FAMILY IMPACTS REPORTED BY PARENTS RAISING CHILDREN WITH PEDIATRIC ACUTE-ONSET NEUROPSYCHIATRIC SYNDROME (PANS)

A DISSERTATION

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To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Marcey Mettica entitled "Family Impacts Reported by Parents Raising Children with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS)." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctorate with a major in Family Studies.

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Accepted:

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DEDICATION

To my wonderful husband Don for your ongoing support throughout this long process. I will finally get out of my office on the weekends and give you some attention!

To my three amazing children—Jordan, Austin, and Tyler. I am so proud and blessed to be your mom. Thank you for your encouragement. I love you all more than you know!

Thank you to my parents for your loving support and always believing in me!

I thank God every day for blessing me with such a marvelous family and for enabling me to complete this process!

To a special young lady, Kayla, and her parents for their unwavering bravery and dedication in their fierce battle with PANDAS. You were my first exposure to this illness and my inspiration for this project. To all the children and families struggling with PANS and associated illnesses – I pray for better answers and more effective treatment.

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ABSTRACT

MARCEY L. METTICA

FAMILY IMPACTS REPORTED BY PARENTS RAISING CHILDREN WITH PEDIATRIC ACUTE-ONSET NEUROPSYCHIATRIC SYNDROME (PANS)

APRIL 2018

The purpose of this online quantitative study was to explore the impact to families when raising a child diagnosed with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS), including the subsets of Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal (PANDAS), and Pediatric Infection Triggered Autoimmune Neuropsychiatric Disorder (PITAND) and what variables may mitigate the impact. The demographic variables examined in this study included relationship status of the person completing the survey, parent and child age, parent and child ethnicity, parent level of education, parent relationship status, and household income. Illness factor variables included the diagnosis, date of onset of symptoms, date of diagnosis, history of family autoimmune disorders, restricted food intake, who first suspected PANS, who diagnosed PANS, number of professionals seen before diagnosis, who and how child is currently being or has ever been treated, and if travel over 50 miles is or was necessary for treatment. Obsessive-Compulsive Disorder (OCD) symptom severity was measured with the Children's Yale-Brown Obsessive-Compulsive Scale – Parent Report (CY-BOCS-PR). Total impact on the family was measured with the Impact on Family Scale (IOFS) (Stein & Jessop, 2003). Parents were recruited through PANDASNetwork.org

and were asked to complete the online survey which included the demographic and illness questions, the CY-BOCS-PR, and the IOFS assessment.

This study examined the differences between demographic variables, symptom severity, and duration between onset of symptoms and diagnosis and their impact on the family's total score on the IOFS tool using three research questions. Subscales from the IOFS assessment were also analyzed. Statistical comparisons were completed to analyze what influence different variables had on the total impact on the family and the IOFS subscales. Significant relationships were found to exist between parent's relationship status and OCD symptom severity when compared to the total impact on the family. No significant relationship was found for duration between onset of symptoms and diagnosis and the total IOFS score but significance was found on the financial and parental strain subscales of the IOFS. OCD symptom severity appeared to have the most profound impact on the family as significant relationships were found on the total impact on the family scores as well as the financial, parental strain, and disruption of social and family relationships subscales.

A primary goal derived from the findings of this study aims to help parents and children gain understanding from the professionals who treat and work with those diagnosed with PANS. Although this illness remains controversial and it is still unknown why this devastating disorder develops in some children, it is known that many children and families are affected and are frantically seeking answers. It is hoped that a greater sense of urgency for more research will be roused by this investigation.

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CHAPTER I

INTRODUCTION

An estimated 10% of children in the United States suffer from a serious mental or developmental impairment (Oruche, Gerkensmeyer, Stephan, Wheeler, & Hanna, 2012). According to the Centers for Disease Control and Prevention (CDC), some estimated 12-13% of children in the United States will suffer from a mental illness and the World Health Organization reports that one out of four youth will be diagnosed with a mental health condition before 18 years of age (Perou et al., 2013). Mental illness can have significant negative effects on a child's cognitive, social, and emotional development and can cause serious ramifications for their families (Perou et al., 2013). The CDC reports that mental health disorders are the costliest conditions to treat and the national economic impact of children with mental illness in the United States averages over $247 billion annually (Perou et al., 2013). Research shows that raising a child with mental health care needs greatly affects a family's economic stability, reduces available resources for siblings, and increases the likelihood of employment disruptions for caregivers (Busch & Barry, 2007).

A common mental health condition in children is pediatric Obsessive-Compulsive Disorder (OCD), affecting an estimated one in one-hundred children or an estimated 3% of the youth population (International Obsessive-Compulsive Foundation [IOCDF], n.d.; Storch et al., 2009). Many of these children are at an increased risk of developing additional psychiatric disorders and will have more than one mental health diagnosis at

one time, which is referred to as a dual diagnosis or comorbidity (Storch et al., 2009). For these children, the comorbid diagnosis is most commonly associated with the neurodevelopmental tic disorder known as Tourette syndrome (Stewart, Greene, Lessov-Schlaggar, Church, & Schlaggar, 2015). In spite of these comorbid mental disorders, Oruche et al. (2012) found that 75% of children with a diagnosable disorder do not receive appropriate treatment.

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) is a subset of pediatric OCD accompanied by a sudden and acute onset of additional neuropsychiatric symptoms (Murphy, Gerardi, & Parker-Athill, 2014). Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal (PANDAS) is an acronym used to designate children with OCD and tic disorders whose symptoms appear to be triggered by streptococcal infections (Swedo & Grant, 2005). Allen, Leonard, and Swedo (1995) first explored the link between streptococcal and OCD after identifying the first 50 suspected cases in young children. In 2012, experts from the National Institute of Mental Health (NIMH) determined that PANDAS was a subset of PANS, which is a broader category and includes similar neuropsychiatric symptoms but may be the result of a bacterial, viral, environmental, or immune dysfunction and not specifically related to streptococcus (NIMH, 2012; Swedo, Leckman, & Rose, 2012). Furthermore, researchers have investigated the similarities and links between infections that lead to autoimmune disorders that may result in other conditions such as Sydenham's chorea (i.e., movement disorder after rheumatic fever), Tourette syndrome (i.e., involuntary tics and

vocalizations), PANS, Attention Deficit Hyperactivity Disorder (ADHD), and autism spectrum disorder (ASD) (Swedo & Grant, 2005).

PANS is a sudden and acute onset of neuropsychiatric symptoms triggered by an infection, environment, or genetic predisposition (NIMH, 2012). Additional diagnostic criteria are: (a) sudden onset of OCD or restricted eating; (b) two or more neuropsychiatric symptoms; and (c) not otherwise better explained by another neurological or medical condition (Swedo et al., 2012). The National Institute of Mental Health (NIMH) currently defines PANDAS with five criteria: (a) abrupt and significant onset of OCD and/or tics; (b) other neuropsychiatric symptoms; (c) prepubertal onset; (d) association with streptococcal infection; and (e) symptoms follow relapsing-remitting course (NIMH, 2012). As more has been learned about the clinical characteristics of the PANDAS subgroup, additional neuropsychiatric criteria have emerged and include emotional instability, separation anxiety, anorexia, impulsivity, distractibility, ADHD, oppositional defiant disorder (ODD), major depressive disorder (MDD), urinary urgency, deterioration in handwriting, and a decline in school performance (Bernstein, Victor, Pipal, & Williams, 2010; Swedo & Grant, 2005). Children with PANDAS, versus children diagnosed with OCD, have an acute and dramatic onset of symptoms including new dramatic fears, obsessions, and compulsions rather than experiencing a gradual and progressive onset typical of childhood OCD (de Oliveira & Pelajo, 2010).

Statement of the Problem

Approximately one in five children will be diagnosed with a mental health disorder at some point during their youth (Mendenhall, Frauenholtz, & Conrad-Hiebner, 2014). Caring for children with a mental health disorder can result in serious impacts to the family system. Busch and Barry (2007) reported that caring for a child with mental health needs creates significantly more financial burden on families than caring for a child with a physical chronic illness because parents spend more time arranging for mental health care services and often need to reduce their time at work.

The symptomology of PANS/PANDAS appears to be only a mental condition and is often misdiagnosed and mistreated as anxiety, ADHD, OCD or a combination of such (Murphy et al., 2014). The symptoms are often severe and the onset sudden; turning a happy and healthy child into a behavioral and emotional mystery seemingly overnight (Matheos & DeMare, 2013). Clinicians have difficulty in distinguishing PANS/PANDAS from OCD or other mental conditions, making it problematic for parents to get a correct and timely diagnosis and pediatricians to recognize and treat the illness (Murphy, Storch, Lewin, Edge, & Goodman, 2012). Since it is often difficult for parents to get confirmation of the illness, they spend considerable time, money, and energy, and experience significant fear of being misled, misdiagnosed, and misunderstood as they try to help their child (Singer, Gilbert, Wolf, Mink, & Kurlan, 2012).

Parents of children with mental health issues struggle daily to obtain treatment, understanding, and support and are often in a state of survival as they deal with constant

family turmoil, financial difficulties, judgment, and insufficient care (Vitanza, Cohen, & Hall, 1999). The negative impacts to the family system of children with PANS/PANDAS may be greater than families of children with other disabilities because of the delay in diagnosis and treatment. The added financial burden, time, and personal pressure on families can increase stress, which may lead to relational difficulties, fatigue, work absences, and physical health problems (Vitanza et al., 1999). In addition, high levels of parental stress can cause serious problems for the family system, including increased behavior problems in children, increased physical and emotional ailments in parents, and social isolation (Morris, 2014). Parents of children with PANS/PANDAS have reported significant fear, frustration, and not feeling heard or understood by medical professionals as they sought treatment for their child (McClelland et al., 2015).

Purpose of the Study

There is little research on how raising a child diagnosed with PANS/PANDAS impacts parents and the family system. The purpose of this quantitative study was to explore the impact on the family system, as reported by parents raising a child with PANS/PANDAS, and what variables may mitigate the impact. This investigation was needed because while it is known that raising a child with a mental illness has serious ramifications on the family system, there is a gap in the research in understanding the impact on the family when raising a child with PANS/PANDAS.

Need and Rationale

With an estimated 10% to 13% of American children diagnosed with a mental health condition, pediatric mental disorders appear to be a frequent occurrence in childhood (Perou et al., 2013). Oftentimes parents are left in an uncertain situation about how their child's syndrome will advance and how their family will be impacted (Berge & Holm, 2007). Research indicates that parents of children with mental health disorders are encumbered with financial strain, parental distress, social isolation, and family discord (Algood, Harris, & Hong, 2013; Berge & Holm, 2007; Busch & Barry, 2007; Stewart et al., 2015; Storch et al., 2009). Raising children diagnosed with PANS/PANDAS may be quite stressful on families due to the controversy about the diagnosis, disagreements within the medical profession about the etiology of the illness, lack of knowledge and experience in the medical profession about treatment protocols, and lack of support for parents (McClelland et al., 2015). To date, research has focused primarily on the etiology, diagnostic criteria, and treatment protocols for the illness.

The severity and sudden onset of what appears to be a mental illness and not an infectious disorder, as well as the difficulty of finding a doctor that can quickly diagnose and treat the disorder, can have devastating effects on the families afflicted (McClelland et al., 2015). This investigation was needed to increase awareness for mental health professionals, family life educators and those in the medical community treating children and supporting families to better understand the necessity for faster and accurate diagnosis and treatment, which may help reduce trauma to the family system.

Description of the Study

This quantitative research study used purposive sampling of parents or guardians that are raising a child diagnosed with PANS/PANDAS between the ages of 4 and 17. Participants were recruited through the PANDASNetwork.org website. This website provides current research information about PANS/PANDAS and offers guidance and support for parents. This research study used a link from the PANDASNetwork website to PsychData to administer a survey to capture demographic information, obtain data about the child's illness, OCD symptom severity, and impact on the family using the Impact on Family Scale (IOFS) (Stein & Jessup, 2003). Detailed descriptions of the variables to be collected are provided in chapter three.

Research Questions

The research questions guiding this quantitative study are:

- Are there differences in the level of family impact, as measured by the IOFS, when raising a child with PANS when compared with parent's relationship status, parents' education level, and household income within the group of participants?
- Are there differences in level of family impact, as measured by the IOFS when raising a child with PANS, when compared by OCD symptom severity as measured by the Children's Yale-Brown Obsessive-Compulsive Scale – Parent CY-BOCS-PR)?
- Are there differences between the levels of family impact, as measured by the IOFS when raising a child with PANS, when compared with the length of time in

months from onset of symptoms to diagnosis?

Hypotheses

The researcher's hypothesis is that the impact on the family will be significantly greater as symptom severity and length of time from onset of symptoms until diagnosis increases. Further, it is hypothesized that the impact on the family will be greater when a parent is single and has lower educational attainment and income.

Expected Outcome and Goals

The expected outcome of the study is to examine relationships between variables (i.e., duration between onset of symptoms and diagnosis and family demographics) and the total score on the IOFS. The goal of the study is to increase awareness about how various factors impact the family system to help mental health professionals, family life educators, and medical professionals gain insight and become better equipped to support families affected by PANS.

Theoretical Framework

Family systems theory and family stress theory were the theoretical lenses used to conceptualize this research study, capitalizing on their usefulness for understanding the impact a serious illness may have on the family and the internal and external interactions that may mitigate the impacts to the family system (Bowen, 1966; Hill, 1958).

Family Systems Theory

Family systems theory views the family as a system with interdependent parts comprised of the members of the family, their relationships with each other, and their

interactions within and outside the family unit, which requires they be analyzed and understood as a whole or system (Whitchurch & Constantine, 1993). In family systems theory, a change in one member of the family impacts the other members of the family both individually and collectively. Family systems theory assumes that all members of the family affect all other members of the family and those effects have reciprocal impacts on other members of the family (Bowen, 1966). Evidence is compelling that PANS/PANDAS creates substantial impairment in both the child and the family's functioning (Calaprice, Tona, Parker-Athill & Murphy, 2017; McClelland et al., 2015; Swedo et al., 2012; Witt, Gottlieb, Hamptom, & Litzelman, 2009). PANS/PANDAS is an illness that not only negatively impacts the child but also siblings and parents as they adjust to the demands of the disorder. A family systems lens encourages the approach of looking at all areas of family impact.

Family Stress Theory

In addition to a family systems framework, Ruben Hill's ABCX model of family coping has shown to be useful in exploring parenting stress and coping practices (Hill, 1958). There are three interactive variables represented by the first three letters of the model. The variables include: (A) stressor event, (B) family resources, and (C) meanings and perceptions assigned. How these variables interact predicts the family's response to the stressful event, represented by the letter X. According to Hill's model, the A factor, or stressful event may have sufficient consequences to alter the family system depending upon if the family has enough resources to handle the event and how much of a crisis the

event is perceived to be (Hill, 1958). Hill's ABC-X model of family stress has shown to be useful in exploring parenting stress, coping practices, and family impacts particularly with regard to raising a child with a mental health disability (Calaprice et al., 2017; McClelland et al., 2015; Swedo et al., 2012). This model can also be useful for understanding how families adjust to a PANS/PANDAS diagnosis over time (Kazak, 1989).

Definitions

- *Anxiety Disorder.* The DSM-V definition is: "Anxiety disorders include disorders that share features of excessive fear and anxiety and related behavioral disturbances. *Fear* is the emotional response to real or perceived imminent threat, whereas *anxiety* is anticipation of future threat. Obviously, these two states overlap, but they also differ, with fear more often associated with surges of autonomic arousal necessary for fight or flight, thoughts of immediate danger, and escape behaviors, and anxiety more often associated with muscle tension and vigilance in preparation for future danger and cautious or avoidant behaviors. Sometimes the level of fear or anxiety is reduced by pervasive avoidance behaviors" (APA, 2013, p. 189).
- *Attention Deficit Hyperactivity Disorder (ADHD).* The DSM-V defines ADHD as "a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development" (APA, 2013, p. 61). In addition, ADHD has symptoms presenting in two or more settings (e.g. at home, school, or work; with

friends or relatives; in other activities), and negatively impacts directly on social, academic or occupational functioning. Several symptoms must have been present before age 12 years (APA, 2013).

- *Family impact*. Family impact is defined by the five subscales on the Impact on Family Scale (IOFS) and the total score on the IOFS (Stein & Jessop, 2003). The five subscales are financial impact, familial-social impact, parental strain/distress, parental coping, and sibling impact. The total family impact is calculated from combining 19 variables' scores from the IOFS.
- *Neuropsychiatric Symptoms.* Additional symptoms seen in PANS/PANDAS include ADHD, severe separation anxiety, generalized anxiety, emotional labiality, depression, irritability, aggression and/or severely oppositional behaviors, irritability, developmental regression, deterioration in school performance, deterioration in handwriting, sensory or motor abnormalities, sleep disturbances, restricted food intake, and urination urgency (NIMH, n.d.).
- *Obsessive-Compulsive Disorder (OCD).* The DSM-V definition is: "OCD is characterized by the presence of obsessions and/or compulsions. Obsessions are recurrent and persistent thoughts, urges, or images that are experienced as intrusive and unwanted, whereas compulsions are repetitive behaviors or mental acts that an individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly" (APA, 2013, p. 235).

- *Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infection (PANDAS).* "PANDAS is characterized as a sudden, acute onset in multiple neuropsychiatric domains and the trigger is a misdirected autoimmune response to streptococcus. PANDAS is defined by five criteria: (a) abrupt, significant onset of OCD and/or tics; (b) other neuropsychiatric symptoms; (c) pre-pubertal onset (vast majority of children are between four and twelve years old); (d) associated with a streptococcal infection; and (e) symptoms follow relapsing-remitting course" (NIMH, n.d., p. 3).
- *Pediatric Acute-onset Neuropsychiatric Syndrome (PANS).* "PANS is characterized as an abrupt, dramatic onset of OCD, including severely restricted food intake, the concurrent presence of additional neuropsychiatric symptoms, with similarly severe and acute onset, from at least two of the following seven categories—(1) anxiety; (2) emotional lability and/or depression; (3) irritability, aggression, and/or severely oppositional behaviors; (4) behavioral or developmental regression; (5) deterioration in school performance; (6) sensory or motor abnormalities; and (7) somatic signs and symptoms including sleep disturbances, bedwetting or urinary frequency. In addition, the symptoms are not better explained by another known neurologic or medical disorder, such as Sydenham chorea, systemic lupus erythematosus, Tourette disorder or others" (NIMH, n.d., p.4).

- *Parent or Guardian.* For this study, parent or guardian is defined as a biological parent, adoptive parent, step-parent, or legal guardian of a child who was diagnosed with PANS/PANDAS when the child was between four and 17 years of age, and that parent or guardian has been a primary caregiver of said child for a minimum of the past six months.
- *Parenting.* For this study, parenting is defined as being the primary caregiver of a child diagnosed with PANS/PANDAS for a minimum of six months after diagnosis. Being a primary caregiver includes providing for the child's physical, social, emotional, and intellectual needs.
- *Tic Disorders.* "A tic is a sudden, rapid, recurrent, nonrhythmic motor movement or vocalization. Tic disorders comprise four diagnostic categories: Tourette's disorder, persistent (chronic) motor or vocal tic disorder, provisional tic disorder, and the other specified and unspecified tic disorders" (APA, 2013, p. 81).
- *Tourette's syndrome/disorder.* "Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently. The tics may wax and wane in frequency but have persisted for more than one year since first tic onset. Onset is before age 18 years. The disturbance is not attributable to the physiological effects of a substance (e.g. cocaine) or another medical condition (e.g. Huntington's disease or post viral encephalitis)" (APA, 2013, p. 81).

Assumptions

The following assumptions were made for this study:

1. Participants in the study will have access to the Internet and the PANDASNetwork.org website with sufficient computer literacy to be able to complete the study.
2. Participants will answer the questions honestly regarding their experiences of parenting a child diagnosed with PANS/PANDAS.
3. Participants completing the study are a parent or guardian of a child that was diagnosed with PANS/PANDAS between the ages of four and 17 by a qualified medical professional.
4. Participants will complete the study in its entirety.
5. Participants will be able to read English and have sufficient comprehension to understand the questions being asked.

Delimitations

The sample is limited to parents or guardians, recruited through the PANDAS Network website, with a child diagnosed with PANS/PANDAS as defined by the NIMH diagnostic criteria, which has demonstrated obsessive-compulsive symptoms during their illness. This study is further delimited by the three research questions.

Ethical Considerations

This study adhered to the ethical requirements of the Institutional Review Board (IRB) for the protection of the confidentiality of the participants and

minimization of any risks. In addition, it adhered to the ethical considerations of the NIMH Collaborative Institutional Training Initiative (CITI) guidelines for the protection of human subjects. Participants were informed of the risks of participation in the study and advised that they could withdraw their participation at any time without penalty. This online survey was anonymous, and a participant's completion of the survey constituted his/her consent to partake in this study. IRB approval can be found in Appendix G.

Summary

An estimated 10 – 13% of children in the United States suffer from a mental illness (Oruche et al., 2012; Perou et al., 2013). A predominant childhood mental disorder is OCD of which PANS/PANDAS is a subset that appears to be triggered by an infection resulting in an autoimmune response causing psychiatric symptoms (Storch et al, 2009; Swedo et al., 2012). Because of the continued controversy in the medical community regarding the etiology and treatment of PANS/PANDAS, parents often find it difficult to obtain a timely accurate diagnosis and treatment for their children because they are often diagnosed with a mental illness and the infectious trigger is left untreated (Murphy et al., 2014). Parents are often left on their own searching for answers on how to best help their child and feel frustrated, blamed, and isolated during this process (McClelland et al., 2015). Families raising children with a mental illness suffer significant financial burdens, employment disruptions, fatigue, social isolation, and physical health problems (Busch & Barry, 2007; Vitanza et al.,

1999). Families raising children with PANS/PANDAS likely suffer similar ramifications but the negative impacts may be greater because of delays in diagnosis and treatment. This quantitative study may contribute to the gap in research and explore the family impacts of raising a child with PANS/PANDAS.

