

From Crisis to Connection: Addressing the Emotional and Relational Challenges of PANS/PANDAS in Families

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Abstract

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infection (PANDAS) are conditions marked by the sudden emergence of complex neuropsychiatric symptoms, including obsessive-compulsive behaviors, severe eating restrictions, and a range of cognitive and emotional disturbances. These symptoms can profoundly disrupt family life, creating challenges that extend beyond the affected child to impact parents and siblings alike. This white paper examines how the complex behaviors associated with PANS/PANDAS influence family dynamics, leading to heightened emotional distress, confusion, and frustration among family members. It underscores the importance of recognizing the interconnectedness of family relationships and the need for comprehensive support strategies tailored to address the unique challenges all family members face. By exploring therapeutic interventions such as trauma-informed family therapy and educational advocacy, this paper aims to provide actionable insights for mental health professionals, educators, and families, ultimately fostering resilience and promoting healing within the family unit.

1. Introduction

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infection (PANDAS) represent significant challenges not only for the children diagnosed with these

of severe symptoms, including obsessive-compulsive behaviors and restrictive eating patterns, which can dramatically disrupt daily family life (Swedo et al., 2012). While much of the focus tends to be on the affected child, it is essential to recognize the broader impact on parents and siblings, who also experience emotional and relational upheaval during this crisis.

Understanding the collective experiences of families dealing with PANS/PANDAS is crucial for developing effective support strategies that promote healing and resilience. As awareness of these conditions grows, it becomes increasingly clear that there is a significant gap in resources and support tailored specifically for families. Addressing these gaps is vital to mitigate the long-term emotional and relational challenges that can arise from these disorders, highlighting the need for comprehensive strategies that consider the unique needs of the entire family unit.

2. Problem Statement

The emergence of PANS/PANDAS presents a multifaceted challenge that extends beyond the child diagnosed with the condition, affecting the entire family system. As the affected child grapples with sudden and severe symptoms, parents often face overwhelming stress and uncertainty, complicating their ability to provide effective support. This situation can be further complicated by the parents' own attachment styles, which may influence their parenting decisions during this critical period. For

example, parents with an anxious attachment may become overly protective, while those with avoidant attachment might struggle to engage with their child's emotional needs. Siblings of the child with PANS/PANDAS are also significantly impacted. They may experience feelings of neglect or anxiety as they navigate the unpredictable behaviors of their brother or sister, which can strain family dynamics and lead to lasting emotional repercussions. The emotional toll on siblings can affect their own development, potentially influencing their attachment styles and future relationships.

Despite the increasing recognition of PANS/PANDAS, there remains a critical lack of resources and support designed specifically for families facing these challenges. The relational and emotional difficulties that arise from PANS/PANDAS can have enduring effects on all family members if not addressed appropriately. This situation underscores the urgent need for targeted interventions and comprehensive support strategies that consider the diverse needs of the entire family, including the child affected by PANS/PANDAS and their siblings, while also addressing the role of parental attachment styles in navigating this crisis.

3. Background

From a family systems perspective, every family member is interconnected (Minuchin, 1974). Within this framework, smaller relationships form subsystems, such as those between mother and father, siblings, or parent and child. Each contributes to the overall dynamics of the family unit. In families with a sibling who has PANS/PANDAS, the well-being of other children can be adversely affected. Parents often allocate a significant amount of their attention and resources to the child with PANS/PANDAS, which can leave

other siblings feeling emotionally neglected. Additionally, the stress associated with caring for a child with PANS/PANDAS can increase parental distress, further reducing the emotional support available to siblings. Consequently, those without PANS/PANDAS may experience heightened distress, leading to declines in quality of life, academic performance, and behavioral stability.

Research on trauma-informed psychotherapy for children, adolescents, and their families dealing with PANS/PANDAS is limited (Gromark et al., 2022). However, existing studies indicate that parents and siblings of children with life-threatening conditions (LTC) report lower resilience, increased symptoms of posttraumatic distress, heightened emotional distress, greater anxiety, more health problems, and poorer overall quality of life compared to families without an LTC (Feudtner et al., 2021). Symptoms of PANS/PANDAS can include obsessive-compulsive behaviors, severe eating restrictions (Swedo, 2017), motor tics, attention deficits, personality changes, emotional instability, insomnia, anxiety, depression, and irritability (Rea et al., 2021). These symptoms often overlap with conditions such as OCD, Tourette syndrome, ADHD, and bipolar disorder, complicating diagnosis and treatment (Ringer & Roll-Pettersson, 2022).

