How Parents of Students with PANDAS or PANS Perceive the Educational Process

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Abstract

This qualitative study examined parent perceptions of the educational process for their children who had been diagnosed with Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) or Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS). In recent years, PANDAS and PANS, conditions in which an overactive immune response causes neurologic and psychiatric complications, have received increasing research and public attention. While the impact of these conditions on school performance has not been systematically studied, it is hypothesized to be substantial, given the intense and disruptive nature of symptoms. This study analyzed data from interviews of twelve parents of children with PANDAS or PANS in order to describe their perceptions of the educational process. Results indicate that parents saw substantial overlap between home and school functioning, that PANDAS and PANS were extremely stressful to the nuclear family, and that parents reported declines in student attendance, academic performance, and behavioral functioning.

How Parents of Students with PANDAS or PANS Perceive the Educational Process

In 1995, National Institute of Mental Health (NIMH) scientists first described a syndrome later known as Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS), thought to be caused by an autoimmune response to streptococcal infection (Swedo & Rappaport, 1995). This syndrome, which has been more fully described in subsequent studies (Swedo, Rose & Leckman, 2012; Chang et al, 2015; Theinemann et al., 2017), results in symptoms such as sudden-onset obsessive-compulsive disorder (OCD), motor and vocal tics, mood swings, rage, and academic challenges (Swedo et al, 1998; Lewin et al., 2011; Calaprice, Tona & Murphy, 2017). Since its identification, increasing attention has been focused on PANDAS and a related, broader condition known as Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) (Chang et al., 2015).

Popular books (Maloney, 2009) and recent neurological and medical research (Platt, Agalliu & Cutforth, 2017; National Institutes of Health, 2015), have increased parent and professional awareness of the sometimes-complex relationship between infection, immunity, and behavior. Research into effective treatment for immune-mediated OCD and related disorders is ongoing and focuses on the role of cognitive-behavioral therapy, a mainstay of treatment for non-immune-mediated OCD (Storch et al, 2012; Theinemann, 2017), immune modulation (Frankovich et al., 2017; Latimer et al., 2015) and prophylaxis against infection (Cooperstock et al., 2017). In the meantime, these neurological disorders have been acknowledged to be tremendously disruptive to both family and school functioning of affected children (McClelland et al, 2015; Tona and Posner, 2011; Rice Doran, 2016; Calaprice, Tona, Parker-Athill & Murphy, 2017) in ways that have been described in anecdotal and exploratory studies of family life but not specifically with respect to school-based experiences or parent perceptions.

This exploratory study seeks to build on this research base in order to describe how parents perceive the educational experiences of their children with PANDAS or PANS. The research question is: How do parents of children with a PANDAS or PANS diagnosis perceive their own, and their children's, experiences with the educational system?

Significance and Implications for Special Education

This research is significant in several ways. First, it is the first study to examine how parents perceive the educational process for their children with PANDAS/ PANS. Particularly given the implications for identification, instruction, and service delivery as awareness increases, this research has potential to immediately influence future research as well as approaches to the IEP process for children with PANDAS/ PANS. Because of a wide variance in symptom presentations and the likelihood that many children with PANDAS/ PANS are inappropriately diagnosed and served, there is a critical need for educator awareness on this topic (Calaprice, Tona, Parker-Athill & Murphy, 2017). The study also contributes to the already-robust literature base on families' involvement in, and perceptions of, special education and school experiences. While specifically focused on a novel disorder, this study underscores the stress placed on families by any disability diagnosis (particularly on considered rare or little-known) and the importance of considering family input, and all appropriate sources, in the identification and planning processes.

The population of students with PANDAS and PANS, while not a high-incidence group in and of itself, is likely to continue increasing as awareness grows and diagnoses become more frequent. It is likely that children with PANDAS and PANS will be particularly in need of understanding teachers and appropriate instruction tailored to the full spectrum of their complex medical, academic and behavioral needs.