CHAPTER II

REVIEW OF LITERATURE

Youth Mental Health, PANS, and Family Impacts

Youth mental health disorders not only have an impact on the child but are also known to have a negative impact on parents and an even greater impact on the family (Richardson, Cobham, McDermott, & Murray, 2013; Stewart et al., 2015). Research suggested the severity and duration of a child's mental disorder is strongly associated with increased parental stress as well as relational problems within the family, peer groups, and school settings (Busch & Barry, 2007). More specifically, parent-related issues such as economic instability, isolation, and low family functioning are common challenges parents face when raising a child with a mental health disorder (Busch & Barry, 2007; McClelland et al., 2015; Richardson et al., 2013). While most mental health issues manifest gradually, PANS/PANDAS is characterized by the sudden and severe onset of OCD and other neuropsychiatric symptoms after an infection (Swedo et al., 2012). Parents who have a child diagnosed with PANS/PANDAS may experience significantly more stress and parenting challenges due to the difficulty families have in getting an accurate diagnosis, the severity of the symptoms, and delays in treatment. The literature review will explore current research on youth mental illness including those most common in comorbidity with PANS/PANDAS—ADHD, OCD, and tic disorders. Additionally, research on the PANS/PANDAS diagnostic criteria, treatment, and the impact to families will also be explored.

Youth Mental Health

An estimated 10 to 25 percent of American children, between the ages of 4 and 17, are diagnosed with a mental health condition (Berge & Holm, 2007). Pediatric mental disorders appear to be a strikingly frequent occurrence in childhood and oftentimes parents are left in an ambiguous situation about how their child's illness will progress and what the future may hold for their family (CDC, 2015; Oruche et al., 2012; Perou et al., 2013). Richardson et al. (2013) estimated that pediatric mental disorders occur in as many as one in every four children in the United States and can include potentially dangerous behaviors, mood disturbances, and significant deficits in social, cognitive and behavioral functioning. According to the U.S. Department of Health and Human Services [U.S. DHHS] (2007), 21.8% of American households have at least one child with a special mental health care need. Children aged 12 to 17 years old are those with the highest prevalence (18.8%), compared to children 6 to 11 years of age (16%) and children birth to age five (8.8%). In terms of gender, young boys are more likely to have a mental health condition (16.7%) compared to young girls (11.6%). With regard to race and ethnicity, multiracial children have the highest prevalence rates (18%). These children and adolescents experience a wide range of physical, emotional, and behavioral health conditions (U.S. DHHS, 2007).

Researchers from the Center for Disease Control and Prevention (CDC) consider mental health disorders as chronic conditions that may continue to impact an individual throughout their lifespan (Perou et al., 2013). Millions of American children live with

mental illnesses including ADHD, anxiety, ASD, depression, OCD, and TS (CDC, 2015). An overwhelming majority of children with these types of neurodevelopmental disorders have at least one, if not several, comorbid diagnoses. It is estimated that 40% of children have at least two mental disorders simultaneously with the most common being ADHD, depression, bipolar disorder, anxiety disorders, ASD, tic disorder, impulse-control disorders, and OCD (Perou et al., 2013).

Pediatric Obsessive-Compulsive Disorder (OCD). Pediatric OCD involves intrusive thoughts, anxiety about places or things, and repetitive behaviors, rituals or reassurance-seeking behaviors (Merlo & Storch, 2006). According to Storch et al. (2009) an estimated 3% of children under the age of seventeen are diagnosed with pediatric OCD and are at a high risk of developing additional psychiatric disorders before adulthood. If not properly treated, pediatric OCD can become a chronic and debilitating problem in adulthood (Storch et al., 2009). Douglass, Moffitt, Dar, McGee, and Silva (1995) agreed that pediatric OCD affects as many as 3% of children and if not properly treated increases the risk of developing additional psychiatric disorders before adulthood. Merlo and Storch (2006) reported that for as many as 80% of cases, OCD originates in childhood. Storch et al. (2009) concurred that pediatric OCD is considered a mental health condition that not only impairs the child, but also their family. OCD can become chronic and result in significant negative ramifications in academia, employment, social, and family functioning (Merlo & Storch, 2006). Common comorbid disorders with pediatric OCD include ADHD (34%-51%) and tic disorders (20%-80%) (Geller, 2006).

When the onset of OCD is before ten years of age, there is a higher rate of comorbidity of tics, a longer duration of OCD, and greater parental psychosocial challenges (Nakatani et al., 2011).

Children with OCD often demand family accommodations to facilitate their compulsions and ritualistic routines (Futh, Simonds, & Micali, 2012). Merlo and Storch (2006) reported that children often become very demanding of family members to participate in their OCD rituals and react strongly if not accommodated. Family accommodation may include providing the child reassurance, completing tasks for them, decreasing expectations for the child, yielding to a child's unreasonable requests, and repeatedly answering questions (Caporino et al., 2012). Many parents reported that their children imposed rules on others, demanded ritualized contact, forbid certain sounds or objects in his/her vicinity, and reacted with rage or violence when these demands were not met (Lebowitz, Omer, & Leckman, 2011). Children with OCD typically have more oppositional behaviors, inattention, and greater dysregulation of emotions than children with other types of anxiety disorders (Jacob, Morelen, Suveg, Brown-Jacobsen, & Whiteside, 2012). The unpleasant and unwanted behaviors of OCD often create disruptions within the family system and create parent/caregiver burdens of reduced quality of life, increased work absenteeism, additional financial burdens, and limited leisure time which may lead to relational difficulties, fatigue, and physical or mental health problems (Möller-Leimkühler, & Wiesheu, 2012; Vitanza et al., 1999).

Tic disorders. Tics are repetitive, rapid, and non-rhythmic movements, sounds, or vocalizations that occur in approximately 20% of children (McBride & Victorio, 2017). There are three categories of tic disorders included in the DSM-5: Tourette syndrome (TS), chronic vocal or motor tic disorder, and provisional tic disorder. The diagnosis depends on the type of tic and how long it has persisted (APA, 2013). Although the etiology of tic disorders is unknown, they typically begin in childhood with onset between four and six years of age and reach their peak around ten to 12 years of age (McBride & Victorio, 2017). Tourette syndrome (TS) is the most severe tic disorder, characterized by unwanted motor and vocal tics that persist for more than a year, and is estimated to affect one to 10 in 1,000 children in the United States (Stewart et al., 2015). According to the CDC, approximately 148,000 children in the United States are diagnosed with TS (CDC, 2015). Kadesjö and Gillberg (2000) estimated that 1% of children have TS. Of children diagnosed with TS, 79% were also diagnosed with at least one other mental health disorder such as ADHD, depression, anxiety, conduct disorder or autism (Perou et al., 2013). Comorbidity with other mental health diagnoses such as ADHD, OCD and anxiety disorders are common and often interferes with a child's development more than the tics (Leckman, 2002; McBride & Victorio, 2017).

Attention Deficit Hyperactivity Disorder (ADHD*).* ADHD is a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, has symptoms presenting in two or more settings and the inattention negatively impacts social, academic or occupational functioning (APA, 2013). ADHD is

the most prevalent diagnosis among children aged three to 17 years old and accounts for approximately 6.8% of mental health diagnosis in children (Perou et al., 2013). Cognitive problems and inattention often seen in ADHD diagnoses were more prevalent in children diagnosed with OCD and ADHD than those not, possibly because the rigid obsessive thoughts may affect concentration (Jacob et al., 2012).

Mallett, Natarajan, and Hoy (2014) argued that ADHD is not only one of the most common mental disorders but is also a highly controversial psychiatric diagnosis. According to the authors, the controversy surrounds its origins, validity, and potential misdiagnosis, as well as over-diagnosis in child and adolescent populations in the United States. After analyzing psychiatric documents, medical records, and empirical research dated from the 1900s to 2013, the authors concluded that validity and reliability of what is considered a proper ADHD diagnosis was not found to be conclusive among social scientists and mental health practitioners (Mallett et al., 2014). The authors discussed how concerning this phenomenon had become due to the growing number of children and adolescents (between two to five million annually) diagnosed with ADHD in the U.S. today.

PANS and PANDAS

Research into children who presented with a sudden onset of OCD symptoms after a pediatric infection began in the 1980s at the NIMH and was first called Pediatric Infection Triggered Autoimmune Neuropsychiatric Disorders (PITAND) (Allen et al., 1995). Research continued to focus on those cases that were triggered by a strep infection

because of its correlation with Sydenham chorea (SC) and acute OCD, but other potential infectious triggers were also surfacing (Swedo et al., 1998). PITAND was renamed PANDAS and a new subclass was defined that linked the sudden onset of OCD or tics with streptococcal infections (Swedo et al., 1998). In 2010 a group of physicians and scientists met to review the current research and clinical presentation of cases studied, which included infectious triggers beyond strep. This resulted in the expansion of PANDAS to the broader diagnosis of PANS (Swedo et al., 2012). In 2013, the first PANS Consensus Conference was held, combining the expertise of researchers and clinicians from numerous medical and psychiatric fields, to refine the diagnostic criteria and research focus (Chang, Koplewicz, & Steingard, 2015). Many studies have highlighted the controversy that continues in the medical community due to inconsistent research results (Esposito, Bianchini, Baggi, Fattizzo, & Rigante, 2014; Kurlan, 2004; Leckman et al., 2011; Murphy et al., 2014; Perez-Vigil et al., 2016) yet, some have suggested the discrepant results are merely linked to methodological differences (Williams & Swedo, 2015).

Research continues as the medical community tries to discover the infectious triggers, autoimmune reactions, basil ganglia impacts, and genetic predispositions that may contribute to the disease manifestation (Murphy, Kurlan, & Leckman, 2010; Perez-Vigil et al., 2016). In some individuals, psychiatric disorders may be the result of an interaction between genetic predispositions and environmental factors that are triggered by an infection and results in brain inflammation causing emotional and behavioral

manifestations (Espposito et al., 2014). The triggering infections reported for children diagnosed with PANS/PANDAS were a step throat infection for 81% and other illnesses such as mycoplasma, Lyme, or an unknown infectious trigger for the remaining 19% (PANDAS Network, n.d.). Chang et al (2015) reported the most common infection triggering PANS appeared to be an upper respiratory infection. Calaprice et al. (2017) found that strep was the most frequent infectious trigger (54%) followed by sinusitis, mycoplasma, colds and then other infections. Mahony et al. (2017) reported that 6.6% of patients evaluated at the Stanford PANS clinic had an infectious trigger of sinusitis which was believed to be related to their neuropsychiatric symptoms.

Mahony et al. (2017) found the majority of children (69%) in their PANDAS study had symptom onset from four to nine years of age, with 11% reporting onset between one and three, 19% between ten and 13, and only 1% after age 14. Other studies found similar results with the average age of onset of symptoms between six and eight years old (Bernstein et al., 2010; Calaprice et al., 2017; Murphy et al., 2015; Swedo et al., 1998). The average age for childhood OCD is between seven and 15 years of age (Anholt et al., 2014; Delorme et al., 2005). The preponderance of PANS/PANDAS is also three times higher for boys than girls (Williams & Swedo, 2015).

The vast majority of the research on PANS/PANDAS has focused on a medical model rather than a family or social impact perspective. One must broaden the search to include OCD and other mental health diagnoses to obtain more information about how a child's mental disorder may impact their family. Little research was discovered that

focused specifically on the impact a PANS/PANDAS diagnosis had on parents and the family system. The following research is organized by PANS/PANDAS diagnostic criteria, comorbidity with other mental illnesses, treatment protocols, and family impacts.

Diagnostic criteria. There are no conclusive blood or neurological tests available to diagnosis PANS/PANDAS, so symptomology as defined by the NIMH's diagnostic criteria is used instead, after ruling out any other medical or neuropsychological disorders (Chang et al., 2015; Murphy et al., 2012). While Swedo at the NIMH published the initial research on PANDAS in 1998, there continues to be controversy in the medical field about PANS/PANDAS as a diagnosis because current research into the etiology of the disease remains inconclusive (de Oliveira & Pelajo, 2010; Perez-Vigil et al., 2016; Swedo et al., 1998). Chang et al. (2015) advised that before a PANS/PANDAS diagnosis is made, a thorough medical and family history be done including psychiatric, autoimmune, neurological, genetic and infectious disease evaluations. The diagnostic process should assess for neuropsychiatric symptoms, autoimmune or auto-inflammatory diseases, and recurrent infections from birth for the child, siblings, and parents and seek to exclude any other plausible diagnoses (Chang et al., 2015).

Sydenham chorea (SC) and PANDAS have similar behavioral symptoms but acute rheumatic fever is the infectious trigger for SC and that condition must be ruled out before a PANS/PANDAS diagnosis can be made (Williams & Swedo, 2015). Calaprice et al. (2017) found that although rheumatic fever is rare—less than five out of 100,000 people—that 3% of mothers and 14% of grandparents of the PANS patients in their study

had the illness. The authors reported that approximately 200 of the 698 PANS patients in their study reported an immune compromised state, which was usually associated with low immunoglobulin levels and more autoimmune disorders among 20% of the mothers (Calaprice et al., 2017). Jaspers-Fayer et al. (2017) found that children diagnosed with PANS/PANDAS were more likely to also have an autoimmune disease than children with pediatric OCD; but Stagi et al. (2014) found no statistically significant differences between PANDAS and non-PANDAS children when comparing autoimmune disorders in both groups. Research has also suggested a possible link between maternal autoimmune diseases and neuropsychiatric disorders in siblings of children with PANS/PANDAS, OCD, and tics (Murphy et al., 2010). It is estimated that only one out of 1200 people in the U.S. suffers from immune deficiency and only 12.5% of women nationally are estimated to be affected (Boyle & Buckley, 2007; Fairweather & Rose, 2004). The link between autoimmune disorders and PANS/PANDAS may deserve further research.

Greenberg (2014) conducted a review of literature and a case study that compared children diagnosed with PANDAS, PANS, and pediatric bipolar disorder (PBD) regarding the role of genetic, environmental, and immunological factors and how the similarities between these disorders may confound an accurate diagnosis. According to Luby and Navsaria (2010), PBD is increasingly reported in children and Greenberg (2014) suggested that the rise in the number of children diagnosed with PBD might be due to a lack of knowledge about PANS/PANDAS in the medical and psychiatric

communities. Childhood bipolar disorder results in significant impairment for the child and their family and continues to be a controversial disorder to diagnose in children (Luby & Navsaria, 2010). In some individuals, psychiatric disorders may be the result of the interaction between genetic predispositions and environmental factors that, when triggered by an infection, result in brain inflammation causing emotional and behavioral manifestations (Greenberg, 2014; Luby & Navsaria, 2010). The review of literature suggested many similarities in symptoms between several disorders and the commonalities raise questions as to whether a psychiatric illness can be triggered by an infection (Greenberg, 2014). Medical and mental health professionals need to understand the overlap of symptoms between PANDAS, PANS, OCD, TS, anxiety, and PBD to increase the accuracy of diagnosis and treatment.

Several studies challenged the diagnostic criteria of PANS/PANDAS, the inconsistent research results, and the lack of longitudinal research of sufficient sizes, which continue to polarize the medical community about PANS/PANDAS as a legitimate and distinct disorder (de Oliveira & Pelajo, 2010; Martino, Defazio, & Giovannoni, 2009; Murphy et al., 2014; Singer & Loiselle, 2003). Additional controversies about PANS/PANDAS included the lack of evidence of a genetic predisposition, diagnostic criteria validation, and exclusion of other possible causes of symptoms (de Oliveira & Pelajo, 2010). Still other studies strongly suggested a definitive link between PANDAS and a previous streptococcal infection (Lewin, Storch, & Murphy, 2011; Murphy, Storch, & Strawser, 2006; Swedo & Grant, 2005).

Murphy et al. (2014) explained the continuing controversy amongst the medical and psychiatric professions about the causes of PANS/PANDAS due to inconclusive research results. Diagnosing PANS/PANDAS in children is difficult because of inconsistent medical research studies but the diagnosis is receiving heightened interest by medical and psychiatric professionals. The authors explained that although PANDAS has been researched for almost three decades, there is still inconsistency in the diagnostic criteria, the medical causes of the disease, and the recommended treatment protocols. Differentiating a PANS/PANDAS diagnosis from OCD in children is difficult because of this inconsistent medical research (Murphy et al., 2014). PANS/PANDAS continues to confuse the medical community because it overlaps with so many other disorders and mental health conditions (Chang et al., 2015).

The latest research suggested a broader diagnostic category be established and a newer term of PANS (Pediatric Acute-onset Neuropsychiatric Syndrome) be used which eliminates the strep pathology controversy and focuses less on the cause and more on the sudden onset of symptoms (Swedo et al., 2012). Consensus among researchers and scientists was met during a NIMH conference in 2013 with agreement that the criteria of acute onset of OCD and/or eating restrictions and at least two additional, concurrent onsets of psychiatric symptoms must be met for a PANS diagnosis (Williams & Swedo, 2015). The additional psychiatric symptoms include: "(1) anxiety; (2) emotional labiality and/or depression; (3) irritability, aggression and/or severely oppositional behaviors; (4) behavioral (developmental) regression; (5) deterioration in school performance (related to

ADHD-like symptoms, memory deficits, cognitive changes, etc.); (6) sensory or motor abnormalities; and (7) somatic signs and symptoms, including sleep disturbances, enuresis or urinary urgency/frequency" (Williams & Swedo, 2015, p. 147). An additional diagnostic criterion is that the symptoms cannot be explained by another medical or neurologic disorder such as Sydenham chorea, Lupus, or Tourette's (Swedo et al., 2012).

As the research grows, the link between psychiatric disorders and brain inflammation caused by infections seemingly becomes more apparent, which may help clinicians learn more about how and why psychiatric disorders develop and who are the most vulnerable (Chang et al., 2015). The etiology of the disease remains ambiguous and why this devastating neuropsychiatric disorder develops in some children is still unclear. What is clear is that many children and families are affected and desperately searching for answers.

Comorbidity. Swedo et al. (1998) found comorbid psychiatric disorders were common in PANDAS patients: ADHD (40%), depression (36%), oppositional defiant disorder (ODD) (40%), generalized anxiety disorder (GAD) (28%), separation anxiety disorder (SAD) (20%), and enuresis (20%). In addition to these symptoms, children with PANS/PANDAS often experienced behavioral changes such as aggression or mood swings, declines in academic performance and handwriting, restricted eating, and fears of choking (Lewin, Storch, Mutch, & Murphy, 2011; Toufexis et al., 2015). Restricted eating can lead to anorexia in approximately 10-20% of PANS/PANDAS patients (Sokol, 2014). Restricted eating was reported in approximately half of the 698 children with

PANS in a recent study (Calaprice et al., 2017). Other psychiatric disorders including OCD, depression, ADHD, TS and BPD may be difficult to distinguish from PANS/PANDAS but an acute-onset of symptoms is a significant differentiator (Chang et al., 2015). Symptom onset typically occurs from several weeks to months following an infection (Williams & Swedo, 2015). Calaprice et al. (2017) also reported that 88% of the children they studied had symptom onset that was sudden and alarming within three days of having no or minimal symptoms.

Pediatric OCD and PANS/PANDAS. Childhood OCD is often difficult to distinguish from PANS/PANDAS and limited research has been conducted to determine differences in OCD symptoms between children with and without PANS/PANDAS. Swedo et al. (2012**)** found that in children with PANS/PANDAS, the anxiety is sudden and appears as irrational fears, phobias, separation anxiety or generalized anxiety. Initially the child may first appear terrorized and then over the course of weeks the panic is replaced with more generalized anxiety with fears of being alone or something bad happening. In some cases, the separation anxiety is reported to get so severe that the child refuses to go to school, sleep alone, or even let the parent use the bathroom alone (Swedo et al., 2012). Murphy et al., (2015) found that all the children in their study also demonstrated comorbid emotional lability and anxiety. Those children with higher strep antibody titers had greater OCD severity. In addition, suicidal ideation, depression, and poorer quality of life were also significantly more frequent in the PANS group (Murphy et al., 2015).

Bernstein et al. (2010) and Murphy et al. (2012) compared children that met the DSM-IV diagnostic criteria for OCD, tics, or both with those diagnosed with PANDAS. OCD and tic severity scores showed no significant difference between the two groups, both in the moderate range of severity but Bernstein et al. (2010) found that the children without PANDAS included other people in their compulsion rituals more often. The most common obsessions (i.e. aggression and contamination) and compulsions (i.e. washing and checking) in OCD were similar between the two groups. Bernstein et al. (2010) and Murphy et al. (2012) both discovered that the children diagnosed with PANDAS had a more dramatic onset of symptoms and also presented with hyperactivity, impulsivity, separation anxiety, urinary urgency, deterioration in handwriting, and declined school performance as compared with children with only OCD. The additional symptoms reported by PANDAS children versus the non-PANDAS group are likely related to functions of the basal ganglia as magnetic resonance images of PANDAS patients have shown inflammation in this region of the brain (Bernstein et al., 2010; Murphy et al., 2012; Swedo et al., 1998). Review of the medical history also found the PANDAS children had a higher percentage of having their tonsils and adenoids removed than non-PANDAS children, likely due to an increased history of streptococcal infections (Bernstein et al., 2010; Murphy et al., 2012).