Given that family members may exhibit symptoms similar to those associated with LTCs, it can be hypothesized that the presence of PANS/PANDAS exacerbates these challenges. Parents may feel a profound sense of failure when witnessing their child's complex behaviors, leading to self-doubt and fears of not meeting societal parenting expectations. Similarly, siblings may experience confusion and frustration, worry about family dynamics, feel embarrassed in

front of peers, and wish they could help their sibling but feel powerless to change the situation.

While research on the direct impact of PANS/PANDAS on family mental health remains scarce (Gromark et al., 2021), studies show that a child's cancer diagnosis can disrupt the psychosomatic balance of the entire family (Lewandowska, 2022). Three primary mental health dynamics may emerge: the mental health of the parents, the mental health of the siblings, and the mental health of the child with PANS/PANDAS. Understanding how the behaviors and emotional responses of parents, siblings, and the PANS/PANDAS patient interact is crucial, as these dynamics can either strengthen or strain the family system during this challenging period.

Under normal circumstances, families navigate a delicate balance between order and disorder, often teetering on the edge of chaos. Even minor changes can lead to significant effects in this environment, resulting in complex behaviors that may not be immediately apparent (Yolles, 2021). Introducing PANS/PANDAS into this balance is not a minor change; it can escalate behaviors among family members, pushing the family dynamic into chaos. This may manifest as increased parental conflict, declining academic performance among siblings, extreme disciplinary measures, and overall decreased family quality of life.

Ringer and Roll-Pettersson (2022) note that PANS/PANDAS can be easily overlooked and left untreated due to its symptom overlap with other psychiatric disorders and its sudden onset. Consequently, the family unit, including parental relationships, is likely to be in crisis long before PANS/PANDAS is diagnosed, leading to further challenges for both the PANS/PANDAS patient and their

siblings. As the family system grapples with this crisis, additional mental health issues may arise within the relationships between the PANS/PANDAS patient and their siblings. Children internalize early attachment experiences with their primary caregivers, and these attachment patterns serve as blueprints for future relationships (Peng & Ishak, 2025). Exposure to extreme punishment, volatile emotions, parental frustration, low emotional support, and neglect can create insecure or anxious attachment styles. Conversely, positive parent-child relationships characterized by sensitive parenting and secure attachments can foster resilience and enhance self-esteem (Stroyer de Voss et al., 2024).

It is important to note that parents cannot bear the sole responsibility for fostering healthy attachment styles in their children. The school environment is also crucial, as interactions with teachers and peers significantly impact mental health. Positive relationships within schools can support the development of secure attachments, underscoring the need for a nurturing educational atmosphere. Collaboration among parents, educators, and the community is essential for promoting healthy attachment styles in young people.

Adolescent attachment styles persist into adulthood, profoundly influencing how individuals navigate future relationships. Understanding these patterns is vital, as they affect emotional intimacy, trust, and communication in future partnerships and friendships. By recognizing the impact of early attachment experiences, individuals can strive for healthier relationship dynamics throughout their lives.

As previously mentioned, PANS/PANDAS symptoms can manifest abruptly and include challenges such as obsessive-compulsive

disorder (OCD), severely restricted food intake, motor tics, anxiety, emotional instability, irritability, aggression, developmental regression, declining academic performance, sensory or motor abnormalities, and somatic symptoms like enuresis and sleep disturbances (Shimasaki et al., 2019). These symptoms can be particularly stigmatizing in school settings, adversely affecting the child's self-esteem and their relationships with peers and teachers. This highlights the urgent need for schools to implement supportive measures that foster understanding and acceptance among students.

Complex behaviors associated with PANS/PANDAS can lead to significant challenges in school environments. Teachers may struggle to empathize with these behaviors, while parents find it difficult to respond positively (Poulton et al., 2022). Viewing behavior as a form of communication rather than a disciplinary issue can help address the underlying environmental challenges faced by the student. This approach may involve being open-minded and adjusting the learning environment, such as changing class schedules or offering preferred seating arrangements.

The complexities of PANS/PANDAS extend beyond the individual experiencing symptoms, deeply impacting the entire family system. The interconnectedness of family members means that the challenges one faces can reverberate throughout the household, affecting emotional well-being, relationships, and overall quality of life. Families must seek comprehensive support that addresses not only the needs of the child with PANS/PANDAS but also those of the siblings and parents. By fostering open communication, understanding, and collaboration among family members,

educators, and mental health professionals, families can create a nurturing environment that promotes healing and resilience. Ultimately, prioritizing the mental health and emotional needs of all family members is essential for navigating the challenges posed by PANS/PANDAS and fostering healthier relationships that can endure beyond adolescence.

