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A Case Study of Children's Encounters with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS)

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Abstract

This syndrome, often referred to as Pediatric Acute-onset Neuropsychiatric Syndrome (PANS), is typified by the abrupt and severe onset of symptoms associated with OCD and other neuropsychiatric conditions. Finding out about the experiences of children with PANS was the main goal of this study. Nine children, ages 10 to 18, which had been diagnosed with PANS participated in the study. Semi-structured interviews were used in the research. Three main themes emerged from an inductive qualitative content analysis of the material under investigation. The first piece of art, "Suffering," illustrates the significant negative effects that PANS can have on a person's physical, mental, and emotional health. The second piece of art, titled "Powerlessness," emphasizes the overpowering sensation of hopelessness that results from dealing with difficult and unpredictable symptoms. Last but not least, the third piece of art, "Being encouraged," highlights the benefits of getting effective, individualized care as well as the steadfast support of committed caregivers. The results show that children with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) have considerably worse quality of life

because they feel unable to control their symptoms. On the other hand, when patients receive individualized treatment plans and consistent support from their caregivers, they feel more in control of their own lives.

Keywords: quality of life, children, neuropsychiatric, psychological disorder.

Introduction

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) is a clinical diagnosis for children who suddenly display severe neuropsychiatric symptoms, such as obsessive-compulsive disorder (OCD) and/or restricted food intake, representing a dramatic change from their usual behavior and emotional state. Additionally, the diagnosis requires the presence of two or more neuropsychiatric abnormalities, including anxiety, emotional instability or depression, irritability, aggression, oppositional behaviors, behavioral or developmental regression, school performance deterioration, sensory or motor abnormalities, and somatic symptoms like sleep disturbances, enuresis, or urinary frequency. These symptoms abruptly emerge and can significantly impact a child's functioning.

According to Johnson et al. (2019) have undertaken recent study that has shown a novel disorder known as Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). The abrupt and severe onset of obsessive-compulsive disorder (OCD) and/or notable dietary intake limits are characteristics of this illness. Multiple researches have indicated that this condition is marked by at least two additional symptoms (Chang et al., 2015; Johnson et al., 2019; Swedo et al., 2012). Anger, impatience, aggression, oppositional behavior, behavioral regression, cognitive decline, sensory or motor impairments, and/or physical manifestations are a few examples of these symptoms. There remains no agreement among physicians regarding the establishment of standard diagnostic criteria or procedures, even though this is a relatively new and occasionally confusing diagnosis (Salani et al., 2021) that can occasionally cause disagreements (Wilbur et al., 2019). (Chang et al., 2015; Prato et al., 2021). PANS can present as a chronic illness with recurrent flare-ups known as "flares" or as isolated occurrences. According to Gromark et al. (2022), Johnson et al. (2019), and Swedo et al. (2012), it is characterized by a sudden onset. During the acute phases, these symptoms have a significant impact on kids and their families (Frankovich et al., 2015)... Some children may go more than a year without experiencing any symptoms, whereas other children may always have symptoms. A 2017 study by Calaprice et al. found that the prevalence of pre-adolescent neuropathy (PANS) symptoms is twice as high in males as in females.

According to Chang et al. (2015), the exact causes of PANS are yet unknown. Nonetheless, the possibility of an immune system control issue is indicated by the children's history of allergies and inflammatory conditions such eczema and asthma (Johnson et al., 2019; Calaprice et al., 2017). Additional evidence supporting this theory can be found in the correlation between PANS

and a number of diseases, including influenza, mycoplasma, streptococcal infections, and Lyme disease (Chang et al., 2015; Swedo et al., 2012). According to research by Gromar et al. (2022) and Swedo et al. (1998), confirmed streptococcal infections are the hallmark of a particular kind of pediatric autoimmune neuropsychiatric disease known as pediatric PANDAS.

PANS is generally treated with antibiotics that are efficient in treating infections as well as drugs that specifically target inflammation, such as intravenous immunoglobulin globulin (IVIG) (Frankovich et al., 2017; Cooperstock et al., 2017). Traditional psychiatric interventions frequently involve the use of selective serotonin reuptake inhibitors (SSRIs) and cognitive behavioral therapy (CBT) (Hesselmark&Bejerot, 2019). According to Pfeiffer et al. (2021), children with severe symptoms should get psychiatric treatment in addition to immunomodulatory and anti-inflammatory medications.