Tic disorders and PANS/PANDAS. According to the NIMH diagnostic criteria for PANDAS, the presence of tics is a significant clinical factor. Murphy et al. (2015) found that children with PANS and tics were more apt to also have a decline in academic

performance, food restrictions, handwriting deterioration and motor impairments than those with PANS and no tic presence. Calaprice et al. (2017) found that at least half of the 698 PANS patients they gathered data on also experienced tics. While it is still considered rare by many professionals, some speculate it is more common than most believe and that as many as 25% of children diagnosed with OCD or TS may actually have PANS/PANDAS instead (PANDAS Network, 2017). This equates to an estimated 162,000 children in the U.S. alone (PANDAS Network, 2017). A 2012 survey of 700 parents with children having PANS/PANDAS found that the predominant symptoms were OCD (37%), Tics (14%), and 49% had both OCD and Tics (PANDAS Network, 2017).

ADHD and PANS/PANDAS. ADHD symptoms, including impulsivity and hyperactivity are often comorbid conditions when a child is diagnosed with PANS/PANDAS (NIMH, n.d.). Swedo et al. (2012) reported that ADHD symptoms often resulted in a deterioration in academic performance and cognitive functioning. They also found that difficulties with concentration, loss of math and writing skills, minimal attention spans, and other problems with cognitive functions were also common (Swedo et al., 2012). Murphy et al. (2015) reported that 47% of the children they studied that were diagnosed with PANS experienced school avoidance and 5% were medicated for their ADHD symptoms. Although it is common for children with OCD to also present with ADHD symptoms, Murphy et al. (2015) reported that typically they do not exhibit ADHD and other neuropsychiatric symptoms at the onset of OCD.

Treatment protocols. Calaprice et al. (2017) emphasized the importance of early diagnosis and treatment to minimize the long-term effects of PANS/PANDAS and children who were treated early experienced a higher likelihood of resolution of symptoms. Until confirmation of the illness is diagnosed, treatment usually focuses on controlling the symptoms and often starts with cognitive behavioral therapy (CBT) to treat the emotional and behavioral concerns and OCD indicators (Mancuso, Faro, Joshi, & Geller, 2010; Merlo & Storch, 2006; Ung, Ale, & Storch, 2012; Walsh & McDougle, 2011). The specific CBT intervention suggested is exposure and response prevention, which helps children learn how to ignore irrational thoughts and respond with healthier coping skills (Jenike & Boaz, 2017; Walsh & McDougle, 2011). OCD symptoms are often inadvertently reinforced by family members when accommodating the child's behaviors in an effort to reduce the associated anxiety (Nadeau et al., 2015). Studies have found that CBT, specifically exposure and response prevention with parent involvement, was helpful in reducing childhood OCD symptoms and temper outbursts (Knox, Albano, & Barlow, 1995; Krebs et al., 2013; Nadeau et al., 2015; Peris, Sugar, Bergman, Chang, Langley, & Piacentini, 2012; Storch et a., 2009). Nakatani et al. (2011) also found that the earlier the OCD was treated with CBT intervention, the better the results and that no differences were found in groups that were treated with CBT alone or in combination with medication (Nakatani et al., 2011).

Once PANS/PANDAS is diagnosed, treatment recommendations usually involve continued CBT as well as prolonged antibiotics, anti-inflammatory drugs, tonsillectomy,

psychotropic pharmacology, plasmapheresis, and/or intravenous immunoglobulin (IVIG) treatments (Esposito et al., 2014; Martino et al., 2009; Murphy et al., 2014; Nadeau et al., 2015; NIMH, n.d.; Singer & Loiselle, 2003; Swedo & Grant, 2005; Williams & Swedo, 2015). Removal of a child's tonsils and/or adenoids has been proposed, but research suggested that it does not prevent PANDAS and may even have adverse side effects due to compromising the child's immune system (Esposito et al., 2014; Murphy et al., 2014). Others recommended it as a viable treatment protocol since PANDAS is thought to be associated with reoccurring strep throat infections (Alexander, Patel, Southammakosane, & Mortensen 2011).

Some studies have shown improvement in OCD and tic symptoms in children with PANDAS when given antibiotics when compared to a control group receiving a placebo (Murphy et al., 2014; Snider, Lougee, Slattery, Grant, & Swedo, 2005; Williams & Swedo, 2015). Bottas and Richter (2002) and Snider et al. (2005) also found that PANDAS patients' OCD symptoms and tics disappeared when the streptococcal infection was treated with antibiotics. However, another study by Garvey et al. (1999) failed to show an improvement in OCD or tics when penicillin was administered. Esposito et al. (2014) explained the inconsistent findings by suggesting that because OCD and tics have an unstable course—remission and exacerbation—the study results could be inconclusive if the course of the symptoms were different. Calaprice et al. (2017) found that most PANS/PANDAS patients experienced a recurrence of symptoms when exposed to an infection or after a vaccination but may not display symptoms of an infection. Doctors

may recommend continuing antibiotics to prevent future recurrences and flares of the behavioral symptoms (Murphy et al., 2010). The NIMH recommends the use of antibiotics to prevent future strep infections and subsequent episodes of PANS/PANDAS (NIMH, n.d.). The NIMH (n.d.) also reported that two clinical trials of antibiotic use to prevent strep infections resulted in a reduced rate of PANS/PANDAS flairs. Williams and Swedo (2015) also found that antibiotics were helpful in reducing PANS/PANDAS symptoms if the antibiotic protected against future strep infections. Murphy et al. (2014) stated that which class of antibiotic to use for treatment needs further research, but Snider et al. (2005) found no difference in 23 youth treated for PANDAS with penicillin versus azithromycin. Current research suggested that early diagnosis and treatment of infections with antibiotics was likely to decrease the probability of a PANS/PANDAS reoccurrence and minimize symptoms (Calaprice et al., 2017).

Additional treatment options include immune-based therapies such as plasmapheresis and intravenous immunoglobulin (Murphy et al., 2014). Plasmapheresis is a procedure where the child's plasma is removed from his/her blood and replaced with good plasma. Murphy et al. (2014) stated that although there were good results reported on improvement in OCD symptoms, there is limited research; therefore, this is not a widely recommended treatment protocol. Another treatment option is intravenous immunoglobulin (IVIG), and it was found to be significantly more effective in clinical trials than the placebo (Murphy et al., 2014). Treatment of PANS/PANDAS with IVIG is generally only recommended for severe cases because of potentially unpleasant side

effects (i.e., vomiting, headaches, or allergic reactions) and it is expensive and often not covered by insurance (Jenike & Boaz, 2017). One small study at the NIMH showed IVIG reduced the OCD severity for 82% of children with PANDAS (Jenike & Boaz, 2017). The NIMH cautioned physicians on their website that immune-based therapies should only be used if PANS/PANDAS is a confirmed diagnosis because children with non-PANDAS OCD showed no improvement when treated (NIMH, n.d.). Doshi, Maniar, and Banwari (2015) suggested that immunotherapies such as IVIG and plasma exchange have shown positive results in diminishing symptoms. Williams (2011) also found that plasmapheresis and IVIG treatment was effective in reducing OCD symptoms 45% to 58%. According to Williams and Swedo (2015), because of the similarities between SC and PANS/PANDAS, immunomodulatory treatments, like IVIG and plasma exchange may be a beneficial treatment approach; however, these remain controversial treatment protocols because they are invasive, costly and considered experimental. Research results are still inconclusive, and it is suggested that these treatments only be considered for the severest cases of PANS/PANDAS, when symptoms interfere daily with normal functioning (Williams & Swedo, 2015).

Others suggested that since there is a lack of consistent clinical evidence to support treatment of PANS/PANDAS with antibiotics or immune-based therapies, psychiatric medicines such as serotonin reuptake inhibitors (SRIs) or selective serotonin reuptake inhibitors (SSRIs) and CBT should be prescribed to treat the OCD and neuropsychiatric symptoms instead (de Oliveira & Pelajo, 2010; Esposito et al., 2014;

Walsh & McDougle, 2011). Macerollo and Martino (2013) espoused that since evidence is not conclusive and studies have not consistently replicated treatment results, the best course is still unknown. According to Jenike and Boaz (2017), the use of psychotropic medication, such as SSRIs, with children diagnosed with PANS/PANDAS is not recommended by many clinicians. However, Storch et al. (2010) claimed that there is sufficient evidence in research that SRIs are effective in treating childhood OCD but admitted the side effects of the medication may be undesirable. Murphy et al. (2006) recommended that if a SSRI is used, lower doses than what are typically prescribed be advised for children with PANS/PANDAS due to being more prone to SSRI-induced behavioral toxicity, such as mood disruptions and suicidal ideation. Mancuso et al. (2010) also cautioned about possible behavioral side effects when administering a SSRI to children, which included possible mania and other long-term impacts on brain development.

As seen from the literature review, there are conflicting opinions and research results guiding physicians and parents on the best treatment options. Many agree that family-based CBT is a good start with positive results and few side effects (Jenike & Boaz, 2017; Merlo & Storch, 2006; Ung et al., 2012; Walsh & McDougle, 2011). Antibiotics that can prevent a future infection likely resulting in an exacerbation of symptoms also appears prudent and supported by research (Murphy et al., 2014; Snider et al., 2005; Williams & Swedo, 2015). More controversial treatments are removal of tonsils and immune-based therapies (Esposito et al., 2014; Murphy et al., 2014). Parents face

difficult choices as they seek treatment for their children because many treatments are expensive, may not be covered by insurance, can be invasive and risky, and some remain controversial (de Oliveira & Pelajo, 2010; Walsh & McDougle, 2011; Williams & Swedo, 2015).

Family Impacts

The enduring and reoccurring nature of childhood mental health disorders can create a considerable amount of stress for most parents and their family. While caring for a child with a special health care need is certainly stressful, Busch and Barry (2007) found that caring for a child with a mental health disorder had more far reaching implications for both the parent and their child. More specifically, parent-related issues such as economic instability, financial burden, low family functioning, significant grief, social isolation, and poorer health are common challenges parents face when raising a child with a mental health disorder (Algood et al., 2013; Busch & Barry, 2007; Richardson et al., 2013). Richardson et al. (2013) also indicated that families often feel judged and blamed for their child's illness and feel unheard by those treating their child. Other studies corroborated that parents often feel burdened and guilty about their child's emotional or conduct disorders and may withdraw from friends because of perceived judgment and social stigma (McClelland et al., 2015; Meltzer, Ford, Goodman & Vostanis, 2011). The severity and duration of a child's mental disorder is strongly associated with caretaker burden and parental stress (Busch & Barry, 2007; Goldberg-Arnold, Fristad, & Gavazzi, 1999; Möller-Leimkühler & Wiesheu, 2012).

Little research was found specifically on the impact of a PANS/PANDAS diagnosis on the family system. A universal search of peer reviewed journals and dissertations and Google scholar searches for keywords such as *PANS, PANDAS, parental stress, family impacts,* and/or *financial impacts* revealed little results. Three websites explored the impact of the sudden onset of symptoms and the trauma it caused to families but these are largely qualitative reports from parents (www.pandasnetwork.org, www.iocdf.org/PANDAS and www.latitudes.org). One study was found that explored how families reacted when their child was diagnosed with PANDAS and how nurses can best help the families (McClelland et al., 2015). The search criteria must be expanded beyond a PANS/PANDAS specific diagnosis to include *youth mental illness, OCD, ADHD,* and/or *anxiety* to find research on the family impacts of raising a child with a mental illness. This literature review will continue with a summary of these findings and is organized around the Impact on Family Scale's (IOFS) subscales of parental distress, financial impacts, familial-social impacts, and sibling impacts (Stein & Jessop, 2003).

Impact on Family Scale. The Impact on Family Scale (IOFS) was designed for caregivers or parents of children with chronic medical conditions to assess the impact of the illness on the family system (Stein & Jessop, 2003). The assessment tool provides scores to measure family impacts in the areas of financial burden, familial-social impacts, parental distress, parental coping, and sibling impact. Although most research found that used the IOFS focused on chronic medical conditions, it has also been used for

populations of behaviorally difficult children, children with tic disorders, and children with developmental disorders (Hsieh, Huang, Lin, Wu, & Lee, 2009; Sheeber & Johnson, 1992; Woods, Himle, & Osmon, 2005).

Sheeber and Johnson (1992) modified the IOFS by eliminating questions that related to physical ailments for use with measuring family impacts while raising a "behaviorally difficult" child and found increased family disruptions. Şimşek et al. (2014) found that mothers of chronically ill children were more significantly impacted than other family members and had greater tendencies for anxiety and depression, likely because they were the primary caregiver. The areas showing the greatest impact on the IOFS were the subscales measuring disruptions of social relations and financial problems, likely because of the additional duties of caring for their special needs' child and less time for work and socializing (Şimşek et al., 2014). Dehn, Korn-Merker, Pfäfflin, Ravens-Sieberer, and May (2014) used the IOFS with 219 parents of children with epilepsy and found that the instrument had strong reliability and construct validity. The researchers reported that parents raising a child with a chronic condition face many psychosocial stressors such as difficulty planning for the future, restricted social activities, increased stress, and decreased quality of life (Dehn et al., 2014).

Hsieh et al. (2009) also found that family impacts for children with developmental delays were negatively correlated with the child's age, suggesting that family members adapt better as the child gets older. Another significant factor in how well a family copes with a chronically ill child is having adequate finances and family resources (Rolland &

Walsh, 2006). Huang et al. (2013) espoused that children with special health care needs place significant burden on caregivers and found that the child's fatigue was a significant factor that correlated to higher total family impact as measured by the IOFS. Another study with children diagnosed with a tic disorder, found that family impact, as measured by the IOFS, was significantly correlated with ADHD symptomology, tic severity, and depressive symptoms of the child (Woods et al., 2005). This research confirmed that higher total family impact scores were positively correlated with the number of the child's psychiatric symptoms. Although the IOFS was originally created to be used to assess family impact with chronic medically ill children, it has shown to be adapted and applied to a variety of pediatric diagnoses with apparent success. Evidence from research using the IOFS supports the use of this assessment tool for analyzing family impacts as reported by parents raising a child with PANS/PANDAS.

Parental distress. Research indicated that parents of children with mental health conditions, like pediatric OCD, are at an increased risk of parental distress (Algood et al., 2013; Berge & Holm, 2007; Busch & Barry, 2007; Stewart et al., 2015; Storch et al., 2009). Pediatric OCD is considered a mental health condition that not only impairs the child, but also their family (Caporino et al., 2012). Storch et al. (2009) investigated parents' experiences of having a child diagnosed with OCD and the relationship between symptom severity, impairment, parental distress levels, family accommodation, caregiver strain, as well as co-occurring internalizing and externalizing behavior problems. The authors found that parents were significantly distressed about their child's OCD

psychiatric condition and expressed significant guilt, worry, unresolved sorrow, anger, and long-term uncertainty. An increase in these feelings was positively associated with OCD symptom severity, OCD-related impairment, family accommodation of symptoms, and internalizing and externalizing behavior problems (Storch et al., 2009). In addition to parents' stress levels being higher, Barrett, Shortt, and Healy (2002) also found that parents of children with OCD demonstrated poorer problem solving, less confidence in their child's abilities, less rewarding of their child's independence, more criticism, and displayed less warmth during parent-child interactions. The additional distress caused by their child's illness may also impact parents' ability to positively interact and discipline their child effectively (Barrett et al., 2002).

Additional research indicated that accommodation of OCD symptoms further elevated parental stress. Jacob et al. (2012) stated that parents were increasingly more frustrated when their child's compulsions involved family members and that their behavior was viewed as being oppositional. Futh et al. (2012) revealed that parents had a negative narrative of their experiences with their child's mental illness and reported elevated levels of stress. More than half of the parents reported that they accommodated their child's compulsions but experienced significant stress while deciding between resistance and engagement in an effort to manage their child's anger and their own distress. The study also found that accommodation rates did not differ significantly between fathers and mothers, but mothers reported stronger negative emotions and use of more coping strategies (i.e. escape-avoidance and using social supports) than fathers

(Futh et al., 2012). Greater OCD severity and greater level of family accommodation were positively correlated with interference in the caregiver's personal life, parents' feelings of irritation or intolerance, and parents' feelings of guilt, insecurity, and embarrassment (Torres, Hoff, Padovani, & Ramos-Cerqueira, 2012). Greater OCD severity affected all domains of parents' perceived burden. A higher level of psychological maladjustment in the caregivers was also associated with the perception of greater interference in their personal life (Torres et al., 2012).

There is significant comorbidity with OCD and tic disorders in some estimated 20-60% of children, but research suggested that having both conditions does not impact children's symptom severity or functional impairment any more than having either disorder alone (Lewin, Chang, McCracken, McQueen, & Piacentini, 2010). Stewart et al. (2015) utilized the Parental Stress Index/Short Form (PSI/SF) and found that parents raising kids with TS indicated their stress was more positively correlated with OCD symptom severity, independent of the severity of the tics. OCD symptoms had a greater impact on the child, parents and the parent-child relationship than tic burden. The authors also found that a majority of children diagnosed with TS have also been diagnosed with a least one additional neuropsychiatric disorder, most often ADHD (50%-62%) and OCD (20%-60%). In this study, the parents of children with TS reported a higher level of parenting stress than parents of typically developing children. In addition, they found that parents' stress was also strongly correlated with ADHD and OCD symptoms, independent of the severity of tics, for children with TS. ADHD and OCD symptoms had

a greater impact on the child, the parents, and the parent-child relationship than tic burden. The authors' findings suggested that comorbid ADHD and OCD affect children with TS and their parents more so than tics themselves (Stewart et. al., 2015).

High levels of parental stress can lead to serious problems for the family system, including parental grief, increased behavior problems in children, and social isolation (Morris, 2014). Richardson, Cobham, Murray, and McDermott (2010) conducted a secondary data meta-analysis of research from 1840 to 2010 focused on the grief experiences of parents with a mentally ill child. According to their research findings, there was a process of awareness, which took place as the child began manifesting symptoms of their mental disorder. Parents began sensing something was off but were in denial. They initially rationalized their child's behavior but then began to fail to be able to do so when their child's behaviors continued to escalate. Parents tended to react slowly because of feelings of fear, confusion and apprehension and their grief increased in intensity over time as parents felt more overwhelmed, frustrated, alienated and confused (Richardson et al., 2010). The researchers noted that social support and perceived degree of burden significantly influenced the levels of reported parental grief. Many parents reported a significant increase in grief at a 10-year follow-up after diagnosis, due to the ambiguous loss of their child and the snowball of losses as the illness progressed. Parents often experienced intrusive thoughts and feelings, and engaged in socially avoidant behaviors (Richardson et al., 2010). The ambiguity associated with an illness, such as PANS/PANDAS, may increase the risk of parents developing depression or anxiety

(Berge & Holm, 2007). Parents felt deep resentment toward the unfairness of their child's mental illness, blamed themselves, and often felt more negative emotion toward and around the child, thus creating a negative parent-child bond, and hence, more guilt (Richardson et al., 2010).

Researchers indicated that parents raising children who were diagnosed with various mental illnesses—GAD, SAD, OCD, adjustment disorder, phobias, anorexia nervosa, depressive disorder, dysthymia, selective mutism, self-injurious behaviors (e.g., cutting), ASD, and OD—often grieved the loss of their child's ideal self because of the drastic behavioral and emotional changes and this created a sense of profound loss (Oruche et al., 2012; Richardson et al., 2013). Parents expressed intrusive thoughts and emotions, avoidance, preoccupation with the mental illness and difficulty accepting their circumstances (Richardson et al., 2010; Richardson et al., 2013). Hamilton, Mazzucchelli, and Sanders (2015) found similar results and that parents not only grieved for the child but also for themselves, their other children, and the ongoing future decisions the family would have to make. Parents reported worries about their own safety and the safety of others at home and school, worries about the impact their child's need for continuous care had on other family members, and concerns that the mental health system was hard to navigate (Oruche et al., 2012). Grief emerged as a significant stressor as parents gained awareness of the impact the mental illness had on their child and the other members of the family (Morris, 2014; Oruche et al., 2012; Richardson et al., 2010). Mental illness is disruptive to family functioning and pushes families into disorder as

they struggle to provide care for their child without sacrificing their entire lives (Frese, 2004).

In another study conducted by the National Alliance for the Mentally Ill (NAMI), families reported struggles to obtain proper diagnosis, treatment, and support when their child had a mental illness and also experiencing high levels of stress due to financial burdens and a lack of understanding by others (Vitanza et al., 1999). Torres et al. (2012) conducted a multi-dimensional analysis of burden on family caregivers of patients with OCD. Six caregiver burdens were identified: (a) interference in the caregiver's personal life; (b) awareness of patient's dependence; (c) feelings of irritation or intolerance; (d) feelings of guilt; (e) feelings of insecurity; and (f) feelings of embarrassment. The authors found that OCD symptom severity and family accommodation levels were positively associated with higher caregiver stress (Torres et al., 2012). Identifying parental burdens that increase stress is the first step in helping to alleviate these risks for parents. Educating parents that accommodating their child's demands may result in more significant symptom severity and higher parental stress may help parents resist their child's requests, which may explain why family focused CBT is an effective treatment protocol (Storch et al., 2010).

The impact of having a mentally ill child affects not only the child but the entire family. Shudy et al. (2006) found that the most prevalent stressors reported by parents were helplessness, loss of parental control, worry for siblings, fatigue, anxiety, poor nutrition, psychological distress, poor physical health, financial worries, and loss of

relationships. Similar to Shudy et al. (2006), in an unpublished qualitative study with five families who had a child diagnosed with PANS/PANDAS, Mettica (2016) found evidence of nine family impact themes repeated throughout the interviews: judgement from others, social isolation, academic difficulties, employment strains, financial strains, marital strains, sibling impacts, uncertainty about the future, and parental health problems. Every participant mentioned feeling judged by family, friends, doctors, teachers, or their spouse and most having their parenting style questioned and critiqued. Four of five participants mentioned feeling dismissed by doctors as overreacting and having to search for medical answers and referrals themselves because their child's symptoms were not taken seriously. All participants mentioned feeling isolated from friends and family and their child also being isolated from friends due to the lack of participation in any outside activities because of the illness.

