



Implications for Advanced Practice Nurses When Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections (PANDAS) Is Suspected: A Qualitative Study

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ABSTRACT

Introduction: Pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections (PANDAS) is a relatively new but controversial diagnosis affecting hundreds of children and their families. It is generally thought to be an autoimmune disorder resulting from a streptococcal infection that causes significant and bizarre behavioral changes

in children. Currently no definitive diagnostic or treatment modalities exist, which has led to misdiagnoses, ineffective treatments, and delayed care.

Methods: A qualitative study was conducted that included 60 families with at least one child diagnosed with PANDAS. The purpose was to explore how families experience the disorder and what nurses can do to provide effective care.

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Conflicts of interest: None to report.

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0891-5245/\$36.00

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Published online April 18, 2015.

<http://dx.doi.org/10.1016/j.pedhc.2015.03.005>

Results: Using paradigmatic analysis of transcribed interviews, three themes were identified: fear, frustration, and not being heard.

Discussion: Results from this study suggest that more information is needed to better understand this challenging phenomenon from both medical and nursing perspectives. The study also reaffirms the importance of practicing the art of nursing, especially when the science is not yet established. *J Pediatr Health Care.* (2015) 29, 442-452.

KEY WORDS

PANDAS, families, nursing care, autoimmune disorders, qualitative research

Pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections (PANDAS) is a relatively new diagnosis. Very little is known about the cause of this disorder, how to diagnose it, or how to provide effective treatments. Most current medical definitions define PANDAS as the term used to describe a subset of children who have obsessive compulsive disorder (OCD) and/

or tic disorders and in whom symptoms worsen after streptococcal infections (Murphy et al., 2015b; National Institutes of Health, 2014; Tan, Smith & Goldman, 2012). PANDAS is often suspected in children who exhibit abrupt, unusual, and challenging behaviors

after having pharyngeal infections. Changes that have been reported include deteriorating grades in school, unusual or aggressive behaviors, loss of ability to read or write, emotional outbursts and lability, change in personality, defiance, excessive or unusual bed time rituals, new-onset separation anxiety, deteriorating changes in personal hygiene, self-injury behaviors, violent outbursts, self-induced food restrictions, urinary symptoms, and nightmares. The acute onset of the aforementioned behaviors in a previously healthy child has significant implications for the child and his or her family members. Because of insufficient information, discrepancy in current knowledge, and inconsistencies in the literature, this study was initiated to contribute to the knowledge relating to PANDAS.

LITERATURE REVIEW

Only two articles about PANDAS from a nursing perspective were identified; neither was a research article. One article (O'Connor & Speros, 2008) was a case study presented by a pediatric nurse practitioner (PNP) regarding a patient with PANDAS, and the other was from a school nurse perspective on the disorder (O'Rourke, 2003).

Although these articles were useful in that they provided a description of PANDAS and included case studies and general practice guidelines, no nursing research has been conducted to contribute to evidence-based knowledge regarding this disorder. The medical literature includes some PANDAS research, most of which is either inconclusive or still being debated. However, in 2013 the first Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) Consensus Conference was held to establish evaluation and diagnostic criteria and urge more research to better understand this elusive and new area of medicine (Chang et al., 2015).

Discrepancies in the Name and Diagnostic Criteria

One of the frustrations that children and their families with suspected PANDAS face is that although the acronym PANDAS was first used in 1998 (Swedo et al., 1998; Esposito, Bianchini, Baggi, Fattizzo, & Rigante, 2014), consensus has not yet been reached regarding the name and presentation criteria of the disorder (Macerollo & Martino, 2013; Morris-Berry, Pollard, Gao, Thompson, & Singer, 2013; Singer, Gilbert, Wolf, Mink & Kurlan, 2012; Vitaliti et al., 2014). Some researchers agree that a link exists between the sudden onset of symptoms and a recent group A beta-hemolytic streptococcus (GABHS) infection in the child, as well as family members being carriers of GABHS (Macerollo & Martino, 2013; Rhee & Cameron, 2012; Vitaliti et al., 2014). However, other researchers have claimed that not enough evidence exists to support a correlation between neuropsychiatric syndromes and streptococcal infections (Morris-Berry et al., 2013; Schrag et al., 2009). Other practitioners reported cases with onset and symptoms similar to PANDAS but referred to the disorder as acute disseminated encephalomyelitis (Muir, McKenney, Connolly, & Stewart, 2013), postinfective autoimmune central nervous system disorder (Wild & Tabrizi, 2007) or childhood acute neuropsychiatric syndrome (Singer et al., 2012). Another author reviewing the disorder acknowledged the newly evolving problem and referred to the spectrum of similar disorders as pediatric inflammatory brain diseases, autoimmune-mediated inflammatory brain diseases, primary central nervous system vasculitis, and autoimmune encephalitis (Van Mater, 2014). Because of the complexity, variability, and unusual presentation of the disorder, additional studies and time will be required before practitioners are able to agree on the name and conditions of the disorder now known as PANDAS.