PANDAS and PANS: Background and Impact on School Functioning

Background

The mechanisms of PANDAS and PANS are thought to be similar, though different agents can trigger the two syndromes (Chang et al., 2015). PANDAS, which involves neurological and psychological dysfunction linked to streptococcal infection, is a specific manifestation of the broader disease category of PANS, in which symptoms can result from exposure to illness (such as influenza), allergic reaction, or another environmental stimulant (Frankovich et al., 2017; Chang et al., 2015; Calaprice, Tona & Murphy, 2017). Symptoms of both disorders involve neurological and motor dysfunction, sudden-onset anxiety or food restriction, sensory, sleep and urinary issues, emotional lability and regression, and cognitive and academic issues. (See Table 1).

Table 1
Diagnostic Criteria for PANDAS/ PANS (Swedo, Leckman, & Rose, 2012; NIMH, (n.d).

PANDAS Diagnostic Criteria	PANS Diagnostic Criteria
Abrupt, dramatic onset of obsessive-compulsive disorder or severely restricted food intake (anorexia). Concurrent presence of additional neuropsychiatric symptoms, with similarly severe and acute onset, from at least two of the following seven categories: Anxiety Emotional lability and/or depression Irritability, aggression and/or severely oppositional behaviors Behavioral (developmental) regression Deterioration in school performance Sensory or motor abnormalities Somatic signs and symptoms, including sleep disturbances, enuresis or urinary frequency Symptoms are not better explained by a known neurologic or medical disorder, such as Sydenham chorea, systemic lupus erythematosus, Tourette disorder or others (NIMH, n.d.).	Presence of obsessive-compulsive disorder and/or a tic disorder Pediatric onset of symptoms (age 3 years to puberty) Episodic course of symptom severity Association with group A Beta-hemolytic streptococcal infection (a positive throat culture for strep or history of Scarlet Fever) Association with neurological abnormalities (motoric hyperactivity, or adventitious movements, such as choreiform movements). (Swedo, Leckman & Rose, 2012)

Both PANDAS and PANS have been the subject of medical and psychiatric research since the late 1990s. Early studies described symptoms, phenotyped patients, and documented overlap of neuropsychiatric symptoms with exposure to pathogens such as *Streptococcus pyogenes* (Swedo et al., 1998; Swedo, Leckman & Rose, 2012). More recently, research has identified subtypes of restricted eating thought to be triggered by infection (Toufexis et al., 2015) figures, and the often-disruptive effects of the disorder, it is likely not only that many school professionals will encounter students with PANDAS or PANS in the years ahead, but also that these students and their families may require significant support.

Impact on Families

There is limited discussion of how PANDAS and PANS impact families specifically, McClelland et al (2015) interviewed families of children with PANDAS or PANS about how they perceived their medical experiences and determined that families frequently felt fearful, dismissed by a hospital or medical staff, and stressed (McClelland et al 2015). This data is borne out in further anecdotal reports (Alleman et al., 2016; Rice Doran, 2016; Candelaria-Greene, 2016), which describe families experiencing extreme stress related to their children's suicidal urges, restrictive eating, and physically aggressive behavior. In other anecdotal writings, families have reported feeling that both medical and school staff were dismissing their experiences (Alleman et al., 2016) and engaging in protracted negotiation with school staff to clarify their child's needs and ensure those needs were met (Alleman et al., 2016). Theinemann (2016) indicates parents of children with PANDAS and PANS have a higher caregiver burden than parents of pediatric cancer patients (2016). While the current literature does not address specific impact of PANDAS and PANS on families and the educational process, there is research demonstrating the stress it may place on families and their children (Thienemann, 2016; McClelland et al., 2015). There is substantial literature to indicate that disability status in general can impact the educational process (Rodriguez, Blatz & Erlbaum, 2014), underscoring the importance of responsive teaching and educator awareness of family challenges (Bacon & Causton-Theoharis, 2013; Zuna et al, 2016).