Previous investigations have mostly utilized several quantitative techniques to examine the clinical and diagnostic facets of PANS, along with the neurobiology and neurochemistry that could potentially induce its symptoms. Numerous studies examining the effects on families have revealed that parents experience high levels of stress as a result of the symptoms, recurrent episodes, and challenges in accessing medical care (Ringer & Roll-Pettersson, 2022). According to McClelland et al. (2015), family members often worry about symptoms and are not happy with the current state of medical knowledge and available treatment options. Parents experience a great deal of stress, which impacts their availability at work and in the classroom, according to Farmer et al. (2018).

Nonetheless, there is a little of research that systematically examines the actual experiences of kids with PANS. The lack of personal accounts raises concerns because they may provide important insights into the subjective experience of those living with the disorder, their coping mechanisms, and their capacity to recognize helpful support systems (Ryan & Sawin, 2009; Shelton et al., 2022).

Methodology

Research Design

The study involved conducting semi-structured individual interviews with children diagnosed with PANS. The objective of employing semi-structured interviews was to explore the distinct perspectives of the children as they articulated them. According to Kvale and Brinkmann (2009) argue that individual interviews are an effective method for conducting a comprehensive examination of a person's intricate evaluations, actions, and feelings. Given the lack of previous research on PANS, this study employed an inductive technique to examine the verbal data.

Participants and Sample

Adolescents and youngsters diagnosed with PANS were recruited from hospitals and waiting rooms of youth and child medical clinics. The study required participants to be children or adolescents between the ages of 10 and 18, who had received a verified diagnosis of PANS from a qualified medical professional such as a pediatric neurologist, child/adolescent psychiatrist, or clinical psychologist. Approximately fifteen parents requested the study's regulations and supplementary written materials, and their child was included. Interviews were conducted with nine youngsters who had willing caretakers. The parents asserted that their children abstained from participation due to their physical well-being. The child's age, disease severity, treatment experiences, sociocultural background, and symptom duration were diverse when questioned and diagnosed. The survey participants originated from small rural areas to large urban centers throughout Punjab.

Procedure of data collection

The study team created an initial interview plan to gather in-depth reports of children's assessments, feelings, and behaviors related to PANS. The original program was based on earlier studies. We surveyed three PANS parents and two social workers who lead parent support groups to get their opinions on the schedule. They recommended distributing the schedule with more generic queries. The extra questions included dinners, daily routines (morning and night), leisure activities, and school life (classes, homework, and peers). Flexible interview instructions and follow-up, probing questions were used to examine the interview findings. Researchers conducted in-person, fifteen to fifty-minute interviews with individuals at their residences from February to April of 2024. The original author conducted all of the interviews in addition to recording and transcribing them. The participants received no compensation.

Analysis Procedure

An inductive method for qualitative content analysis used as a framework for data analysis. This approach was chosen because it can help academics explore the meanings of communication and is sensitive to content. Through deliberate transitions from the raw data to meaning categories derived from it, researchers can examine each interview in great detail. Because of our modest sample size, we were able to evaluate our transcribed interviews using this method. We used an inductive approach to analyze our verbal data because it is advised to develop categories from data when there is limited knowledge about a phenomenon, such as children's PANS experiences.

Elo and Kyngäs (2008) evaluated manifest content using open coding, subcategorization, and abstraction. When open coding first started, it broke down data into its component pieces and described its properties using the actions and interpretations of users. Meaning units were coded using semantic content. At this stage, codes that are applicable to all content are created. In the second stage of data analysis, codes were sorted, organized, and synthesized under higher-order titles to create subcategories. We classified them by contrasting and comparing the codes. Elo and Kyngäs (2008) categorized codes based on whether or not they belonged to a subcategory.

The third step included choosing a content-characteristic rubric, abstracting the subject, and grouping similar components into subcategories. Citation2020 claims that data analysis was aided by NVivo 12. Throughout this study, the authors engaged in many discussions and disagreements about how to interpret the data as well as our own opinions in an effort to improve the transparency and dependability of data collection and analysis. Disagreements in the classification and interpretation of the data led to adjustments in the coding.