4. Recommendations

PANS/PANDAS presents a complex challenge that necessitates a multifaceted treatment approach, incorporating both medical care and environmental support. This white paper outlines a framework for addressing PANS/PANDAS that highlights the importance of seeking specialized medical guidance while considering the critical roles of family and school environments in a child's recovery journey. Although this document does not provide medical advice and is not authored by a medical professional, it encourages readers to consult physicians specializing in PANS/PANDAS to develop tailored treatment plans. Furthermore, this paper explores how trauma-informed family therapy and educational advocacy can create supportive environments that foster healing and resilience for children affected by PANS/PANDAS. Through collaboration among medical professionals, families, and educational advocates, we can work towards a comprehensive approach that addresses these children's and their families' unique needs.

4.1 Specialized Psychotherapy

In supporting families dealing with PANS/PANDAS, a child and adolescent family therapist serves as an ideal resource. These therapists receive specialized training that equips them to understand the intricate

dynamics within family systems and how these dynamics influence individual behaviors and emotional well-being. Unlike counselors who typically focus on individual concerns and symptom reduction, family therapists adopt a holistic approach that considers the entire family unit and the necessary changes to prevent the emergence of symptoms. This enables them to work effectively with both the child affected by PANS/PANDAS and their family members, fostering open communication and collaboration. Child and adolescent family

By involving the family in the therapeutic process, therapists can help create a supportive environment that addresses the unique challenges of chronic illness. This can ultimately promote resilience and healthier relationships among all family members.

Additionally, child and adolescent family therapists are equipped to support married, divorced, and blended couples as they navigate the complexities of caring for a child with PANS/PANDAS. These professionals understand the unique dynamics present in each family structure and can facilitate discussions that align treatment objectives for the affected child while also considering the needs of their siblings. By promoting open and constructive communication, the therapist helps couples express their concerns, share parenting responsibilities, and establish collaborative strategies that enhance the child's recovery. They also guide parents in setting achievable goals that prioritize the well-being of the PANS/PANDAS child while ensuring that siblings feel supported and valued. This comprehensive approach fosters a nurturing environment, allowing all family members to feel heard and understood, which is crucial for effectively managing the challenges associated with PANS/PANDAS.

It is also beneficial to work with a therapist who is trauma-informed and knowledgeable about child and adolescent brain development and attachment styles. Such a professional can provide valuable insights into how trauma influences emotional and behavioral responses, particularly for children coping with PANS/PANDAS. By creating a nurturing atmosphere, the therapist can help establish a solid foundation for the affected child and their siblings, fostering healthy attachment patterns and supporting their future relationships. This approach addresses the immediate challenges associated with PANS/PANDAS and equips children with the tools needed for successful interpersonal connections as they grow. By emphasizing developmental understanding and trauma awareness, the therapist can facilitate meaningful healing and growth for the entire family.

Ideally, the therapist should be trained in the NeuroAffective Relational Model (NARM), which focuses on the impact of complex trauma on emotional and relational development. While complex trauma may not always be explicitly identified, it can manifest in environments where children and adolescents are exposed to chronic stressors, such as those associated with caring for a sibling with a chronic illness like PANS/PANDAS. This model underscores the importance of understanding how early relational experiences shape an individual's ability to form secure attachments and navigate relationships throughout life. Engaging with a trauma-informed NARM therapist is a proactive approach to preventing the adverse effects of trauma, as these professionals are equipped to recognize and address the underlying issues that may arise from such challenging circumstances.

4.2 Education Advocate

An educational advocate plays a crucial role in supporting families of children with PANS/PANDAS by navigating the complexities of the school environment and ensuring that the child's educational needs are met. Having someone knowledgeable about school operations and the laws governing education for children with chronic illnesses can significantly benefit families. This expertise allows advocates to effectively communicate with school personnel, ensuring that the child receives the necessary accommodations and support.

Educational advocates can help secure special accommodations for making up missed assignments or tests due to the child's symptoms, ensuring they do not fall behind academically. They can also assist in developing Individualized Health Plans (IHPs), which are tailored to address the child's specific health and behavioral needs within the school setting. IHPs focus on managing the child's health requirements while ensuring that educational goals are still pursued.

In addition to IHPs, advocates can assist in creating Individualized Education Programs (IEPs) and 504 Plans. IEPs outline the educational goals and services required to support the child's learning, while 504 Plans provide accommodations to ensure that the child has equal access to education. These plans are essential for addressing the unique challenges faced by children with PANS/PANDAS.

Furthermore, advocates can work with schools to implement behavior plans that provide clear guidelines and strategies for addressing any behavioral challenges that may arise due to PANS/PANDAS. By collaborating with educators, therapists, and

school administrators, educational advocates help create a supportive and inclusive environment that allows children with PANS/PANDAS to thrive academically and socially. Ultimately, their involvement ensures families have the resources and support necessary to navigate the educational system effectively, promoting the child's overall well-being and success.