All participants mentioned declining school performance and three of the five parents began homeschooling their child because of their child's refusal or inability to attend school outside the home. Financial strains were reported by four of the five families with two families selling their homes to meet expenses related to their child's illness and two mothers quitting work because their child required constant care. Two mothers mentioned traveling out-of-state to medical experts for treatment because they were unable to find local medical professionals familiar with treating the illness. Three of the five parents interviewed noted that every member of the family needed counseling due to the trauma experienced because of their child's illness, but financial constraints

prohibited them from seeking mental health services. Four parents reported increased stress and having less time for themselves. Three of the five parents mentioned the impact their child's illness had on increasing stress for their sibling(s). All participants expressed hesitation and fear of the future because the prognosis and treatment outcomes were unknown. Several mentioned that it was impossible to plan what the next steps (e.g. school or activities) might be for their child and their family. Several parents mentioned severe physical and emotional fatigue due to caring for their PANS/PANDAS child (Mettica, 2016).

Because of the sudden onset of psychiatric symptoms, parents often described their child as changing abruptly and becoming "possessed" (Swedo et al., 2012). The PANDAS Network website provided consistent reports from parents expressing tremendous fear and helplessness when their child abruptly changed. It is common for parents to be able to recall the exact moment in time when their child began to exhibit symptoms because they appeared so suddenly and were so severe and memorable (Swedo et al., 2012).

Much of the reviewed research on family impacts when raising a child with a mental disorder used focus groups in which participants were interviewed (Morris, 2014; Oruche et al., 2012; Richardson et al., 2010). Other studies utilized measurements that could more accurately help determine parental distress levels (Futh et al., 2012; Möller-Leimkühler & Wiesheu, 2012; Richardson et al., 2010; Stewart et al., 2015). For example, Stewart et al. (2015) utilized the Parental Stress Index/Short Form (PSI/SF) and

found that parents raising kids with TS, which encompasses symptoms associated with ADHD and OCD, had a higher level of stress compared to other parents. Futh et al. (2012) used the Ways of Coping Questionnaire (WOCQ), the Depression Anxiety Stress Scale (DASS) and the Family Accommodation Scale (FAS) to elicit from parents what it was like to raise a child with OCD. As predicted, they found elevated levels of stress and negative affect. Childhood mental health disorders can lead to stress and caregiver burden as well as problems with siblings, relationships, and finances (Goldberg-Arnold et al., 1999). Additional themes that emerged in the literature which are relevant to this review included financial impacts and familial-social impacts, which are two of the subscales on the IOFS.

Financial impacts. Mental illness in children can have significant negative financial ramifications for families and may be even greater for families with children diagnosed with PANS/PANDAS. Many of the treatment protocols, consultations with specialists, and experimental treatments for PANS/PANDAS may not be covered by insurance (PANDAS Network, 2017). Busch and Barry (2007) found that families with children with mental health disorders had more significant financial hardship than families with children with other chronic medical health conditions (e.g. diabetes, epilepsy, or asthma). The cost of raising and supporting children with mental health conditions is far higher than for families without these problems and can lead to ongoing negative financial implications (Beecham, 2014).

Busch and Barry (2007) investigated four reasons why the economic effects of caring for a sick child may be more severe among families with children diagnosed with a mental health disorder. The first reason is that private health insurance covers mental health services less generously than it covers general health care. Secondly, some mental disorders might be less predictable than other child health disorders, potentially leading to greater parental employment disruption. Third, a child's mental health diagnosis may be viewed as more subjective than a physical health condition, thereby reducing the social acceptability of a parent taking time off work to care for the child. Lastly, increased familial-social impacts may occur if parents are not able to receive adequate support and understanding from family members and friends (Busch & Barry, 2007). Parents of children needing mental health care were significantly more likely to cut their work hours, spend more than four hours per week arranging their child's mental health care, or to stop working altogether yet also reported that additional income was needed to care for their child (Beecham, 2014; Busch & Barry, 2007). This is likely even more significant for PANS/PANDAS families because Calaprice et al. (2017) found that of the 698 parent participants interviewed, 35% reported that their child needed to miss at least a week of school during a PANS/PANDAS symptom flair and 9% could no longer attend school at all.

Familial and social impacts. McClelland et al. (2015) uncovered similar results as Richardson et al. (2013) during a qualitative study with 60 families who had a child diagnosed with PANDAS. The authors asked families what they most struggled with

after their child was diagnosed with PANDAS. Three broad themes were identified to explain parents' reactions to their child's PANDAS diagnosis: fear, frustration, and not feeling heard by medical professionals. Parents reported significant fear for their child's well-being, safety, long-term prognosis, ability to function in public, and his/her future. They also feared being able to provide financially, physically, and emotionally for their child. They feared being judged by other parents, family members, and medical staff. Parents were frustrated with the lack of knowledge the medical community had about PANDAS and the difficulty they had finding proper diagnosis and treatment. Parents reported they were often dismissed as being the cause of their child's problem or that it was solely a psychiatric condition (McClelland et al., 2015).

In a recent study by Calaprice et al. (2017) with 698 PANS patients, parents reported that PANS left 30% of the children unable to perform developmentally appropriate activities, 27% unable to perform even basic daily tasks to function and the rest were unable to perform age appropriate tasks in a normal fashion. In addition, the researchers noted that 46% of the PANS patients in the survey reported having an incapacitating episode of symptoms with another 31% reporting at least one severe occurrence of symptoms. The researchers concluded that most parents are often alone searching the Internet for answers because clinicians have difficulty diagnosing and treating this disorder (Calaprice et al., 2017). When children are unable to perform age appropriate tasks and activities, parents are more likely to experience physical and mental health problems and an increased inability to work (Witt et al., 2009).

For parents raising children with a mental health disorder, there is a continuous struggle to meet the needs of the whole family and to find a balance between the child's special needs and the needs of other family members, especially siblings (Goldberg-Arnold et al., 1999). Kilmer, Cook, Munsell, and Salvador (2010) expressed concern about the limited availability of research regarding the impact and stress on siblings of children with significant emotional problems. Research indicated that neglecting other family members when a child is diagnosed with a chronic illness can have negative consequences for the other family members, such as increased stress and depressive symptoms (Kilmer, Cook, Taylor, Kane, & Clark, 2008; Sharpe & Rossiter, 2002). Siblings of children with mental health, chronic health conditions, or disabilities exhibit greater emotional problems such as anxiety and depression (Kilmer et al., 2010). Summers, White, and Summers (1994) found that siblings of children with special needs experienced more peer conflict, fear, resentment, irritability, guilt, and aggression. The authors indicated that several factors, such as how much the sibling needs to help and the quality of the sibling relationship, may also influence the impact of the child's illness on their siblings (Summers et al., 1994). Siblings of children with emotional disturbance also experienced higher levels of stress and the need for additional family support (Kilmer et al., 2010). Shudy et al. (2006) found that siblings' stress increased because of changes in their parents' behaviors and having less time to spend with them. Research suggested that the healthy siblings needed more family cohesion, developmentally appropriate information, and distractions from the family's focus on the ill child (Kao, Plante, &

Lobato, 2009; Shudy et al., 2006).

Theoretical Frameworks

Family systems theory and family stress theory will be the theoretical lenses used to conceptualize this research study, capitalizing on their usefulness for understanding the impact a serious illness may have on the family and the internal and external interactions that may mitigate the impacts to the family system (Bowen, 1966; Hill, 1958).

Family Systems Theory. Family systems theory provides a theoretical basis from which to consider the relationships between family dynamics, external systems the family interacts with, and family stress management (Kazak, 1989). Bowen (1978) espoused that an individual does not interact and develop as an individual unit but within the context of the family as an emotional system. Differentiation of self is a term he coined to identify the balance of individuality and cohesion within the family system. Bowen (1978) described this differentiation as a spectrum with autonomy at one end and emotional dependence on the other end. In a family with a child diagnosed with PANS/PANDAS, there is likely a significant enmeshment as the emotional dysfunction and chronic anxiety within the family escalates. According to Bowen's theory, dealing with chronic anxiety within the family leads to health or emotional problems of children and parents, relationship conflicts, and triangulation with other people (Bowen, 1978). Triangulation happens when the chronic stress between two people is spread to a third person in an attempt to diffuse the anxiety (Bowen, 1978). Raising a child with a mental illness produces significant anxiety and stress on the parent-child dyad and on the marital dyad

which may result in triangulation by bringing in the other spouse or another family member for support (Bowen, 1978; Busch & Barry, 2007).

All family members use personal boundaries to regulate the type and amount of interaction that occurs between the individual, family members, and external systems such as work, school, or treatment providers (Whitchurch & Constantine, 1993). These boundaries and differential levels of power each family member has influence interactions within and between the family and their external interactions outside the family system (Whitchurch & Constantine, 1993). The family system is further comprised of relational subsystems within the family such as marital, parental, and parent-child subsystems (Bowen, 1978). Research indicated that these relational subsystems are negatively impacted when a child is diagnosed with PANS/PANDAS (Calaprice et al., 2017; McClelland et al., 2015; Swedo et al., 2012). A family systems perspective also considers the family's functioning over time and how the demands of the PANS/PANDAS diagnosis changes as the family changes (Kazak, 1989). At the onset of the illness, before a formal diagnosis or treatment has been made, the family is confused and tumultuous (McClelland et al., 2015). Over time, the family learns more about the illness and treatment options which may help the family return to a more balanced homeostasis or the illness progresses and the family moves towards crisis mode, becoming more unbalanced (Kazak, 1989; Swedo et al., 2012).

Family systems theory espouses that all individuals within the family affect all other members of the family and the emotional health of one member can disturb the

relationships in the family system (Bowen, 1978). A child with PANS/PANDAS experiences sudden impairment, throwing the family into a state of confusion and impacts each member of the family. Families struggle to obtain proper diagnosis, treatment and support when a child has a mental illness, but due to the controversy with PANS/ PANDAS, the stress and impact on the family system is likely to be even greater. The illness is not contained within the child but rather causes changes in other members of the family as well. These changes may include a parent needing to leave employment to care for the child, increased parental distress, and less time for siblings (Kazak, 1989).

Family Stress Theory. The family stress theory was originally espoused by Hill (1958) to analyze why some families react negatively to a stressor while others cope more positively. Hill's (1958) ABC-X model identifies (A) as the event that the family is dealing with, (B) as the family's available resources and support to deal with the event, (C) as the perception and meaning given to the event, and (X) as the potential resulting crisis. There are several assumptions outlined in the model: (1) unexpected events typically cause stress; (2) events within the family (e.g. serious illness) are more stressful than events outside the family; (3) no prior experience with the event causes more stress; and (4) events that are ambiguous are more stressful than clearly known events (Hobfoll & Spielberger, 1992). For families with a child with PANS/PANDAS, at the onset of symptoms, the stressor event is considerably high as parents do not know why their child has suddenly changed. If the family is fortunate enough to have significant financial and family support resources, the PANS/PANDAS stressor may have less impact on the

family than on a family with limited resources. In addition, as a diagnosis and treatment are found, the family's response to the stressful event may change. Because of the controversy surrounding PANS/PANDAS and the difficulty parents often have getting proper diagnosis and treatment, it is likely to cause more family stress than an illness that has well-known etiology, treatment plan, and prognosis (Calaprice et al., 2017; McClelland et al., 2015; & Witt et al., 2009). If the stressor event is now perceived as a crisis by the family, then it may lower family functioning and take longer for the family to adjust and reorganize to address the stressful event (Hobfoll & Spielberger, 1992). Continued stress may result in a crisis "pile up" which any additional stressful events would further reduce the family's ability to cope and function (McCubbin & Patterson, 1983).

The ABCX model of adaptation was later modified by scholars and became known as the double ABCX model. The double ABCX model focused on events that occur after the stressful situation and how much stress continued that may drain the family's resources and ability to cope effectively (McCubbin & Patterson, 1983). Boss (2002) later modified the ABC-X model by adding an additional external context in which families have no control over and that included family structure, values, beliefs, genetics, culture, and where the family members were in the life cycle. These external factors influence the A, B, and C variables in the model and play a critical role in determining if the stressor event will lead to a crisis or the family's ability to positively cope (Boss, 2002). This contextual model is useful in understanding how a family may

cope with a PANS/PANDAS diagnosis. For example, a single parent family structure may have less family support to rely on for caregiving relief which may result in higher levels of stress, anxiety, and dysfunction. A family's values and belief system may influence how they seek care, such as if only medical interventions are sought or psychiatric and spiritual ones might be considered as well. The family members place in the life cycle could also greatly impact how the family is able to cope with a PANS/PANDAS diagnosis. The age of the child, siblings, and parents could impact how the stressor is dealt with. Families with very young children in need of constant care or with additional responsibilities, such as caring for aging parents, would also affect a family's ability to cope.

Summary

Difficulties in discerning PANS/PANDAS from other presentations of OCD or other pediatric mental disorders make it challenging for parents to get a correct and timely diagnosis and doctors to provide appropriate treatment (Murphy et al., 2012). Although there is much controversy in the existing research, scholars seem to agree on the need for more longitudinal studies to refine the diagnostic criteria, increase knowledge on the pathology, and design useful treatment protocols (Bernstein et al., 2010; Martino et al., 2009; Murphy et al., 2012; Singer et al., 2012; Singer & Loiselle, 2003). Meanwhile, parents who search for answers regarding why their child suddenly woke up very different one day are often left with little help. Parents experience worry, confusion, denial, anger, and helplessness when their child suddenly changes and often

feel overwhelmed, not knowing where to turn for help (Matheos & DeMare, 2013). The hallmark symptom of a sudden onset creates confusion and desperation for families facing a PANS/PANDAS diagnosis. The impact this sudden change in the mental and behavioral health of a child has on the family system has received scant attention in research. The controversy surrounding the validity of a PANS/PANDAS diagnosis does not dispel the very real challenges experienced by the family system and the need for further research.

Using family system and family stress frameworks as the theoretical approaches to this study, the literature review addressed three areas related to how raising a child with PANS/PANDAS affects the family system. The first section addressed research related to general mental health disorders in children and those specifically often considered as comorbid diagnoses with PANS/PANDAS, including OCD, tic disorders, and ADHD. The second section focused on research studies about PANS/PANDAS including diagnostic criteria, comorbidity, and treatment protocols. The last section of the literature review discussed research related to family impacts while raising a child with a mental health disorder and literature on PANS/PANDAS using the IOFS subscales of parental distress, financial impacts, and familial and social impacts. This study will help fill a gap in research in understanding how a child diagnosed with PANS/PANDAS impacts the family system.

CHAPTER III

METHODOLOGY

Childhood mental health disorders can create a considerable amount of stress for parents and their families as they struggle to meet their child's needs as well as balance the needs of the family (Busch & Barry, 2007). The complexities of differentiating PANS/PANDAS from other mental health disorders like pediatric OCD make it problematic for parents to get an accurate and timely diagnosis (de Oliveira & Pelajo, 2010). It is likely that parents who have a child with PANS/PANDAS experience significant distress and life adjustments; however, little is known about how raising a child with PANS/PANDAS impacts the family system.

In an attempt to fill a gap in current research, this quantitative, descriptive study explored the relationship between various demographic factors (i.e., parents' relationship status, parents' education level, and household income) and the child's illness factors (i.e., OCD symptom severity and duration between onset of symptoms and diagnosis) with the impact PANS/PANDAS has on the family system. Impact on the family will be measured using the Impact on the Family Scale (Stein & Jessup, 2003). The three research questions addressed by this study are:

1. Are there differences in the level of family impact, as measured by the IOFS, when raising a child with PANS/PANDAS when compared with parent's relationship status, parents' education level, and household income?
2. Are there differences in level of family impact, as measured by the IOFS when

raising a child with PANS/PANDAS, when compared to OCD symptom severity as measured by the CY-BOCS-PR?

3. Are there differences in the level of family impact, as measured by the IOFS, when compared with the length of time in months from onset of symptoms to the PANS/PANDAS diagnosis?

Setting

This online quantitative study was conducted through the PANDASNetwork.org website that provides information and support for parents and guardians raising a child with PANS/PANDAS. Participants could complete the study in the privacy of their homes, offices, or any place they desired that has Internet connectivity.

Participant Sample

The sampling procedure was purposive sampling because specific people with specific characteristics (i.e. parents, step-parents, or guardians of children with PANS/PANDAS that have displayed OCD symptoms during their illness) were required for this research study. These parents or guardians were 18 years of age or older and the primary caregivers of the focal child for a minimum of the past six months to ensure adequate experiences dealing with the child and the illness. The child needed to be between four and seventeen years old when diagnosed with PANS, PANDAS, or PITAND. The researcher gained approval from the Executive Director of the PANDAS Network to post a recruitment script on the PANDAS Network website with a link to a PsychData questionnaire (see Appendix A). The recruitment script can be found in

Appendix B. The initial sample size was 345 parents or guardians but was reduced to 312 participants due to removal of cases for not meeting the inclusion criteria or missing critical data.

Protection of Human Subjects

This study was presented to and approved by the Institutional Review Board (IRB) at Texas Woman's University in Denton, Texas. The IRB approval can be found in Appendix G. Participants who volunteered for the study remained anonymous and any personal information remained confidential. There is no connection between the participants and the data. All data is currently stored in a password protected file that can only be accessed by the primary investigator and her supervising professor. All identifying data will be destroyed by December 30, 2018.

Measures

Demographic factors about the child and his/her family, information about the child's illness, OCD symptom severity, and family impacts were collected through an online survey. The demographic and illness questionnaire can be found in Appendix C. The CY-BOCS-PR used to measure OCD symptom severity can be found in Appendix D and the IOFS used to measure family impacts can be found in Appendix E.

Participant Demographics

A questionnaire was created to gather demographic information about the child and family including relationship status of the person completing the survey, parent and child age, parent and child ethnicity, parent level of education, parent relationship status,

and household income.

Illness Factors

This portion of the questionnaire also gathered information about the child's illness. Information collected included the diagnosis, date of onset of symptoms, date of diagnosis, history of family autoimmune disorders, restricted food intake, who first suspected PANS, who diagnosed PANS, number of professionals seen before diagnosis, who and how child is currently being or has ever been treated, and if travel over 50 miles is or was necessary for treatment.

Children's Yale-Brown Obsessive-Compulsive Scale – Parent Report

Since PANS is a subset of OCD, the Children's Yale-Brown Obsessive-Compulsive Scale – Parent Report (CY-BOCS-PR) was used to measure OCD symptom severity (Storch et al., 2006). The CY-BOCS-PR scale has five questions that parents answer regarding their child's compulsions and an additional five questions about their child's obsessions that combine for a total score between zero and 40 ($\alpha = .86$) (Storch et al., 2006). A score between zero and seven indicated subclinical severity, 8-15 mild severity, 16-23 moderate severity, 24-31 severe symptom severity, and 32-40 extreme severity. Positive correlations between the CY-BOCS-PR and other OCD symptom rating scales, including the self-report version of the CY-BOCS confirms the validity of this tool (Storch et al., 2006; Uher, Heyman, Turner, & Shafran, 2008). The instructions for the CY-BOCS-PR were modified slightly, asking parents to select the option that best described their child's symptoms at the time they had the most impact on their family,

rather than over the past week. Since children with PANS often display dramatic ups and downs in the severity of their OCD symptoms, rating a child's symptoms based upon the past week may not be an accurate reflection of their overall symptom severity (Calaprice, 2017; Murphy et al., 2014; Snider et al., 2005; Williams & Swedo, 2015). According to the NIMH, many children with OCD have good days and bad days, or even good weeks and bad weeks. However, children with PANS have a very sudden onset or worsening of symptoms, followed by a gradual improvement and this tends to remit and relapse (NIMH, n.d.). The CY-BOCS-PR can be found in Appendix D.

Impact on Family Scale

The Impact on Family Scale (IOFS) was used to measure the dependent variable, family impact (Stein & Jessop, 2003). The instructions for the IOFS were modified slightly, asking parents to select the option that best described their child's symptoms at the time they had the most impact on their family, rather than at the present time. Since children with PANS often display dramatic ups and downs in the severity of their symptoms, rating the impact to the family presently may not be an accurate reflection of the family's experiences because the focal child may currently be in a stage of remission of symptoms. Each item in the scale was rated as (1) strongly agree, (2) agree, (3) disagree or (4) strongly disagree. The scale has a total of 33 items of which 19 items combine for a total score on family impact ($\alpha = .88$) ranging from 19 to 76, with the higher score reflecting more significant family impact when raising a child with a chronic illness (Stein & Jessop, 2003).

There are four IOFS subscales that assess financial impact, familial-social impact, parental strain/distress, and parental coping. The financial impact subscale is measured by four items (α = .72) and reflects how the illness negatively changed the economic status of the family. The higher the score, the more financial impact the illness has had on the family. A sample question on the financial impact subscale is: *The illness is causing financial problems for the family.* The familial-social impact subscale consists of nine items (α = .86) and considers the quality and quantity of interactions within and outside of the family unit. The higher the score, the more social and family relationships have been disrupted by the illness. A sample question on the familial-social impact subscale is: *I don't have much time left over for other family members after caring for my child*. The parental strain subscale has ten items (α = .81) and evaluates the level of strain placed on the caregiver as a result of the child's illness. The higher the score, the more parental distress has been experienced due to the illness. A sample question on the parental strain/distress subscale is: *Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, okay when things are stable.* The parental coping subscale has four items (α = .60) and focuses on parental strengths. The lower the score the higher the level of positive parental coping. A sample question on the parental coping subscale is: *Because of what we have shared we are a closer family.* Parenting coping items are not used in computing total impact (Stein & Jessop, 2003).

