



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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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.

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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

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