

FAMILIES' EXPERIENCES WITH PANDAS AND RELATED DISORDERS

Patricia Rice Doran, Ed.D. and Elizabeth O'Hanlon, Ph.D.

Council for Exceptional Children 2015 Annual Convention, San Diego, CA

April 11, 2015

Background: Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infection (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) are recently discovered conditions in which students experience abrupt onset of neurological and psychiatric symptoms. While medical understanding of these conditions is still evolving, symptoms are thought to result from an autoimmune reaction that leads to brain inflammation (Swedo, Leckman & Rose, 2012; Chang et al, 2015). Children with PANDAS and PANS are at high risk for academic and behavioral difficulties in school (Tona & Posner, 2011; Candelaria-Greene, 2014), but there is a dearth of research on how these disorders impact student success or family experience. This study examines how parents perceived the educational experiences of their children who have PANDAS or PANS.

Research question: How do parents perceive the educational experiences of their children who have PANDAS or PANS?

Methods: This study utilized qualitative, interpretive methodology, grounded in a phenomenological approach to capture the “lived experience” of families of children with PANDAS or PANS through interviews (Kvale & Brinkmann, 2014). The researchers conducted 60-90 minute interviews with 12 parents of children diagnosed with PANDAS or PANS (two families had two or more children with PANDAS/ PANS related health issues). Participants were recruited in partnership with a national research and advocacy organization.

Results: Qualitative analysis identified themes, grouped into broad categories:

1) School-related experiences at home

Stress: Families described multiple instances of emotional and financial stress. Some families reported mortgaging or selling their homes or draining retirement accounts due to the cost of treatment for their children. Parents reported children experiencing challenges at home due to school-related stress: “I used to relay the story of him ... literally crawling up the stairs to his bed because he would be so mentally exhausted from holding it together all day at school.”

Resilience and coping: Parents often report employing unique coping strategies to deal with PANDAS symptoms: “We have a name for it, the “worry bully.” So I say, Is the worry bully getting to you? And he says, yes.”

2) School experiences

Communication: Families commented on issues with school communication about PANDAS/ PANS and the impact on their child: “I’d like schools to know they have the power to make or break relationships with families who have PANDAS.”

What school “looks like”: Approximately half of the students involved were reported by parents to be enrolled in homeschool or receiving home and hospital services due to physical illness, immunocompromised status, or unremitting anxiety. Half attended public or private school with accommodations or support (formal or informal). Accommodations and supports most frequently mentioned included flexible attendance, flexible school schedules, access to “safe spaces” in schools,

sensory supports such as special seating or fidgets, extended time, use of keyboards and laptops, and expedited transitions to home teaching.

3) Perceptions of the child

Sudden onset: Some parents described onset at age three or four, with symptoms not recognized till the child began school. In one parent's words, "Out of nowhere he would just cry for hours and...say he wanted to wash. He never had anything like that before."

Child's awareness: Generally, parents described their children as being aware of some changes at the time, though several parents indicated their children did not remember episodes after the fact. One parent reported her child saying he had "strobe lights in my brain." Another spoke of his brain "feeling puffy" when he was symptomatic and feeling healthy when symptoms resolved.

Behavior and disability: Parents described a variety of experiences with school personnel regarding their child's behavior. Several parents described their children experiencing violent episodes at school while testing positive for strep or experiencing other acute illness or allergies. Further, parents commented that the nature of the disability often led others to interpret the manifestations of the disability as behavior choices. One parent commented: "My kids were just fine, they didn't look sick... I think it would have been easier if PANDAS wasn't such an invisible disability. ...When you see him missing silly questions or looking like he's not concentrating, you need to look a little differently into why that might be happening."

Preliminary conclusions:

- Parents report a variety of challenges related to their children's school experiences when dealing with PANDAS or PANS.
- Parents report that it can be difficult for both families and school personnel to distinguish among student choices, challenging behaviors and neurological symptoms.
- Parents perceive strong communication with school staff and proactive school planning to be essential to school success of their children with PANDAS and PANS.

References

- Candelaria-Greene, J. (2014). Considerations regarding academic accommodations, compensatory strategies, and services for students with PANDAS/ PANS. Retrieved from <http://pandasnetwork.org/wp-content/uploads/2014/09/School-Considerations-2014.pdf>
- Chang, K., Frankovich, J., Cooperstock, M., Cunningham, M., Latimer, M. E., Murphy, T, ... Swedo, S. (2014). Clinical evaluation of youth with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS): Recommendations from the 2013 PANS Consensus Conference. *Journal of Child and Adolescent Psychopharmacology*. Online ahead of print. doi:10.1089/cap.2014.0084.
- Kvale, S. and Brinkmann, S. (2014). *InterViews: Learning the craft of qualitative interviewing, 3rd ed.* Thousand Oaks, CA: Sage.
- Swedo, S., Leckman, J., & Rose, N. (2012). From research subgroup to clinical syndrome: Modifying the PANDAS criteria to describe PANS (Pediatric Acute-onset Neuropsychiatric Syndrome). *Pediatrics & Therapeutics* 2:113. doi:10.4172/2161-0665.1000113
- Tona, J., & Posner, T. (2011). Pediatric Autoimmune Neuropsychiatric Disorders: A new frontier for occupational therapy intervention. *OT Practice*, November 2011, 14-22.