Insufficient or Inappropriate Diagnostic Measures

No specific diagnostic tool exists to confirm a PANDAS diagnosis. Most studies report unremarkable results of brain imaging studies in suspected PANDAS cases (Muir et al., 2013; Vitaliti et al., 2014). No specific

TABLE 1. Sample of diagnostic tests and treatments used and reported by health care providers when PANDAS is suspected*

Diagnostic procedures and treatments	Notes
Family history Determine history of familial neurologic disorders, autoimmune disorders, immunodeficiency disorders, and frequent infections Genetic components may be present Medical history with physical and mental examination Assess for sudden, dramatic onset of symptoms, including anxiety, somatic signs and symptoms (bed wetting, urinary frequency, sleep disturbances), emotional lability, irritability, developmental regression, sensory/motor abnormalities, and deteriorating school performance A full neurologic assessment is necessary Consider a genetic evaluation Determine recent infectious process Laboratory studies Complete blood cell count Erythrocyte sedimentation rate C-reactive protein Metabolic panel Urinalysis Throat culture ASO and anti-DNase B ANA Antiphospholipid antibody Ceruloplasmin 24-hour urine copper test	PANDAS is common among siblings; maternal autoimmune disorders are common in children with PANDAS; neuropsychiatric disorders are common in siblings of patients with PANDAS; increased rates of OCD and tic disorders are noted among first-degree relatives of patients with PANDAS Identification of two or more signs/symptoms (from list in left column) suggestive of PANDAS; multiple comorbidities are common; OCD and tic disorders are a common finding; positive neurologic findings must be differentiated from other potential neurologic conditions (such as Sydenham chorea); mental examination may reveal a terrified, hyperalert child; consider psychiatric consultation if symptoms are found; some patients with PANDAS have a greater propensity to develop infections; patients may still have a neuropsychiatric disorder without evidence of recent infection (often known as PANS); evidence of separation anxiety is a common finding; self-determined food restrictions are common ASO and anti-DNase B elevations are indicative of recent group A streptococci infection; ANA should be obtained if inflammatory markers are also elevated; if ANA is elevated, lupus also needs to be ruled out; obtain antiphospholipid antibody testing only in the presence of chorea, petechiae, migraines, stroke, clotting disorders or livedo rash; obtain ceruloplasmin and copper urine test if liver enzymes are also elevated
Treatments (combinations are typically used for optimal outcomes)	Notes
Methylprednisone 1000 mg once a day × 3 days (with slow taper of 60 mg by mouth twice a day × 4 weeks then a 10% reduction every 3 days) IVIg 1.5-2 g/kg Plasma exchange; 1.5 volume exchange for 3 consecutive days Therapeutic plasma apheresis Rituximab, 750 mg per IV infusion × 2, with the second dose to be given 2 weeks after the initial dose Mycophenolate mofetil, 15 mg once a day (can be used in conjunction with steroids to control symptoms) Risperidone, 0.25-4 mg oral Valproic acid, divalproex 100-500 mg, oral or injectable Antibiotics (often for several weeks at a time): cefadroxil, azithromycin, 250-500 mg once a day; amoxicillin, 500 mg twice a day; cefdinir, 14 mg/kg bid twice a day (600 mg max) oral Nonsteroidal anti-inflammatory drugs Cognitive behavioral therapy	Reduction of inflammatory process in brain; tapering may be challenging with return of symptom; a second round of high-dose steroids may be required if worsening symptoms return Risk of life-threatening hemolytic reactions Also known as plasmapheresis Shown to be more effective than IVIg in some studies; hypothesized to remove autoantibodies that may be contributing to symptoms Monoclonal antibody drug often used in the treatment of rheumatoid arthritis; common adverse effects include fever, rigors, and chills Immunosuppressant; can contribute to infections Atypical antipsychotic medication Useful for the treatment of patients with convulsions, migraines, and bipolar-type symptoms Used for prophylaxis of streptococcal infections; if the patient is able to swallow, oral routes are sufficient; may also consider treating family members prophylactically Risk for bleeding and gastric ulcers Used to address anxiety and mood disorders
<i>Note.</i> ANA = antinuclear antibody; anti-DNase B = antideoxyribonuclease B titers; ASO = antistreptolysin O; IV = intravenous; IVIg = intravenous gamma globulin; OCD = obsessive-compulsive disorder; PANS = Pediatric Acute-onset Neuropsychiatric Syndrome; PANDAS = Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections. *Treatments were reported in published case studies of patients with suspected PANS and/or PANDAS. This list is not exhaustive (see the reference list).	