The IOFS has been used with large normative samples including Pediatric Ambulatory Care Treatment Study (PACTS) and Family Advocacy and Coordination

Effort (FACE) (Stein & Jessop, 1984; Stein & Jessop, 2003). The IOFS has been adapted cross-culturally and includes a French, Turkish, Spanish, Italian, German, and Portuguese translation with similarly positive psychometric properties (Boudas et al., 2013). The IOFS has been used to assess the impact on the family system when dealing with chronic pediatric illnesses or other chronic illness lasting three or more months (Stein & Jessop, 2003; Williams, Piamjariyakul, Williams, Bruggeman, & Cabanela, 2006). This instrument was selected because of its strong psychometric results, cross-cultural applicability, use with various pediatric illnesses, and ease of administration. The IOFS assessment can be found in Appendix E.

Data Collection Procedures

Participants were recruited through PANDASNetwork.org using a recruitment flyer distributed by the website. The recruitment script can be found in Appendix B. Parents or guardians raising a child with PANS/PANDAS were directed to a link from the flyer to PsychData where they completed the demographic questions, the child illness questions, the CY-BOCS-PR, and the IOFS survey. The survey opened with the title of the study and a consent form that explained the study's purpose, participants' inclusion criteria, and rights and risks of completing the study. The consent form can be found in Appendix F. Participants were advised that they could stop the study at any time and withdraw their consent. Participants were asked to electronically give consent before answering the questions. This process was expected to take participants less than 60 minutes to complete.

Data Analysis

The data was entered into the Statistical Package for Social Sciences (SPSS) for analysis. Descriptive statistics were conducted for the independent (e.g. demographics and illness factors) and dependent (e.g. IOFS) variables. For variables that are interval or ratio data, tests of parametric assumptions were done including testing for a normal distribution of data, homogeneity of variance, and independence. Measures of central tendency including means and standard deviations, as well as frequencies and percentages were calculated to describe the sample.

Demographics

Descriptive statistics—frequencies, mean, standard deviation, and range—for each of the demographic variables are displayed in tables one and two. These demographics include: relationship to child of person completing the survey, parent and child's age, child's age at time of diagnosis, child's gender, parent and child's ethnicity, parent's highest level of education, parental type, parent's current relationship status, and total household income range.

Illness Factors

Descriptive statistics—frequencies, mean, standard deviation, and range—for each of the illness factor variables are displayed in tables 3-7. The illness factor variables displayed are: a family history of autoimmune disorders, length of time between the onset of initial symptoms and the PANS/PANDAS diagnosis (calculated in months using the dates from onset of symptoms and diagnosis), who first suspected and who made the

PANS/PANDAS diagnosis, the number of and what type of health providers were seen, past and current treatment modalities, restricted food intake, date of most recent exacerbation of symptoms, and symptom severity. Symptom severity was measured by the CY-BOCS-PR and was reported by the total score from the assessment.

Impact on Family Scale

The Impact on Family Scale (IOFS) was used to measure the dependent variable, family impact (Stein & Jessop, 2003). This is an interval level of measurement. Descriptive statistics including the mean, standard deviation, and range were calculated and reported for the IOFS total and the four subscales—financial, parental strain, social and family relationship disruption. Tests of parametric assumptions for normality, homogeneity of variance, and independence were also conducted. Tests for the assumptions of running a regression analysis were also done including tests for non-zero variance, linearity, homoscedasticity of relationships, independent residuals, and multi-collinearity. Pearson Product Moment Correlation analysis was conducted on duration between onset of symptoms and diagnosis (measured in months) and OCD symptom severity with the total impact on family score as well as with each of the four subscales.

Research Questions

Statistical tests were run to test for differences and predict relationships to answer the three research questions guiding this quantitative study. The first research question was: Are there differences in the level of family impact, as measured by the IOFS, when raising a child with PANS/PANDAS when compared with parent's relationship status,

parents' education level, and household income? To answer this question, a series of Factorial ANOVAs were conducted to test for differences between the groups as they related to the dependent variable, the total score on the IOFS. Post hoc tests were also run as appropriately.

The second research question asked: Are there differences in level of family impact, as measured by the IOFS total score, when compared by OCD symptom severity as measured by the CY-BOCS-PR? To answer this question, a linear regression was conducted to determine the relationship between impact on the family reported and level of OCD symptom severity. Parametric assumptions and assumptions for linear regression analysis were conducted. Results of the regression were analyzed to determine how strongly the independent variable of OCD symptom severity influenced the dependent variable, impact on family. The total variance in the impact on the family was analyzed with R^2 to see how much of the variance was explained by the model.

The last research question was: Are there differences between the level of family impact, and the length of time in months from onset of symptoms to diagnosis? To analyze this, a linear regression was conducted to discover the relationship between impact on the family reported and the time it took for the child to get diagnosed. The length of time between onset of symptoms and diagnosis was calculated in months. Parametric assumptions and assumptions for linear regression analysis were also conducted. Results of the regression helped discover how strongly the independent variable of length of time in months between onset and diagnosis influenced the

dependent variable, impact on family. The total variance in the impact on the family was analyzed with R^2 to see how much of the variance was explained by the model.

Hypotheses

The researcher explored three hypotheses for the purpose of examining relationships between demographic variables, the child's illness factors, OCD symptom severity, and the total impact on the family reported by parents. This study proposed these three null hypotheses:

Ho_1. There will be no significant differences in scores of total impact on family as measured by parents' self-reports using the IOFS when compared with current relationship status, educational attainment and income level for the parents.

Ho_2. There will be no significant differences in scores of total impact on family as measured by parents' self-reports using the IOFS when compared with child's OCD symptom severity using the CY-BOCS-PR.

Ho_3. There will be no significant differences in scores of total impact on family as measured by parents' self-reports using the IOFS when compared with length of time in months from onset of symptoms until diagnosis.

Summary

This chapter presented the methodology that was utilized in this quantitative study that explored the relationships between demographic variables in the family (e.g. parents' relationship status, education level, and income) and the child's illness factors (e.g. severity of OCD symptoms and length of time between onset of symptoms ad diagnosis)

to see how they influenced the impact on the family as scored by the IOFS (Jessop & Stein, 2003). Distinguishing PANS/PANDAS from pediatric OCD is convoluted, making it difficult for pediatricians to recognize and treat the illness (Murphy et al., 2014). Research showed that parents of children with mental health disorders are at an increased risk of family disruptions and mental and physical health ailments (Busch & Barry, 2007). Raising a child diagnosed with PANS/PANDAS is likely to be more stressful on parents due to the difficulty in obtaining a diagnosis, disagreements within the medical profession about the etiology of the disease, lack of knowledge and experience in the medical profession about treatment protocols, lack of knowledge of diagnostic criteria in the mental health profession, and lack of support for parents (de Oliveira, & Pelajo, 2010; McClelland et al., 2015). Raising awareness of the impact on the family when raising a child diagnosed with PANS/PANDAS, as well as what mitigating factors may influence the impacts, may help guide mental health professionals, family life educators, and medical professionals to better understand how to help these children and parents reduce trauma to the family system.

CHAPTER IV

RESULTS

The purpose of this online quantitative study was to explore the impact to a family while raising a child diagnosed with PANS and investigate what factors may mitigate the impact. A total of 345 participants completed the online survey for this study; however, 33 participants were excluded from the analysis, resulting in a final sample size of 312. The data set was examined for invalid data such as not giving consent, duplicate cases, not meeting the inclusion criteria, not completing the last 50%-65% of the survey, or having no variance across items in the survey. Cases were removed if they met at least one or more removal reason(s). The data set was of sufficient size for the observed powers for analysis being above .80 indicating a reduction in Type I Error or falsely rejecting the alternative hypothesis.

After preparing the data for analysis, it was found that out of 312 recorded cases, 6.6% of the cases contained all missing values. Of the 131 variables, 76 variables contained missing data (58%). To assess whether the pattern of missing values was missing completely at random (MCAR), Little's MCAR test was conducted (Little, 1988). Using an expectation-maximization algorithm, the MCAR test estimates the univariate means and correlations for each of the variables. The results revealed that the pattern of missing values in the data of this study was MCAR, $\chi 2\ (24) = 55.95\ p = .000$. Overall missingness was not a significant issue and the pattern of missing data is MCAR which allows more flexibility in addressing the missing data. Multiple imputation was not

recommended because Little's MCAR test was significant at $p = .000$. Missing data is handled with either Pairwise or Listwise deletion. Pairwise deletion removes a case only if there are missing values for each pair of variables in an analysis. Pairwise better maximizes all of the data available in the analysis. Listwise deletion removes a case if it has any missing values for any of the variables. Pairwise deletion was chosen for this data analysis, which is also the SPSS default.

Descriptive Statistics

Sample Description

As seen in Table 1, the majority of participants were biological mothers (87.1%) with the remaining participants being biological fathers (6.8%), adoptive mothers (3.5%), grandmothers (1.6%), and other (1.0%). Parents and guardians ages ranged between 22 and 73 years, with the mean age of 48. The majority of participants were married (84.1%) for 11 to over 20 years (72.8%). Most participants had a four-year college or graduate degree (77.1%) compared to those with an Associate degree or less (22.9%). The vast majority of participants reported being white (92.9%) and having a net household income over $100,000 (64.7%). Due to differences in group sizes, marital status was collapsed into two categories of married and unmarried (i.e., divorced, cohabitating, single, separated, widowed); education level was collapsed into three categories of graduate degree, 4-year degree and less than bachelor's degree; and household income was collapsed into five categories of less than $50,000; $50,001 - $75,000; $75,001 - $100,000; $100,001 - $200,000; and $200,001 or more.

Table 1

Frequencies and Percentages for Parent Categorical Variables

	n	%
Relationship to Child		
Biological Mother	271	87.1
Biological Father	27	6.8
Adoptive Mother	11	3.5
Grandmother	4	1.6
Other	2	1.0
Relationship Status		
Married	260	84.1
Divorced	18	5.8
Cohabitating Couple	9	2.9
Single, Never Married	8	2.6
Separated	7	2.3
Remarried	5	1.6
Widowed	2	0.7
Parent Education		
Graduate Degree	124	40.0
College or other 4-year Degree	115	37.1
Associate Degree or Other 2-Year Degree	44	14.2
High School or GED	26	8.4
Some High School	1	0.3
Parent Ethnicity		
White	288	92.9
Hispanic or Latino	11	3.5
Asian	3	1.0
African American or Black	1	0.3
Other	7	2.3
Household Net Income		
$100,000 - $200,000	131	42.4
$200,001 or more	69	22.3
$75,001 - $100,000	47	15.2
$50,000 - $75,000	33	10.7
$25,001 - $50,000	20	6.5
$25,000 or less	9	2.9

As seen in Table 2, the majority of children in this study were male (59.2%) compared to female (40.4%). The majority of focal children in this study were white (88.4%).

Table 2

Frequencies and Percentages for Child Categorical Variables

	n	%
Gender of Focal Child		
Male	184	59.2
Female	127	40.4
Other	1	0.4
Ethnicity of Focal Child		
White	275	88.4
Other (more than one race indicated)	18	5.8
Hispanic or Latino	11	3.5
Asian	5	1.7
African American or Black	1	0.3
American Indian or Alaska Native	1	0.3

Illness factors for the focal child can be found in Table 3. Participants were asked if there was a family history of autoimmune disorders and of those participants who answered this question, 16.9% indicated yes, 58.4% selected no, and 24.7% did not know. Those participants that indicated a family history of autoimmune disorder reported the following diagnosis in a related family member: diabetes, rheumatoid arthritis, celiac, lupus, crone's, celiac, underactive thyroid disease, alopecia, aerate, Sjogren's Syndrome, fibromyalgia, or Guillian-Barre Syndrome. Restricted food intake is often a symptom of PANS and 53.7% of parents reported this as being true for their child, 36.3% denied

restricted food intake, and 10% selected other for their answer. Of those parents selecting other, some noted that although food intake was restricted, there was not weight loss but also not normal developmental weight gain. Other parents stated that the restricted food intake was due to sensory reasons, fear of vomiting, or OCD symptomology including restriction on the number of bites allowed or contamination fears. Parents were the most likely to first suspect PANS (50.6%), followed by other—friends, integrative doctors, functional medicine specialists, Stanford Bipolar Clinic (14.7%), pediatricians (11.2%), psychiatrists (5.4%), neurologists (4.8%), general practitioners (4.5%), mental health professionals (4.2%), psychologists (2.9%), school personnel (1.3%), and family life educators (0.4%).

Table 3

Frequencies and Percentages for Illness Factors of Focal Child

	n	%
Family History of Autoimmune Disorders		
No	97	58.4
Unknown	41	24.7
Yes	28	16.9
Restricted Food Intake		
Yes	167	53.7
No	114	36.3
Other	31	10.0
Who First Suspected PANS		
Parent	158	50.6
Other	46	14.7
Pediatrician	35	11.2
Psychiatrist	17	5.4

Neurologist	15	4.8
General Practitioner	14	4.5
Mental Health Professional	13	4.2
Psychologist	9	2.9
School Personnel	4	1.3
Family Life Educator	1	0.4

As seen in Table 4, of the children in the study, 69% were diagnosed with PANDAS, 25.2% with PANS, 0.6% with PITAND, and 5.2% indicated some other type of initial diagnosis (e.g. Lyme, post infectious autoimmune encephalitis, Sydenham chorea, and hypogammaglobinemia). The year the child was diagnosed ranged from 1998 to 2018 with 82% of the respondents' children being diagnosed between 2012 and 2017. A neurologist made the diagnosis for 24.1% of the children and a pediatrician for 22.8%. Additional professionals who more often diagnosed the focal child (32.2%) with PANS included biomedical doctors, nurse practitioners, integrative doctors, immunologists, Stanford PANS Clinic, functional medicine specialists, PANDAS specialists, pediatric rheumatologists, pediatric neurologists, naturopath treatment providers, and the NIMH. Parents reported they often had to see many licensed health providers before a diagnosis was made—more than five (31%) and between two and five for a total of 51.6%.

Table 4

Frequencies and Percentages for Diagnostic Factors

	n	%
Diagnosis		
PANDAS	214	69.0
PANS	78	25.2
Other	16	5.2
PITAND	2	0.6
Who Diagnosed Child		
Other	100	32.2
Neurologist	75	24.1
Pediatrician	71	22.8
Psychiatrist	28	9.0
General Practitioner	28	9.0
Psychologist	5	1.6
Mental Health Professional	4	1.3
Number of Doctors Seen Before Diagnosis Made		
More Than Five	96	31.0
Three	59	19.0
Two	49	15.8
One	48	15.5
Four	30	9.7
Five	22	7.1
None	6	1.9

When asked if their child was currently displaying PANS symptoms, 68.3% of respondents reported yes but 74.4% of parents reported that their child was currently being actively treated for PANS. This likely indicates that the treatment is effective in eliminating the PANS symptoms for 6.1% of those respondents. Those children currently being treated are seen by various practitioners and the frequencies can be found in Table 5. A reported 25.6% of participants indicated that their child was not currently being

treated. Other current treatment providers included: biomedical doctors, rheumatologists, integrative medical doctors, functional medicine specialists, naturopathic doctors, PANS clinic, and PANDAS specialists. Regarding current treatment protocols, those participants that selected 'other' indicated the following treatment protocols: nutritional and dietary supplements, homeopathy, methylphenidate, clonidine, turmeric, vitamins C and D, Claritin, Benadryl, Naltrexone, Cannabidiol oil, probiotics, naturopathic, herbs, homeopathic supplements, Andy Cutler Chelation protocol, immune system supplements, antifungals, MTHFR gene mutation supplement, and microbial defense supplements. Some parents (36.6%) reported currently having to travel more than 50 miles to get treatment for their child and 54.4% reported ever having to travel more than 50 miles. Of those currently having to travel more than 50 miles for treatment, 62.4% reported having to do so once a month. Twenty-nine participants reported frequency of travel more than 50 miles as occurring: yearly, quarterly, every six months, one to three times a year, every other month, or as needed. Several participants mentioned having phone consultations with providers more than 50 miles away several times a year as well. Frequencies for each can be found in Table 5.

Table 5

Frequencies and Percentages for Current Treatment Variables

	n	%
Currently Displaying Symptoms		
Yes	211	68.3
No	98	31.7
Currently Being Treated		
Yes	232	74.4
No	80	25.6
Current Treatment Providers		
Pediatrician	90	28.8
Psychiatrist	73	23.4
Neurologist	71	22.8
Immunologist	58	17.3
General Practitioner	54	15.1
Psychologist	45	14.4
Mental Health Professional	27	8.7
Behavioral Therapist	27	8.7
Occupational Therapist	16	5.1
Physical Therapist	7	2.2
Other	97	31.1
None	50	14.7
Current Treatment Protocols		
Antibiotics	178	57.1
Anti-inflammatories	122	39.1
Other	110	35.3
Psychotropic Pharmacology	84	26.9
IVIG	46	14.7
Child Counseling (Not CBT)	48	15.4
PANS Support Groups	44	14.1
Child CBT Counseling	43	14.4
Tonsillectomy	34	10.9
Behavioral Therapy	28	9.0
Family Counseling (Not CBT)	19	6.1
Family CBT Counseling	13	4.2
Plasmapheresis	2	0.6
No Treatment	54	17.3
Frequency of Travel More than 50 Miles for Treatment		
Once a Month	63	62.4
Other	29	28.6
Twice a Month	3	3.0
Three Times a Month	3	3.0
Four Times a Month	2	2.0
More Than Five Times a Month	1	1.0

Note. The percentages for treatment providers and treatment protocols will not add to 100% because participants selected as many that applied.

Participants were also asked who had ever treated their child and the treatment protocols they had ever received, which are displayed in Table 6. For the 'other' category, participants indicated the following providers: biomedical doctors, rheumatologists, nurse practitioners, integrative doctors, homeopathic approaches, nutritionists, PANS Clinic teams (rheumatologist, internist, and allergist), functional medicine specialists, chiropractors, ear-nose-throat doctors, naturopathic doctors, orthopedic doctors, alternative holistic doctors, speech pathologists, and PANDAS specialists. Regarding past treatment protocols, those participants that selected 'other' indicated the following alternative treatments: antiviral supplements, nutritional and dietary supplements, homeopathy, methylphenidate, clonidine, turmeric, vitamins C and D, probiotics, fish oil, curcumin, naturopathic, herbs, homeopathic supplements, Andy Cutler Chelation protocol, immune system supplements, antifungals, chiropractic care, neurofeedback, occupational therapy and equine therapy. Participants were also asked if they ever had to travel more than 50 miles to receive treatment for their child and 54.4% indicated yes. The frequencies of past travel more than 50 miles away for treatment can also be found in Table 6.

Table 6

Frequencies and Percentages for Past Treatment Variables

	n	%
Past Treatment Providers		
Pediatrician	193	64.8
Neurologist	157	50.3
Psychiatrist	154	49.4
Mental Health Professional	119	38.1
Psychologist	117	37.5
General Practitioner	114	36.5
Immunologist	111	35.6
Behavioral Therapist	89	28.5
Occupational Therapist	59	18.9
Physical Therapist	31	9.9
Other	102	32.7
Past Treatment Protocols		
Antibiotics	288	92.3
Anti-inflammatories	219	70.2
Child CBT Counseling	151	50.7
Child Counseling (Not CBT)	155	49.7
Psychotropic Pharmacology	141	45.2
IVIG	109	34.9
Tonsillectomy	107	34.3
PANS Support Groups	90	28.8
Behavioral Therapy	87	27.9
Family Counseling (Not CBT)	78	25.0
Family CBT Counseling	40	12.8
Behavioral Therapy	26	8.7
Plasmapheresis	16	5.1
Other	94	30.1
No Treatment	1	0.3
Past Travel More than 50 Miles for Treatment		
Once a Month	88	55.7
More than Five Times a Month	33	20.9
Twice a Month	20	12.7
Three Times a Month	7	4.4
Four Times a Month	5	3.2
Five Times a Month	1	0.6
Other	3	2.5

Note. The percentages for treatment providers and treatment protocols will not add to 100% because participants selected as many that applied.

According to the NIMH, children with PANS often display dramatic ups and downs in the severity of their OCD. Children with PANS have a very sudden onset or worsening of their symptoms, often followed by a gradual improvement and this tends to remit and relapse. A sudden worsening of OCD is considered an exacerbation of symptoms (NIMH, n.d.). Parents were asked to use this definition of flare when answering questions about their child's most recent exacerbation of symptoms or flare and the frequency of these flares. The winter months of October through January were reported to have the highest incidence of flares (71.6%). Parents reported that in the past year, 28.6% of children had more than five flares and the greatest number of flares in any year was reported to be more than five by 57.6% of the participants. The information provided is displayed in Table 7.

Table 7

Frequencies and Percentages for Symptom Flare Variables

	n	%
Month Flares Occurred		
January	94	32.1
December	54	18.4
October	37	12.6
November	25	8.5
September	21	7.2
August	13	4.4
June	12	4.1
May	11	3.8
February	9	3.1
April	7	2.4
July	6	2.0
March	4	1.4
Year of Most Recent Flare		
2017	156	53.6
2018	85	29.2
2016	25	8.6
2015	12	4.2
2014	5	1.7
2013	4	1.4
2012	2	0.7
2011	1	0.3
2005	1	0.3
Number of Flares in Past Year		
More than Five	86	28.6
Three	46	15.3
Two	41	13.6
One	36	12.0
Four	30	10.0
Five	18	6.0
None	43	14.5
Greatest Number of Flares in Any Year		
More than Five	174	57.6
Three	39	10.9
Five	27	8.9
Two	28	9.3
Four	23	7.6
One	16	5.4
None	1	0.3

Preliminary Analysis

Standard deviations, means, and range are displayed for the continuous demographic variables in Table 8. Participants' ages ranged from 22 to 73 years (M = 48.16, SD = 6.93). Focal children's ages ranged from 5 to 33 years (M = 13.81, SD = 4.75). Child's age at the time of their onset of symptoms ranged from 1 to 17 years (M = 6.39, SD = 3.76). Child's age at the time of their diagnosis ranged from 4 to 17 years (M = 9.12, SD = 3.19). The duration in months between the time the child displayed symptoms until the child was diagnosed ranged from 0 to 143 months or 11.92 years (M = 24.87, SD = 33.27). Six outliers that were at the extreme number of months were removed from the duration variable in an effort to further normalize the data.

