Little is known about pediatric autoimmune neuropsychiatric syndrome (PANS), but its affect on children is abrupt and often debilitating. Author Kathryn Gilliam has more on this alarming disorder.

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Imagine your child turning into a different person, seemingly overnight. Suddenly your sweet, lighthearted child is moody, aggressive, defiant, and anxious. He laughs or cries at inappropriate times. He develops sleep problems and begins wetting the bed and having nightmares. Out of the blue, he has developed obsessive-compulsive behaviors, performs ritualistic repetitive behaviors, and is experiencing uncontrollable body movements. What on earth is happening?

Your child may have a type of acute-onset obsessive-compulsive disorder (OCD).[1] This disorder is characterized by a variety of presentations and symptoms, and as a result, the medical community has failed to come to a consensus on the etiology or definition of this disorder, leaving clinicians and parents at a loss for the appropriate and most effective treatment.

This abrupt onset of OCD has been known as childhood acute neuropsychiatric symptoms (CANS), pediatric infection-triggered autoimmune neuropsychiatric disorders (PITANDS), and pediatric autoimmune neuropsychiatric disorder associated with strep (PANDAS).[2] Initially, it was hypothesized that the symptoms were a result of an autoimmune reaction to the streptococcal infection we know as strep throat.[3] Now it is generally referred to as pediatric autoimmune neuropsychiatric syndrome (PANS), which doesn't link the disorder to any specific cause.[4]

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As the name suggests, PANS appears to be an autoimmune disorder.[5] It is thought to be the result of an infection that causes the body's defense system to turn on itself and attack healthy brain cells. When this happens, the immune system attacks the brain, triggering a cluster of mental health symptoms exhibited as a severe form of acute-onset OCD.[5]

Parents have reported that children who never had OCD before they had strep throat, or another infection, suddenly begin displaying OCD behaviors such as tics and repetitive actions. These symptoms are described as starting abruptly, virtually overnight.[6]

There have been instances of children as young as 3 and 4 years old exhibiting symptoms such as eating restriction, rage, depression, and even suicidality. These behavioral changes come on suddenly, reaching full-scale intensity within 24 to 48 hours.[7]

According to experts, a child suffering from PANS might suddenly need constant reassurance or become obsessive about handwashing or food.[7] Often, these children worry about food contamination, choking, or vomiting, which can develop into anorexia and weight loss, sometimes requiring hospitalization and a feeding tube.[7]

Panic attacks are common among children who develop PANS.[7] According to Susan E. Swedo, MD, chief of the Pediatrics and Developmental Neuroscience Branch at the National Institute of Mental Health, the child may be in a near-constant state of panic in the first few days of illness. Even older children may request to sleep with their parents. Typically these children are unable to attend school or participate in normal childhood activities.[7]

Diagnosis

It's the acuity of symptom onset that is the hallmark feature of this disorder, according to Swedo.[7] Three diagnostic criteria have been proposed for PANS:[8]

I. Abrupt, dramatic onset of OCD (or severely restricted food intake)

II. Concurrent presence of additional neuropsychiatric symptoms, with similarly severe and acute onset, from at least two of the following seven categories:

1. Anxiety (including separation anxiety)
2. Emotional lability and/or depression
3. Irritability, aggression, and/or severely oppositional behaviors
4. Behavioral (developmental) regression
5. Deterioration in school performance
6. Sensory or motor abnormalities
7. Somatic signs and symptoms, including sleep disturbances, enuresis, or urinary frequency.

III. Symptoms that are not better explained by a known neurologic or medical disorder, such as Sydenham's chorea, systemic lupus erythematosus, Tourette's disorder, or others.

According to clinicians and scientists who met to discuss the challenges of diagnosis and determination of the etiology of this condition, the differential diagnosis "may involve infectious, post-infectious, drug-induced, autoimmune, metabolic, traumatic, psychogenic, and other factors, but there is not yet a scientific association with streptococcus."[9]

Because of the continuing controversy and unresolved questions surrounding the etiology of PANS, the management of children suffering from this disorder remains a challenge to clinicians and parents.

Normally, children who develop OCD attempt to manage unwanted thoughts or impulses through repetitive rituals that they develop *gradually*.[10] They become hypervigilant, impulsive, and perform ritualistic, repetitive behaviors or language. They develop anxiety, apprehension, panic attacks, depression, or fear.[10] Nightmares are common in children with OCD, as are food aversion and compulsive, repetitive thoughts. But these symptoms occur and are compounded over time.[10] With PANS, the onset is *abrupt*, and this is the differentiating factor according to Swedo.[7]

Children with OCD often exhibit tics, which are sudden twitches, movements, or sounds that occur outside of the child's control.[10] The child may jerk their head or another body part, blink repeatedly, clear their throat constantly, or repeat words.[10] A child with existing OCD or tics will develop significantly worse symptoms upon the development of PANS.[7]

Other symptoms commonly seen in PANS include:[11]

- Uncontrolled, jerky movements
- Hyperactivity, fidgeting, difficulty paying attention
- Anxiety or panic attacks; irrational fear of separation from parents or other caregivers
- Depression or aggression
- Reversion to behaviors they had previously outgrown, such as baby talk or temper tantrums
- Moodiness, irritability, crying or laughing inappropriately
- Light sensitivity and sensory problems such as seeing or hearing things that are not real
- Joint pain
- Sleep problems, such as bedwetting and nightmares

Treatment

According to the experts, treatment is most effective when a diagnosis is made sooner rather than later. Treatment typically involves both medication and psychotherapy. Antibiotics are used to treat any underlying infection, and anti-inflammatory medications are used to quiet the immune system. Steroids may be used initially, and nonsteroidal anti-inflammatory drugs (NSAIDs) may also help reduce systemwide inflammation.[12]

Cognitive-behavioral therapy can help control obsessive-compulsive disorder. Strategies to cope with OCD thoughts and fears are used by therapists who work with children.[12]

Antidepressants such as selective serotonin reuptake inhibitors (SSRIs) are also used to help manage OCD; however, according to experts, these medications can be dangerous for children. Additionally, children with PANS are likely to have side effects from SSRIs.[12]

In severe cases and cases where other treatments are ineffective, more extreme procedures may be used to reset the immune system. IVIG is an intravenous infusion of normal antibodies from other people. Plasmapheresis is another option in which the child's blood is extracted and filtered through a machine that removes the antibodies that are attacking the child's brain, then reintroduced into the body.[12]

Surgery such as tonsillectomy and adenoidectomy have also been studied as potential treatments for PANS. As with the other treatment modalities, there is controversy surrounding these surgical interventions, with no definitive studies yet.[12]

The good news is that most children with PANS typically recover completely with treatment.[12] Symptoms typically resolve slowly over several months.[12] PANS is an episodic condition, in which symptoms may disappear for extended periods, and then reappear, stimulated by exposure to strep or some other bacteria or virus. The symptoms may get increasingly severe with each recurrence.[2]

Vigilance in maintaining healthy habits such as avoiding sick people, frequent handwashing, changing toothbrushes frequently, getting plenty of sleep, and consuming a nutritious diet are all recommended. Experts recommend family members be tested to be sure no one is carrying the strep bacteria in case it is found to be an etiologic factor.[12]

There are few things more distressing to a parent than a child who is suffering. Experts agree that given this disorder's severe and debilitating nature, more clinical research must be done to establish evidence-based, effective therapies.[9]

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