serum biological marker to aid in the diagnosis has been identified (Vincenzi, O'Toole, & Lask, 2010). The presence of autoantibodies in children with suspected PANDAS is contested as a definitive diagnostic tool (Singer, Hong, Yoon & Williams, 2005). A combina-

tion of serologic markers such as erythrocyte sedimentation rate, C-reactive protein, and antineuronal antibodies are useful in identifying nonspecific inflammation and autoimmune reactions common to a variety of disorders. Throat swabs, antistreptococcal

antibodies, and antistreptolysin can be useful in determining if the child had a streptococcal infection but are not definitive for a PANDAS diagnosis (Vincenzi et al., 2010). Some authors have described very specific diagnostic criteria for PANDAS but argued that Lyme disease, OCD, Tourette's syndrome, and tic disorders can also present with similar diagnostic criteria, including streptococcal infections, thus leading to misdiagnosis (Mell, Davis, & Owens, 2005; Rhee & Cameron, 2012). However, recently, Murphy, Storch, Lewin, Edge, and Goodman (2012) presented findings suggesting that diagnostic criteria should include the following findings: dramatic onset, definite remissions, improvement of neuropsychiatric symptoms during antibiotic therapy, surgical history positive for tonsillectomy/adenoidectomy, evidence of group A streptococcal infection, and clumsiness when combined with a parent history of PANDAS-like symptoms. Perhaps additional studies and clinical practice will validate these findings.

Fortunately, work continues to be performed in this developing area. Recent authors (Chang et al., 2015; Van Mater, 2014) have studied this elusive phenomenon and suggested a diagnostic approach based on key distinguishing features to differentiate PANDAS from other disorders with similar presentations. Swedo and her team have also been studying the disorder for many years and recently proposed three specific diagnostic criteria for PANS based on identified behaviors (Swedo, Leckman & Rose, 2012). Additionally, a systematic strategy for evaluating suspected cases of PANS and PANDAS was recently developed at the PANS conference in May 2013 (Chang et al., 2015).

Uncertain Etiology

One factor that may be contributing to the uncertainty and variability in diagnosing the disorder is the lack of an evidence-based cause. Some investigators attribute the symptoms to an inflammatory demyelinating process and white matter abnormalities (Muir et al., 2013). Other investigators have hypothesized that autoantibodies may be causing the sudden and erratic symptoms and used various pathology tissue-staining methods to test their theories (Morris-Berry et al., 2013). However, the results of their study did not show any statistical differences in serum and tissue autoimmune biomarker levels between patients with PANDAS and the control groups. High antistreptolysin O and antidesoxyribonuclease B titers were found in children with suspected PANDAS in another study (Vitaliti et al., 2014), but the presence of these high titers is not yet considered a definitive diagnostic indicator of PANDAS. Regional inflammatory changes in the neurologic system, cortico-subcortical network dysfunction (Macerollo & Martino, 2013), genetic components, a family history of autoimmune disorders, inappropriate basal ganglia development (Ray et al., 2013), and envi-

ronmental and infectious triggers (Muir et al., 2013) have also been suggested as contributing to the onset of PANDAS-like symptoms (Esposito et al., 2014). Despite all of the proposed theories, consensus about why this devastating neuropsychiatric disorder develops in some children has yet to be achieved.