Impact on School Functioning

Children with PANDAS and PANS are thought to be at high risk for academic and behavioral difficulties in school (Tona & Posner, 2011; Candelaria-Greene, 2016; Hoppin, 2016). The acute onset and disruptive nature of symptoms can cause challenges in school as well as at home. One study demonstrated increased tics and motor abnormalities among schoolchildren with active streptococcal infections (Murphy et al., 2007). PANDAS has been demonstrated to impact cognitive and executive functioning (Lewin et al, 2011; Hirschtritt et al., 2009) as well as fine motor skills (Chang et al., 2015; Swedo, Rose & Leckman, 2012). Pawela et al. (2017) identified four cases of children with basal ganglia encephalitis, a condition considered to be closely related to PANDAS and PANS, who demonstrated executive function impairment months and sometimes years after recovery. Individual teacher accounts suggest students with PANDAS or PANS often require academic accommodations, curriculum modifications and services that may include counseling, behavioral support, and assistive technology (Crombez & Rice Doran, 2016). Parents of children with PANDAS and PANS have anecdotally shared experiences consistent with these teacher PANS can be difficult within the parameters of the typical Individualized Education Program (IEP) process, as a student's status and symptoms may fluctuate rapidly in a matter of months, weeks or even days (Crombez & Rice Doran, 2016). Similarly, the rapid onset and disruptive symptoms may cause these disorders to have a significant effect on family dynamics and functioning, a conclusion that has been borne out in one exploratory study (McClelland, 2015).

Framework and Methods

Framework

This paper draws on current neurological and psychiatric research (Swedo et al, 1998; Swedo, Leckman & Rose, 2012; Murphy, Storch & Lewin, 2012; Frankovich et al., 2017 Cooperstock et al., 2017) for descriptions of PANDAS and PANS. While PANDAS and PANS are well-described in the medical and neurological literature, there is no peer-reviewed research in the educational domain addressing student characteristics, family experiences, or ways in which either disorder impacts school functioning. This exploratory qualitative research, which aims to capture and describe the experiences of families whose children have a PANDAS or PANS diagnosis, leverages educational constructionism (Crotty, 1998), in which individuals can construct meaning from their own experiences and share it with others. Shared experiences of parents and family members, in this study, can contribute to an increased body of knowledge about the effects of this complex disorder and identify topics for future qualitative and knowledge (2014). This approach (Moustakas, 1994; Creswell, 1998; Kvale & Brinkmann, 2014) allowed the researchers to elicit each family's unique story and was appropriate to the exploratory nature of this inquiry into an emerging field. The research protocol was approved by the Institutional Review Board (IRB) at the researchers' institution. Semi-structured interviews (Kvale & Brinkmann, 2014) are the primary data source. The interview protocol is provided in the appendix. Using the semi-structured format, the researchers probed as appropriate for more information, particularly for specific incidents or details to illustrate parent ideas. Twelve (12) interviews were conducted with parents of children diagnosed with PANDAS/ PANS, recruited through partnership with a national PANDAS advocacy organization. Three (3) interviews were conducted face-to-face and nine (9) were conducted by telephone due to distance. Member checking was conducted via email and follow-up phone calls. It was assumed that all participants answered questions honestly and to the best of their ability; limitations include participant self-selection, which may skew the participant group toward knowledgeable, involved parents, and exclusive consideration of parents' perceptions rather than incorporating perspectives of other stakeholders in the educational process. The researchers saw this as a necessary first step in addressing the dearth of research from any perspective in this particular area and prioritized parent perceptions consistent with the consensus in special education literature that parent perspectives are central to understanding families' experiences.

Participants were drawn from eight different states and had varying levels of education. All parents interviewed were female, heterosexual and married. The gender of parents may have affected results in that mothers and fathers tend to have slightly different perceptions of the special education process (West & Pirtle, 2014). It is possible the number of married participants is a result of selection bias, as single parents may have less time to participate in research. Families generally reported stable relationships, though one described brief separation between spouses as a result of family needs related to illness. Children of interviewees had been diagnosed for varying lengths of time, from five years to six months. All children, as reported by parents, were diagnosed by a general practice physician or nurse practitioner or a specialist physician. Diagnosis and medical information was self-reported by participants. Some participants shared medical and school documentation to facilitate the description of symptoms, although researchers did not request this. Reported family characteristics are summarized in