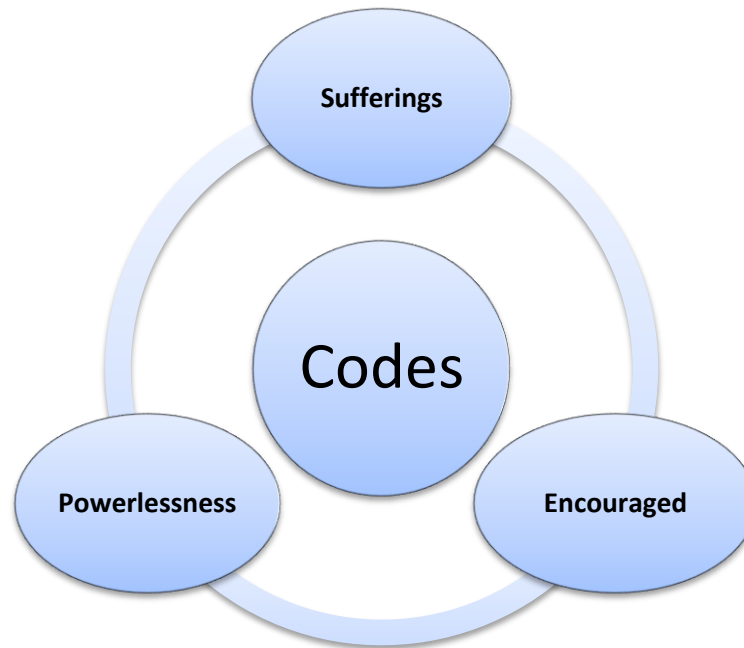
Results

Table 1 Demographic Information of the Children with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) (N=9)

| Variable | F(%) | mean |
|------------------------------|----------|------------|
| Male | 6 (70.0) | |
| Female | 3 (30.0) | |
| Children age | | 14.4 (3.1) |
| Symptoms | | |
| Mild | 3 | |
| Moderate | 4 | |
| Severe | 2 | |
| Treatment Method | | |
| Antibiotics | 4 (44.5) | |
| Psychiatric Medicines | 4 (44.5) | |
| Therapies | 1 (10.0) | |

Table 1 provides the demographic information for a study on Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) involving nine children. The gender distribution shows 70% (6 children) are male and 30% (3 children) are female. The average age of the children is 14.4 years with a standard deviation of 3.1 years. Regarding symptom severity, three children presented with mild symptoms, four with moderate symptoms, and two with severe symptoms. For treatment methods, 44.5% (4 children) were treated with antibiotics and another 44.5% with psychiatric medicines, while therapies were used for 10% (1 child) of the cases.

Figure 01 Code of the identified from the Interview



From the viewpoint of children with PANS, the interview study produced three main categories that aid in explaining the illness. In the first section, "Suffering," we discuss the ways in which the disease impacts the general well-being, growth, and functioning of children. In the second group, "Powerlessness," people report feeling helpless and unable to control their symptoms. "Being encouraged" refers to situations in which children receive positive reinforcement and affirmation. The categories are summarized in Figure 01.

1. Sufferings

The term "suffering" was frequently used by children to characterize their symptoms. Physical symptoms and the emotional toll they impose on the daily life of the sufferer have been shown to cause suffering. Anxiety and bewilderment ensued due to the sudden and radical onset of the symptoms. PANS caused mental, emotional, and physical trauma to the children. Physical pain, anxiety, concerns, exhaustion, wrath, self-blame, detachment from reality, concentration difficulties, impatience, and difficulties with problem-solving were among the emotions that the children encountered. It was astounding to see the severity with which the children described the incident. As the subsequent remark demonstrates, they frequently emphasized the magnitude of their experiences when describing their distress or annoyance:

“Even minor irritations can exacerbate my pancreatitis. It's irrelevant and of no consequence to me. It rarely bothers me, to be honest. I become enraged by such matters when I am wearing pants”.

According to the children's testimonies, PANS significantly transformed their lives. It contaminated all facets of existence, including self-sufficiency, meeting fundamental necessities,

familial success, social connections, and intellectual advancement. Widespread was the abrupt transition from life with PANS to life without it. Life was amazing and unrestricted prior to PANS, but it was dreadful and restricted thereafter. Describe how the child's illness impacted his academic performance:

“I was an excellent student prior to PANS. In general, I excel in the subjects of mathematics and Swedish. Subsequently, my student persona underwent a profound transformation. Classwork, such as listening and reading, became more difficult. Roughly no schoolwork was completed. I caused more disruptions in class and conflicts with my peers. It halted my mind, so I reread the entire document. Even the most elementary equations can be challenging to solve”.

2. Powerlessness

Regarding their illness, everyone felt weak and defenseless. Three reasons for feeling powerless were found: losing control over symptoms, having trouble articulating them, and not receiving attention from medical professionals. Experiencing powerlessness led to feelings of anger and sadness. PANS were dubbed a monster by a few children. Control loss has three components. 1. The children thought their symptoms outweighed their ability or desire to lessen them. They tried to control the symptoms but were unable to do so. This event is best described by the following quote:

“I can't really control myself; it just happens. For instance, you cannot halt the flow of water if a pail overflows and the water continues. I feel that way”.