Lack of Evidence-Based Treatment Modalities

Treatment modalities are also debated in the literature, making therapeutic interventions equally as unclear as the diagnosis and cause. Some studies have suggested that antibiotic therapy is useful in the reduction of symptoms (Frankovich, Thienemann, Rana & Chang, 2015; Murphy, Parker-Athill, Lewin, Storch, & Mutch, 2015a; Vitaliti et al., 2014). Other investigators have reported that high-dose steroid (methylprednisone) therapy has been effective in ameliorating symptoms (Muir et al., 2013). Intravenous immunoglobulin therapy has been reported to be ineffective in treating tics (Hoekstra, Minderra, & Kallenberg, 2004) but effective in improving PANDAS symptoms (Kovacevic, Grant, & Swedo, 2015) and lowering immunoglobulin G levels (Ballow et al., 2003), which have been reported to be elevated in some cases of autoimmune disorders, including PANDAS (Ray et al., 2013). A recent study by Latimer, Etoile, Seidlitz, and Swedo (2015) demonstrated that therapeutic plasma apheresis is more effective than intravenous immunoglobulin in reducing PANDAS symptoms. Plasmapheresis, immunosuppressants, tetrabenazine (Xenazine), haloperidol (Haldol), clonidine (Catapres) and serotonin reuptake inhibitor antidepressants have also been used to treat PANDAS symptoms (Besiroglu et al., 2007; Das & Radhakrishnan, 2012). Nonetheless, there is still no consistent treatment regimen, and outcomes are varied. Most families have reported going to a variety of health care providers and trying various interventions in the hope of finding healing for their children. Some diagnostic and treatment modalities that have been reported in case studies are shown in Table 1.

The lack of diagnostic consensus, unknown cause, unproven treatment modalities, inconsistent interventions, and uncertain outcomes surrounding PANDAS have a significant impact on patients

The lack of diagnostic consensus, unknown cause, unproven treatment modalities, inconsistent interventions, and uncertain outcomes surrounding PANDAS have a significant impact on patients and families.

and families. Although much more research is needed to better understand all of the aforementioned aspects of PANDAS, a significant gap also remains with regard to how patients and families perceive the experience. No studies have been performed thus far to examine the emotional, relational, and social aspects associated with PANDAS. Advanced practice registered nurses (APRNs) and PNP in particular cannot ignore the human aspects of any disease, especially one with such devastating symptoms. Enhancing knowledge in the unknown areas of PANDAS will improve both the art and science of advanced nursing care for this vulnerable population.

METHOD

A qualitative method using narrative inquiry was used to study the problem. The objective of using narrative inquiry was to understand the experiences of living with suspected or confirmed PANDAS from the perspective of the children living with the disorder and their families. The primary purpose of narrative inquiry is to understand the meaning people give to life events and experiences (Howie, 2010). The thoughts, feelings, stories, and experiences told by the participants are considered to be valid and useful forms of knowledge (Fossey, Harvey, McDermott, & Davidson, 2002; Snelgrove, 2014). Interview questions were developed based on a review of PANDAS blog sites and parent support group narratives. Additionally, the interview questions were reviewed by a nurse researcher, a PANDAS expert, a mother of a child with PANDAS, and a sister of a sibling with PANDAS. The questions were initially pilot tested with one family affected by PANDAS. Revisions were made based on suggestions after the pilot test, and a final questionnaire was created. Questions were designed to help APRNs, PNPs, and other health care professionals better understand the PANDAS experience. Participants were encouraged to provide additional information, stories, thoughts, and feelings, which were included in the data analysis. After Institutional Review Board approval and receipt of signed informed consents (adult participants signed the consents for themselves and assents for any children interviewed), children with PANDAS and their families were interviewed regarding their experiences. Subjects were contacted by members of the research team using membership lists from the Association for Comprehensive Neurotherapy: Latitudes, PANDAS Network, PANDAS Resource Network, Saving Sammy, and Great Lakes PANDAS Support.

Interviews were conducted in person or over the phone. All interviews were audio recorded and then transcribed verbatim. In the majority of interviews, the primary caregiver (most often the mother) was the predominant interviewee, but participation by the entire family was encouraged when possible.

No children with PANDAS were interviewed apart from their parents, and in most cases, the children allowed the parents/caregivers to answer the questions. The children with the disease were often uncomfortable talking about their symptoms and unusual behaviors.