Table 8

Means and Standard Deviations of Continuous Variables

	n	*M*	*SD*	Min	Max
Parent Age	310	48.16	6.93	22	73
Child Age	309	13.81	4.75	5	33
Child's Age at Onset	304	6.39	3.76	1	17
Child Age at Diagnosis	281	9.12	3.19	4	17
Duration in Months	282	24.87	33.27	0	143

Note. Duration in months refers to the duration between the onset of symptoms and when the child was diagnosed.

A series of cross tabulations with Pearson's chi square were calculated between all the categorical demographic variables (i.e., parent and child age, parent and child gender, parent relationship status, parent education level, and family income). There were not any significant relationships among these variables.

Scale scores. The child's OCD symptom severity was measured by the CY-BOCS-PR which has an obsession subtotal, a compulsion subtotal, and the CY-BOCS-PR total for clinical interpretation of symptom severity ranging from subclinical to extreme. Means and standard deviations for the CY-BOCS-PR are shown in Table 9. Scores on the obsession subscale ranged from 5 to 25 (M = 18.49, SD = 3.99), compulsion subscale scores ranged from 5 to 25 (M = 17.26, SD = 4.65), and total OCD severity scores ranged from 10 to 50 (M = 35.75, SD = 7.69).

Table 9

Means and Standard Deviations of CY-BOCS-PR Instrument

	n	*M*	*SD*	Min	Max
Obsession Subscale	279	18.49	3.99	5	25
Compulsion Subscale	273	17.26	4.65	5	25
Total OCD Severity	270	35.75	7.69	10	50

The CY-BOCS-PR scores are classified into five categories for interpretation. A score of 0-7 indicates subclinical symptoms, 8-15 mild symptoms, 16-23 moderate

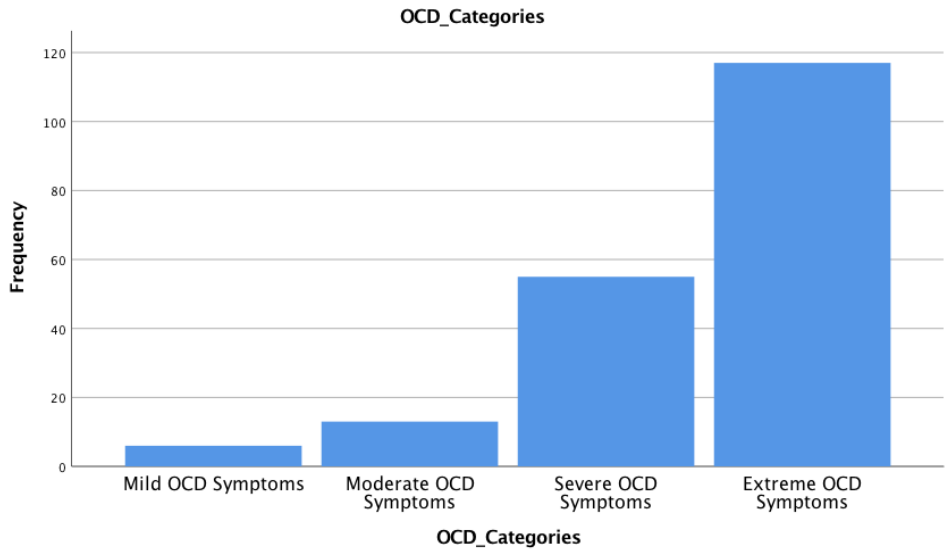
symptoms, 24-31 severe symptoms, and 32-50 extreme symptoms. As seen in Table 10 and Figure 1, most (61.3%) parents reported their child's OCD symptom severity as extreme and 90.1% fell into the severe and extreme categories.

Table 10

Frequencies and Percentages for OCD Symptom Severity

	n	%
Subclinical	0	0.0
Mild	6	3.1
Moderate	13	6.8
Severe	55	28.8
Extreme	117	61.3

Figure 1



Total family impact was measured by the IOFS which has financial, parental strain, disruption of social/familial relations, and parental coping subscales with a total impact computed by combining numerous variables within the assessment. Means and standard deviations for the IOFS are shown in Table 11. Scores on the financial subscale ranged from 3 to 12 (M = 9.59, SD = 2.35), parental strain subscale scores ranged from 12 to 40 (M = 31.27, SD = 5.71), disruption of social/familial relations subscale scores ranged from 10 to 34 (M = 25.82, SD = 5.64), and parental coping subscale scores ranged from 4 to 15 (M = 8.56, SD = 2.15). Total family impact scores ranged from 19 to 76 (M = 58.02, SD = 11.26).

Table 11

Means and Standard Deviations of IOFS Instrument Scores

	n	*M*	*SD*	Min	Max
Financial Subscale	271	9.59	2.35	3	12
Parental Strain Subscale	233	31.27	5.71	12	40
Disruption of Relations Subscale	155	25.82	5.64	10	34
Parental Coping Subscale	256	8.56	2.15	4	15
Total Impact on Family	145	58.01	11.26	19	76

Relationships between OCD symptom severity and IOFS subscales and total. Pearson's Product Moment correlations were computed to test for relationships between OCD symptom severity and the IOFS subscales and IOFS total score. As can be seen in Table 12, OCD symptom severity was significantly positively related to four of the IOFS subscales and IOFS total score (r ranging from .46 to .95, $p < .001$) indicating that those who scored higher on OCD symptom severity also scored higher on all scales of the IOFS, indicating that the impact to the family is greater when symptom severity is worse. There was no significant correlation between OCD symptom severity and the IOFS coping subscale.

Table 12

Correlations Between OCD Symptom Severity and IOFS Subscales and IOFS Total

	OCD Symptom Severity	IOFS Financial Subscale	IOFS Strain Subscale	IOFS Social Subscale
IOFS Financial Subscale	.46			
IOFS Strain Subscale	.60	.75		
IOFS Social Subscale	.61	.74	.87	
IOFS Total	.62	.83	.95	.95

Note. All $p < .001$

Primary Analysis

Research Question One

Research Question One: Are there differences in the level of family impact, as measured by the IOFS, when raising a child with PANS/PANDAS when compared with parent's relationship status, parents' education level, and household income?

Ho_1. There will be no significant differences in scores of total impact on family as measured by parents' self-reports using the IOFS when compared with current relationship status, parents' education level, and household income.

A series of Analysis of Variance (ANOVA) were conducted to determine if the IOFS subscales and IOFS total score differed by demographic variables (e.g., parent education level, relationship status, and household income), which can be found in Table 13 through Table 17. As shown in Table 13, results revealed a significant effect of parent relationship status, $F(1, 267) = 11.62$, $p < .01$ and household income $F(4, 264) = 3.97$, $p < .01$ on the IOFS's financial subscale. Tukey's post hoc analysis could not be run on marital status because there were only two groups. Tukey's post hoc analysis for household income revealed that family income less than \$50,000 ($M = 10.74$, $SD = 1.86$) had significantly higher scores on the IOFS financial subscale than families with household income greater than \$200,001 ($M = 9.05$, $SD = 2.28$), $p < .05$. Tukey's also showed significantly higher scores on the IOFS financial subscale for family income in the \$50,001 - \$75,000 range ($M = 10.62$, $SD = 1.70$) than families with household income greater than \$200,001 ($M = 9.05$, $SD = 2.28$), $p < .05$. These results intuitively make

sense that a family's financial distress would be higher at a lower household income level. Results did not yield a significant effect for parent education ($p > .05$) as related to the IOFS financial scale, indicating relatively equivalent scores across differing levels of education as they related to financial distress. Levene's was also significant for parent's marital status and financial status with the IOFS financial subscale. These group sizes are unequal as the majority of participants are married and have a household income between $100,001 - $200,000 causing homogeneity of variance to be violated. Because Levene's was violated, the corrected model was interpreted for the *F* and *p* values.

Table 13

Means and Standard Deviations of IOFS Financial Subscale by Parent's Relationship Status, Parent's Level of Education, and Household Income

	n	*M*	*SD*	*F*	*p*
Parent Relationship				11.62	.001**
Married	232	9.39	2.37		
Unmarried	37	10.78	1.86		
Parent Education				.37	.693
Less than Bachelor	63	9.59	2.26		
Bachelor's Degree	93	9.44	2.53		
Graduate Degree	115	9.72	2.25		
Household Income				3.97	.004*
Less than $50,000	23	10.74	1.86		
$50,001 - $75,000	29	10.62	1.70		
$75,001 - $100,000	44	9.66	2.48		
$100,001 - $200,000	114	9.41	2.38		
$200,001 or More	59	9.05	2.28		

Note. *$p < .01$, **$p = .001$

As shown in Table 14, results revealed a significant effect of parent relationship status, $F(1, 229) = 4.79$, $p < .05$ on the IOFS's parental strain subscale. Tukey's post hoc analysis could not be run on marital status because there were only two groups. There is a significant difference in size between the two groups, as the majority of participants were married. These results indicate that being in a marital relationship reduced parental strain when raising a child diagnosed with PANS. Results did not yield a significant effect for parent education, $F(2, 230) = 1.02$, $p > .05$, or household income $F(4, 227) = 2.17$, $p > .05$ as related to the IOFS parental distress scale, indicating relatively equivalent scores across differing levels of education and income levels as they related to parental strain. Levene's was also significant for parent's marital status with the IOFS parental strain subscale. If Levene's test is significant then equal variance cannot be assumed.

Table 14

Means and Standard Deviations of IOFS Parental Strain Subscale by Parent's Relationship Status, Parent's Level of Education, and Household Income

	n	*M*	*SD*	*F*	*p*
Parent Relationship				4.79	.030*
Married	202	30.95	5.75		
Unmarried	29	33.41	5.13		
Parent Education				1.02	.363
Less than Bachelor	52	30.48	6.83		
Bachelor's Degree	81	31.09	5.63		
Graduate Degree	100	31.83	5.12		
Household Income				2.17	.073
Less than $50,000	19	33.95	4.70		
$50,001 - $75,000	23	33.26	4.63		
$75,001 - $100,000	37	31.00	6.20		
$100,001 - $200,000	100	30.70	5.74		
$200,001 or More	53	30.72	5.86		

Note. *$p < .05$

As shown in Table 15, results did not yield a significant effect for parent relationship, $F(1, 152) = 2.46$; parent education, $F(2, 243) = .62$; or household income, $F(4, 150) = 1.76$, all $p > .05$ as related to the IOFS disruption of social and family relationships subscale, indicating relatively equivalent scores across differing levels of marital status, education and income levels as they related to disruption of social and family relationships.

Table 15

Means and Standard Deviations of IOFS Disruption of Social and Family Relationships Subscale by Parent's Relationship Status, Parent's Level of Education, and Household Income

	n	*M*	*SD*	*F*	*p*
Parent Relationship				2.46	.119
Married	130	25.50	5.63		
Unmarried	24	27.46	5.62		
Parent Education				.62	.537
Less than Bachelor	36	24.92	6.61		
Bachelor's Degree	55	26.22	5.44		
Graduate Degree	155	25.98	5.23		
				1.76	.139
Household Income					
Less than $50,000	18	27.00	5.79		
$50,001 - $75,000	15	28.07	4.22		
$75,001 - $100,000	25	26.92	5.67		
$100,001 - $200,000	64	24.66	5.79		
$200,001 or More	33	25.58	5.51		

Note. All ps, ns.

As shown in Table 16, results revealed a significant effect of parent relationship status, $F(1, 252) = 21.41$, $p < .001$ on the IOFS's parental coping subscale. Tukey's post hoc analysis could not be run on marital status because there were only two groups. There is a significant difference in size between the two groups, as the majority of participants were married. These results indicate that being in a marital relationship increased parental coping when raising a child diagnosed with PANS. The lower parental coping scores on this subscale indicates a higher level of coping skills. Results also suggested no

significant effect of parent education level, $F(2, 253) = .75$, $p > .05$ or household income $F(4, 249) = .71$, $p > .05$ on the IOFS's parental coping subscale, indicating relatively equivalent scores across differing levels of education and income as they related to parental coping.

Table 16

Means and Standard Deviations of IOFS Coping Subscale by Parent's Relationship Status, Parent's Level of Education, and Household Income

	n	*M*	*SD*	*F*	*p*
Parent Relationship				21.41	.000*
Married	225	8.35	2.06		
Unmarried	29	10.24	2.18		
Parent Education				.75	.473
Less than Bachelor	55	8.27	2.09		
Bachelor's Degree	93	8.72	2.00		
Graduate Degree	108	8.56	2.30		
Household Income				.71	.589
Less than $50,000	21	9.29	3.04		
$50,001 - $75,000	25	8.48	2.18		
$75,001 - $100,000	38	8.68	1.80		
$100,001 - $200,000	110	8.47	2.09		
$200,001 or More	60	8.48	2.05		

Note. *$p < .001$

As shown in Table 17, results did not yield a significant effect for parent relationship, $F(1, 142) = 3.17$, $p > .05$ or parent education $F(4, 140) = 2.54$, $p > .05$ as related to the total IOFS scale, indicating relatively equivalent scores across differing levels of marital status and education as they related to the total IOFS. Results did reveal a significant effect of household income, $F(4, 140) = 2.54$, $p < .05$ on the total IOFS.

However, Tukey's post hoc analysis for household income levels revealed no significance at any income level so the significance of household income's effect on IOFS total score is questionable.

Table 17

Means and Standard Deviations of IOFS Total by Parent's Relationship Status, Parent's Level of Education, and Household Income

	n	*M*	*SD*	*F*	*p*
Parent Relationship				3.17	.077
Married	125	9.39	2.37		
Unmarried	19	10.78	1.86		
Parent Education				.13	.876
Less than Bachelor	34	57.29	12.21		
Bachelor's Degree	53	57.91	10.80		
Graduate Degree	58	58.53	11.26		
Household Income				2.54	.043*
Less than $50,000	15	63.93	9.96		
$50,001 - $75,000	15	62.33	8.84		
$75,001 - $100,000	24	58.92	10.06		
$100,001 - $200,000	59	55.44	12.04		
$200,001 or More	32	57.28	11.07		

Note. *$p < .05$.

Research Question Two

Research Question Two: Are there differences in level of family impact, as measured by the IOFS when raising a child with PANS/PANDAS, when compared by levels of OCD symptom severity as measured by the Children's Yale-Brown Obsessive-

Compulsive Scale – Parent Report (CY-BOCS-PR)?

Ho_2. There will be no significant differences in scores of total impact on family as measured by parents' self-reports using the IOFS when compared with child's OCD symptom severity level using the CY-BOCS-PR.

A linear regression was run to test the relationship between OCD symptom severity and the impact on the family using the IOFS total score. This equation can also be used to predict values of the dependent variable or the IOFS total score based on OCD symptom severity. Tests for normality, independence, linearity, homoscedasticity, and collinearity assumptions were also verified. The overall model predicting total impact on family scores (IOFS) from OCD symptom severity was significant, $F(1, 135) = 84.00$, $p < .001$, and accounted for 38.4% of the variance. The results can be found in Table 18.

Table 18

Summary of Linear Regression Analysis Predicting Total Impact On Family with OCD Symptom Severity

Variable	*B*	*SEB*	*β*	*95% CI*
OCD Severity	0.91	0.10	0.62*	[18.90, 32.94]
R^2	0.38			
F	84.00*			
ΔR^2	0.38			
ΔF	84.00*			

Note. $N = 137$. CI = confidence interval. *$p < .001$. $F(1, 135) = 84.00$.

Additional linear regressions were run to test the relationship between OCD symptom severity and the impact on the family using the IOFS subscales. This equation can also be used to predict values of the dependent variable or the IOFS subscale score based on OCD symptom severity. Tests for normality, independence, linearity, homoscedasticity, and collinearity assumptions were also verified. The overall model predicting financial impact using the IOFS financial subscale from OCD symptom severity was significant, $F(1, 252) = 67.51$, $p < .001$, and accounted for 21.1% of the variance. The results can be found in Table 19.

Table 19

Summary of Linear Regression Analysis Predicting Financial Impact with OCD Symptom Severity

Variable	*B*	*SEB*	*β*	*95% CI*
OCD Severity	0.14	0.02	0.46*	[3.48, 5.91]
R^2	0.21			
F	67.51*			
ΔR^2	0.21			
ΔF	67.51*			

Note. $N = 254$. CI = confidence interval. *$p < .001$. $F(1, 252) = 67.51$.

The overall model predicting parental strain using the IOFS parental strain subscale from OCD symptom severity was significant, $F(1, 218) = 120.86$, $p < .001$, and

accounted for 35.7% of the variance. The results can be found in Table 20.

Table 20

Summary of Linear Regression Analysis Predicting Parental Strain with OCD Symptom Severity

Variable	*B*	*SEB*	*β*	*95% CI*
OCD Severity	0.44	0.04	0.60*	[12.82, 18.56]
R^2	0.36			
F	120.86*			
ΔR^2	0.36			
ΔF	120.86*			

Note. $N = 220$. CI = confidence interval. *$p < .001$. $F(1, 218) = 120.86$.

The overall model predicting disruption of social and family relationships using the IOFS social disruption subscale from OCD symptom severity was significant, $F(1, 145) = 85.77$, $p < .001$, and accounted for 37.2% of the variance. The results can be found in Table 21.

Table 21

Summary of Linear Regression Analysis Predicting Disruption of Social and Family Relationships with OCD Symptom Severity

Variable	*B*	*SEB*	*β*	*95% CI*
OCD Severity	0.46	0.05	0.61*	[6.08, 13.09]
R^2	0.37			
F	85.77*			
ΔR^2	0.37			
ΔF	85.77*			

Note. $N = 147$. CI = confidence interval. $^*p < .001$. $F(1, 145) = 85.77$.

There was no significant relationship between OCD symptom severity and the IOFS coping subscale. The overall model predicting parental coping using the IOFS parental coping subscale from OCD symptom severity was not significant, $F(1, 238) = 1.78$, $p > .05$.

Research Question Three

Research Question Three: Are there differences between the levels of family impact, as measured by the IOFS when raising a child with PANS/PANDAS, when compared with the length of time in months from onset of symptoms to diagnosis?

H_{O3}. There will be no significant differences in scores of total impact on family as measured by parents' self-reports using the IOFS when compared with length of time from onset of symptoms until diagnosis.

A linear regression was run to test the relationship between the duration in months between onset of symptoms and diagnosis with the impact on the family using the IOFS total score. This equation can also be used to predict values of the dependent variable or the IOFS total score based on duration between onset and diagnosis. Tests for normality, independence, linearity, homoscedasticity, and collinearity assumptions were also verified. The overall model predicting total impact on family scores (IOFS) from duration between onset and diagnosis was not significant, $F(1, 132) = 1.84$, $p > .05$, and accounted for only 1.4% of the variance. The results can be found in Table 22.

Table 22

Summary of Linear Regression Analysis Predicting Total Impact On Family With Duration Between Onset and Diagnosis

Variable	*B*	*SEB*	*β*	*95% CI*
Duration	0.04	0.03	0.12	[55.11, 59.81]
R^2	0.01			
F	1.84			
ΔR^2	0.01			
ΔF	1.84			

Note. $N = 134$. CI = confidence interval. $p > .05$. $F(1, 132) = 1.84$.

Additional linear regressions were run to test the relationship between the duration in months between onset of symptoms and diagnosis with the impact on the family using the IOFS subscales of financial, parental strain, and disruption of social and

family relationship impact. The overall model predicting the financial impact on the family from duration between onset and diagnosis was significant $F(1, 248) = 9.16$, $p < .01$, but accounted for only 3.6% of the variance. The overall model predicting parental strain from duration between onset and diagnosis was also significant $F(1, 212) = 5.69$, $p < .05$, but accounted for only 2.6% of the variance. The overall model predicting disruption of social and family relationship impact from duration between onset and diagnosis was not significant, $F(1, 142) = 3.15$, $p > .05$, and accounted for 2.2% of the variance. The results can be found in Tables 23 through 25.

Table 23

Summary of Linear Regression Analysis Predicting Financial Impact on Family With Duration Between Onset and Diagnosis

Variable	*B*	*SEB*	*β*	*95% CI*
Duration	0.01	0.00	0.19*	[8.91, 9.64]
R^2	0.04			
F	9.16*			
ΔR^2	0.04			
ΔF	9.16*			

Note. $N = 250$. CI = confidence interval. *$p < .05$. $F(1, 248) = 9.16$.

Table 24

Summary of Linear Regression Analysis Predicting Parental Strain With Duration Between Onset and Diagnosis

Variable	*B*	*SEB*	*β*	*95% CI*
Duration	0.03	0.01	0.16*	[29.81, 31.68]
R^2	0.03			
F	5.69*			
ΔR^2	0.03			
ΔF	5.69*			

Note. $N = 214$. CI = confidence interval. $^*p < .05$. $F(1, 212) = 5.69$.

Table 25

Summary of Linear Regression Analysis Predicting Disruption of Social and Family Relationship Impact With Duration Between Onset and Diagnosis

Variable	*B*	*SEB*	*β*	*95% CI*
Duration	0.02	0.01	0.15	[24.24, 26.51]
R^2	0.02			
F	3.15			
ΔR^2	0.02			
ΔF	3.15			

Note. $N = 144$. CI = confidence interval. $p > .05$. $F(1, 142) = 3.15$.