Children struggled for a second reason: there were no good symptom control strategies. Most didn't think such strategies existed. Some children believed that staying in a room alone or getting lots of sleep was the only way to manage the symptoms. The third reason for feeling out of control was the unpredictable nature of symptoms. The majority of kids reported sporadic symptoms. The children struggled to identify trends. While some could not identify a prerequisite, others thought that the symptoms were more noticeable when they were hungry or tired. For other children, there was constant distress and fear of symptoms since they could not predict how they would feel during the day or for a longer duration. Some kids used PANS as a comparison for more stable and predictable medical conditions like diabetes or neuropsychiatric illnesses in order to express how uncomfortable they were with unpredictability. The citation that follows says:

“I have trouble reading because of my dyslexia. Not in the case of PANS. This doesn't seem to go on forever. Why it keeps coming back is beyond me”.

Many people found it difficult to articulate their symptoms. Since they were unable to communicate their physical, mental, and emotional difficulties, they found it difficult to seek for assistance. One child, for example, said that they were unable to explain PANS to their friends. I spoke with pals on the phone. It was challenging. I was at a loss for words. I didn't feel uncomfortable telling them, but I was at a loss for words. Shame was another reason given by participants for keeping their difficulties to themselves. They feared that people would perceive them as "mad," and they were ashamed of their emotions and lack of self-control. Every child reported feeling unheard by medical professionals. According to their

observations, healthcare professionals frequently just listened to about half of what they had to say, didn't believe them, or were simply incredulous:

“Talking when seated seems as though no one is paying attention. I'll write, like, medicine,” they imagine. As like they're not paying attention. They put together what they hear themselves wanting. “You have this diagnosis, so you should have this medicine,” they say after picking out a few pieces”.

3. Encouraged

They found encouragement and hope in individualized care and an adult role model who persevered in the face of adversity. Parental involvement in children's treatment was infrequent, with clinicians typically dictating the course of action. Medication and cognitive-behavioral therapy are included. Some patients improved as a result of personalized attention as opposed to generic treatment based on recommendations or a manual. These participants claimed that rigidly regulated therapy exacerbated symptoms, resulted in dissatisfaction, and caused depression. However, the children felt more in control when the treatment was flexible, personalized to their circumstances, and based on their individual objectives. This quote serves to describe such an occurrence:

“My physician regarded me as a person, not a disease. Due to the fact that she treated me as an individual, she provided me with the most assistance. My preferences, previous experiences, and aspirations. The conversation at her place of employment resembled the following: “This describes you as an individual; what is your ideal way of life, and how can we collaboratively ensure that you achieve that life despite the presence of pans?”

The idea of being abandoned with PANS evoked fear in a number of the young individuals who were interviewed. It was therefore extremely reassuring to have an adult who supported and assisted them in coping with their illness, regardless of its severity. The experience is succinctly encapsulated in the subsequent statement:

“Mom alone persisted. She was not deterred by it. I am extremely appreciative that she was present. Regarding treatment, her scope of practice is limited. She executed her presumption that would prevent my rescue. That is extremely useful. Why? Due to my firm conviction that she is the rationale behind my presence. When at all feasible, Mom offered to assist”.

Discussion

The purpose of this qualitative investigation was to comprehend how children with PANS manage their symptoms, how others perceive their condition, and how they feel regarding the support they receive from others. The authors are unaware of any prior research that examines the condition from the standpoint of minors afflicted with PANS.

Our interview data indicates that PANS has a substantial negative effect on the health and daily functioning of children. The youthful individuals who participated in the interviews disclosed that they encountered challenges across all facets of life, encompassing their mental faculties, emotional state, and physical well-being. Furthermore, the symptoms induce considerable

anxiety in the children due to the abrupt and dramatic onset of the illness as well as the unfamiliarity with the situation. Furthermore, the perceived threat is exacerbated by the episodic nature of PANS and the stark contrast between symptomatic episodes, during which the child experiences life as a typical child, and asymptomatic periods, during which life is a challenge. In addition, the results revealed that children with PANS experience a sense of helplessness when confronted with their symptoms. A feeling of powerlessness ensues as a result of the subsequent elements: the symptoms appearing to be more formidable than one's own motivation, the lack of strategies to manage them, and the capricious nature of their initiation.