Participants

Sixty people participated in interviews for the study. Interviewed participants included and represented: 59 parents of a child with PANDAS, 1 grandparent whose granddaughter had the disease, 2 adults (ages 24 and 49 years) who reported they had the disease in their childhood, and 62 children diagnosed with PANDAS, totaling 124 people. The age range of the children was 5 to 18 years ($M = 10$). Length of time since diagnosis ranged from 10 months to 37 years ($M = 4.9$ years). Participants lived throughout the world, including the United States, Canada, and Australia. All participants spoke English as their primary language. All families (100%) contacted for possible inclusion in the study agreed to be interviewed. Many participants reported being grateful for the opportunity to discuss their experience with the medical community.

Data Analysis

The research team initially analyzed the data by reading, taking notes, re-reading, and identifying ideas and concepts from individual transcripts to maintain an inductive approach. Individual concepts were next compared with the entire data set to identify common meanings and themes. Research team members performed an independent analysis and then shared findings with the rest of the team, at which point comparisons of findings began. A paradigmatic analysis of the identified themes common throughout the narratives was then identified (Polkinghorne, 1995). Twenty-three (23) themes were initially identified by members of the research team. From these preliminary findings, nine broader themes emerged from the data. The research team continued to discuss their findings, revise, and re-examine each initial theme. The themes were linked to the actual transcribed data. Finally, when data saturation had been achieved and analysis was considered exhaustive, three final broadly encompassing themes were considered representative of the participants' meaning relating to their experience with PANDAS.

Experts who had personal experience living with PANDAS and were included on the research team verified and confirmed the identified themes. The primary investigator (PI) has extensive training, education, and experience with regard to conducting qualitative data analysis. The PI also holds a PhD with a minor in linguistics, lending credibility to the oversight of the language coding process. All other members on the research team involved in coding data were trained in the coding

process. Additionally, they all have a minimum of a bachelor's degree, have taken at least one research course, and have health care experience, further contributing to the credibility of the findings.

RESULTS

Fear, frustration, and not being heard were the three dominant themes that emerged from the data. The themes were extracted from the language and stories

of the participants. Excerpts of language used to develop the themes are shown in the [Box](#).

Theme 1: Fear

One of the most prominent themes that emerged from the data was the notion of fear. The children with PANDAS and their families described the onset and experience of symptoms as being very scary. Parents/grandparents were terrified at the behavioral,

BOX. Excerpts of language from participants leading to identified themes

Fear

- It's a nightmare.
- It was terrifying.
- I'm always so scared that the symptoms will return.
- It's so frightening when she gets like that.
- She gets scared when she knows the symptoms are starting again.
- I worry all the time.
- It's like a bad dream I can't wake up from.
- She ran at me with a knife; I feared for my life and our other kids.
- I was horrified when they tied him down in leather restraints and went in to see him and his wrists were all bloody.
- I was scared for me, our family, and her.
- The unknown is the worst.
- Sometimes he would scream, punch, slap, and try to hit me; it was so scary and I just didn't know what to do. I was afraid he would hurt his siblings too.
- It freaked all of us out.
- Not knowing what to do was so frightening. Was I doing the right thing or not? I never knew.
- My sweet little boy threw a chair right through the wall!

Frustration

- It was so annoying to have to keep going from one doctor to the next and nobody had any idea what was going on.
- I thought the doctors and nurses were supposed to know what to do and how to help; that is not what we experienced.
- It's so frustrating knowing something is very wrong with your kid and all the medical people kept telling me it was all in his head.
- Ugghh, I would get so angry and annoyed.
- The nurses in the emergency room were not helpful.
- It's irritating to be sitting there feeling judged by everyone, they [nurses] just thought we must be the worst parents.
- I've never been so frustrated in my whole life.
- Why don't they [medical people] know what to do?
- They [medical people] just kept telling us it was a psychiatric problem. I knew it wasn't but had to keep talking to the psychiatrists who didn't know anything either.
- It's such an aggravating place to be, especially when it's your kid.
- Putting him in the psych ward was just so frustrating. It wasn't a psych issue, he had an infection in his brain.