Table 2

Family status of participants

Married	12/12
No other children	1/12
One or two other children	11/12*
Three or more other children	0/12
Parents ever separated	1/12**

*One family reported three children in total, all of whom had PANDAS/PANS

**One family reported brief (less than a year) separation to ensure safety of other children during period of acute crisis experienced by child with PANDAS

As some parents reported having more than one child diagnosed with PANDAS or PANS, there are more reported children described in the study (15) than participants (12). Email correspondence with parents and selected documents provided by parents (correspondence, medical records, educational documents and student work samples) were reviewed and analyzed as secondary data sources. Table 3, below, summarizes reported age of children at time of interview and at time of symptom onset, as well as school attendance status (home education or home and hospital instruction through the local school system).

Table 3
Participant, child age at onset and currently, and school attendance status

Participant	Child age at symptom onset	Child age at interview	Currently educated at home (homeschool or home/hospital instruction)	Ever educated at home (homeschool or home/hospital instruction)
1	8	16	Yes	Yes
2	4	7	No	Yes
3	4*	10	No	No
4	5	12	Yes	Yes
5	7	16	No	Yes
6	9	12	No	Yes
7	2*	13	No	Yes
8	6	11	Yes	Yes
9	7	16	No	No
10	4	10	No	Yes
11	12	14	No	No
11	11	11	No	No
12	3	17	Yes	No
12	6	15	Yes	No
12	8	13	Yes	No

Prior to qualitative analysis, each interview was transcribed and downloaded into individual text documents. To analyze the data, several methods were used to identify themes among the data. Initially, researchers separately skimmed the transcribed interviews several times to identify patterns and themes (Ryan & Bernard, 2003; Bogdan & Biklin, 2003). Relevant phrases and keywords were identified and listed by each researcher separately, then reviewed jointly and combined. Key statements were identified, grouped into significant units, and analyzed to determine meaning across interviews (Creswell, 1998). Categories and units of analysis were organized both in linear, table form (Table 2) and in a visual diagram in order to facilitate mapping of relationships among and between categories. For visual diagramming, researchers used the Mindly application for IPAD to organize and present broader themes.

Results

Qualitative analysis revealed themes across several broad categories describing parent experiences and perceptions of the educational process. These categories are described below. It should be noted that while the intent of this study was to examine school perceptions and school-related experiences among parents of children with PANDAS and PANS, participants reported substantial impact on day-to-day functioning in school and at home, both as a result of the illness itself and as a result of school-related expectations and challenges. Particular areas of impact are:

Category 1: Parent perceptions of their child

Impact of sudden onset. Family and child relationships were complicated, according to parents, by the rapid and unexpected change in their children's behavior. Symptoms were described as arising suddenly for the majority of children: "Out of nowhere, he would just cry for hours and…say he wanted to wash. He never had anything like that before." One parent described her formerly outgoing son's change: "But it was more that he pulled away from all his friends because he could not, he wouldn't leave the house, he didn't want anyone to come over, he wanted to…. follow me around and follow my husband around." Some parents described the onset of behavioral change at age three or four, with other symptoms not recognized till the child began school, delaying a formal diagnosis. Three parents mentioned feeling traumatized or referenced post-traumatic stress symptoms in their own reactions. Family separation occurred in one instance, as the child with PANDAS was unable to live in her family's home due to severe obsessions and aggressive behavior. The child moved out with her mother for several months and returned once her behavior had stabilized. It should be noted that most parents participating in the survey reported that their children had stabilized; this may be a function of selection bias rather than being reflective of the typical course of illness, as parents whose children are not stable may lack the time or emotional capacity to participate in studies.

Child's awareness and ability to discuss symptoms. Generally, parents described their children as being aware of some symptoms and their impact on functioning, though several parents indicated their children did not remember symptoms or occurrences during times of acute exacerbation. One parent reported her child describing his altered perceptions: "It feels like I have strobe lights in my brain." Another parent reported her son saying that his brain felt "puffy" when he was entering a period of exacerbation. Several parents voiced frustration that their children were hesitant to discuss symptoms after they occurred, even if symptoms had resulted in inappropriate behavior that needed to be addressed from the standpoint of consequences.