A further obstacle to treatment is the fact that children frequently have difficulty communicating, either out of embarrassment or because they are at a loss for words. Moreover, encounters with healthcare professionals who disregarded the patient's input or eroded their sense of authority may contribute to a diminished perception of treatment alternatives. Consequently, children diagnosed with PANS encounter a triple whammy: an imminent threat to their well-being, an insurmountable challenge to confront that threat independently, and limited avenues to seek support from others. Conversely, children experience a heightened sense of empowerment when their healthcare providers demonstrate flexibility in attending to their specific requirements. The results indicated that children expressed greater levels of treatment satisfaction when healthcare professionals were accommodating and customized therapies to meet the specific needs and preferences of each child, as opposed to relying on preconceived notions or established protocols. It is also encouraging to have a persistent adult by their side who facilitates with symptom management.

Our findings align with prior research (Frankovich et al., 2015; Wilbur et al., 2019) that establishes a strong correlation between a PANS diagnosis and profound psychosocial impairments. Furthermore, previous investigations have demonstrated that parents of children diagnosed with PANS have expressed similar sentiments of fear and helplessness when confronting their symptoms (McClelland et al., 2015), which aligns with the accounts provided by the children in the present study. In accordance with recent Swedish and international guidelines regarding the management of PANS (Karolinska Universitetssjukhuset; Pfeiffer et al., Citation2021; Socialstyrelsen, Citation2021), the participants in our research emphasized the importance of tailoring treatments to accommodate their specific needs and preferences. It is concerning that all participants felt unheard and uninvolved in healthcare decision-making (Salani et al., Citation2021) and that the controversy surrounding the diagnosis (Wilbur et al., Citation2019) may be associated with the clinical misinterpretation of the condition.

The findings of our research also indicate that parental presence is vital when children are coping with PANS. Prior studies have underscored the importance of offering assistance to guardians of children who are afflicted with chronic or uncommon medical conditions (Smith & Kaye, 2012; Pelentsov et al., 2016). Consequently, this may not be unexpected. The significance of offering psychosocial support to parents of children with PANS, in conjunction with the psychiatric and medical treatment their child may receive, may be a significant implication of our findings. This is due to the fact that PANS has been shown to have a substantial and adverse effect on parental stress (Ringer & Roll-Pettersson, 2022) and paternal burden as a whole (Farmer et al., 2018). This would ensure that parents are able to provide their offspring with ongoing support.

Limitations of the Study

It is imperative to illuminate the numerous methodological deficiencies present in the present study. A small degree of variation was observed among the participants with regard to sex, but not significantly with regard to age, sociocultural background, severity of illness, or clinical experiences. The lack of consideration for the experiences of females within the proposed paradigm renders the results potentially unapplicable to different contexts (Shenton, 2004). Furthermore, our sample encompassed individuals across all age groups, which introduces the possibility that the experiences and aptitudes for expressing them could significantly diverge, for instance, between those of a 10-year-old and an 18-year-old. Consequently, one might contend that transferability pertains exclusively to children across various age groups and not to adolescents or smaller children with PANS.

Additionally, only nine children participated in the present study, which may not have provided a comprehensive depiction of what it is like to have PANS. Additionally, we neglected to conduct saturation analysis to ensure that we had collected all the necessary data; therefore, future investigations may benefit from a more substantial sample size (Sargeant, 2012; Saunders et al., 2018; Vasileiou et al., 2018). However, due to the rarity of the disorder and the fact that no prior research has given voice to children who have been diagnosed with PANS, we continue to believe that the current study could make a substantial contribution to the field (Jaspers-Fayer et al., Citation2017). Additionally, it is crucial to emphasize the social and cultural context, as with any research endeavor (Shenton, 2004). In the realms of parental responsibilities, medical care, and general support systems, among others, children with PANS might have unique experiences. Further qualitative research from diverse social and cultural backgrounds could shed light on these variations.

Conclusion

In conclusion, PANS is a novel diagnostic labeling an abrupt and severe onset of OCD accompanied by additional neuropsychiatric symptoms. The objectives of this qualitative investigation were to determine how children with PANS manage their symptoms, the degree to which their condition is under control, and the extent of social support they receive. PANS is a debilitating disorder that causes children great distress and renders them powerless in the face of their symptoms, according to our research. Healthcare professionals can enhance their ability to support children with PANS by collaborating to customize therapies according to the specific needs and preferences of each individual child. Moreover, parental involvement seems to be necessary for children who have been diagnosed with PANS. Previous research on parental burden and stress emphasizes the critical need to provide psychosocial support to parents with PANS so that they, in turn, can aid their children in managing the illness.

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