Not Being Heard

- I had to repeat the same story over and over again.
- I felt like a broken record.
- Nobody [medical people] seemed to hear what I was telling them.
- They [medical people] all had their own idea of what was happening.
- I just wanted someone to listen to me.
- I don't understand why I had to keep repeating the same thing over and over. Don't they write that stuff down somewhere, or isn't anyone else reading what was recorded?
- It was like no one wanted to take the time to hear our story.
- It was so frustrating that no one would listen.
- Hello! I keep telling you [medical people] the same thing; pay attention to what I'm saying.
- I wish they would just listen.
- If they [medical people] would take the time to hear what I was saying, he might have gotten appropriate care.
- Half of the time I just have to appease the docs and try something I know wasn't going to work just to get them to listen to what I was trying to tell them in the first place.

FIGURE. A previously healthy 15-year-old boy after hospitalization for exacerbation of Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS).



More than 500 restraints were applied throughout the course of this boy's hospitalization. The boy's parents stated that the restraints were applied as a result of inappropriate treatment of suspected PANDAS, leading to subsequent delayed healing and additional complications (foot drop and joint reformation). (The patient's bilateral ankle joints were without defects and no foot drop was noted prior to admission to the psychiatric unit). This figure appears in color online at www.jpedhc.org.

emotional, and intellectual changes evident in their children. Adult participants voiced the following causative factors contributing to fear: fear for the child's well-being, fear of harm/injury from the child during exacerbations, fear about needing to provide long-term care, fear that the child would not be able to function in society, fear of medical expenses, fear of disruption in family dynamics, fear of how they would be perceived by medical staff, fear of being judged by other parents, fear of not knowing when symptoms would return, fear that other illnesses (such as colds/flu) would lead to the onset of symptoms, and fear of not being able to provide the proper care.

The children who participated were significantly less likely to want to discuss their condition; however, the

children who did talk about their experience described having a premonition that the symptoms were returning, which brought a sense of fear and dread. Children described not being able to think as clearly, losing the ability to read and write, the development of heightened irrational behaviors, and knowing the return of PANDAS was imminent. They feared what their friends would think about their irrational behaviors, they feared losing the ability to attend school and other social events, they feared medical interventions, and they feared the loss of established friendships.

Theme 2: Frustration

Another dominant theme expressed by the participants was the concept of frustration. The participants reported being frustrated at the lack of knowledge about PANDAS. Additionally, participants expressed specifics relating to frustration with the medical community. Participants were frustrated that health care providers didn't have a consistent diagnosis, gave a variety of diagnoses each time the child was brought to a medical facility, didn't have accurate diagnostic procedures, hadn't heard about PANDAS, considered it a psychiatric condition, lacked education about the disorder, lacked resources to provide appropriate care, lacked compassion, considered the parents ineffective, and blamed the parents for child's behavior, and they were frustrated about the paucity of local health care providers skilled in providing necessary care for their children. Participants were especially frustrated that members of the health care community, to whom they were looking for help, were ill equipped to provide care. The participants all desired more education, knowledge, and an increased sense of urgency from the medical community relating to the care and treatment of persons with PANDAS.

Theme 3: Not Being Heard

The third dominant theme voiced by the participants was the notion that members of the health care community were not listening to what the parents or children were saying. Many participants reported that they had to continually repeat the scenarios they were experiencing at home. The participants stated that often their stories were met with a sense of disbelief by medical staff. When the parents would try to explain their child's behavior and symptoms, the health care providers appeared to not believe the story, attempted to attribute symptoms to another disorder, or made facial expressions suggesting a patronizing attitude. Some participants reported that emergency department (ED) health care providers were particularly ineffective at hearing what the parents were saying about their children. Some parents reported that providing home care during a PANDAS exacerbation was often easier and resulted in better outcomes than taking the child to the ED, where they "didn't know what to do" and "often made things worse." They also reported that