5. Treatment

Therapy sessions for parents dealing with the complexities of PANS/PANDAS can be conducted both in-person and via telehealth, providing flexibility to accommodate varying schedules and preferences. Each session typically lasts 50 minutes and offers a dedicated space for couples to express their parental, marital, or individual concerns. In-person sessions allow for direct interaction and a more personal connection, while telehealth options provide convenience and accessibility, enabling parents to participate from their homes. Regardless of the format, these sessions focus on fostering open communication, addressing challenges, and developing strategies that support the well-being of the child affected by PANS/PANDAS and the family.

Individual therapy for children with PANS/PANDAS can also be conducted through both in-person and telehealth formats, ensuring that young patients receive the support they need in a manner that is convenient and comfortable for them. Each session typically lasts 50 minutes and provides a safe, confidential environment for the child to explore their thoughts, feelings, and behaviors related to their condition. In-person sessions allow for direct, face-to-face interaction, which can be particularly beneficial for building rapport and trust between the therapist and the child. Alternatively, telehealth sessions offer

flexibility, making it easier for families to attend therapy without traveling.

During these individual therapy sessions, the therapist employs age-appropriate techniques to help the child process their experiences with PANS/PANDAS, develop coping strategies, and address any emotional or behavioral challenges they may face. The therapist may also build resilience and enhance the child's social skills, which their condition can impact. By providing tailored support through either format, therapists can help children navigate the complexities of PANS/PANDAS and foster a sense of empowerment and healing.

Therapy for siblings of children with PANS/PANDAS is an essential component of the overall support system. It can also be delivered through both in-person and telehealth formats. Each session typically lasts 50 minutes, providing a safe and supportive space for siblings to express their feelings, concerns, and experiences related to their brother or sister's condition.

In-person sessions allow for direct interaction with the therapist, fostering a sense of connection and trust. At the same time, telehealth options offer convenience and accessibility, making it easier for siblings to participate without traveling. During these therapy sessions, therapists employ age-appropriate techniques to help siblings process their emotions, such as feelings of anxiety, jealousy, or neglect that may arise from the challenges of having a sibling with PANS/PANDAS.

The therapist may also focus on building coping strategies, enhancing emotional expression, and promoting healthy communication skills. Additionally, these sessions can provide siblings with tools to manage their stress and develop resilience,

ensuring they feel supported and valued within the family dynamic. By addressing the unique needs of siblings, therapy can play a vital role in fostering a more harmonious family environment and strengthening the bonds between all family members.

Group therapy sessions for families impacted by PANS/PANDAS can be a valuable resource, providing a supportive community for parents, patients, and siblings alike. These sessions can be conducted in person or via telehealth, making them accessible to a broader audience. Each group typically lasts around one hour and allows participants to connect with others who share similar experiences and challenges. For parents, group sessions provide a platform to share insights, strategies, and emotional support, helping them feel less isolated in their journey. Hearing from others navigating the complexities of PANS/PANDAS can foster a sense of camaraderie and understanding, allowing parents to learn from one another's experiences and coping mechanisms.

Participating in group sessions can help children and adolescents normalize their experiences, reducing feelings of isolation and stigma. Sharing their stories with peers who understand their struggles can be empowering and validating. It also provides a space for them to practice social skills and develop friendships with others facing similar challenges. Siblings also benefit from group therapy, allowing them to express their feelings and concerns in a supportive environment. They can connect with other siblings who may feel neglected or overwhelmed, which can help them feel understood and less alone in their experiences.

Overall, group therapy sessions create a sense of community and shared understanding, fostering resilience and hope for all

participants. Families can build valuable connections and gain insights that contribute to their healing journey by engaging with others affected by PANS/PANDAS. These collective experiences provide emotional support and empower families with practical strategies for managing the challenges associated with PANS/PANDAS, ultimately enhancing their ability to cope and thrive together.

6. Conclusion

PANS/PANDAS poses significant challenges that extend beyond the affected child, impacting the emotional and relational dynamics of the entire family. The sudden onset of complex neuropsychiatric symptoms creates a ripple effect, leading to heightened stress and emotional turmoil among parents and siblings. By recognizing the interconnectedness of family members and the unique challenges they face, we can develop comprehensive support strategies that address the needs of all individuals involved. Therapeutic interventions, including trauma-informed family therapy, educational advocacy, and group support, play a crucial role in fostering resilience and healing. Ultimately, prioritizing the mental health and emotional well-being of the entire family is essential for navigating the complexities of PANS/PANDAS and promoting healthier relationships that can endure beyond adolescence. Through collaboration among mental health professionals, educators, and families, we can create a supportive environment that empowers families to thrive despite the challenges posed by PANS/PANDAS.

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Chris Putnam received his Ph.D. in Business Administration, specializing in Organizational Leadership, from

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