Parents also reported their children being aware of their altered abilities or status as those might relate to school. One parent described her high school-aged daughter's altered cognitive process, as the student experienced significantly impaired processing time when ill: "[It becomes a] huge process to think and it doesn't seem logical anymore." Sometimes, students could recognize their own symptom patterns and communicate those feelings to their parents or teachers. In particular, recognition of symptoms and self-advocacy was an explicit goal for one student, whose mother stated: "She had me in junior high and now she's going to need to advocate for herself. Unless she's in a full-blown [crisis] state and needs my intervention. She needs to learn how to survive in life."

Category 2: Interrelationship of School and Home Experiences

Stress. Families experienced emotional and financial stress as a result of illness and diagnosis, which was exacerbated by school and, at the same time, had a substantial impact on school functioning as well. Some families reported mortgaging or selling their homes or draining retirement accounts to pay for treatment for their children or to supplement wages lost when their child needed a full-time caregiver. Parents reported children experiencing challenges at home due to school-related stress: "[In IEP meetings] 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." This stress was described as having substantial impact which might or might not be apparent to school personnel:

> I don't think people realize how devastating [this] is for the whole family. The kids can't sleep, the parents can't sleep, and the other kids are woken up at night because their sibling is screaming their head off. My daughter went to take the ACT having been up all night because [her sister] was screaming and punching holes in the wall. How are you going to the function of your immediate family as well as your extended family? When she was 7, it was terrifying for my 9 and 11-year-old to go through this experience.

Coping strategies. In dealing with PANDAS and PANS, families often developed and employed new coping strategies. For example, one parent described her method for helping her six-year-old son understand and address his anxiety and intrusive thoughts: "We have a name for it, the "worry bully." So I say, is the worry bully getting to you? And he says, yes." Two-thirds of the parents described had accessed some form of mental health, school counseling or therapy services for their children, and multiple parents described accessing such services for themselves as a result of the ongoing stress of the illness. Several parents indicated they had also accessed, or considered accessing, counseling or therapy services for siblings of children with PANDAS or PANS as a result of the stress the illness placed on their other children. Two parents indicated they had begun taking anti-anxiety or antidepressant medication during their child's illness.

Some parents described the experience of parenting a child with PANDAS or PANS as bringing out skills or assets they did not know they had previously: "As a parent who's been through PANDAS times three, punting and stretching and working with what I've got has really become my strength." Several parents had involved themselves actively in community-based work and advocacy related to PANDAS and PANS and described this work as helping them to feel an additional sense of purpose. One parent, who worked in a school-based setting, for example, described how she hosted informal conversations with colleagues about the effects of PANDAS, PANS and related illnesses in order to improve their awareness in serving their own. One parent recounted: "It really took video [of my son's symptoms] to show the school nurse [what these symptoms involved]. And at the time I was pretty traumatized by what my kids were going through and that the school wasn't supporting us. And once I showed a video to the school nurse I got her on board, she was a great ally." Another parent described an educational planning meeting where school personnel challenged the validity of her medical documentation because it was signed by an out-of-state specialist physician. The parent described her daughter's team as stating that they would not accept a letter from an out-of-state physician. The parent subsequently withdrew her daughter from public school and began homeschooling, citing her concern that her daughter would not receive appropriate services. One parent described the ongoing conflict with school and district officials over her son's inconsistent attendance at school, resulting both from physical illness and intense separation anxiety. Another parent described having the school administrator and the attendance officer for her district show up unannounced at her home to discuss her son's inconsistent attendance, a visit which she described as increasing his anxiety. Explaining the illness and the sudden change in her child's behavior was stressful for one participant: "So the teachers thought that was real strange, so that's when I kind of had to tell her what [we went through at home]."