TABLE 2. PANDAS resources

Type	Name	Source
Blog	Bearing P.A.N.D.A.S	http://bearingpandas.wordpress.com/
Newsletter	P.A.N.D.A.S	http://pandasnetwork.org/
Web site	Association for Comprehensive Neuro Therapy: Latitudes	http://latitudes.org/
Web site	PANDAS Resource Network	http://www.pandasresourcenetwork.org/
Book	Saving Sammy	http://bethalisonmaloney.com/books/saving-sammy/
Facebook page	Great Lakes PANDAS Support	https://www.facebook.com/GreatLakesPANDAS
Autoimmune and infection expert	Madeleine W. Cunningham, PhD	http://www.oumedicine.com/mi/faculty/madeleine-w-cunningham-phd
Clinical laboratory	Moleculera Labs	http://www.moleculera.com/
News item	Kids catch OCD from form of strep	http://www.wmcactionnews5.com/story/22297818/kids-catch-ocd-from-form-of-strep
News story	Youthful victim of rare disease looks to spread word about PANS	http://warwickonline.com/stories/Youthful-victim-of-rare-disease-looks-to-spread-word-about-PANS,82326?category_id=4&town_id=1&sub_type=stories
Foundation/blog	PANDAS/PANS	http://www.pandasfoundation.org
Diagnostic tool for PNPs	PANS Symptom Scale	http://pandasnetwork.org/wp-content/uploads/2012/11/pandas_pans_scale.pdf

Note. OCD = obsessive-compulsive disorder; PANS = Pediatric Acute-onset Neuropsychiatric Syndrome; PANDAS = Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections.

many physicians did not want to listen to their story about their child's experience and often stopped the conversation to give their diagnosis and treatment (which were often inaccurate). Many families reported being referred to psychiatric facilities, where interventions such as heavy sedation and leather restraints were implemented. The results were not only ineffective but often caused harm (see the [Figure](#)).

The participants reported a sense of relief and hope when they encountered medical staff who were willing to hear their entire story, were not judgmental or condescending, and were not quick to impose an opinion. A network of families experiencing PANDAS formed in 2009 and have found great comfort and support in being able to share and understand similar stories (see [Table 2](#)).

DISCUSSION

Despite a lack of consensus surrounding PANDAS, children and their families are experiencing very real, frightening, and frustrating symptoms that require medical and nursing care. PNPs must become aware of this new disorder and learn the signs, symptoms, and current options for treatments. Pediatric nurses, ED nurses, and APRNs working in both pediatric care and ED settings are especially responsible for learning about PANDAS and its impact on children and their families, because they are most likely to be the first health care providers to assess this population. Additionally, the results of this study serve as a reminder to all nurses that behind the mysteries and uncertainties of medicine are humans who are scared, frustrated, and need the support, knowledge, and care of a nurse. PNPs need to bridge the gap between developing research and waiting for evidence-based interventions and

providing care for people desperate for answers. Sometimes when evidence-based practice is not yet established, as is the case with PANDAS, PNPs must still provide care inclusive of therapeutic communication, empathy, excellent listening skills, compassion, understanding, and comfort.

As a starting point, PNPs should prescribe care based on the evidence found in this study. For example, the identified theme of fear could be addressed based on evidence from other studies also addressing the phenomenon of fear. [Carneval and Gaudreault \(2013\)](#) found that worry about the unknown, medical procedures, unfamiliar hospital personnel, and physical symptoms all contributed to a sense of fear in sick children. Strategies that include allowing/encouraging the presence of parents, visitors, and friends; kindness from nurses and staff; allowing the child to have an item from home (such as a blanket or stuffed animal); providing various forms of entertainment; providing play time away from the hospital room; and providing gifts all contributed to increased comfort and reduction in anxiety and fear for ill children. Another study examining anxiety in mothers of sick children found that uncertainty, increased frequency of exacerbation of symptoms, and insufficient information about the disorder lead to statistically significant higher levels of fear and anxiety for parents. Interestingly, these investigators too found that the theme of uncertainty was the dominant contributing factor to increased fear and anxiety ([Ju et al., 2011](#)). A simple but often overlooked nursing intervention to ameliorate fear of the unknown is to offer education to the patients and their families. PNPs should practice and teach nurses the art of education by explaining pending procedures, explaining the pathophysiology behind the symptoms, describing symptoms and relating them to the disorder, and taking

the time to talk with parents, answering their questions surrounding the experience of illness. These types of nursing interventions should be further studied to determine their effectiveness in the PANDAS population.

Although less studied, the identified theme of frustration has also been noted in other nursing research. Frustration often resulted from physical and financial consequences related to the chronic illness, communication with community agencies, bureaucracy delays, and human error (Scharer et al., 2009). In a mixed-methods approach, Scharer and colleagues (2009) found evidence suggesting that nurse interventions aimed at providing emotional, informational, and appraisal support for mothers of children with serious mental illnesses noted a reduction in frustration. Their evidence demonstrated that provision of such support using the telephone and Web-based approaches was effective. As technology advances, nursing interventions aimed at reducing frustration within the PANDAS population could also be implemented using telephone, Internet, and Web-based support.

