, thank the child for being helpful and assure the child that what the child has told you is confidential. If the child has given you information that you think is important to share with the neurologist/epileptologist and/or the parents, particularly if it involves the child's safety, ask for the child's permission to do this.

Explain to the child that you need to talk with the parents and the neurologist/epileptologist to come up with a plan of how to help stop the seizures and the problems the child brought up in the interview. Most importantly, do not talk with the child or adolescent about the treatment plan until the parents have agreed to the plan.

Strategies to Use in the Parent Interview

The following topics in the interview of the parents will add to what you learned during your comprehensive assessment of the child. It will provide you with information needed to confirm the conversion disorder and comorbid psychiatric diagnoses. You will also get a sense of how open the parents are to acknowledging that the child has problems other than seizures and, more specifically, to the possibility of a psychiatric rather than an epilepsy diagnosis. Depending on how open the parents are, you will also learn about the impact of the child's illness on the family's functioning.

NES Episodes

Ask the parents to describe the episodes in terms of:

- The clinical presentation.
- Where the seizures occur.
- Who is with the child during an episode.
- How long episodes last.
- The child's awareness and functioning once an episode ends.
- How parents handle the episodes.

If the child also has epilepsy, ask the parents to describe how the seizures present. Express empathy for the impact of the child's episodes and/or seizures due to epilepsy on the parents' lives and on the family. This helps build rapport with the parents.

Stress

As for the child, explain that stress might trigger seizures and then find out what stressors the child might have. If parents describe the child's stressors, empathize with how difficult this might be for the child and for them. If the parents deny stressors, gently ask if the family is experiencing any stressors. When parents state that seizures are the only stressor for the child and for the family, this increases the likelihood of a conversion disorder diagnosis. Then ask what events and child behaviors precede episodes. Most parents usually deny any antecedent factors.

The Child's Medical History

Ask about past and current medical illnesses and hospitalizations. Determine what the parents do now and have done in the past when the child has physical complaints. Do they seek medical help and/or let the child miss school?

Psychopathology

Help the parents understand that seizures due to epilepsy impact different aspects of the functioning of the child and family. To help reduce the frequency of the child's seizures, explain that you will ask them questions about the child's behavior, emotions, and functioning. Inquire about symptoms of mood disorders, anxiety disorder, ADHD, learning disorders, psychotic disorders, eating disorders, conduct disorder, oppositional defiant disorder, substance abuse, autism spectrum disorders, and trauma. Find out about conflicts/problems between the parents and child and express empathy accordingly. The parents might deny that the child has any emotional or behavioral symptoms and conflicts in the family. Explain that the above occur to some degree in most children and families and that they might act as potential stressors that induce seizures.

Discipline

Find out if parents have made any changes in how they discipline the child since the onset of seizures. Clarify how both parents approach this topic. If they have different approaches, ask them to share how they resolve their differences. Inquire how the child responds to their different approaches and attempts to manipulate their differences.

Burden of Illness and Childcare

Inquire if both parents or one parent deals with the child's illness. How does this affect the other children and family functioning?

Schedule the Feedback on the Diagnosis and Treatment Plan

Explain to the parents that the team (minimally involving you and the neurologist/epileptologist) will review the information collected during the vEEG, the child's psychiatric/psychological interview, and the parents' interview. Then schedule a feedback session with the team about the diagnosis and treatment plan for the parents and child.

Summary

Diagnosis of Pediatric PNES

The possibility of PNES should be considered in:
Every child with intractable seizures that do not respond to AEDs

This diagnosis is confirmed through:

A vEEG with no epileptic activity during "seizures"
A comprehensive psychiatric evaluation that reveals evidence for a conversion disorder

Triggers

Undiagnosed and untreated
 Learning difficulties
 Social problems
Domestic strife (parenting, marital relationships)
Unrealistic performance expectations (child, parents)
Psychological abuse, bullying, and other forms of trauma

Risk factors

Somatopsychiatric
 Past medical illnesses, hospitalizations, and ER visits
 Psychiatric diagnoses, past emotional problems
 Passive avoidant coping
 Fearful response to physical sensations (anxiety sensitivity)

Adversity

Treatment with psychotropic medications

Adversities

Bullying

Domestic or community violence

Serious personal illness, surgery, or medical procedures

Red flags

Other than seizures, child has no problems

Inconsistent seizure pattern

Long duration of seizures

Seizures occur in presence of others

Diagnostic techniques

Separate child and parent interviews

Concrete language with “What?” and “How?” and follow-up validation questions and few “Yes/No” questions

Empathize

Provide positive feedback for information the child provides

Normalize stressors, problems, difficulties, and negative emotions

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