In addition, Pearson's Product Moment correlations were computed to test for relationships among duration in months between onset of symptoms and diagnosis and OCD severity, IOFS subscales and IOFS total score. As can be seen in Table 26, duration was significantly positively related to OCD symptom severity, the IOFS financial subscale, and the IOFS parental strain subscale but not to IOFS coping subscale or IOFS total score (r ranging from .12 to .19, $p < .05$) indicating that the longer it takes to get a diagnosis, the higher the impacts on the OCD symptom severity. IOFS financial and IOFS parental strain scales but no significant relationship was found between duration and IOFS disruption in family and social relations subscale, IOFS coping or the total IOFS score.

Table 26

Pearson Product-Moment Correlations Between Duration Between Onset of Symptoms and Diagnosis with OCD Symptom Severity, IOFS Subscales and IOFS Total

	OCD Symptom Severity	IOFS Financial Subscale	IOFS Strain Subscale	IOFS Relations Subscale	IOFS Coping Subscale	IOFS Total	*M*	*SD*
Duration	.12*	.19**	.16*	.15	.07	.12	24.87	33.27
M	35.75	9.59	31.27	25.82	8.56	58.01		
SD	7.70	2.35	5.71	5.64	2.15	11.26		

Note. *$p < .05$, **$p < .001$

Summary

The three research questions guiding this investigation were analyzed using descriptive statistics, ANOVAs, and regression analysis.

Research Question One

The findings indicated that the first null hypotheses (Ho_1: There will be no significant differences in scores of total impact on family as measured by parents' self-reports using the IOFS when compared with current relationship status, educational attainment and income level for the parents) should be accepted. As seen in Table 17, results did not yield a significant effect for parent relationship or parent education ($p > .05$) as related to the total IOFS scale, indicating relatively equivalent scores across differing levels of marital status and education as they related to the total IOFS. Results did reveal a significant effect of household income, $F(4, 140) = 2.54$, $p < .05$ on the total IOFS. However, Tukey's post hoc analysis for household income levels revealed no significance at any income level so the significance of household income's effect on IOFS total score is questionable. However, when analyzing the subscales of the IOFS, significant relationships were found for these demographic variables.

Financial subscale. As seen in Table 13, results revealed a significant effect of parent relationship status, $F(1, 267) = 11.62$, $p < .01$ and household income $F(4, 264) = 3.97$, $p < .01$ on the IOFS's financial subscale. Tukey's post hoc analysis for household income revealed that family income less than $50,000 ($M = 10.74$, $SD = 1.86$) had significantly higher scores on the IOFS financial subscale than families with household

income greater than $200,001 ($M$ = 9.05, SD = 2.28), $p < .05$. Tukey's also showed significantly higher scores on the IOFS financial subscale for family income in the $50,001 - $75,000 range ($M$ = 10.62, SD = 1.70) than families with household income greater than $200,001 ($M$ = 9.05, SD = 2.28), $p < .05$. Results did not yield a significant effect for parent education ($p > .05$) as related to the IOFS financial scale, indicating relatively equivalent scores across differing levels of education as they related to financial distress.

Parental strain subscale. As seen in Table 14, there was a significant effect found for parent relationship status, $F(1, 229) = 4.79$, $p < .05$ on the IOFS's parental strain subscale. These results indicated that being in a marital relationship reduced parental strain when raising a child diagnosed with PANS. Results did not yield a significant effect for parent education or household income ($p > .05$) as related to the IOFS parental distress scale, indicating relatively equivalent scores across differing levels of education and income levels as they related to parental strain.

Disruption of social and family relationships subscale. As seen in Table 15, results did not yield a significant effect for parent relationship, parent education, or household income, all $p > .05$ as related to the IOFS disruption of social and family relationships subscale, indicating relatively equivalent scores across differing levels of marital status, education and income levels as they related to disruption of social and family relationship.

Parental coping subscale. As shown in Table 16, results revealed a significant effect of parent relationship status, $F(1, 252) = 21.41$, $p < .001$ on the IOFS's parental coping subscale. These results indicated that being in a marital relationship increased parental coping when raising a child diagnosed with PANS. The lower the parental coping scores on this subscale indicates a higher level of coping skills. Results also suggested a significant effect of parent education level, $F(2, 253) = .75$, $p < .05$ on the IOFS's parental coping subscale. Tukey's post hoc analysis for parent education levels revealed that having less than a bachelor's degree ($M = 8.27$, $SD = 2.09$) or a graduate degree ($M = 8.56$, $SD = 2.30$) had slightly lower scores on the IOFS coping subscale than parents with bachelor's degree ($M = 8.72$, $SD = 2.00$), $p < .05$. These results indicated that being educated at a level below or above a bachelor's degree may increase parental coping skills slightly. Results did not yield a significant effect for household income ($p > .05$) as related to the IOFS parental coping scale, indicating relatively equivalent scores across differing levels of income as they related to parental coping.

Research Question Two

The second null hypotheses (Ho_2. There will be no significant differences in scores of total impact on family as measured by parents' self-reports using the IOFS when compared with child's OCD symptom severity using the CY-BOCS-PR) should be rejected. As seen in Table 18, the overall model predicting total impact on family scores (IOFS) from OCD symptom severity was significant, $F(1, 135) = 84.00$, $p < .001$, and accounted for 38.4% of the variance.

Financial subscale. As seen in Table 19, the overall model predicting the financial impact on the family from OCD symptom severity was significant $F(1, 252) = 67.51$, $p < .001$, and accounted for 21% of the variance.

Parental strain subscale. As seen in Table 20, the overall model predicting parental strain on the family from OCD symptom severity was significant $F(1, 218) = 120.86$, $p < .001$, and accounted for 36% of the variance.

Disruption of social and family relationships subscale. As seen in Table 21, the overall model predicting the disruption of social and family relationships from OCD symptom severity was significant $F(1, 145) = 85.77$, $p < .001$, and accounted for 37.2% of the variance.

Parental coping subscale. There was no significant relationship between OCD symptom severity and the IOFS coping subscale, $p > .05$.

Research Question Three

The third null hypotheses (Ho_3. There will be no significant differences in scores of total impact on family as measured by parents' self-reports using the IOFS when compared with length of time in months from onset of symptoms until diagnosis) should be accepted. As seen in Table 22, the overall model predicting total impact on family scores (IOFS) from duration between onset and diagnosis was not significant, $F(1, 132) = 1.835$, $p > .05$, and accounted for only 1.4% of the variance. Additional linear regressions were run to test the relationship between the duration in months between onset of symptoms and diagnosis with the impact on the family using the IOFS subscales of

financial, parental strain, and disruption of social and family relationship impact, and also with OCD symptom severity.

Financial subscale. As seen in Table 23, the overall model predicting the financial impact on the family from duration between onset and diagnosis was significant $F(1, 248) = 9.16$, $p < .05$, but accounted for only 3.6% of the variance.

Parental strain subscale. As seen in Table 24, the overall model predicting parental strain from duration between onset and diagnosis was also significant $F(1, 212) = 5.69$, $p < .05$, but accounted for only 2.6% of the variance.

Disruption of social and family relationships subscale. As seen in Table 25, the overall model predicting disruption of social and family relationship impact from duration between onset and diagnosis was not significant, $F(1, 142) = 3.15$, $p > .05$, and accounted for 2.2% of the variance.

OCD symptom severity. Pearson Product Moment correlations were computed to test for relationships among duration in months between onset of symptoms and diagnosis and OCD severity, IOFS subscales and IOFS total score. As can be seen in Table 26, duration was significantly positively correlated to OCD symptom severity, the IOFS financial subscale, and the IOFS parental strain subscale but not to IOFS coping subscale or IOFS total score (r ranging from .12 to .19, $p < .05$). The results suggested that the longer it takes to get a diagnosis, the higher the impact on OCD symptom severity, IOFS financial and IOFS parental strain subscales. No significant relationships were found between duration and IOFS disruption in family and social relations subscale,

IOFS coping or the total IOFS score.

CHAPTER V
DISCUSSION AND CONCLUSIONS

This chapter is a summary of the findings that resulted from this online quantitative study about family impacts while raising a child diagnosed with PANS. This research examined the total impact on the family using the IOFS assessment scale as reported by parents. The researcher explored how demographic variables (e.g. parent's relationship status, parent's education level, and household income) and illness factors (e.g. OCD symptom severity and duration in months between onset and diagnosis) mitigated the total score on the IOFS. In addition, subscales of the IOFS were also calculated to explore their relationship to OCD symptom severity and duration between onset of symptoms and diagnosis. A discussion about the study's results, limitations, implications, and recommendations for future research will also be addressed in this chapter.

Theoretical Framework

Family systems theory and family stress theory were the theoretical lenses used to guide this examination of how a family is impacted when raising a child with PANS (Bowen, 1966; Hill, 1958). These theories were chosen for their usefulness in understanding the impact a serious illness may have on the family and the internal and external interactions that may mitigate the impacts to the family system (Bowen, 1966; Hill, 1958). Family systems theory views the family as a system with interdependent parts comprised of the members of the family, their relationships with each other, and

their interactions within and outside the family unit, which requires they be analyzed and understood as a whole or system (Whitchurch & Constantine, 1993). A change in one member of the family impacts the other members of the family both individually and collectively. Evidence from past research is compelling that PANS creates substantial impairment in both the child and the family's functioning (Calaprice et al., 2017; McClelland et al., 2015; Swedo et al., 2012; Witt et al., 2009). Findings from this study indicate that the total impact on the family is significant when raising a child with PANS as evidenced by the subscale and total scores on the IOFS. This investigation also revealed that being in a marital relationship was a protective factor and allowed the parents to cope better as indicated by the IOFS parental coping subscale and IOFS parental strain subscale. Children with PANS display significant OCD symptoms and in this study the vast majority of the children (90.1%) were rated in the severe and extreme clinical ranges. The unpleasant and unwanted behaviors of OCD often create disruptions within the family system and may reduce quality of life, increase parent's work absenteeism, add financial burdens, and limit social time which can lead to relational difficulties, fatigue, and physical or mental health problems (Möller-Leimkühler, & Wiesheu, 2012; Vitanza et al., 1999). The results of this investigation were consistent with those findings because OCD symptom severity was a significant predictor of total impact on the family scores.

In addition to a family systems framework, family stress theory has shown to be useful in exploring parenting stress and coping practices (Hill, 1958). According to Hill's

model, the stressful event may have sufficient consequences to alter the family system depending upon if the family has enough resources to handle the event and how much of a crisis the event is perceived to be (Hill, 1958). The findings of this study support the notion that parents being in a marital relationship and having a higher household income enabled them to cope more positively with their child's PANS illness as evidenced by scores on the IOFS financial and parental strain subscales. In addition, being married was also significantly related to the IOFS coping subscale.

Discussion

A total of 345 parents completed this online quantitative study and provided information on how their family was impacted when raising a child diagnosed with PANS. Due to exclusion criteria, the sample size was reduced to 312 participants for analysis. Not all 312 participants completed every question, so the sample size was smaller when data was missing. The specific sample size for each analysis was noted.

Demographic Factors

The majority of participants were biological mothers (87.1%), married (85.7%), Caucasian (92.9%), college degreed (77.1%), and had a total household income greater than $75,000 (79.9%). The sample was not very diverse with only 22 participants not being white, only 27 having no college education, and only 29 having a household income less than $50,000. It may be helpful in future research to have a more diverse sample to see if results would vary. The majority of the children in the study were male (59.2%) which was expected, but not consistent with research that indicated the

preponderance of PANS is three times higher for boys than girls (Williams & Swedo, 2015).

The average age of parent participants was 48 years old and the average age for the focal child at the time of this study was 14 years old. The majority of parents in this study were married (85.7%) which demonstrated significance in being a positive coping factor. Having the support of a partner seemed to mitigate the total impact on the family as evidenced by significance for the coping subscale on the IOFS. The majority of the participants (77.1%) have been married over eleven years.

Illness Factors

Data were also gathered about any family history of autoimmune disorders, but the data did not suggest a relationship with only 9.1% of respondents indicating yes. Research has suggested a possible link between maternal autoimmune diseases and neuropsychiatric disorders in children but the results of this study did not support those findings (Murphy et al., 2010). Restricted food intake is often linked as a symptom of PANS and 53.7% of parents reported this as being the case for their child. This was consistent with other research where approximately half of the children studied in a recent PANS study also reported restricted eating (Calaprice et al., 2017). Several parents commented on this question with explanations of their child's avoidant or restricted food intake being related to sensory issues and fears of vomiting or contamination. This is consistent with other research that found that these disordered eating patterns are typically related to fears of choking, vomiting, swallowing, or contamination (Toufexis et

al., 2015). Restricted eating can lead to anorexia in approximately 10-20% of PANS patients (Sokol, 2014).

According to the NIMH, children with PANS often display dramatic ups and downs in the severity of their OCD. Children with PANS have a very sudden onset or worsening of their symptoms, often followed by a gradual improvement and this tends to remit and relapse. A sudden worsening of OCD is considered an exacerbation of symptoms or a flare (NIMH, n.d.). Parents were asked to report information about the number of flares their child had per year and in which months the flares occurred. The months of September, October, November, December and January were reported as the worst months for an exacerbation of symptoms and most children had more than five flares in any given year. In the winter months after school starts, children tend to be exposed to more viruses which may explain why children have more flares during these months (CDC, n.d.).

Diagnostic Factors

Diagnosing PANS in children is difficult because of inconsistent research results but the diagnosis is receiving heightened interest by medical and psychiatric professionals. Differentiating a PANS diagnosis from OCD in children is difficult because of this inconsistent medical research (Murphy et al., 2014). PANS continues to confuse the medical community because it overlaps with so many other disorders and mental health conditions (Chang et al., 2015). In this study, many parents reported being the first to suspect a PANS diagnosis (50.6%) and seeing more than five doctors before

being diagnosed with PANS (31%). The findings also suggested a wide range of professionals diagnosing and treating children. On the survey, parents were offered choices of neurologist, pediatrician, psychiatrist, general practitioner, psychologist, or mental health professionals and most often selected 'other' and filled in another type of professional. These included PANS specialists, immunologists, rheumatologists, biomedical, integrative, and naturopathic doctors as well.

The child's age at the time of onset of symptoms averaged six years with a range from three to ten years. Several studies have reported the average age of onset of symptoms to be between four and nine years of age (Bernstein et al., 2010; Mahony et al., 2017; Murphy et al., 2015). The current investigation appears consistent with other research, but with a slightly broader range. The child's age at the time of diagnosis averaged nine years with a range from six to twelve years. Parents reported the average time between onset of symptoms and diagnosis was over two years. The most surprising result from this current investigation was not finding a significant relationship between the length of time it took for the child to get diagnosed and the scores for total impact on the family. This may be due to the smaller sample size for the IOFS total score because parents skipped questions used to compute the total score. A significant relationship was found between duration and the IOFS financial subscale and the IOFS parental strain subscale but not between duration and the IOFS disruption of social and family relationship subscale or total score on the IOFS.

Treatment Factors

Parents answered questions about who was currently treating or had treated their child in the past, as well as current and past treatment protocols. Participants were presented with 10 doctor types to choose from – pediatrician, psychiatrist, neurologist, immunologist, general practitioner, psychologist, mental health professional, behavioral therapist, occupational therapist, and physical therapist and could select as many that applied. For current treatment providers, the 'other' category was selected most of the time (31.1%) followed by pediatrician at 28.8%. Participants provided 18 different write-in treatment providers. For current treatment protocols participants were presented with 13 options including antibiotics (57.1%), anti-inflammatories (39.1%) and an 'other' category (35.3%).

One hundred and ten participants wrote in another type of current treatment protocol. In regards to past treatment providers and protocols, the percentages were lower but approximately 100 parents added additional providers and protocols than those listed on the survey. This suggests that PANS is very difficult to effectively treat and it appears that parents are willing to see multiple treatment providers and try multiple treatment protocols searching for who and what will work for their child. In addition, more than 50% of the parents responded that they had to travel more than 50 miles at some point during their child's illness in order to receive treatment.

OCD Symptom Severity Factors

Since PANS is a subset of OCD, the Children's Yale-Brown Obsessive-

Compulsive Scale – Parent Report (CY-BOCS-PR) was used to measure OCD symptom severity (Storch et al., 2006). This scale is comprised of a total of ten questions, five about the child's compulsions and five about the child's obsessions that combine for a total score between zero and fifty. In this study, the vast majority of parents (90%) indicated their child's OCD symptoms were in the severe to extreme clinical ranges, meaning their symptoms are significantly interfering with daily functioning. OCD symptom severity was compared with the three IOFS subscales (e.g., financial, parental strain, and disruption of social and family relationships) and the IOFS total score. Significant positive correlations were found between OCD symptom severity and all three subscales as well as IOFS total score. In addition, regression modeling indicated that OCD symptom severity accounted for 38.4% of the variance in the total impact on the family scores.

These results are not surprising because children with OCD often involve family members in their rituals and compulsions (Futh et al., 2012). Family accommodation may include yielding to a child's unreasonable requests and children may react with rage or violence when these demands are not met (Caporino et al., 2012; Lebowitz et al., 2011). Further research by Jacob et al. (2012) revealed that parental stress was higher when the child's compulsions involved family members. Futh et al. (2012) also found that more than half of the parents reported struggling with deciding between resistance and engagement in accommodating their child's compulsions.

This investigation's findings are consistent with other research indicating that tic

severity was also positively correlated with higher total family impact scores (Woods et al., 2005). Research also indicated that parents of children with OCD had an increased risk of parental distress and in this study that was demonstrated with the high parental strain scores on the IOFS (Algood et al., 2013; Berge & Holm, 2007; Busch & Barry, 2007; Steward et al., 2015). Storch et al. (2009) also found that parents were significantly distressed about their child's OCD symptoms and feelings of worry, anger, uncertainty, and unresolved sorrow were also positively correlated with symptom severity. Greater OCD symptom severity and greater levels of family accommodation were also positively correlated with parent's feelings of irritation, intolerance, guilt, insecurity, and embarrassment (Torres et al., 2012).

Limitations

Limitations of the current study may affect its ability to be generalized to the entire population. One limitation of this study was the proportion of mothers who participated. Getting more fathers to participate may allow researchers a broader perspective on understanding how a PANS diagnosis impacts the family. A second limitation was the lack of diversity of the sample being that the vast majority were well-educated white parents with relatively high social and economic status (SES). Results may be different if a more diversified sample of participants was included and analysis could be done to see if SES variations would affect research results. Additional limitations included mortality of subjects that dropped out of the survey before completion of all the questions. The interaction of the setting (e.g., lighting, time of day,

noise levels) was also not controlled for because participants could complete the study any place where they had Internet connectivity.

The age of the child at the time s/he was diagnosed was restricted to four to seventeen years which excluded some participants. Several parents contacted the investigator unhappy about this exclusion criteria because their child was not diagnosed until they were older than 17. Another parent also reached out with additional information about how many different doctors and other professionals they had seen and did not feel the survey allowed her to express this adequately. Another mom expressed concern about the flare questions on the survey. She indicated that for some children who have had PANS for a prolonged period of time they no longer follow a flare and remission pattern as indicated by the NIMH. This parent indicated that sometimes children experience symptoms that never abate, but rather have constant symptoms that only increase or decrease in severity. The variability of responses from participants revealed that the PANS journey is different for each child and family. A quantitative study does not necessarily allow this variability in experiences to be fully captured and future supplemental qualitative research may be helpful.

Implications

The findings from this study may be useful to parents, educators, mental health professionals and medical professionals who work with children diagnosed with PANS and their families.

1. The severity of the OCD symptomology should be given serious attention. Over

90% of the participants indicated that their child's OCD symptom severity was in the severe and extreme clinical categories. Treatment of childhood OCD is often approached therapeutically from a CBT perspective but this treatment protocol alone may not provide sufficient relief for these children and their families.

2. In this study, OCD symptom severity was the most significant predictor of the total impact on the family. Other research has shown similar results (Barrett et al., 2002; Jacob et al., 2012; Storch et al., 2009; Torres et al., 2012). Parents may benefit from education and training on ways to resist accommodation of their child's OCD rituals. Professionals working with families that have a child diagnosed with PANS should work closely with parents to help them learn and implement new strategies to avoid accommodating their child's demands which may result in increased symptom severity and higher parental stress (Storch et al., 2010).
3. Having a strong support system, such as being in a long-term marital relationship, appeared to mitigate some of the negative impact to the family. For unmarried parents, having a strong support system of extended family or PANS support groups may help reduce stress.
4. The average time it took families to get a PANS diagnosis was two years. Most parents reported seeing multiple medical professionals before receiving a diagnosis. Although this study did not find a significant relationship between the time between onset of symptoms and diagnosis and the total impact on the family,

it did find a relationship between duration and the financial impact to the family and parental strain. The burden families face as they search for a provider to treat their child can be costly, both financially and emotionally.

Recommendations for Future Research

The findings of this study suggest the need for more research to better understand what variables mitigate the impact to families and how to best strengthen families facing a PANS illness. The majority of the participants in this study were mothers who are likely the primary caretakers, but additional research involving more fathers' perceptions of how PANS impacts their family may be useful. The lack of diversity in the sample was surprising and future research with a more diverse sample may be helpful to see if any differences exist. Although the IOFS has a sibling scale, it was not included in this study, but perhaps future research could also examine how a PANS illness impacts siblings in the family. Additional research regarding how IOFS scores for PANS compare with other childhood illnesses may also be insightful. Another consideration could be to focus on how a PANS illness may impact marital satisfaction. Marital satisfaction is not a subscale on the IOFS but perhaps an additional assessment tool could be included in future research. Most research continues to focus on the medical aspects of the illness with little attention given to family impacts. This investigation may help researchers gain more knowledge about what factors are associated with negative ramifications for families raising a child with PANS which in turn, may help professionals when working with these families.