Multiple parents referenced the importance of positive relationships and the active role school personnel should take in creating such relationships. One parent stated, for example: "I'd like schools to know they have the power to make or break relationships with families who have PANDAS." Another parent described receiving valuable support from school personnel: "[The counselors] are my lifelines, really." She described the counselor as facilitating accommodations, serving as a liaison between parents and teachers, and providing a safe space for the student when behavioral symptoms became overwhelming. One parent commented: It would have been easier if PANDAS wasn't such an invisible disability. [School personnel] said, we rarely see [tics or behaviors]. Because he's holding himself together in ways you don't believe. He is only concentrating on his neck [to avoid ticcing]; he is not concentrating on algebra. When you see him missing silly questions or looking like he's not concentrating, you need to look … into why that might be happening. Trust surfaced as an important element of communication and home-school relationships. One parent summarized her feelings thus: "You need to trust me that he is not at his best, medically speaking, and we are working on that as best we can. It's not the partnership it's supposed to be.… This is a scary process."

Category 3: Impact of Health on School Experience.

Parents described PANDAS and PANS as impacting their children's school experiences in multiple ways. One of these ways was by increasing anxiety, which itself affected academic performance. For example, the parent of a previously-successful student described the impact of PANDAS-related anxiety on her daughter's school performance post-diagnosis: "She would see other kids finish tests and she would think she should be done, and she would have a panic attack and just fill in bubbles. And her teachers would tell me later, you could actually see [on the test] where she fell off a cliff because somebody else would finish in front of her." One parent described her son, a senior in high school, retaking a third-grade handwriting class as part of his homeschool curriculum due to fine motor deterioration. Multiple parents recounted challenges in academic areas, primarily handwriting but also including mathematics, foreign languages and language arts. These included both difficulties in comprehending and remembering content and challenges due to numerous missed days of school. One parent recounted her son failing every one of his middle school classes due to symptoms (a follow-up interview six months later, after intensive treatment, found him passing his classes and much improved).

Attendance and accommodations. Approximately half of the students involved were 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 (usually formalized in a 504 plan or Individualized Education Program, though two parents reported receiving informal accommodations without a written plan). All but one parent reported some negative impact upon attendance during times of illness, with absences, late arrivals or both increased. Some parents reported students reacting negatively to illness or exposure in school, prompting them to require additional support or behavioral interventions. Sometimes, accommodations needed to be tailored or tweaked because of the impact of obsessive-compulsive disorder, anxiety or other issues. "[My daughter] has three safe spaces [because if] you go to the library and there's a bunch of people there, it's not safe anymore," one parent reported. Parents of students participating in homeschool or home and hospital instruction reported that they required varied supports in transitioning back to traditional school, including immediate provision of home and hospital services when needed (without a waiting period), shortened days, returning for social events prior to full school days, and visits to school before re-enrolling. The fluctuating nature of PANDAS and PANS symptoms made it difficult for IEP teams to identify and provide appropriate supports, according to several parents. One described the dilemma: "It's hard to make accommodations, because the symptoms keep changing…the accommodations that you wrote three months ago may not be appropriate."

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. One parent related the story of her son being escorted off school grounds by law enforcement after an episode of rage at school. Multiple parents reported that it was challenging to gain an understanding of behavioral issues from school personnel, as students sometimes fluctuated between stable and unstable behaviors; one parent stated: "I think they had a hard time seeing that he has a disability because he seems so neurotypical most of the time."

Discussion and Conclusion

The purpose of this study was to describe the ways in which parents of students with PANDAS or PANS perceived their school experiences. In general, parents perceived these conditions as having a significant impact on their child's educational experiences and their family functioning. Symptoms of PANDAS and PANS, particularly including disruptive behaviors, were reported to be a stressor for many parents. The sudden appearance of symptoms was reported to be particularly difficult. These conditions also had an academic impact, with many students missing large amounts of school and requiring accommodations and supports for access once they returned. Parents reported misperceptions and misunderstandings with both medical and school personnel, particularly related to awareness of the child's functioning and function or role of challenging behaviors.