Finally, a narrative literature review conducted by Crawford, Brown, Kvangarsnes, and Gilbert (2014) suggested that improved communication between health care providers and patients leads to an enhanced perception of compassion in health care. The simple strategy of listening and hearing the stories of patients and their families is one way PNP's can show compassion and could help reduce the sense of not being heard. A reduction in the sense of not being heard could then yield an improved sense of compassion and caring, which ultimately leads to an improved sense of well-being. However, Crawford and colleagues (2014) also found that despite the intervention of compassion by individual nurses, institutional and organizational barriers may exist to threaten the delivery of compassionate care. The tension between inadequate corporate strategies to promote compassion and PNP's' desire to deliver it must be ameliorated if the sense of not being heard is to be overcome. More work needs to be done to develop effective nursing and organizational strategies to improve ways to hear what patients are saying, thus showing compassion to vulnerable population groups.

Implications for Nursing Education

The results of this study have significant implications for nursing education. PNP programs need to include the new and growing disorder of PANDAS into their curriculums so new PNP's will recognize it, diagnose it, and appropriately treat the condition in their practices. Nurse educators need to teach all APRN and nursing students about the complex of autoimmune neuropsychiatric disorders to increase the likelihood of proper treatment, early and accurate diagnosis, and appropriate referrals. Information about this developing disorder needs to be included in nursing textbooks

and nursing curriculums and disseminated throughout the nursing community.

Additionally, more emphasis needs to be placed on teaching and practicing the art of nursing. APRN's, PNP's, and nurses need to be taught how to provide nursing care in the absence of evidence-based practice. New disorders will continue to be discovered. As research is conducted to understand the newly identified disorder, there will be a period of uncertainty and trials before evidence-based practices are established. During these times nurses and nurse practitioners should be standing in the gap to provide support and care to the people experiencing such disorders.

Nurse educators need to teach all APRN and nursing students about the complex of autoimmune neuropsychiatric disorders to increase the likelihood of proper treatment, early and accurate diagnosis, and appropriate referrals.

Implications for Nursing Practice

Table 1 lists some current diagnostic and treatment practices that PNP's and APRN's can implement when assessing a patient who is suspected to have PANDAS. In addition, the results of this study should remind PNP's to always listen to patients and their families without imposing judgment or preconceived notions. PNP's should encourage bedside nurses and nurses in management positions to be proactive in working with hospital and clinic administration to develop organizational strategies designed to improve compassionate nursing care. All patients and their families deserve compassion, understanding, patience, and care from nurses. A similar analogy occurred with autism several years ago. Parents began describing symptoms in their children before the medical community fully understood the disorder. Similar expressions of frustration, fear, and lack of understanding were reported within the autism population. Initial skepticism and misdiagnoses were ultimately replaced with increased awareness, research, diagnostic methods, established treatment methods, and enhanced understanding of the rising disorder. A similar phenomenon may be occurring in the PANDAS population. PNP's must practice empathy and understanding even though specifics of the disorder are not fully known.

Implications for Nursing Research

There is a significant paucity of nursing research relating to PANDAS. While our medical colleagues are

researching effective diagnostic methods and treatment modalities, nursing researchers need to contribute to what is known about the disease and study effective advanced practice nursing interventions. It is imperative to understand how this disorder affects children socially, emotionally, intellectually, and spiritually. Not enough is known about how the disorder affects children without PANDAS who are living in the same household with a sibling who has PANDAS. Parents' stress, the financial impact on the family, the effect on marriage relationships, the ability to work or keep a job, the physical impact, and a plethora of human conditions could and should be studied from a nursing perspective for this little-known population group.

CONCLUSION

Very little is known about the etiology, diagnostic methods, treatment modalities, or long-term effects of PANDAS. However, while this disorder is being studied and better understood, hundreds of children and families are experiencing its devastating effects. It is well within the scope of advanced practice nursing to provide care and empathy to families facing frustration, fear, and anxiety from disease and illness even in the absence of evidence on which to base interventions. PNPs must become aware of the signs and symptoms of PANDAS, assist our medical colleagues in understanding more about this disorder, and reach out to the children and families experiencing the nightmare of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections.

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