Summary

The goal of this study was to contribute to the research and knowledge base regarding how a family is impacted when a child is diagnosed with PANS and what factors may mitigate that impact. The researcher discovered only one other study that examined PANS from a family impact perspective and this study adds to the limited amount of existing research in this area (McClelland, 2015). Furthermore, this study explored variables that were thought to possibly influence family impact and explored relationships between demographic factors, illness factors, and symptom severity with impact on the family.

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Appendix A

Permission from PANDAS Network

August 10, 2017

Texas Woman's University
Institutional Review Board
ACT, 7th Floor
304 Administration Drive
Denton, TX 76201

Dear Institutional Review Board at Texas Woman's University:

On behalf of the PANDAS Network, I am writing to grant permission for Marcey Mettica (PhD Candidate in Family Systems) to conduct her research titled, "*Family Impacts Reported by Parents Raising Children Diagnosed with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS)"* online through the PANDAS Network website. Marcey Mettica has informed me of the design of the study and the estimated time to complete the online survey. I understand she will recruit up to 200 of our network subscribers to complete an online survey over the next six months.

We are happy to participate in this study and contribute to this important research. I support this effort and will provide any assistance necessary for the successful implementation of this study. If you have any questions, please do not hesitate to call. I can be reached at (619) 370-5828.

Sincerely,

Diana Pohlman
Executive Director, PANDAS Network
www.PANDASNetwork.com

Appendix B

Participant Recruitment Script
Announcement of an anonymous online research study
posted on the PANDASNetwork.org website and in electronic newsletter

You are invited to participate in an
anonymous online research study
to explore how PANS impacts a family.

For the purposes of this study, PANS (Pediatric Acute-Onset Neuropsychiatric Syndrome) is inclusive of diagnoses of PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep) and PITAND (Pediatric Infection-Triggered Autoimmune Neuropsychiatric Disorder) and all will be referred to as PANS. PANS is defined by the National Institute of Mental Health as an abrupt, dramatic onset of Obsessive-Compulsive Disorder (OCD) and the concurrent presence of additional neuropsychiatric symptoms. "OCD is characterized by the presence of obsessions and/or compulsions. Obsessions are recurrent and persistent thoughts, urges, or images that are experienced as intrusive and unwanted, whereas compulsions are repetitive behaviors or mental acts that an individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly" (APA, 2013, p. 235).

If you are a biological or adoptive parent, stepparent, or legal guardian at least 18 years of age and have been the primary caregiver for the past six months of a child, between the ages of 4 and 17, who has been diagnosed with PANS
and your child has displayed OCD symptoms during their illness,
you are invited to participate.

As a parent of a child diagnosed with PANS this is your opportunity to help medical, psychological, and educational professionals gain better insight in understanding how the family is impacted by the child's illness.

Your participation is voluntary and the survey should take
no more than 60 minutes of your time and you may stop at any time.

If interested, please click on the link below to be connected to the survey
http://www.PsychData.com/s.asp?SID=777000

Note: This research is part of a doctoral degree requirement in Family Studies at Texas Woman's University (TWU) in Denton, Texas and will be approved by the TWU Institutional Review Board before launching. There is a potential risk of loss of confidentiality in all email, downloading, and internet transactions. Confidentiality will be protected to the extent that is allowed by law. This is an anonymous online survey. No one will know your name and no identifying information will be asked during the online survey. If you have any questions about the study or your participation in it, you may contact the principal researcher, Marcey Mettica, at mmettica@twu.edu or her faculty advisor, Dr. Hwang at shwang@twu.edu

Appendix C

Questionnaire

Directions: Please answer the following questions about your family.

1. What is the relationship of the person completing the survey to the child with PANS (select one):

    - ☐ Biological Mother
    - ☐ Adoptive Mother
    - ☐ Biological Father
    - ☐ Adoptive Father
    - ☐ Step-Mother
    - ☐ Step-Father
    - ☐ Grandmother
    - ☐ Grandfather
    - ☐ Female Legal Guardian
    - ☐ Male Legal Guardian
    - ☐ Other: _____(please specify)

2. Date of birth of person completing the survey: _____ (mm/dd/yy)

3. Current Relationship Status (check one):

    - ☐ Married
    - ☐ Remarried

- Separated
- Divorced
- Widowed
- Single, never married
- Cohabitating Couple
- Other: _____ (please specify)

4. How many years have you been in your current relationship status (check one):
   - Less than one year
   - One to five years
   - Five to ten years
   - Ten to fifteen years
   - Fifteen to twenty years
   - Over twenty years
5. Highest level of education completed by person completing this survey (check one):
   - Some High School
   - High School or GED
   - Associate's Degree, Vocational, or other 2-year Degree
   - College or other 4-year degree
   - Graduate Degree
6. Ethnicity of person completing this survey (check one):

- ☐ African American or Black
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Hispanic or Latino
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White
- ☐ Other: _____ (please specify)

7. Total Household Net Income (check one):

- ☐ $25,000 or less
- ☐ $25,001 - $50,000
- ☐ $50,001 - $75,000
- ☐ $75,001 - $100,000
- ☐ $100,001 - $200,000
- ☐ $200,001 or more

Directions: Please answer these questions about the focal child diagnosed with PANS.

8. Gender of focal child (check one):

- ☐ Male
- ☐ Female
- ☐ Other: _____ (please specify)

9. Ethnicity of focal child (check one):

- African American or Black
- American Indian or Alaska Native
- Asian
- Hispanic or Latino
- Native Hawaiian or Other Pacific Islander
- White
- Other: _____ (please specify)

10. Month and year of focal child's birth: _____ (mm/yyyy)
11. Month and year focal child first experienced onset of symptoms: _____ (mm/yyyy)
12. Who first suspected a PANS/PANDAS diagnosis? (check all that apply)

- Parent
- Pediatrician
- Medical doctor (general practitioner)
- Neurologist
- Mental health professional
- Family life educator
- Psychiatrist
- Psychologist
- School personnel

- Other: _____ (please specify)

13. Please indicate who diagnosed the focal child with PANS/PANDAS:

- Pediatrician
- Medical doctor (general practitioner)
- Neurologist
- Psychiatrist
- Psychologist
- Mental health professional
- Other: _____ (please specify)

14. What diagnosis was made:

- PITAND
- PANDAS
- PANS
- Other: _____ (please specify)

15. Is there any family history of autoimmune disorders?

- Unknown
- No
- Yes
- If yes, Please specify who and what disorder: _____

15. Month and year of focal child's birth: _____ (mm/yyyy)

16. How many licensed health providers did you see before a diagnosis was made?

- None
- One
- Two
- Three
- Four
- Five
- More than five

16. Is your child CURRENTLY displaying PANS symptoms?

- Yes
- No

17. Is your child CURRENTLY being actively treated for PANS?

- Yes
- No

18. Who is CURRENTLY treating your child or family for PANS? (select all that apply)

- No one currently
- Pediatrician
- Medical Doctor (General Practitioner)
- Neurologist

- ☐ Mental Health Professional
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Behavioral Therapist
- ☐ Immunologist
- ☐ Physical Therapist
- ☐ Occupational Therapist
- ☐ Other (please specify) _____

19. How is your child and/or family CURRENTLY being treated for PANS? (select all that apply)

- ☐ Cognitive Behavior Therapy (CBT) for child only
- ☐ Cognitive Behavior Therapy (CBT) for the family
- ☐ Individual Counseling for child (not CBT)
- ☐ Family Counseling (not CBT)
- ☐ Behavioral Therapy
- ☐ PANS Support Groups
- ☐ Antibiotics
- ☐ Tonsillectomy
- ☐ Anti-inflammatory Drugs
- ☐ Psychotropic Pharmacology

- Intravenous Immunoglobulin (IVIG)
- Plasmapheresis
- No treatment currently
- Other (please specify) _____

20. Do you CURRENTLY have to travel more than 50 miles to get treatment for your child?
    - No
    - Yes
21. If you CURRENTLY have to travel more than 50 miles to get treatment for your child, how many times per month?
    - Once a month
    - Twice a month
    - Three times a month
    - Four times a month
    - Five times a month
    - More than five times a month
    - Other (please specify): _____
22. What type of treatment has your child and/or your family EVER received for your child's PANS diagnosis? (select all that apply)
    - Cognitive Behavior Therapy (CBT) for child only

- Cognitive Behavior Therapy (CBT) for the family
- Individual Counseling for child (not CBT)
- Family Counseling (not CBT)
- Behavioral Therapy
- PANS Support Groups
- Antibiotics
- Tonsillectomy
- Anti-inflammatory Drugs
- Psychotropic Pharmacology
- Intravenous Immunoglobulin (IVIG)
- Plasmapheresis
- No treatment currently
- Other (please specify) _____

23. Who has EVER treated your child or family for PANS (select all that apply):

- Pediatrician
- Medical Doctor (General Practitioner)
- Neurologist
- Mental Health Professional
- Psychiatrist
- Psychologist

- Behavioral Therapist
- Immunologist
- Physical Therapist
- Occupational Therapist
- None of the above
- Other (please specify) _____

24. Have you EVER had to travel more than 50 miles to get treatment for your child?

- No
- Yes

25. If you EVER had to travel more than 50 miles to get treatment for your child, how many times per month did this occur?

- Once a month
- Twice a month
- Three times a month
- Four times a month
- Five times a month
- More than five times a month
- Other (please specify): _____

26. Has your child EVER demonstrated restricted food intake as defined by limiting their eating based on a food's appearance, smell taste texture or past negative experience with the food that has resulted in weight loss for your child?

- Yes
- No
- Other (please specify): _____

According to the NIMH, children with PANS often display dramatic ups and downs in the severity of their OCD. Many children with OCD have good days and bad days, or even good weeks and bad weeks. However, children with PANS have a very sudden onset or worsening of their symptoms, followed by a gradual improvement and this tends to remit and relapse. OCD indicators that are almost always present at a relatively consistent level do not represent an exacerbation of symptoms or flare. A sudden worsening of OCD is considered an exacerbation of symptoms or a flare.

Directions: For the next three questions, please use the definition of flare outlined above as your child displaying a sudden onset or worsening of symptoms after a period of noticeable improvement.

27. Date of most recent exacerbation of symptoms: _____ (mm/yyyy)

28. How many flares or exacerbation of symptoms did your child have the past year?

- None
- One
- Two

- Three
- Four
- Five
- More than five

29. Please indicate the greatest number of flares or exacerbation of symptoms your child had in any given year?

- None
- One
- Two
- Three
- Four
- Five
- More than five

Appendix D

The Children's Yale-Brown Obsessive-Compulsive Scale – Parent Report
(CY-BOCS-PR)

Directions: Please select the option that best describes your child's symptoms at the time they had the most impact on your family. Please answer the next five questions about the obsessions or thoughts your child cannot stop thinking about. Obsessions are thoughts, ideas, or pictures that keep coming into your child's mind even though he or she does not want them to.

1. How much time does/dis your child spend thinking about these things in a day?
   - ☐ None
   - ☐ Less than 1 hour a day
   - ☐ Between 1 to 3 hours a day
   - ☐ Between 3 to 8 hours a day
   - ☐ More than 8 hours a day

2. How much do/did these thoughts get in the way of school or doing things with his or her friends?
   - ☐ They don't get in the way
   - ☐ They get in the way a little
   - ☐ They get in the way sometimes
   - ☐ They get in the way a lot
   - ☐ They keep him/her from doing everything

3. How much do/did these thoughts bother or upset your child?
   - ☐ Not at all
   - ☐ They bother him/her a little
   - ☐ They bother him/her some
   - ☐ They bother him/her a lot
   - ☐ They bother him/her so much that it is hard to do anything

4. How hard does/did your child try to stop the thoughts or ignore them?
   - ☐ He/she always tries to resist the thoughts
   - ☐ He/she tries to resist the thoughts most of the time
   - ☐ He/she tries to resist the thoughts sometimes
   - ☐ He/she usually doesn't try to resist the thoughts but wants to
   - ☐ He/she does not try to resist the thoughts

5. When your child tries to fight the thoughts, can he or she stop them?
    - He/she always can beat or stop them
    - He/she can usually beat or stop them
    - He/she can sometimes beat or stop them
    - He/she does not beat or stop them very often
    - He/she never beats or stops them

Directions: Please select the option that best describes your child's symptoms at the time they had the most impact on your family. Please answer the next 5 questions about the compulsions or habits your child cannot stop doing. Compulsions are things that your child feels he or she has to do although he or she may know they do not make sense. Sometimes your child may try to stop from doing them but this might not be possible. Your child might feel worried or angry or scared until he or she has finished what he or she has to do.

6. How much time does/did your child spend doing these things in a day?
    - None
    - Less than 1 hour a day
    - Between 1 to 3 hours a day
    - Between 3 to 8 hours a day
    - More than 8 hours a day

7. How much do/did these habits get in the way of school or doing things with his or her friends?
    - They don't get in the way
    - They get in the way a little
    - They get in the way sometimes
    - They get in the way a lot
    - They keep him/her from doing everything

8. How upset would your child feel if he or she could not do his or her habits?
    - Not upset at all
    - He/she would feel a little upset or scared
    - He/she would feel pretty upset or scared
    - He/she would feel very upset or scared
    - He/she would feel as upset or scared as possible

9. How hard does/did your child try to stop or fight the habits?
    - He/she always tries to resist the habits
    - He/she tries to resist the habits most of the time

- He/she tries to resist the habits sometimes
- He/she usually doesn't try to resist the habits but wants to
- He/she does not try to resist the habits

10. When your child tries/tried to fight the habits, can he or she beat them?
    - He/she always can beat or stop them
    - He/she can usually beat or stop them
    - He/she can sometimes beat or stop them
    - He/she does not beat or stop them very often
    - He/she never beats or stops them

Appendix E

Impact on Family Scale (Stein & Jessop, 2003)

Below are some statements that people have made about living with an ill child. Please select strongly agree, agree, disagree, or strongly disagree for each statement.

Strongly Agree 1	**Agree 2**	**Disagree 3**	**Strongly Disagree 4**

1. The illness is causing financial problems for the family	**1**	**2**	**3**	**4**
2. Time is lost from work because of hospital/doctor appointments	**1**	**2**	**3**	**4**
3. I am cutting down the hours I work to care for my child	**1**	**2**	**3**	**4**
4. Additional income is needed in order to cover medical expenses	**1**	**2**	**3**	**4**
5. I stopped working because of my child's illness	**1**	**2**	**3**	**4**
6. Because of the illness, we are not able to travel out of the city	**1**	**2**	**3**	**4**
7. People in the neighborhood treat us specially because of my child's illness	**1**	**2**	**3**	**4**
8. We have little desire to go out because of my child's illness	**1**	**2**	**3**	**4**
9. It is hard to find a reliable person to take care of my child	**1**	**2**	**3**	**4**
10. Sometimes we have to change plans about going out at the last minute because of my child's state	**1**	**2**	**3**	**4**
11. We see family and friends less because of the illness	**1**	**2**	**3**	**4**
12. Because of what we have shared we are a closer family	**1**	**2**	**3**	**4**
13. Sometimes I wonder whether my child should be treated "specially" or the same as a normal child	**1**	**2**	**3**	**4**
14. My relatives have been understanding and helpful with my child	**1**	**2**	**3**	**4**
15. I think about not having more children because of the illness	**1**	**2**	**3**	**4**

16. My partner and I discuss my child's problems together				
17. We try to treat my child as if he/she were a normal child	**1**	**2**	**3**	**4**
18. I don't have much time left over for other family members after caring for my child	**1**	**2**	**3**	**4**
19. Relatives interfere and think they know what's best for my child	**1**	**2**	**3**	**4**
20. Our family gives up things because of my child's illness	**1**	**2**	**3**	**4**
21. Fatigue is a problem for me because of my child's illness	**1**	**2**	**3**	**4**
22. I live from day to day and don't plan for the future	**1**	**2**	**3**	**4**
23. Nobody understands the burden I carry	**1**	**2**	**3**	**4**
24. Traveling to the doctor/hospital is a strain on me	**1**	**2**	**3**	**4**
25. Learning to manage my child's illness has made me feel better about myself	**1**	**2**	**3**	**4**
26. I worry about what will happen to my child in the future (when he/she grows up, when I am not around)	**1**	**2**	**3**	**4**
27. Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable	**1**	**2**	**3**	**4**

Appendix F

TEXAS WOMAN'S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title: Family Impacts Reported by Parents Raising Children with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS)

Investigator: Marcey Mettica, M.S…….mmettica@twu.edu (214) 914-1018
Advisor: Shann Hwa (Abraham) Hwang, Ph.D....shwang@twu.edu (940) 898-3155

Explanation and Purpose of the Research

You are being asked to participate in an anonymous online research study for Ms. Mettica's dissertation at Texas Woman's University. The purpose of this research is to explore how raising a child with PANS impacts the family. According to the National Institute of Mental Health (NIMH), **PANS** (Pediatric Acute-Onset Neuropsychiatric Syndrome) is inclusive of diagnoses of **PANDAS** (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep) and **PITAND** (Pediatric Infection-Triggered Autoimmune Neuropsychiatric Disorder) and ***for the purposes of this study, all will be referred to as PANS***. You have been asked to participate in this online study because you are a parent or guardian raising a child diagnosed with PANS. In order to be a participant in this study, you must be at least 18 years of age or older, be the parent or guardian of a child that was diagnosed with PANS between the ages of 4 and 17 and been the primary caretaker of said child for the past six months.

Description of Procedures

As a volunteer participant in this study you will be asked to spend less than sixty minutes of your time completing an anonymous online survey to provide information about your family and how a PANS diagnosis has impacted your family. You will first be asked questions about your family and your child such as age and gender, household income, education level, relationship status, and questions about your child's illness. Then, you will be asked more specific questions about the severity of your child's obsessions and compulsions and how PANS has impacted your family. The *Children's Yale-Brown Obsessive-Compulsive Scale – Parent Report* form consists of 10 questions that help determine the severity of your child's obsessive and compulsive symptoms. The *Impact on Family Scale* consists of 33 statements that you will be asked to rate your agreement to regarding how your child's illness has impacted your family. All

information will be given anonymously in survey-form through an online website called PsychData. Your answers will be submitted and tabulated in an anonymous fashion. This study is completely voluntary and at no time will you be personally contacted by the investigator or anyone associated with the study.

Potential Risks

Loss of confidentiality. There is a potential risk of loss of confidentiality in all email, downloading, and internet transactions. Confidentiality will be protected to the extent that is allowed by law. This is an anonymous online survey. No one will know your name and no identifying information will be asked during the online survey. You may save your progress in the online survey and return at a later time to finish. You will be asked to register anonymously via a nickname and password which allows you to stop and restart the survey using the anonymous nickname and password you created. The registration data you provide is viewed and downloaded separately from the survey data. All information and data from the online survey will be stored in a password protected file that only the principal researcher and her advisor will have access to. The results of the study may be reported in scientific magazines or journals but no identifying information will be included.

Coercion. Your involvement in this online study is completely voluntary and you may withdraw from the study at any time without penalty. You are free to decline to answer any particular question you do not wish to for any reason. Participation or lack of participation, will in no way impact your relationship with the PANDAS Network agency or the websites allowing recruitment and/or data collection.

Loss of time. Participants may experience fatigue and a loss of time while completing the online survey. Although it is estimated that this online study will take less than 30 minutes to complete, participants can take as long as they need to complete the online survey. Participants also have the option to stop the online survey at any time and return to it at a later time to complete it. Participants also have the option to stop the online survey at any time and not return to complete it.

Emotional discomfort. The researcher will ask you questions about your family, your child's illness, and how the illness has impacted your family. A possible risk in this study is emotional discomfort with the questions you are asked or a recurrence of stress when thinking about your child's illness and family situation. If you become tired or upset you may take breaks as needed. You may also stop answering questions at any time and end the online survey. If you feel you need to talk to a professional about your discomfort,

you can find a licensed professional in your area by visiting www.apa.org/topics/therapy or www.psychologytoday.com.

The researchers will try to prevent any problem that could happen because of this research. You should let the researcher know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

For your participation, you will receive no direct benefits. A summary of the results of the study will be posted on the PANDASNetwork.org website within six months of the study's completion.

Questions Regarding the Study

If you have any questions about the research study or your participation in it, you should ask the researchers; their Email addresses and phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at IRB@twu.edu.

Electronic Consent

Clicking on the "Agree" button below indicates that you have read the above information, including risks of participation, and would like to proceed with this online survey. The return of your completed questionnaire constitutes your informed consent to act as a participant in this research. You may print a copy of this consent form for your records.

- ☐ Agree

Appendix G

Institutional Review Board Approval Form

Institutional Review Board
Office of Research and Sponsored Programs
P.O. Box 425619, Denton, TX 76204-5619
940-898-3378
email: IRB@twu.edu
http://www.twu.edu/irb.html

DATE: December 15, 2017

TO: Ms. Marcey Mettica
Family Sciences

FROM: Institutional Review Board (IRB) - Denton

Re: Approval for Family Impacts Reported by Parents Raising Children with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) (Protocol #: 19864)

The above referenced study has been reviewed and approved by the Denton IRB (operating under FWA00000178) on 12/13/2017 using an expedited review procedure. This approval is valid for one year and expires on 12/13/2018. The IRB will send an email notification 45 days prior to the expiration date with instructions to extend or close the study. It is your responsibility to request an extension for the study if it is not yet complete, to close the protocol file when the study is complete, and to make certain that the study is not conducted beyond the expiration date.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. A request to close this study must be filed with the Institutional Review Board at the completion of the study. Because you do not utilize a signed consent form for your study, the filing of signatures of subjects with the IRB is not required.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Karen Petty, Family Sciences
Dr. Shann Hwa Hwang, Family Sciences
Graduate School