Like other research, this research points to the important and interconnected relationship between families, children and the educational system (Collier, Keefe & Hirrel, 2015; LaBarbera, 2017). Collier, M., Keefe, E. B., & Hirrel, L. A. (2015). Family members in this study reported feeling alienated and frustrated by their experiences with the school system; a few families reported more positive experiences, which shaped their perceptions and their child's experiences as well. This is consistent with other findings in literature regarding families of children with disabilities in general (Friend & Cook, 2013) and families of children with autism spectrum disorder in particular (Zuna et al., 2016). Communication with school staff, particularly around the unusual symptoms and course of these disorders, appeared to be challenging. In particular, communication and planning related to ongoing supports were difficult due to the wide variation in symptoms experienced by some students with these disorders. Parents saw themselves as advocates and, in many cases, relied upon supportive school staff members to serve as advocates for relationships with other school staff. Parents expressed the importance of team approaches, supportiveness and shared goals, a finding consistent with other studies (Bacon & Causton-Theoharis, 2013). The presence, or absence, of such advocates, made a significant difference in families' reported experiences of the educational process. Future studies might profitably examine the role of school staff, particularly counselors and nurses, in the education of students with PANDAS and PANS. School experiences may hold particular importance given the stress that families report facing at home, both in this study and in other literature on the course of PANDAS or PANS (Calaprice, Tona, Parker-Athill & Murphy, 2017). Indeed, a positive school experience may provide some relief for students or parents. In contrast, the need for school staff to differentiate between choice-based behaviors and neurological symptoms was a source of tension for parents who felt the staff were not able to differentiate appropriately. Parents reported difficulty in explaining that their children were not making deliberate decisions when demonstrating the inappropriate behavior.

This research adds to the slim body of knowledge regarding PANDAS, PANS and their impact on educational experiences. Like parents of children with other disorders, parents of children with PANDAS and PANS report being under severe stress. They also report difficulty in certain areas of communication with schools, particularly around advocacy and the nature of the autoimmune illness. Given their disruptive nature, it is critical for educators to be informed about how best to support students with these disabilities. As one of the first studies addressing the nature and impact of PANDAS and PANS in schools, this research offers insight into how parents perceive their lived experience and how school staff might improve understanding of these disorders in order to provide effective and appropriate supports to affected students.

These findings suggest that PANDAS and PANS have a significant impact on school experiences of families and students. Further quantitative, qualitative and mixed-methods research is warranted to examine these impacts on a broader scale. Future research might also profitably examine perspectives of teachers on school impact, accommodations and supports related to PANDAS and PANS. Last, these findings suggest an urgent need for additional research on curriculum access, appropriate modifications and adaptations, and inclusion for students with PANDAS and PANS.

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Appendix: Interview Protocol

1. Thank you for agreeing to participate in this interview. As a reminder, you can stop at anytime if these topics are upsetting to you or if you feel you need to continue at a different time. Tell me a little about your family. How many children do you have? How old are they? (Probe if necessary: Do they all live with you full-time, or do they live with another parent or guardian elsewhere some of the time? Which parent is responsible for most of the communication with your child's/ children's teachers?

2. You have agreed to participate in this study because you are the parent of a child with PANS or PANDAS. Do you have one child with PANS/ PANDAS or more than one? (Probe if necessary: How many?)

3. Tell me a little about your child with PANDAS/ PANS (select appropriate condition). When did you first notice concerns with him or her? (Probe if necessary: What made you decide to request a PANDAS/ PANS diagnostic evaluation?)

4. How has this diagnosis affected your son or daughter?

5. Has this changed your family's activities or priorities at all?

6. Has this diagnosis affected school performance for your son or daughter? (Probe if necessary: How so? Were there specific areas of difficulty for your son or daughter?)

7. When did you first share your concerns with school personnel? Does your son or daughter currently have a 504 plan or IEP?

8. Does your son or daughter currently receive any accommodations or curriculum modifications? If so, what are they?

9. What are some of the most helpful things that school personnel have done to support your child or your family? (Probe if necessary: What might those be?

10. Are there any things school personnel have done that have not been helpful to your child or your family? (Probe if necessary: What might those be?)

11. As you look toward your son or daughter's future schooling and educational needs, are there additional concerns or supports you anticipate you will need to discuss with school personnel? If so, what are they?

12. Thank you for your time. Is there anything else you would like to share today? I will send you a copy of the summary and notes from your interview and you are welcome to add or correct anything at that time.